40th Anniversary ~ A Ten-Year Retrospective

40e anniversaire ~ Une rétrospective des dix dernières années

Volume 41, N° 1 CJNR March / mars 2009

CONTENTS / TABLE DES MATIÈRES

40th Anniversary ~ A Ten-Year Retrospective

40e anniversaire ~ Une rétrospective des dix dernières années

---

SECTION I

The Decade in Context: Reflections by Four Canadian Nursing Leaders on the Forces That Shaped Canadian Nursing Research

Mise en contexte d'une décennie : réflexions de quatre leaders canadiennes en sciences infirmières sur les forces qui ont façonné la recherche dans cette discipline

McGill University School of Nursing

SECTION II

Memorable Passages From Editorials and Discourses of the Past Ten Years

Des passages mémorables tirés d'éditoriaux et de discours publiés dans les dix dernières années

---

SECTION III

Landmark Articles From Volumes 31–40

Des articles-jalons tirés des volumes 31 à 40

CJNR 2009, Vol. 41 Nº 1, 7–9

Ten-Year Retrospective: Our Guest Editors
Nos rédacteurs invités durant la dernière décennie

The following persons oversaw the preparation of *CJNR* focus issues during the past decade. The Journal's editors are grateful for their dedication and support.

Les personnes ci-dessous ont supervisé la préparation des numéros thématique de CJNR *durant la dernière décennie. Les rédactrices de la revue leur sont reconnaissantes de leur dévouement et de leur soutien.*

1999 ~ VOLUME 31

Heather F. Clarke
University of British Columbia
Research Utilization
L'utilisation des résultats de recherche

Nicole Ricard
Université de Montréal
Mental Health
La santé mentale

Susan E. French
McMaster University
International Nursing
Les sciences infirmières sur la scène internationale

Bonnie Stevens
University of Toronto
Alternative Therapies and Symptom Management
Thérapies de remplacement et gestion de symptômes

2000 ~ VOLUME 32

Karen I. Chalmers
University of Manitoba
Primary Health Care
Les soins primaires

Joy L. Johnson
University of British Columbia
Philosophy/Theory
La philosophie / La théorie

Sally Thorne
University of British Columbia
Chronicity
La chronicité

Jacquelyn C. Campbell
Johns Hopkins University
Abuse and Violence
L'abus et la violence

2001 ~ VOLUME 33

Gina Browne
McMaster University
Laurie N. Gottlieb
McGill University
Economics of Nursing Care
L'aspect économique des soins infirmiers

Patricia McKeever
University of Toronto
Home Care
Les soins à la maison

Anita J. Gagnon
McGill University
Women's Health
La santé des femmes

Linda O'Brien-Pallas
University of Toronto
Health Resource Planning
Planification des ressources de santé

2002 ~ VOLUME 34

Judith A. Ritchie
McGill University
Coping/Adaptation
Le soutien et l'adaptation

Franco A. Carnevale
McGill University
Ethics and Values
L'éthique et les valeurs
Decision-Making
Le processus décisionnel

2003 ~ VOLUME 35

Pamela A. Ratner
University of British Columbia
Addiction and Dependence
La dépendance

Judy Mill
University of Alberta
Nancy Edwards
University of Ottawa
Culture and Gender
La culture et l'appartenance sexuelle

Sandra LeFort
Memorial University
of Newfoundland
Nursing Care Effectiveness
L'efficacité des soins infirmiers

Carol McWilliam
University of Western Ontario
Gerontology
La gérontologie

2004 ~ VOLUME 36

Marilyn Ford-Gilboe
University of Western Ontario
Health Promotion
La promotion de la santé

Margaret B. Harrison
Queen's University
Continuity and
Transitional Care
La continuité et les soins
liés à la transition

Souraya Sidani
University of Toronto
Advances in
Research Methods
L'amélioration des
méthodes de recherche

Colleen Varcoe
University of Victoria
Diversity and Health
Santé et diversité

2005 ~ VOLUME 37

Judith C. Kulig
University of Lethbridge
Rural Health Research
La santé en milieu rural

Susan McClement
Lesley Degner
University of Manitoba
Palliative Nursing and
End-of-Life Care
Les soins infirmiers palliatifs
et les soins au terme de la vie

David Gregory
University of Manitoba
Aboriginal Health Research
Recherche en santé autochtone

2006 ~ VOLUME 38

Judith Wuest
University of New Brunswick
Women's Health: A Social Determinants Perspective
La santé des femmes : une perspective axée sur les determinants sociaux

Joan L. Bottorff
University of British Columbia
Risk and Safety
Les risques et la sécurité

Jacquelyn C. Campbell
Johns Hopkins University
Angela Henderson
University of British Columbia
Violence and Health
La violence et la santé

2007 ~ VOLUME 39

Carmen G. Loiselle
McGill University
Sylvie Cossette
Université de Montréal
Information Technology and Nursing Care
Technologie de l'information et soins infirmiers

Kate Seers
Royal College of Nursing Research Institute
Judy Watt-Watson
University of Toronto
Pain Management Research
Recherche en matière de gestion de la douleur

Shirley M. Solberg
Christine Way
Memorial University of Newfoundland
Geography and Health
Géographie et santé

Franco A. Carnevale
McGill University
Ethics, Values, and Decision-Making
L'éthique, les valeurs et le processus décisionnel

2008 ~ VOLUME 40

Carol L. McWilliam
University of Western Ontario
In-home and Community Care for Seniors
Le soin des ainés à la maison et dans la communauté

Carole A. Estabrooks
University of Alberta
Knowledge Translation in the Health Sciences
La traduction des connaissances en sciences de la santé

Carol Jillings
Sally Thorne
University of British Columbia
Chronic Illness Management
Prise en charge des maladies chroniques

CJNR 2009, Vol. 41 N° 1, 11–18

EDITORIAL

CJNR Celebrates Its Ruby Anniversary

This issue of *CJNR* marks a significant milestone for the Journal and for Canadian nursing scholarship. With this special commemorative issue we look back on 40 years of continuous publication. This, our ruby anniversary, is a time to pause, to reflect, and to celebrate what has been accomplished in a relatively short span of years, in part because of the unusual partnership that has developed between the Journal and the community of Canadian nurse scholars.

Wedding anniversaries mark the passing of another year of a couple's life together, their commitment to each other, and an accumulation of time that is irreplaceable. The practice of celebrating an anniversary with a symbol that increases in value or in strength with each passing year reflects the investment that the couple has made in the partnership and in the other (Scoble & Field, 2004).

These same ideals apply to the anniversary of a publication. This journal has been a labour of love and commitment for many people. To not merely survive but actually thrive is a rarity among academic journals housed within universities. Ours is one of a few independent journals owned and operated by a university, in this case McGill University. The investment of time, energy, and space has been enormous, on the part of many. I will return to this topic shortly, but first I would like to comment on the ruby.

With its inherent strength and unparalleled beauty, the ruby is the 40th-anniversary symbol. Red is the colour most associated with love, passion, power, vitality, warmth, dynamism, and purpose. Ruby is the colour we chose for the cover of this issue of the Journal. Our designers, Cait Beattie and Jean Louis Martin, retained their original cover design for this special issue, but with a difference. If you look carefully, you will see that they inserted, as background filigree, a list of focus topics we have featured over the past decade. And they chose different shades of ruby, to communicate the power of ideas, the vitality, warmth, and dynamism that we share with our readers and our community of scholars, and our determination to create a journal dedicated to nursing research as a basis for compassionate and informed nursing care. Finally, red is the symbol of heart and fire — appropriate metaphors for guiding us in the production of this quarterly publication.

Toasting Our Partners

In the past few years several of our editorials have celebrated the achievements of nursing scholarship (see, for example, Gottlieb, 2007). In this 40th-anniversary editorial I would like to focus on *CJNR* itself and the many partners that make it possible. The Journal, originally called *Nursing Papers,* was founded by Moyra Allen. Dr. Allen envisaged the creation of a forum for the exchange of scholarly ideas among researchers across our vast country. Following through on this vision, Mary Ellen Jeans, the second editor, transformed *Nursing Papers* into a research journal and renamed it the *Canadian Journal of Nursing Research.* Her own vision was to establish a credible journal for the dissemination of original research. Dr. Jeans set out to create a peer-review system and to capture the emergence of nursing scholarship.

In 1992 I assumed the editorship, and in partnership with three successive associate editors — Mary Grossman (1992–98), Anita Gagnon (1999–2003), and Sean Clarke (2004–present) — have put systems in place that have allowed us to respond to changing demands and anticipate new trends in nursing, nursing research, health care, and publishing. We have attempted to set new directions in order to capture Canadian nursing scholarship for the purpose of transforming nursing practice. All of my associate editors have been superb — visionary, passionate, daring, committed, and hardworking. They have been true partners in this adventure.

In the first year of my editorship, I came to the realization that for *CJNR* to be truly Canadian it would have to capitalize on the talent and expertise of leading Canadian nurse scholars. The challenge was how to remain a general research journal while focusing on emerging areas. Rather than choose one approach over the other, I decided to combine the two. I visited Joan Anderson at the University of British Columbia. We brainstormed, came up with focus topics, and identified some possible guest editors. In that first year I also sat in Mary Grossman's kitchen as we developed a new format for the Journal. We came up with three features that would appear in every issue and would be written by leading thinkers in nursing and other health-related fields. Thus were born Discourse, Happenings, and Designer's Corner. The Designer's Corner feature has now been replaced by Best Practices in Research Methods, a column expertly overseen by Feature Associate Editor Souraya Sidani. Dr. Sidani has brought rigour to the emerging area of research into nursing methodologies.

Since 1993, with the publication of our first focus issue — Coping and Adaptation, with Judith Ritchie as guest editor — I have worked with more than 60 guest editors. Together we have laboured hard to craft each issue. It has been an honour and a privilege to collaborate with these leading nurse scholars. The guest editors have enthusiastically embraced the role, giving generously and tirelessly of their time, energy, and expertise. They have enlisted friends and colleagues to submit manuscripts, serve as reviewers, and write invited pieces. They have been superb teachers, encouraging authors to improve their manuscripts and guiding them along the road to publication. It is with a sense of awe that we witness each issue come into being. Our guest editors are not only our partners but also the midwives of *CJNR*'s focus issues.

For five years our editors at large, Sean Clarke (formerly of the United States), Sioban Nelson (formerly of Australia), and Kate Seers (the United Kingdom and Europe), brought an important perspective to the Journal. Their support, involvement, and wisdom proved critical at an important juncture in the Journal's development.

We also have paid tribute to our many reviewers (see, for example, Gottlieb & Clarke, 2007). We know that our reviewers hold the key to the quality of the articles that we publish in the Journal. We rely on their knowledge, skills, and judgement to guide us in our decisions and to help authors refine their manuscripts. Under the leadership of first Anita Gagnon and now Sean Clarke, a system for maintaining a bank of reviewers and working closely with them has developed and evolved over the years. Our reviewers donate countless hours to *CJNR,* and we are indebted to them for imparting to researchers their knowledge and expertise, which ultimately translate into improved nursing practice. These are the Journal's other unsung heroes, and our indispensable partners.

Another critical partner, and the glue that holds *CJNR* together, is our managing editor. We have been fortunate to have two outstanding managing editors, first Jill Martis (1993–97) and now Joanna Toti. Jill set the standard. She created the structure that would enable us to produce an independent journal of the highest quality on a shoestring budget. She set the bar very high and left an indelible mark on the Journal.

Joanna Toti has served as *CJNR*'s managing editor for the past 12 years, and we are deeply indebted to her. Joanna is a joy to work with. She is the consummate professional and a behind-the-scenes magician who makes everything look effortless as she juggles a hundred balls in the air at once. She is committed, compassionate, and caring. She is the perfect orchestra conductor, coordinating the activities of many, including Melanie Girard, our assistant managing editor; Jane Broderick, our meticulous copy editor; Cait Beattie and Jean Louis Martin, our layout and design team; Lou Lamontagne, our translator; and countless other individuals, so that they work in harmony and synchronicity. And she is the face of *CJNR*, communicating with the associate editor, the guest editors, and our reviewers, authors, and readers. Everyone sings her praises.

The Journal would not exist without the support of McGill University and its School of Nursing. The School's current director, Hélène Ezer, continues the tradition of the directors offering their unwavering support. Although independent in every aspect of its operations, *CJNR* relies on the School for office space and on the University for administrative support.

These are our partners, and one could not wish for better ones. They have supported, nurtured, and sustained *CJNR*.

Celebrating the Past Ten Years of Publication

Ten years ago we published a 30th-anniversary commemorative issue covering our first three decades. When we realized that *CJNR*'s 40th anniversary was upon us, we made the decision to publish another commemorative issue. We have been party to the acceleration of knowledge generation and changes in the health-care culture with respect to nursing scholarship and its valuable role in shaping health-care policy and health-care research. In planning this milestone issue, we wanted to capture the excitement of these past 10 years. We settled on three sections: The Decade in Context, Memorable Passages From Editorials and Discourses of the Past Ten Years, and Landmark Articles From Volumes 31 to 40.

The Decade in Context

What better way to begin a commemorative issue than to put the past in context? We invited nursing leaders to assist us with this task. Who better than Judith Shamian to help us understand the social, political, and economic forces that have shaped the health-care, nursing, and research agenda during the past 10 years? Dr. Shamian, in her role as Executive Director of Nursing Policy at Health Canada (1999–2004), travelled this country, listened to the concerns of nurses, enjoyed the confidence of government, and acted as the voice of nurses and nursing. She has a gift for seeing the larger picture and understanding the interrelationship among forces, and she is able to distil complexity and communicate the essence. In the pages that follow, Dr. Shamian provides us with important insights and perspectives.

It is well known that the growth in nursing scholarship is due in large measure to the establishment of PhD programs in nursing, the building of nursing research capacity, and the dedication of grant monies to nursing research. These developments did not spring out of nowhere. It was the vision and tireless efforts of the first and second wave of nurse scholars, and their determination to gain legitimacy for nursing scholarship and secure adequate funding, that made the difference. We invited Mary Ellen Jeans and Dorothy Pringle to reflect on these matters. Dr. Jeans, in her role as Director General of the National Health Research and Development Program (1992–96) and Executive Director of the Canadian Nurses Association (1996–2001), and Dr. Pringle, in her position as Dean of the Faculty of Nursing at the University of Toronto (1988–99) and President of the Canadian Association of University Schools of Nursing (1997–99), took up the torch of early nurse leaders and carried it, along with others, to the finish line. Because they were key players at the helm of the charge in securing funds for nursing research and creating PhD programs in nursing, Drs. Jeans and Pringle are able to share their unique perspectives. They recount in detail for us how events unfolded.

Finally, we invited Joan Anderson to comment on conceptual and methodological issues in nursing research over the past decade. Dr. Anderson is a pioneer in Canadian research, breaking new ground with her creativity and her innovative approaches to nursing scholarship. She has played a role in *CJNR* since its inception, working first with Moyra Allen and then with me during the 17 years of my stewardship. She has been a regular contributor, as guest editor, author, and reviewer, and has penned more of the Journal's Discourses than any other contributor. A unique wisdom, honed through years of study, accumulated knowledge, and experience, is evident in her beautifully written piece capturing the major trends in nursing research over the past decade.

Memorable Passages From Editorials and Discourses of the Past Ten Years

We decided to excerpt memorable passages and key ideas from editorials and from Discourses by leading scholars that appeared in *CJNR* during the past decade.

We originally intended to extract "sound bites" to convey a *double entendre* based on a dissection of each word. The first *entendre,* or meaning, with emphasis on the word "sound," would convey the importance of an idea — a sound idea. The second would place emphasis on the word "bite." A "bite" serves to communicate a big idea using a few pithy words or an insightful phrase. We met our first objective of finding passages from past editorials and Discourses that provided important insights. However, we failed to find the one "bite" that captured the message in a memorable sentence or phrase. Instead, we settled on brief excerpts from past editorials and Discourses, and hope they will pique the interest of our readers such that they will be motivated to consult the full text.

Editors use their publication's editorial column in very different ways. Some use it to introduce the current issue of their journal or magazine. We have used *CJNR*'s editorial column to raise awareness, share concerns, make a point, inform, instruct, and celebrate. Nursing research is our primary focus: we examine issues such as current societal, economic, or health-care forces in terms of how they will affect nursing research. Our editorials have focused on matters of immediate concern that may have long-term as well as short-term effects. We have written editorials to inform our readers about current debates in the publishing world — a world for which the past 10 years have been tumultuous. We have devoted editorials to laying bare our decision-making process and making our editorial decisions transparent.

We have been privileged to have leading scholars in nursing and other health fields, from Canada and abroad, agree to write the Discourse on various focus topics. These eminent scholars have given considerable thought to their Discourse contribution. Many have been provocative, asking us to question sacred myths and assumptions. Some have been comforting, encouraging us to reaffirm nursing's core values in the face of challenges. And others have pointed us in new directions. The Discourses, like our guest editorials, are an invaluable resource, replete with historical insights, wisdom, and unique perspectives. They are well worth reading.

Landmark Articles From Volumes 31–40

Our third section belongs to our authors. We wrote to the guest editors of the past decade inviting them to nominate one article from their focus issue and to give us their rationale for this choice. We decided to include only articles that had appeared in the focus section. A total of 38 articles were nominated — a list that had to be whittled down to a selection of 15. We discussed the merits of each nomination. We drew up our lists, defended our choices, provided our rationale, and in the end came to agreement. We selected articles that we considered *groundbreaking* inasmuch as they identify new directions for nursing or nursing research ("Values That Matter, Barriers That Interfere: The Struggle of Canadian Nurses to Enact Their Values," by Brenda Beagan and Carolyn Ells; "Discourses Influencing Nurses' Perceptions of First Nations Patients," by Annette J. Browne; "Mapping the Research Utilization Field in Nursing," by Carole A. Estabrooks), could become a *classic* in the field by setting a new standard for research ("Nurse Staffing and Patient Outcomes: Evolution of an International Study," by Julie Sochalski, Carole A. Estabrooks, and Charles K. Humphrey), are *innovative* either in their approach to research or because they look at old problems through new lenses ("Considering *Place* in Community Health Nursing," by Amy

Bender, Laurie Clune, and Sepali Guruge; "A Narrative Study of Refugee Women Who Have Experienced Violence in the Context of War," by Helene Berman, Estella Rosa Irías Girón, and Antonia Ponce Marroquín; "Evaluation of the AIDS Prevention Street Nurse Program: One Step at a Time," by B. Ann Hilton, Ray Thompson, and Laura Moore-Dempsey; "Lesbian Disclosure: Disrupting the Taken for Granted," by Carol McDonald; "An Exploration of Participants' Treatment Preferences in a Partial RCT," by Joyal Miranda; "Navigating Towards a Moral Horizon: A Multisite Qualitative Study of Ethical Practice in Nursing," by Paddy Rodney, Colleen Varcoe, Janet L. Storch, Gladys McPherson, Karen Mahoney, Helen Brown, Bernadette Pauly, Gwen Hartrick, and Rosalie Starzomski), serve to remind us of the *essence of nursing* ("The Costs and Effects of Addressing the Needs of Vulnerable Populations: Results of 10 Years of Research," by Gina Browne, Jacqueline Roberts, Carolyn Byrne, Amiram Gafni, Robin Weir, and Basanti Majumdar; "Transforming Hope: How Elderly Palliative Patients Live With Hope," by Wendy Duggleby and Karen Wright; "Economism, Efficiency, and the Moral Ecology of Good Nursing Practice," by Sara M. Weiss, Ruth E. Malone, Joseph R. Merighi, and Patricia Benner), or serve the cause of *health* within an *important population* ("Sticks and Stones: Racism as Experienced by Adolescents in New Brunswick," by Cynthia Baker, Manju Varma, and Connie Tanaka; "Learning to Live With Early Dementia," by Leona Werezak and Norma Stewart).

Sponsors, Supporters, and Sustainers

We have been deeply moved and heartened by the financial support and encouragement we have received. Our financial partner for this landmark issue is Associated Medical Services. AMS has made a significant contribution to the history of medicine, bioethics, and education. It has long supported the documentation of nursing history through the Hannah Development Grant. AMS generously provided *CJNR* with a grant to help offset the costs associated with the publication of this commemorative issue. In so doing, AMS recognizes the critical role played by the Journal in documenting the historical development of Canadian nursing research.

We are indebted to the many colleagues and friends who have supported *CJNR* over the past four decades. We are gratified by the enthusiastic endorsement of so many, in the form of advertisements and congratulatory messages.

This commemorative issue has been two years in the making. The publication process has involved a great many people. However, I want to single out Sean Clarke, the associate editor, who has been a true collaborator, involved in all aspects of producing this special issue, and Joanna Toti, the managing editor, who has taken our ideas and made them happen. Our work is conducted in an atmosphere of respect for even the most outlandish ideas, kibitzing, laughter, and great fun.

This issue reflects what *CJNR* is all about. It embodies our values and our commitment to excellence in nursing scholarship and nursing practice that is respectful of its roots in caring, compassion, and humanism.

This anniversary issue communicates what makes the Journal unique. It reflects a 40-year commitment, not by one or two players but by the many players who are our partners. It embodies the ruby — love, passion, vitality, and dynamism. This is the bedrock upon which *CJNR* is built, the bedrock that will sustain *CJNR* as it advances towards its jubilee 50th anniversary.

Laurie N. Gottlieb
Editor-in-Chief

References

Gottlieb, L.N. (2007). Canadian nursing scholarship: A time to celebrate, a time to stand guard. *CJNR, 39*(1), 5–10.

Gottlieb, L.N., & Clarke, S.P. (2007). A salute to our reviewers: Partners in the scientific endeavour. *CJNR, 39*(4), 5–9.

Scoble, G., & Field, A. (2004). *The meaning of wedding anniversaries*. San Francisco: Chronicle Books.

The Decade in Context

Mise en contexte d'une décennie

CJNR 2009, Vol. 41 N° 1, 21–29

Putting Health Care During the Past Decade in Context: An Interview With Dr. Judith Shamian

Laurie N. Gottlieb: *The past decade has been a period of great change in health care, nursing, and nursing scholarship. Can you review some of the major changes in health care during this period and put them in context, considering the political, social, and economic landscape?*

Judith Shamian: The early part of the 1990s was marked by downsizing investment in health care. The health-care system underwent some hard times, which included layoffs, reduced seats for nursing education, and deep cuts for the system. Canada was in a major deficit position. The legacy of the prime minister at the time, Jean Chrétien, and the finance minister, Paul Martin, is that they turned the Canadian economy [around, transforming Canada from] a country with a significant deficit and a poor economic performer among the G7 [Group of Seven] to one of the best-performing countries among the G7, with a significant surplus. The surplus allowed them both to reinvest in health care and to pay down the national debt in the late 1990s. At the beginning of 2000 several provincial and territorial agreements were signed between the provincial and territorial premiers and the prime minister that outlined the investments of the federal government in the health-care system.

While the federal government was investing billions of dollars in the health-care system, it also continued to relinquish its moral and legal authority of holding the provinces and territories accountable for the funds they received. The federal government has become more a banker of the health-care system than a partner in decision-making. We see this on many fronts, such as in the minimal enforcement of the *Canada Health Act*, lack of a national home care policy, lack of comprehensive primary health care, lack of national health human resources strategy, and more. In 2009 we find ourselves in Canada once again in a worldwide economic crisis. The impact of this economic crisis on the health-care system will play itself out over the coming months and years.

What are some of the reasons for this shift?

It's mostly political and it's mostly the horse-trading of what provinces and territories want from the federal government and what the federal government wants from the provinces. Our health-care system is mostly funded by public dollars, so when the economy gets into trouble it has a serious impact on health-care funding.

Has there been any shift in ideology towards health care?

Until the Harper government came into power and until the environment became such a major concern worldwide, health continued to be the number one concern for Canadians. Quality of health care and access to services were the major drivers of some of the agreements in the late 1990s and early 2000s. Therefore health was central to every provincial and every federal election. That has shifted in the last 3 to 4 years, and it's becoming increasingly worse. In our most recent federal election [2008], while many of the polls suggested that the public still places health as number one on the party platforms' agenda, the issues that were debated and promoted by the various political leaders were very thin on health. The first Speech from the Throne [in November 2008] contained very little on health. This is a serious shift, and it doesn't mean that we've solved all the health-care problems. If the agenda has shifted because we thought that health concerns have been resolved, that would be great. But that's not the case. I believe there's a larger political agenda to take health off the table so provinces can quietly invest less and get out of various health-care services they offer. For example, if you look at the legal landscape in Quebec, in 2008 legislation was enacted that allowed for the privatization of over 300 procedures outside of the publicly funded system — publicly funded, privately delivered. And the argument shifted in a very interesting way, where everyone talked about "Oh, we all support the publicly funded system but we'd like to see private delivery." Which is brilliant in the mind of the naysayer because they can guarantee revenue and profit stream that otherwise wouldn't be there. There aren't too many Canadians who'll pay $5,000 to get a procedure done if they can get it in the publicly funded and publicly delivered [not-for-profit] system.

Have there been other changes?

I think regionally — what I told you was more at the macro, international level.

What were the other pressures at the international level?

We can't ignore the impact of SARS on the whole public health agenda — infectious disease — and discussions around chronic disease. They have all surfaced during the past 5 to 10 years. I think bioterrorism became another issue of major concern; we don't hear much about it, but it really gained a lot of attention after 9/11. As of late 2008 we are also entering a new world order with the international economic collapse. It's too early to predict its impact on international health, but it is safe to assume that it will have a major impact on poverty and other social determinants of health that affect health status and a country's health systems.

You mention bioterrorism and its impact on health care. Link the two for me.

The whole discussion around anthrax and so on, or communicable diseases, or the technology of being able to spread gases — because of these events each government has allocated many more funds to public health and general security. It had a large impact on the economy for a while and made the developed countries realize that they can't ignore public health.

You talked of regionalization. Could you elaborate?

Regionalization has continued to dominate the management of health care. We used to talk about 10 provinces and 3 territories and the federal government — in effect, we were talking about quasi-14 health-care systems. With the establishment of and the power invested in health authorities, we now talk about many more systems, because each health authority makes decisions to run its own operation differently. While, on the face of it, regionalization itself sounded like a brilliant idea, there is insufficient evidence, as far as I am aware, to demonstrate its impact. From my perspective, looking at home and community care in my current position as president and CEO of VON [Victorian Order of Nurses] Canada, I've started to reflect on whether regionalization has done harm to this sector rather than good. We need research on these issues.

Can you give me an example?

For example, several provinces have reduced their services for homemaking as they do not consider it essential for health. The reality is that a few hours of home support with cooking and other chores can keep individuals at home for many years without the need to place the person in a long-term-care facility. When you sit around the table of a health authority and you negotiate budgets, inevitably acute care consumes a lot of the resources. One would have thought that, because there is a clear understanding that the more you invest in the community the more you can alleviate your acute-care pressures, there will be investment in the home and the community agenda, but that doesn't seem to be the case.

And just relate this to regionalization. I'm missing something, because you say that it would be a good idea and it turned out not to be such a good idea.

[There are] two main areas to consider. First, when regionalization was put in place it was expected that it would lead to a coherent integration of the various sectors (acute care, LTC, home care, and others). The second expectation was that funding would be allocated in a more rational way that would meet the needs of the communities. Neither of these expectations has been met. It would be very helpful to have studies evaluating the outcomes of regionalization.

Are there any other significant changes?

In terms of the social agenda and the political agenda, we have an aging population with the baby boomers who will have a significant impact on our health-care system. And the other thing that is happening is that one in five Canadians is a family caregiver. And, again, no attention to those issues.

Given all these changes, what do you think have been the biggest challenges that nursing faced during this period and how did nursing respond?

The biggest fallout from the early 1990s economic policies that led to mergers and downsizing of the health-care system was the downsizing in human resources, together with removal of funding to the health-care and education sectors. We went from annual graduating classes of anywhere from 9,000 to 12,000 in the late 1980s to as low as 4,000 to 5,000 in the 1990s. When we emerged from this downsizing period and started to re-invest in health care, we realized that we didn't have the people to take on the positions. In addition to the reduction in the number of graduates, we also lost several graduating classes to the United States, because there were no positions generally and full-time positions in particular here in Canada. Another major impact was in work life and working conditions, and that impacted the professional sense of belonging and having the commitment to the organizations. We have seen a significant change in nurses who continue to be committed to patient care and to patients but who are not as committed to the organizations and to the teams they work with.

What about the elimination of leadership and management positions that was part of downsizing? That must have had an impact — not only the shortage of nurses but the lack of manpower and leadership to ensure quality nursing care.

This started in the 1980s when organizations went into what was called "program management." It shifted the power, the influence, and the control from the position of the senior nursing person and the senior nursing team to an array of physicians, health-care administrators, and financial types, and in many places removed line responsibilities of nursing leadership. This trend led to a shift among emerging nurse leaders toward professional roles such as nurse practitioner positions, education, clinical nurse specialist. We currently do not have a bell curve or age curve in leadership. The research of Dr. Heather Laschinger of the University of Western Ontario shows very clearly that we have a very flat age group of 45 years and over between frontline, middle-line, and senior line. There's limited interest among the younger generation in management positions in the current environment and current structures. Another issue is that we have four generations of nurses in the workplace while the majority of the leadership comes from another, older generation [baby boomers]. Any failure to understand the generation differences in the workforce will further complicate workplace issues.

These are two very interesting and important points you are making. How does this next generation learn and profit from experience without that mentoring and modelling? And who are they going to learn it from?

I don't see anyone dealing with this issue. When I was at the Office of Nursing Policy at Health Canada, we put the topic of workplace health on our policy agenda. It's an area of focus that is now embraced by all. I hope that by building healthy work environments we will be able to support and retain novice nurses.

I now want to talk about nursing research, nursing scholarship, and what is needed from nursing scholars to respond to all these challenges. First, how did nursing scholarship, nursing research, either shape the debate or respond to these challenges?

At the beginning of 2000 we found ourselves in an interesting situation. While the demand for nursing faculty was growing in order to produce the growing number of nurses that are required to meet the practice demand, at the same time the research funding available to nurse scientists expanded too. With the shift from MRC [Medical Research Council] to CIHR [Canadian Institutes of Health Research], some of our dreams and advocacy came through. Canada moved from primarily biomedical bench research funding to a more population-based bio-psycho-social funding paradigm. Nursing faculties and nurse scientists were in a race to both meet educational needs and grow the capacity of scientist and nursing research. In a very short time frame of 10 to 15 years we have made amazing strides. Hopefully this will continue to grow as university schools of nursing receive significant donations and scientists get major grants. We need to make sure that we continue to build capacity that can compete in the national and international funding arenas. The other area where I think nursing has taken serious initiatives is in the field of health-services research. One of the things that has happened in the last 10 years, of which Canada should be very proud, is the establishment of CHSRF [Canadian Health Services Research Foundation]. CHSRF has made a very significant contribution to this country and to nursing in drawing attention to health services, educating decision-makers and policy-makers about the importance of data. The federal government, in the late 1990s, established a 10-year nursing research fund that helped to support and advance nursing research and scholarship. The federal investment in the prominent granting agencies has slowed down now, but hopefully there is an awareness that in order for Canada to take its place in the G8 we need to continue to invest in research.

Link the dots between those political, economic, and social challenges we talked about in the first part of our discussion and how nursing scholarship or research responded.

In the early 1990s there were a handful of senior nurse scientists who were slowly building small programs of research by having a couple of doctoral students, having researchers, and literally working in a small shop. Once the opportunity opened up and funding became available, they were very well positioned to be successful in a competitive research environment nationally and internationally.

We've had different models of how to build nursing research. I think the model we've looked at was the American model, and the Americans were 10 to 20 years ahead of us by having a nursing institute as an institute in NIH [National Institutes of Health] for the advancement of nursing science. The nursing community in Canada was hoping to have a similar model here when the CIHR was established. The political readiness to have a nursing institute just wasn't there.

On the other hand, the minister of health in 1999, Allan Rock, in addition to the establishment of the CHSRF also established a $25-million nursing fund to be spent over 10 years focusing on health services and clinical research. This investment in health-services research led to significant development of health-services research generally and among nurse scientists in particular. While the investment in health-services research made it possible to build both capacity and knowledge, to transform the system, we have not seen the same type of investment in clinical nursing research. Some of the experienced nursing scholars are funded well through the CIHR system. Others, primarily from resource-poor settings, don't do as well. [What] we're starting to see is more interdisciplinary and multi-site collaboration, which will strengthen scholarly productivity.

The focus and investment in interdisciplinary practice came out of the FFM [First Ministers' Memorandum] when I was at the Office of Nursing Policy. It's one of the things that I consider my legacy. I hope that the initiatives triggered by the FMM investment in interdisciplinary practice will transform our practice and research.

And people were really scared when they saw the shortages — about what was going to happen.

It took a while for FPT [Federal, Provincial, Territorial] decision-makers to accept that we were heading into a nursing shortage. In the late 1990s many of the individuals who sat around the FPT Health Human Resources table didn't think there was going to be a nursing shortage. They believed that there was no shortage and [that the shortage] was a nursing-infused idea. By 2001 people understood that the shortage was real and there were data to help [people] to understand the challenges we were facing in Canada. Once it was widely accepted that we were entering a shortage, the solutions started to be developed and a nursing plan was passed by all ministers of health across the country.

Do you think we need to concentrate on a few areas of research rather on many, given the number of nurse researchers we have here in Canada?

I think what could be useful is to build virtual networks, where nurse scientists and scholars from across the country and beyond work together. This could help with capacity-building and smooth out the have and have-not faculties. It could be very useful to map out where the leading research programs and expertise [are] and build networks around them. I worry about small faculties that at times are left behind because they don't have access to expertise and resources.

When I was at the Office of Nursing Policy [1999–2004] we organized several think tanks to move the research agenda in an integrated way. At that time I was hoping we could close the gap and grow research capacity and funding in a strategic way. While we're making some progress, we're not where I hoped we would be. I believe we could benefit from a coordinated approach.

I'm also hopeful that the Harper government will renew the Nursing Research Fund, which comes to an end in 2009.

What are the challenges we can anticipate coming down the pipeline in health care? As researchers what role could we play or should we play? Where should we be putting our efforts and our priorities?

I think we need to figure out the relationship between research and teaching. I think in the next 5 to 10 years we'll see multiple colleges that will grant undergraduate degrees, and many of them will go on to grant master's and PhD degrees. The challenge will be to build teaching and research capacity simultaneously. The United States has gone through a similar situation — in the 1980s — which led to some of their universities being very research-intensive and others…not as productive. We should try to avoid that happening in Canada. We should learn from the US experience and try to do it better.

There's also an inherent academic challenge between being a researcher and being an educator. And within nursing, because we are a practice profession, a practice discipline, we need very, very competent educators and clinical instructors. But the way most universities are structured, educators are often considered second-rate citizens. So we need to figure out if something can be done where teaching faculty can be tenured based on education and scholarly work so that there isn't this pull and push between scientists and teachers. The other thing that we need to figure out is how to engage our star researchers in undergraduate and graduate teaching without overloading them with teaching responsibilities.

The other big challenge is that we have a shortage of individuals interested in becoming deans. Over the last few years at any given time there have been several vacant dean positions.

There's a growing trend for nurse scholars/researchers to be embedded in the service settings. While this trend can be very helpful in strengthening practice, we need to structure these roles in a way that these individuals can build programs of research while collaborating with service. This is a trend we need to pay careful attention to.

What do you see happening in health care and how do you see nursing positioning itself?

My biggest worry is that the next 3 to 5 years will be marked by continuing privatization and economic downturn. Both privatization and economic downturn will lead to reduced investment in research and will remove available dollars from the public system. I worry that these will lead to a repeat of the early 1990s, when we removed from the system many of the educators, CNS's, and we reduced the number of seats for nursing education and much more. And last, there will be less and less opportunity for scholarly development — staff going to conferences; it will become much more of a service model than a professional discipline model.

What do you need from nurse researchers and nursing scholarship to help deal with this challenge?

Above everything else we need more research on what is the best practice and what are the best interventions to support patients, families, and communities. And when I say that it doesn't make a difference if a patient is in the hospital or in the community in order [for us] to deal [with the situation] in a comprehensive way, we also need nurse scientists to help us switch from an acute-care lens to a health-care lens with the associated health outcomes. Nurses are the largest group, outside of basic scientists and physicians, who have the skill set to do this kind of research.

To what extent do nurses really value that?

We lost the emphasis on patient-centred care in the 1990s during the last economic downturn and we didn't regain it. We talk the talk, we talk about patient-centred care and the wellness model, we talk about the health perspective, the need to have care inside and outside of institutions, but we don't seem to be able to make it happen. I hope that the nursing community can work together to role-model how to build healthy communities, healthy families, and healthy individuals.

Thank you, Judith, for a most fascinating and insightful interview.

Judith Shamian, RN, PhD, LLD, DSci, is President and Chief Executive Officer of Victorian Order of Nurses Canada and President-Elect of the Canadian Nurses Association. She served as Executive Director of Nursing Policy at Health Canada from 1999 to 2004.

CJNR 2009, Vol. 41 Nº 1, 31–40

The Quest for Money to Support Nursing Research and Nursing Research Capacity: An Interview With Dr. Mary Ellen Jeans

Laurie N. Gottlieb: *What were some of the historical milestones and turning points in securing funding for nursing research and capacity-building? Could you place the events in the social and political context of the time?*

Mary Ellen Jeans: Let me start with some of my observations. If I go back, some of the barriers and challenges to the development of nursing research were that we didn't have our own PhD programs, so many of us got our PhDs in other disciplines or other countries. Some of us left nursing and/or Canada and some didn't. But the development of PhD programs was a major impetus to the development of research, because we were training more nurses who could do research. Since 1990, 15 PhD programs in nursing have been developed in Canadian universities. That's a relatively short period of time for such a development. And the number of doctoral students rose from eight in 1990 to 390 in 2005. These are the last available data that I could find.

Financial support for doctoral and postdoctoral students was another challenge. Until CIHR [Canadian Institutes of Health Research] was created, there were limited sources of scholarship funding for nurses. The majority of federal health research funding focused primarily on basic biomedical research. So, too, did national and some provincial health research funding organizations. Today this has changed and funding for a more comprehensive research agenda is available. Financial support for doctoral and postdoctoral students has increased over the past 7 to 10 years, but the amount falls far short of what is needed given the increase in enrolment in doctoral programs. So there's a gap. It's better than it was but it's not anywhere near the need or demand. There must be a tremendous number of doctoral students who either aren't financially supported or are being supported by their university or a local community or are enrolled part-time and/or continue to work.

The other observation is that, as we have started to develop these PhD programs, and possibly, I might even argue, too quickly, we now have a human resource crisis in the number of people prepared to teach. We don't have a lot of research-prepared faculty yet. One of the things we need right now is a strategic initiative, maybe a 10-year initiative, to support postdoctoral preparation in nursing. We need to build the faculty complement and speed up the development of researchers.

Funding for nursing research was as much if not more of a challenge than scholarship funding, for similar reasons, and in the early years we were navel-gazing: What is nursing research? or What is nursing? — heaven forbid — conceptually. And in a way we were probably creating barriers that didn't need to focus on questions such as these.

And part of it was that we were being asked these questions by other faculties that no one would have asked of other disciplines. No one would have asked medicine, What is medicine? or What is medical research?

There was an attitude that we were not an academic discipline [but] rather a practice profession. We were partly forced to explain what we were doing and why. The first real initiative, at least the first national initiative, to stimulate research capacity in nursing was the joint MRC [Medical Research Council] and NHRDP [National Health Research and Development Program], which was a 5-year initiative started in the 1980s to provide salary support to nurse scholars and an amount of funding for research operating expenses. And even though it only funded six or seven people it did demonstrate that a small or modest investment in nurse scholars made a huge difference. All of those nurse scholars who were supported by this initiative are holding chairs today and/or have made significant contributions to the field. And their students, some of them, are holding chairs.

How did the MRC/NHRDP initiative come about?

I was not in at the beginning of that initiative but I did lobby to have it renewed for 5 more years. And that was a worthwhile thing. The other thing that happened of course was that MRC evolved into CIHR. There was an opening of the doors for research beyond the bench. When I was in NHRDP, nursing got way less than 1% of the MRC budget. Now it's approaching 5%. We really are doing very well. I was also involved with the National Cancer Institute of Canada [NCIC], because when I was at NHRDP I often represented Health Canada on various research-related committees and initiatives and was responsible for Health Canada's role in targeted research initiatives. So I actually co-chaired the Canadian Breast Cancer Research Initiative [CBCRI], with Dr. Henry Friesen, then President of MRC. We were able to ensure that the research funded wasn't all biomedical. We funded research about how to help women with various aspects of breast cancer. Dr. Lesley Degner from the University of Manitoba helped move nursing research in the National Cancer Institute of Canada, because she was well funded by them. And then there were groups like the Alzheimer's Society, and Dr. Dorothy Pringle influenced it, as did others. These groups began to look at nursing research differently. Most of these groups also had lay people on their boards. And lay people started to say: "It's all very well to study cells for 20 years until you find a cure, but how are we going to cope with things in the meantime? How are we going to deal with all of this? What kind of health services are needed?"

Another milestone was the establishment of the Nursing Research Fund that ended up being administered by CHSRF [Canadian Health Services Research Foundation]. That wasn't part of the original plan. In fact we wanted it all to go to the Canadian Nurses Foundation [CNF] so that we could use it strategically for the development of capacity. But the night before the budget [was announced] we got called into a room and were told that the money would go to CHSRF and would be dedicated to certain issues in nursing research more related to health services and capacity development. And in the end it's done a good job. They've funded a number of chairs who have become very successful in attracting large grants. Right now there is lobbying to get it renewed. That fund was a 10-year initiative. It has been evaluated and has definitely contributed. I think it should be renewed at a much higher level and used for some strategic capacity development such as postdoc and some areas of research from a qualitative perspective, where there might be some strategic development. For instance, chronic disease management is something we do well and we do a lot across different kinds of illnesses. There are many areas of research that nurses are doing that actually fit with Health Canada's priorities.

Another milestone was that as nurse researchers began to be successful in their research funding applications they began to be invited to sit on peer-review committees. This was also a source of capacity development as they became part of the established research community. They learned quickly the characteristics of a good scholarly proposal and the subtle influences that affect success or failure. Today nurse researchers not only sit on peer-review committees, they often chair those committees, and at CIHR two nurse researchers have headed two of the institutes.

Is there anything else that comes to mind?

I think the only other observation really isn't so much about milestones as it is about our inability to capture the benefits of the milestones. We haven't got proper databases. CASN [Canadian Association of Schools of Nursing] and CNA [Canadian Nurses Association] have tried to establish databases together.

There's been an incredible growth in PhD programs in Canada, the establishment of CIHR. Can you put these milestones in context? What was the sociopolitical climate that allowed them to take off now, because these ideas had been floated around for a long time?

Quite frankly, on the PhD program front it was the persistence of an older generation of nurses before us who were our mentors. They just kept hammering away at it. And it was the dominance of medicine that was a huge barrier, because that was who we had to convince [of the legitimacy of nursing research]. And we ultimately did, but it was a struggle. There were committed people who knew we had to get there. We all had roles to play in our own universities and in CASN and others, but once we got one or two [PhD programs started] it was "me too, me too." So the people who followed didn't have nearly the fight to fight; they just had to say, "Well, McGill has one [a PhD program], and [the] University of Alberta, and the University of Toronto has one, and all of our people are leaving and going there so we've got to have one too."

In your position as Director General of NHRDP you had access to ministers. The funding pot was being stirred and granting agencies were being rethought. Could you talk a little bit about what went on behind the scenes?

I had many opportunities to meet with the minister and the minister's staff, as did Dr. Henry Friesen. I reported through an assistant deputy minister and then a deputy minister, whereas the President of MRC [Dr. Friesen] reported directly to the minister. I got called more often to write briefing notes for the minister for questions, not about biomedical research, obviously, but about what kinds of research we were doing in epidemiology or breast cancer care. There's no question that every time you got to write a briefing note or meet the minister you'd pitch some of the stuff that you wanted to pitch and try to explain. I think the two ministers who really got it were the minister of health, the Right Honourable Allan Rock, and the Right Honourable Paul Martin, then minister of finance. Minister Rock really understood what we were talking about. He really was supportive. And I think Paul Martin was supportive as minister of finance. But you had to be assertive and confident. And I would say to the minister, "Of course you have to fund biomedical research, but you can't wait to organize your health-care system until you get a cure for something — that just doesn't make any sense." And I'd always be presenting the other side of the argument, that there are things we need to know about the impact of disease on families and about risk factors. We need to know a lot more about the payoffs of health promotion instead of pouring all of this money at acute health-care problems. We need to be preventing a whole lot of this stuff. Of course everyone who met with MPs and ministers were trying to influence the amount of research funding available and the direction/focus of research. There are many groups, particularly in medicine and the health-care industry, who have powerful lobbying capacity. The increases in research funding through the federal funding agencies over the past several years, and the evolution of MRC to CIHR, were the result of many groups who had input into the discussions, and nursing was certainly one of those groups.

To what extent do you think your arguments resonated with them, or do you think those reports, like the Lalonde and Epp reports, were ideological?

I think most politicians and public servants understood and many were highly committed, but the political influences that determine the final decision have more to do with powerful lobbying than with what makes sense. One thing I learned: If I was to recycle myself, and I don't think I will, I would build a powerful lobby behind me. Because universities, faculties of medicine…if you look at the Association of Faculties of Medicine, which is the equivalent of CASN, the resources they have are phenomenal and their power is immense.

In your role as Executive Director of CNA, what was happening to influence nursing research?

The way that we pitched it, we knew that we were heading into a human resource crisis. The nursing shortage was deepening and there were pockets where certain kinds of expertise weren't there, and we were also pushing evidence-based practice and practice guidelines, things like that. From my perspective, to get the federal government to put money into anything that would help nursing, it had to be something that the provinces wouldn't likely do or object to. The federal government wasn't going to say, "Well let's put $20 million to hire more nurses." How would they administer such a thing? But they could fund research. We knew they were creating CIHR. We knew they were increasing science and technology funding. I had excellent connections when I was at NHRDP, because I represented the deputy on many things dealing with science. So I was on the federal review of science and technology committee and on several reviews of Health Canada itself. I knew where the government was likely to put money. That's how we at CNA settled on research. And we brought the union along by saying, "Look, you care about the workplace and its impact? We need research on that. You need evidence to argue for some of the things you want." And they bought completely into this argument. We finally had a front that was not divided. CASN supported it. CNA supported it. The provincial and territorial nursing organizations supported it. The unions supported it.

We asked for about $200 million and we ended up with $25 million. It wasn't that much money, but, again, a modest investment led to a significant payoff. And another thing that we argued, and that a lot of people could understand, was that it takes decades to develop capacity. Nursing research isn't going to hit its peak for another 20 years.

The argument was sort of double-edged with finance minister Paul Martin. It was that the public was concerned about the quality of care. The public was and still is worried about the shortage of nurses. The federal government has to be seen to be doing something. It didn't take that much to sell it to Minister Martin and his staff.

And also the shortage was affecting medical practice. So what role did medicine, the medical lobbyists, play? Was there an alliance between the medical lobbyists and CNA when it came to pushing an agenda for nursing?

Well, CMA [Canadian Medical Association] didn't push any agenda for nursing, although they would support us on most things if we needed them. And we also had HEAL, the Health Action Lobby, comprised of about 30 groups, that I co-chaired for more than 5 years. We were a pretty close group, actually. We often lobbied government together.

But an interesting story where medicine, the research enterprise in medicine, suddenly realized it needed nursing was when centres of excellence were being funded and when CFI [Canadian Foundation for Innovation] was created. A group of medical scientists had applied for a stroke network. They were not successful on the first go around and I have a feeling that I had both a back door and a front door on this. I was asked to review that application. And I critiqued the absence of nursing and stroke prevention. I said, "You know, nurses can run blood-pressure clinics anywhere, and the evidence is that when they do they prevent a significant number of strokes, and that's not in here." The lead scientist on that grant application made an appointment with me at CNA, because I had obviously not reviewed it from CNA; I had reviewed it when I was in government. And he asked, "How can I get nursing support involved in this?" I gave him some advice and he took a nurse researcher on board as part of the team. They were successful on the second round. And I also think the breast cancer initiative really changed how a lot of this is done, by involving policy-makers and the public by demonstrating that research priorities can be established with a collaborative approach and not just one group.

So in your role at CNA there were important efforts to secure more funding for research. Who were the major players?

We made the decision to go for research because we wanted something from the government. We got people on board, we had documents, we produced a lobby, we met with committees, we met with MPs. We met with the minister of health, obviously, because one of the things that you learn is that you don't go to the minister of finance without letting the minister of health know. So we secured a lot of support along the way that did help. And we had people like Dr. Dorothy Pringle, Dean of the Faculty of Nursing at the University of Toronto, and other nursing leaders who would reinforce what we were saying at any opportunity they had.

Who were the major players at that time, to secure capacity building and research funding?

Jonathan Lomas, head of CHSRF at the time, got on board and supported us. As I said, the union understood and supported us. The Office of Nursing Policy — and at that time it would have been Judith Shamian — was obviously very supportive of what we were doing. And Pat Griffiths had taken on the leadership of CASN. She was supportive of what we were doing and helped. I also started a national forum to bring nurses from across the country together. CNA represents more than half the nurses of Canada.

I wanted a national forum to bring all nurse leaders together, because I knew from government and my work with CNA that we were too divisive on the big issues, that we weren't going to get anywhere unless we could find a way to come together to decide what we believed in and to agree on actions. Some of that was focused on research and trying to get an investment. And other groups, like Heart and Stroke, had targeted monies for nursing. And there were now precedents for the support of nursing research to develop capacity. There was the NHRDP/MRC initiative in the 1980s, and later the Heart and Stroke Foundation of Canada, and a few of their provincial counterparts had targeted initiatives to develop nursing research and researchers. Finally, you ask who were the major players — there were so many. The lobby we formed called The Quiet Crisis was very well organized, and many, many nurses sent postcards and met with their MPs. In Ottawa we lobbied the ministers of health and finance. We gained the support of other national health organizations. Our member provincial associations and colleges lobbied their provincial governments to support our request for targeted funding for research.

Were there low points, where you thought, "Oh, we aren't going to get this thing; we're not going to get what we need"?

The low point was finding out that we were going to get about 10% of what we had requested. And the other low point, where I just had to swallow it, was that the money that we had successfully received was going to go to CHSRF and we would lose a lot of control over it. But $25 million was better than nothing and the fund would have to support nursing research in some way. I wasn't as excited about it as I might have been, but I had to go in front of the cameras the night the budget was announced and sound positive.

But that's just one aspect of funding. The other low point of capacity building, PhD programs, or giving money for —

Every time there was an initiative to support nursing it was a high point, because we knew how many years of grunt had gone into it — people wanting it and trying. We were always after some kind of investment in nursing and nursing scholarship. The founding of CNF, actually — we shouldn't forget that — that was nurses at least trying to help themselves. That's way back. But CNF benefited from the Nursing Research Fund. CNF got money for clinical nursing research. When I found out that the nursing fund was going to CHSRF, we knew that a lot of what we wanted was clinically based research to improve practice. We set up a committee and said, "This is your research advisory committee." We put a few key people on it and convinced CHSRF that at least $5 million of the $25 million be designated to support clinical nursing research. And since they couldn't do that under their mandate, they could have a partnership with CNF. It took a bit of hammering out. CNF was really committed to making sure it worked. We went out and met with various agencies that funded some nursing research — Heart and Stroke, NCIC, Alzheimer's and so on — and negotiated partnerships to contribute one third of the funding from the CNF/CHSRF clinical research money and the partners would contribute two thirds. In some instances it had to be 50/50 but in the end we added a very large amount of money and stimulated growth of clinically based research as well. At the end of the day all of these initiatives have had a significant positive impact on the number of nurse researchers and the amount of funding to support researchers, research programs, and capacity development. I hope the Nursing Research Fund will be renewed for another 10 years at a higher level of funding.

When you look back over these 10 years, given the seeds that have been planted over the 20 years before us, have expectations been met?

I'm astounded at just how much money is going to nursing research. Nurse scholars are doing extremely well. They are very competitive and hold important leadership roles.

As we look to the future, what are some of the things we need to be concerned about?

The same old, same old — the power of medicine. What is going to change, though — and I'm committed to this although it isn't going to be easy — but the disciplinary boundaries are going to continue to crumble and we're going to have more integrated teams, just like the pain clinic I helped to establish in 1975 was interprofessional; we worked together. And more and more areas are developing in the same way. Nursing expertise is integral to the clinical teams and the research teams. I think we're going to see much better training in the future in terms of research and the methods that we use. And we're also going to learn, assome nurses are beginning to do, more basic research. And you're going to see teams where they have programs that span different methodologies and different levels of analysis, from the cells to the psyche. You're going to see a lot of programs and centres of research that are very much interdependent.

What do you think we should be concerned about when it comes to funding?

You always have to ensure that the relevance of your work is understood. We can't just assume that everything we're doing is relevant. We have to stay on top of the problems in health care and health promotion.

So it's really being relevant and staying relevant and the funding will follow from that. Is there any advice that you have for future leaders about funding?

One of my concerns about the next generation is that the successes we've created may have some deterrents associated with them. There's a generation of fabulous researchers out there who want nothing to do with administration. And they want less than nothing to do with politics. Unfortunately we still need somebody to do that work. In our generation we had no choice.

Many young researchers today don't see the point of some of this stuff. But we need leadership that does know about it. One of the things that I personally want to work for, in the next 10 years at least, is leadership development for nurses. My belief is that if we actually did interprofessional leadership development we might be able to share those human and social values that underlie health and health care. And if we shared those values across disciplinary lines we would work much better together, clinically and scientifically.

Do you think that this generation might be focused on their research but as they get into their fifties and sixties they might then turn their attention to this kind of giving, or do you think they'll be so focused on themselves and their own research —

I think eventually some of that might happen. My concern is that there could be a bit of a dip. So we need to make sure that there's somebody in the Office for Nursing Policy at Health Canada and CNA and the head of CASN who have this kind of political savvy.

Final word, final statements of wisdom?

Actually, when you think about the development of nursing science, I think the last 10 years have really been remarkable, comparatively speaking. And we're on a roll, and I think we'll keep going. We've certainly got — when you can remember a handful of people — now we've got hundreds.

It's remarkable that we have lived to see this period.

When you see your own students who have now become deans and chairs and leaders of all types. And I think we'll see more men in nursing — more women in medicine, more men in nursing.

Thank you, Mary Ellen, for a fascinating hour.

Mary Ellen Jeans, RN, PhD, is President and Chief Executive Officer of Associated Medical Services, Inc., Toronto, Ontario, Canada. She served as Director General of the National Health Research and Development Program from 1992 to 1996 and as Executive Director of the Canadian Nurses Association from 1996 to 2001. In addition, she was Director of the School of Nursing, McGill University, Montreal, Quebec, Canada, from 1983 to 1992 and Editor-in-Chief of CJNR *from 1984 to 1993.*

CJNR 2009, Vol. 41 Nº 1, 41–45

Funding for Nursing Scholarship, Research, and Capacity-Building: An Interview With Dr. Dorothy Pringle

Sean P. Clarke: *What were some of the historical milestones and turning points in securing funding for nursing research and capacity-building?*

Dorothy Pringle: I would go back a little further than 10 years — to 20 years. Because 20 years ago nursing was dependent on funding from the National Health Research and Development Program. NHRDP was essentially our only source. MRC [Medical Research Council] had not to that point been particularly supportive of nursing research. In 1987–88 there was an announcement of a joint NHRDP/MRC initiative for 5-year non-renewable career awards for nurse researchers. This was the first money that covered 75 to 80% of faculty members' time. When this initiative came into being, we began to be able to identify the top nursing researchers in Canada. Early names included Hilary Llewellyn-Thomas, Annette O'Connor, Celeste Johnston, and Lesley Degner. Those researchers were given a leg up. In turn, through the excellent calibre of work they produced, they gave credibility to the notion of funding nurse researchers.

In the mid-1990s Henry Friesen made the decision to expand MRC's mandate to all of the health sciences, not just basic health sciences. And nurses were integral to that transformation. Mary Ellen Jeans, by the time of these developments, was Director General of NHRDP and also helped create new federal funding opportunities for nurses.

A major accomplishment was securing access by nurses seeking doctoral training to relatively higher levels of salary support from training awards — levels that were previously given only to physicians, dentists, veterinarians, and pharmacists seeking PhDs. These higher levels made securing research training a viable career option for nurses several years into their careers.

In terms of research funding, nurses were looking not to have exceptions made to accommodate their research career trajectories. They wanted opportunities to succeed. And when these opportunities were presented they made use of them. Not only did the first cohorts of funded nurse scientists produce excellent return on investments, [but] the availability of training and career awards helped change thinking about research and [created] positive environments for productivity for all nurse faculty. These awards, and the success of the recipients, established in nursing deans'/directors' minds the need for faculty to have protected time in order to develop sound research programs.

In the late 1990s the Canadian Health Services Research Foundation [CHSRF] was established. This benefited our emerging strength in nursing administration. Those scientists now had a source of funding not available through any other funding body at that time. When Mary Ellen Jeans, as CNA [Canadian Nurses Association] Executive Director, convinced the federal government to make $25 million available for nursing research over 10 years, the funds were entrusted to CHSRF, and this benefited nursing research more broadly. Approximately $500,000 per year was allocated to the Canadian Nurses Foundation to fund clinical research, in addition to the funds from CHSRF to stimulate nursing administration research. This fund also created five nursing chairs across the country: Linda O'Brien-Pallas, Lesley Degner, Alba DiCenso, Nancy Edwards, and Janice Lander. This was huge, particularly when considered along with the research scholar awards held through the MRC/NHRDP program. Finally we had excellent researchers who could devote most of their time to research.

In 2001, when the Canadian Institutes of Health Research [CIHR] emerged, NHRDP and MRC were both folded into this body, with perhaps more of MRC's traditions taken up. However, by this time nurse researchers had really demonstrated that they could succeed on the funding playing field and critical masses of scholars were coming together in university nursing schools from coast to coast, sometimes in clusters that had national recognition. A clear sense of research-intensive schools and faculties of nursing had taken root.

Over the past 10 years, drawing on successes and developments from earlier on, nursing has become an important and recognized player in the Canadian health research funding world — no more exceptions needed or requested for them. Drs. Nancy Edwards and Joy Johnson are directors of two CIHR institutes, nurses sit on advisory boards across CIHR and chair peer-review committees, and CIHR leaders have become well-informed about nursing and respectful about the research capacities of nurse researchers. And when Nancy Edwards was appointed to CIHR's governing council, she rapidly ascended to become its chair.

To sum up, over the past 10 years nursing research has become accepted into CIHR, led by the researchers who received funding in the MRC/NHRDP initiative.

The past 10 years has been a major turning point in funding for nursing. How did you prepare the ground?

I did a little, along with a lot of other people. I managed to become an insider on the funding front. In Canada, the path to influence is less through lobbying and more through demonstrating competence and expertise and showing that you'll step up when called upon. You demonstrate competence, which opens doors in the power structure in funding agencies, and you become one of the "go to" people who get called upon, which helps in gaining inside knowledge critical to success. And then, of course, you use the power you've gained judiciously. It's important not to use these opportunities for personal gain, but to use them to advance the careers of colleagues and students whenever possible.…

I haven't been the only insider. Researchers themselves have a remarkable ability to bring ideas to competitions on the basis of the high quality of their work, and later by establishing their connections within funding agencies.

Who were the major players?

I have to say the researchers themselves who capitalized on the opportunities to grow their programs under the big national funding sources, especially CIHR. But a number of nurse researchers — I think of Drs. Kathryn King and Heather Arthur in cardiovascular nursing research and Lesley Degner in cancer in particular — have built a national profile in the foundations dedicated to advancing research for particular diseases, and have had enormous influence on the access of nurses to existing and emerging programs through these groups.

Why has the past decade been such a great time for nursing research?

In a word, PhD program development. For the first time, we needed more than two hands to count the number of good nurse researchers in Canada. The early 1990s saw the development of the big doctoral training programs in the country, and by the late 1990s they were producing high-quality graduates. We still need more nurse researchers, but until we began to have this critical mass of well-prepared investigators we weren't in any position to advance things to the level they are at now.

Disappointments, surprises?

When CIHR was being developed you could apply to develop an institute and the CHSRF made money available for the purpose of developing application. CIHR had made it very clear that they were not going to fund discipline-specific institutions. Nursing decided to try anyway. The CNA, CANR [Canadian Association for Nursing Research], and CASN [Canadian Association of Schools of Nursing] applied for and received funding to develop a proposal for an institute — we held a 3-day meeting at the University of British Columbia. We were split.

Half of us were saying that we should pay attention and not write a nursing-specific proposal. Half of us felt that NINR [National Institute of Nursing Research] was so successful in the United States under the National Institutes of Health structure that it was too tempting not to propose something similar. Caregiving, a broader term that could accommodate many areas of research nurses were interested in but encompass concerns beyond the profession, was the umbrella term we worked on. So we proposed a National Institute for Nursing and Caregiving as a compromise. It didn't get funded — not accepted. At the time it was disappointing, but it forced us to get a toe-hold in the institutes that were created. Nurses weren't segregated in their own institute and so established their presence on the inside of the multidisciplinary institutes that were formed. In retrospect, if we had been successful with the proposal for a NINR-like institute we would not have seen the development of nurses as insiders at CIHR to the degree that we have.

More recently, I think that while at the beginning of the past decade funding was more available to nurse researchers, we're now in a phase where CIHR's funding is not increasing fast enough… At one time a lot of researchers were funded as new investigators and then moved on to career awards and chairs. Now, as the result of funding cuts that have resulted in the cancellation of scientist and senior scientist awards, the path doesn't exist the same way. We have to figure out what we can do to secure lines of funding for excellent nurse researchers across their careers, to help them maintain their productivity.

If you were to put on your prophet's hat, where do you think nursing scholarship/science will be 10 or 20 years from now?

The development of nursing research in a country is an incremental process. I don't necessarily see any striking changes in the next decade or two…nursing research will continue to grow and our discipline — and especially our best scholars — will be even bigger players in the pond.

What do we need to be concerned about?

We are handicapped by not having a clear national voice for nursing research in Canada. Stakeholders complain about [lack of clarity] regarding which people to go to when they have questions or need representatives — apart from individual researchers… We don't necessarily have only one view of nursing research in Canada, but we need a clear voice that represents all of us.

We need to be cautious about the balance between education and research in academic units that has historically handicapped the development of research programs. The education enterprise can be huge, and the details involved in coordinating large programs can swamp research if we're not careful.

And I don't think we've established ourselves (except maybe for RNAO [Registered Nurses' Association of Ontario]; CNA is developing this capacity) as the "go to" discipline for health-policy issues. I think we have to have a louder and more authoritative voice. I think our researchers are some of the best people to do this, because they can speak from an evidence-based perspective. It's not common enough for nurse researchers to be consulted by the press or to come forward with new policy suggestions. When you read Canadian Medical Association documents and attend CMA conferences, the minister of health is there and policy proposals are being actively discussed. We're not there in nursing yet; it's part of an evolutionary process.

Any advice to this generation of leaders with respect to funding?

Try not to whine [about nursing's status in the world of research]. It doesn't help much and we don't need to. CIHR has been good news for nurse researchers. We're now insiders at CIHR and are an accepted part of its work and its funding — not exceptional or remarkable.

Never frame efforts to advance funding opportunities just for nurses; work to advance opportunities for health professionals on the applied side who may need special programs and mechanisms and considerations to advance their research. Family medicine and the rehabilitation professions are some of our natural allies in terms of the types of career paths their members pursue, the questions that are of most interest to them, and the research designs they employ.

Finally, organized nursing in Canada has to be seen as an active and strong supporter of CIHR every chance it gets. The other professions are there. We need to be seen as part of the research establishment. It might cost us a bit of money, but it's the price you pay for being a member of the club.

Dorothy Pringle, OC, RN, PhD, FCAHS, is Professor Emeritus and Dean Emeritus (having served as Dean from 1988 to 1999), Faculty of Nursing, University of Toronto, Ontario, Canada. She is also Executive Lead for Health Outcomes for Better Information and Care, Ontario Ministry of Health and Long Term Care, and Editor-in-Chief, Canadian Journal of Nursing Leadership.

CJNR 2009, Vol. 41 Nº 1, 47–55

Discourse

Looking Back, Looking Forward: Conceptual and Methodological Trends in Nursing Research in Canada Over the Past Decade

Joan M. Anderson

I am deeply honoured to have been invited by Professor Laurie Gottlieb to contribute to this anniversary issue. Since the last anniversary issue, in March 1999, nursing research has gained new ground in Canada, and *CJNR* has been in the forefront, publishing topics at the cutting edge of nursing science. I want to reflect here on the outstanding achievements of the Canadian nursing research community in the past decade and some of the factors that shaped these developments. I also want to consider conceptual challenges and opportunities for the future.

Looking Back

Opportunities Over the Past Decade

The giant steps forward within the fairly short time span of 10 years have been made possible, in part, by the synergies created through the resources that became available to the nursing research community, enhanced research training, interdisciplinary collaboration, and a climate that has fostered the communication of nursing research. One of the milestones in Canadian health research has been the launching of the Canadian Institutes of Health Research (CIHR) in the year 2000. This has had a profound impact on the development of nursing science in this country and on the conceptual shifts over the past decade. CIHR's mandate is to "excel, according to internationally accepted standards of scientific excellence, in the creation of new knowledge and its translation into improved health for Canadians, more effective health services and products and a strengthened Canadian health-care system" (CIHR Web site: http://www.cihr-irsc.gc.ca/e/7155.html). Without a doubt, CIHR's conceptual focus on health research (inclusive of but not exclusive to medical research), with the emphasis on research training, interdisciplinarity, partnerships, collaboration, and knowledge translation, has benefited nursing research. The mandate of CIHR has created new opportunities for investigation in substantive areas that might have remained untapped in the nursing community. Funding opportunities have opened up investigation not only in biomedically oriented and clinical research but also in population health and health services research, with attention to the complex historical, sociopolitical, economic, and cultural contexts of health. These concepts are central to the development of nursing science, as we seek to understand the tangled nexus of the human experience of health, illness, suffering, and recovery across population groups.

The launching of research-intensive doctoral programs in nursing across the country, and the pursuit of doctoral studies by nurses in complementary disciplines, prepared a generation of researchers to be ready for new funding opportunities as they came along. But all of this did not happen by chance. I would be remiss to reflect on how far we have come without acknowledging the leaders who paved the way. Not only have nurse researchers provided leadership in CIHR since its inception, but generations of nurse leaders before them worked tirelessly and selflessly to promote baccalaureate education for nurses, launch master's programs, and, later, establish research-intensive doctoral programs in nursing. This was often done in a climate where scepticism about the merits of academic nursing ran rampant. Many of our leaders engaged with governments, funding bodies, and academic administrators to interpret the discipline of nursing to them, even when faced with questions about the legitimacy of nursing as a profession. During the transition from Medical Research Council to CIHR, many nurse leaders played a key role in the restructuring process, and in charting the new direction for health research in Canada. They insisted on a broader definition of health research, inclusive of different health disciplines, and on research conducted in partnership with other scientists, clinicians, government policymakers, health-care administrators, and consumers. Nurse leaders have continued to interpret nursing science and nursing scholarship to their colleagues from other disciplines on peer-review panels. They have done so in order to open up funding opportunities for new generations of nurse researchers. So, to use a well-worn expression attributed to Sir Isaac Newton, if we "have seen further, it is by standing on the shoulders of Giants."

Conceptual and Methodological Trends

Alongside the increased opportunities for research funding, the visionary leadership of the *Canadian Journal of Nursing Research* over the past decade has been key in the communication, and hence the development, of nursing science in Canada. In reviewing Journal issues as far back as

1969, one can track the conceptual shifts that have marked our profession. For example, a question posed in the November 1969 issue was "Profession or Union: Who Will Call the Shots?" (Gilchrist, 1969). Concern with "the profession" has been giving way, over the decades, to development of the knowledge base for nursing practice. Among the areas addressed over this past decade have been issues pertaining to health, illness, healing, and health-care delivery systems, and how health-care systems *shape* the experiencing of illness, across the lifespan and across different population groups (including Aboriginal peoples, women, and people living in rural communities), and the translation of this knowledge into practice and policy.

There is emerging attentiveness to examining the social context of experience and to addressing the complex ethical issues that underpin the advancement of science, practices within health-care delivery systems, and new approaches to conducting research. One surmises that the scope of the research now being undertaken will continue to shift, and hence continue to redefine the conceptual boundaries of our discipline. We know that knowledge is "not just out there" waiting to be "discovered"; it is constructed within complex sociopolitical, cultural, economic, and historical contexts, and is shifting, partial, and incomplete. So, alongside our deep commitment to translating nursing knowledge into practice, we are always exploring innovative strategies for translation that make transparent the tenuous nature of "truth" and its contextual embeddedness. Increases in operational funding, new opportunities for research training, and improved communication technologies, among other factors, are all coalescing to fuel knowledge construction and translation. Not only are we witnessing a shift in the questions being addressed; a new approach is being taken to addressing "old" questions. For example, Estabrooks (2008), in discussing the emergence of knowledge translation science over the past 10 years, apprises us of developments since the publication of the Research Utilization issue in June 1999, namely opportunities for international collaboration, joint research, shared trainees, and so forth. Similarly, Jillings and Thorne (2008), in their Guest Editorial for the September 2008 issue on Chronic Illness Management, tell us: "This issue of the Journal differs from previous issues dedicated to the topic of chronic illness in that it highlights a new conceptual 'spin' on the theme of documenting the chronic illness experience" (p. 5).

The new conceptual "spin" on "old" topics goes hand in hand, I think, with our receptiveness to different methodologies and our conceptualizing of "science" and "scientific rigour." The legitimacy of different methodological perspectives necessary to pursue the broad spectrum of research that makes up our discipline is now more widely accepted. We have made significant strides, both in conceptualizing the content and scope of nursing knowledge and in using methodological approaches that will allow us to pursue complex questions. As I look back on nursing research in Canada and internationally, I am struck with how far we have come in the debates about methodological issues. Clearly, we are moving beyond the polarizing, sometimes simplistic, either/or, quantitative/qualitative, positivist/interpretive, critical perspectives that were so prevalent in the 1980s and into the 1990s. For the most part we recognize the multiplicity of perspectives that make up our science. As we have matured in our interpretation of science, and as we have embraced the complexity of our discipline, naturalistic, critical, and interpretive methods of inquiry and other innovative approaches have found a place in the construction of nursing science, alongside rigorous quantitative methods of inquiry. We now accept that the production of a rigorous science of nursing can be accomplished from different ontological, epistemological, and methodological perspectives. We have shown a willingness to explore new terrain. As Estabrooks (2008) says in her recent Guest Editorial: "We also have contributions that will challenge readers to think outside of their usual comfort zones. They are published deliberately in this issue of *CJNR* because it is important for us to think broadly and creatively" (p. 13). She refers to articles on knowledge translation that review, for example, appreciative inquiry as a knowledge translation intervention and that provide a feminist critique within knowledge translation science.

We now take "our place at the table" among scientists and scholars from other disciplines, as leaders in explaining innovative research methodologies and how we can bridge different disciplines. In fact, as I speak with colleagues from other disciplines I find that many are now looking to nursing scholars for leadership in different methods of inquiry. Many of us continue to explore how different perspectives complement one another, so we can do better science and generate knowledge that will be translated into practice and policy. We acknowledge that to understand and respond to the complex phenomena that are nursing's prerogative, and to engage in interdisciplinary research, we need to be able to measure, describe, and interpret — quite often in the same program of research. No longer do some of us believe that feminist and postcolonial inquiry, for example, can be pursued solely through a "qualitative" lens; no longer do we think of gender studies as synonymous with "women only." In fact, a nurse scientist, Dr. Miriam Stewart, led the CIHR Institute of Gender and Health, as its first Scientific Director, to promote interdisciplinary research, to forge new conceptualizations of gender studies, and to open up this area as a field of inquiry inclusive of men and women, boys and girls. We now recognize that the inclusion of men and women in gender studies does not minimize, diminish, trivialize, or obscure women's health issues; to gain greater conceptual clarity we need to view the issues in broader perspective.

The research conducted under the umbrella of the Institute of Gender and Health (now being led by Dr. Joy Johnson, another nurse scientist), sometimes in partnership with other CIHR institutes, provides an excellent example of how biomedical scientists, nursing scientists, social scientists, and scholars from other disciplines have developed programs of research that require the use of different methodological perspectives. Perhaps more importantly, researchers have learned to make the distinction between multidisciplinary research and interdisciplinary research, the latter requiring the learning of a new language to facilitate the construction of new knowledge beyond the boundaries of any one discipline.

Put succinctly, many nurse researchers now acknowledge that addressing complex questions requires interdisciplinary collaboration and multiple methods — measurement and rigorous qualitative methods go hand in hand. As Thorne (2008) puts it, "nursing indelicately straddles the social and biomedical sciences to find its methodological direction" (p. 15). By recognizing the strengths that different theories and methodologies have to offer, we can creatively explore new ways to address pressing issues in health and health care. Furthermore, receptiveness to different epistemologies and methodologies has allowed us to address questions that previously we did not think it possible to address. As we celebrate how far we have come, we must look to the future and contemplate the challenges that lie ahead, because with challenges come new opportunities.

Looking Forward: Conceptual Challenges and Opportunities

Reading through back issues of *CJNR* leaves me with no doubt that nurses have been deeply concerned with a broad range of topics, including the biomedical aspects of disease, the human experience of illness, and the delivery of health care/illness care. These issues cut across population groups. The increasing attentiveness to *the contextual dimension of health and illness* is striking. This marks a major shift in the conceptualization of nursing knowledge over the past 20 years, and especially during the past decade, as we have gained deeper insights into the complex context in which human experience is nested. Alongside this, knowledge translation science as a topic for nursing research has loomed large, and one expects it will continue to be pivotal in the decade ahead.

The focus on "context" meshes well with the discourse on the social determinants of health that is now centre stage in health research. It is not that social determinants are always named as such, but pertinent concepts are finely threaded throughout many of the Journal's issues, such as those on home care, culture and gender, women's health, and chronic illness. One focus issue is devoted to a social determinants perspective. "The strength of a social determinants perspective," Wuest (2006) tells us,

> is its acknowledgement of the influence of social context, at macro and micro levels…, not only on health outcomes but also on patterns of promoting, maintaining, and regaining health. Neither biology nor personal responsibility are ignored, but rather they are understood within the context of social, economic, environmental, and political contexts at the societal, familial, and individual levels. (p. 3)

One expects that a social determinants perspective will continue to gain ground in nursing research, given the ever-expanding literature on the topic and the conceptual issues that remain to be addressed. Raphael (2007) notes: "Study after study finds that the experience of living under conditions of material and social deprivation is the best predictor of health outcomes, and its effects swamp the influence of behavioural risk factors such as diet, physical activity, and even tobacco use" (p. 239). The Canadian Nurses Association underscores the importance of social determinants in nursing practice: "Working on the front lines of the health care system, nurses see the impact of the social determinants of health every day" (2005, p. 5).

So, my intention is not to privilege the social determinants perspective over other areas of nursing science. Rather, I want to draw attention to major conceptual trends over the past decade, and what is sure to be in the forefront in the decade ahead. The social determinants of health intersect in powerful ways with nursing's mandate. This body of knowledge is as relevant to the nurse who practises in an acute-care setting as it is to the nurse who practises in a walk-in community clinic or a wellness clinic. The recovery of a patient from an acute illness, for example, may well depend on the economic resources available to him or her and the social networks within the social environment; similarly, material or social deprivation may play a major role in the quality of life of a woman living with a chronic illness, or a family caring for a chronically ill child, or an aging person living in isolation in his or her home. Understanding these concepts and how they operate in people's lives enables nurses to work with their patients, to harness the resources that foster health or recovery from illness. I am reminded of a story that was told to me by a nursing instructor some time ago. A patient to whom one of her students was assigned was quite restless after his surgery. According to the nurse on the previous shift, he was a "difficult patient" who was not "complying" with the medical regimen and was putting his postoperative recovery at risk. When the student engaged with the patient, she learned that he was worried about his finances, his work situation, and the welfare of his family. The student was able to work with him so that he could deal with the issue (this might have been no more than helping him to set up his immediate environment in a way that allowed him to make some phone calls). After this intervention by the student, the patient became calm and continued his recovery without incident. While this anecdote may not portray how we conceptualize social determinants in all of its complexity, I use it to show that a nurse's appreciation of the social context of people's lives (reflected in the minutiae of everyday existence) can have a significant impact on patient outcomes.

But as important as understanding social context is, the social determinants of health as a framework for nursing research poses conceptual challenges that are yet to be resolved. Wuest (2006) tells us, in referring to research on women's health:

> While nurses recognize the importance of a social determinants model…, rarely do they explicitly situate their research studies in this framework. More often, the social determinants framework is introduced after the fact. If a social determinants model guides the research, frequently the focus is on one or two determinants or solely at an individual level. (p. 3)

One of the challenges in pursuing this area of research is, I believe, a challenge that many social scientists have grappled with: *making the conceptual links between the micro level of experience and macro social structures* and addressing the complexity of intersectionalities among the ever-growing list of social determinants and the pathways that mediate relationships. For example, Raphael (2007) argues:

> Race is also becoming an important pathway mediating the poverty and health relationship. The poverty situation of Aboriginal Canadians is well established.... Other people of colour in Canada earn less income, are more likely to be unemployed, and experience more precarious employment than other Canadians.… This all comes together to produce higher rates of poverty for people of colour in Canada. (pp. 253–254)

The Canadian Nurses Association also recognizes that "Aboriginal people and people of colour are more than twice as likely to live in poverty and three times as likely as the average Canadian to be unemployed, despite their level of qualifications" (2005, p. 4).

Some scholars have been trying to explain how concepts such as "race" and "poverty" — the ones mentioned above — intersect with one another in determining health. The attempt to understand intersections is not new. As far back as the early 1990s, scholars such as Patricia Hill Collins (1990) provided insights into the workings of intersections (e.g., gender, race, and class), and Rose Brewer's (1993) thoughtful work on the "simultaneity of oppressions" has provided the conceptual scaffolding for understanding intersections not as additive but as multiplicative. Yet there are conceptual challenges. How do we conceptualize "race," for example? Often this term is conflated with "ethnicity," "culture," and the like; some conceptualize it as sociopolitical, others as "biological." And how do we make the *conceptual link* between race and employment? *Why* is "race" a pathway to poverty? And how do we conceptualize "class" relations in intersection with other health determinants? Estabrooks (2008) makes an excellent point: "A thoughtful class analysis or series of class analyses is long overdue, and is of particular relevance to nurses working in the rigidly hierarchical systems still found in hospitals and other health-care organizations" (p. 14).

The cataloguing of determinants, or the examination of determinants in isolation from one another, is not what is needed at this time. We need to grapple with conceptual issues and move towards an understanding of how determinants work in order to construct knowledge that can be translated into both policy and practice. This will require theoretical and methodological perspectives that allow us to engage in historical, social, political, and economic exploration that encompasses both rigorous narrative description and complex quantitative analyses, so that we can unpack the conceptual linkages between micro and macro levels. This kind of rigorous theoretical and methodological work may be beyond the capacity of any one discipline.

The opportunities to undertake the kind of rigorous work that is needed are to be found, I believe, in the structure of health research in Canada. The different CIHR institutes provide opportunities for collaboration among disciplines. With confidence in the science of nursing, we can move beyond the boundaries of our discipline, to work in collaboration with others to address questions that are complex and multifaceted. But the construction of interdisciplinary knowledge takes time and energy. The time-release opportunities for researchers available through CIHR should therefore facilitate the kind of engagement that is needed. The training opportunities for undergraduate and graduate students through CIHR are creating a new generation of researchers who are able to navigate the interdisciplinary terrain. Our discipline stands to benefit; the synergies created through interdisciplinary dialogue will strengthen nursing knowledge for translation into policy and practice.

Generations of nurses before us harnessed opportunities and demonstrated the political skill to move the profession forward to a place of which we can all be proud. The current generation of nurses must use the knowledge we have acquired, and construct new knowledge to advance nursing practice and strengthen health-care delivery systems. We can combine our knowledge with wisdom to work within health-care systems and political systems to bring about policy change that will address the complex contexts of health and illness. And *CJNR* can help us to move our science forward by encouraging the same boldness and creativity in developing and sharing our ideas that it has fostered in the past decade.

References

Brewer, R. (1993). Theorizing race, class and gender: The new scholarship of Black feminist intellectuals and Black women's labor. In S. M. James & A. P. A. Busia (Eds.), *Theorizing Black feminisms: The visionary pragmatism of Black women* (pp.13–30). London and New York: Routledge.

Canadian Nurses Association. (2005). *Social determinants of health and nursing: A summary of the issues.* Ottawa: Author.

Collins, P. H. (1990). *Black feminist thought: Knowledge, consciousness and the politics of empowerment.* Boston: Unwin Hyman.

Estabrooks, C. (2008). [Guest editorial.] Renegotiating the social contract? The emergence of knowledge translation science. *CJNR, 40*(2), 11–15.

Gilchrist, J. M. (1969). Profession or union: Who will call the shots? *Nursing Papers, 1*(2), 4–10.

Jillings, C., & Thorne, S. (2008). [Guest editorial.] Shifting the rhythm of chronic illness care. *CJNR, 40*(3), 5–6.

Raphael, D. (2007). *Poverty and policy in Canada: Implications for health and quality of life.* Toronto: Canadian Scholars Press.

Thorne, S. (2008). *Interpretive description.* Walnut Creek, CA: Left Coast Press.

Wuest, J. (2006). [Guest editorial.] Towards understanding women's health through a social determinants lens. *CJNR, 38*(1), 3–5.

Joan M. Anderson, PhD, RN, is Professor Emerita and Founding Director, Culture, Gender and Health Research Unit, School of Nursing, University of British Columbia, Vancouver, Canada.

Memorable Passages From Editorials and Discourses of the Past Ten Years

Des passages mémorables tirés d’éditoriaux et de discours publiés dans les dix dernières années

CJNR 2009, Vol. 41 N° 1, 59–71

Highlights From Editorials Published in Volumes 31–40

Throughout North America, nursing is on the defensive, and sometimes on the offensive. As hospitals and other health-care institutions try to cut costs, they are sacrificing nursing care at the bedside and in the community. Hospital units are chronically short-staffed. Nurses are having difficulty finding full-time work. Demoralized and depressed at the conditions under which they must work, nurses are burning out. They are leaving the profession. Worse still, they are discouraging young men and women from entering the profession.

If the profession is to survive, we clearly need energized nurses who believe in the possibility of change and who believe that they will be able to practise their profession in the way they have been taught, dispensing what they believe is quality care. We need nurses who believe they can change the public system in ways that will result in more support for nursing practice.

Strengthening the position of our clinicians who are involved in direct patient care will require a concerted effort that is supported by nursing academics and researchers.

Nightingale said it best when she talked about nursing and the imperative of scientific observation. "In dwelling upon the vital importance of sound observation, it must never be lost sight of what observation is for. It is not for the sake of piling up miscellaneous information or curious facts, but for the sake of saving life and increasing health and comfort."

From **Addressing the Nursing Shortage:**
Researchers and Clinicians Unite
by Laurie N. Gottlieb and Suzanne Gordon
(*CJNR* 1999, Vol. 31 N° 3, 3–5)

The goals of peer review are several: (1) to help authors maintain credibility by identifying errors they might have overlooked, (2) to protect readers from inaccurate or irrelevant information, (3) to protect clients from practice that is based on unclear or incorrectly presented research results, and (4) to help editors determine which submissions merit publication… A well-executed review process will have beneficial outcomes even when a manuscript is not ultimately published: for the author, an improved manuscript and greater clarity of thought on the topic being addressed; for the reviewer, a firsthand look at the latest research and an opportunity to participate in the research community by helping to improve the work of colleagues. However, the literature on the topic of peer review suggests that the process also presents difficulties… It is slow, time-consuming, and subjective; and it can stifle innovation, harbour conflict of interest, be hurtful to the author if not conducted respectfully, fail to detect errors, and fail to respect confidentiality.

An excellent reviewer is one with high standards, knowledge of the subject matter — including an ability to cite references that the author may have missed — and an ability to identify key issues and defend his or her comments. An excellent reviewer can see how a manuscript might add to the body of knowledge in the field and communicates suggestions to the author clearly, making specific recommendations on content, organization, and style in a constructive and courteous manner. An excellent reviewer is able to go beyond an emotional reaction to the topic or the results, shows a willingness to learn from the author, and identifies any conflict of interest to the editors.

From **The Journey to Publication and Support for the Peer-Review Process**
by Anita J. Gagnon (*CJNR* 2000, Vol. 32 N° 1, 3–6)

Let me preface my comments by saying that I have personally experienced and observed sensitive, dignified, respectful, knowledgeable nursing care. But I have also experienced, far too often, both as a patient and as a family member, an appalling lack of nursing when quality nursing care could have made a significant difference in recovery. I have listened to nursing colleagues despair over the deterioration in the level and quality of nursing care. I have read research reports documenting how nurses spend a disproportionate amount of time on non-nursing activities and even provide very little direct patient care. The lack of nursing care has been ascribed to the shortage of nurses. This is too facile and superficial an explanation. The reasons for the lack of nursing care are more complex. They are embedded in nursing education; in the lack of a clear vision and framework for nursing; in an attitude on the part of nurses, their leaders, and others that devalues nursing activities and over-values medical activities; and in the resource-allocation choices of nursing leaders, front-line nurses, and others.

If front-line nurses, nursing leaders, and researchers do not enter into this discussion now, choices will be made for us that will result in a further deterioration and erosion of nursing. The nursing profession is an endangered species, as evidenced by the shortage of nurses. However, I believe that the shortage of *nursing* will result in a further shortage of *nurses,* rather than vice versa. This trend must be reversed before it is too late.

From **Shortage of Nurses, Shortage of Nursing**
by Laurie N. Gottlieb (*CJNR* 2000, Vol. 32 N° 3, 3–5)

Although every profession must re-interpret and re-think the way it fulfils its mandate in light of new scientific advances and changing societal realities, at the same time it must look to the past to ensure that it is being faithful to its basic principles and values. Continuing from Nightingale's legacy, for example, how does nursing "put the patient in the best condition for nature to act upon him"? A measure of our faithfulness to our principles and values is reflected in the choices we make and the directions we take. What does society require of nursing today, and what will it require of nursing in the future? How are we to address such needs within Nightingale's vision?

If I am correct and these *are* the conditions for nursing to flourish, then the present is a fertile time for nursing. Many have compared the technological revolution to the Industrial Revolution in its sweeping effects on society. The nature and rapidity of the current changes brought about by technology and in response to technology are resulting in a world that is, for many, overwhelming, stressful, and taxing beyond the limits which nature intended. We have only to look around us to see the direct and indirect effects of this new revolution: unprecedented increases in mental illness, physical breakdown, violence, and burnout. What is the role of nursing in helping people to deal with the effects of technology on their lives? What is our role as nurses in promoting health and preventing disease and breakdown, using technology but not substituting technology for care?

Clearly, in this age of increasing technological advances, we need the compassionate and knowledgeable services of nursing more than ever before. Ironically, with the new advances in technology we now have ways of measuring the efficacy of nursing acts, acts that until now have been devalued and minimized. For example, technology can now be used to demonstrate that when nurses provide comfort or stay with patients during periods of vulnerability they significantly affect a person's immunological system. Nursing is beginning to integrate these new technologies into its research, and must continue to do so. Again, Nightingale should be our guide. She understood that bringing about change required visible proof, provided in a truly persuasive form. One of Nightingale's greatest contributions was her use of statistical analysis, a novel approach in her time, to influence policy. She made the invisible visible, the trivial relevant and important to those who were in power. Nursing often hides behind "hard" indicators of impact (i.e., mortality rates) instead of tackling the "softer" outcomes of nursing care that may be just as significant to a person's health and well-being. Nursing needs to utilize the available technologies to ensure that it is heard. Advances in technology may be costly, but they may prove to be an important ally, showing that compassionate, knowledgeable, and skilled nursing is what society requires of us now and in a future world transformed by technology.

From **Envisioning the Future: Nightingale Continues to Guide**
by Laurie N. Gottlieb (*CJNR* 2002, Vol. 34 Nº 1, 3–6)

It takes about 40 years for cutting-edge ideas to find their way into mainstream thinking. The first application of our knowledge of genes took place in the early 1970s, in the screening for carriers of the defective genes involved in sickle-cell anemia and Tay-Sachs disease. In both of these cases, the disease was a simple, single-locus gene alteration with readily identified and unique genetic changes. For most inherited disorders, however, the underlying genetic alterations would have to wait until the start of the sequencing of large portions of the human genome, which culminated in the mapping of the entire human genome. And it took the discovery of polymerase chain reaction (PCR), a technique that allows for the amplification of DNA, for scientists to be able to carry out the actual sequencing. This knowledge has opened up an entirely new level of understanding about how gene alterations can contribute to disease, and the application of this knowledge has revolutionized and will continue to revolutionize the practice of medicine, and subsequently the practice of nursing.

These discoveries have changed medical practices, which, in turn, have required nursing to change. Because nursing has often been at the end of this chain of events, its role has been reactive rather than proactive. It has been unaware of the new developments in science and therefore has been hampered in predicting and preparing for the future.

However, nursing is no longer in this position, because information on scientific developments is no longer the purview of just a few. Thus, nursing has an opportunity to alter the sequence of events and become one of the architects of future health-care services. But nursing will be invited to the table only if it has something unique to offer. Our research programs must anticipate the new directions and ask the type of questions that will contribute to new insights into how practices such as genetic screening affect people's health.

From **The Human Genome Impact on Health-Care Services: Are Nurses Prepared?**
by Laurie N. Gottlieb (*CJNR* 2002, Vol. 34 Nº 3, 3–4)

The e-version should make *CJNR* more visible and accessible to the international community. *CJNR* has a distinct Canadian character. Although Canadian scholars continue to be the major contributors in terms of submitting manuscripts and serving as reviewers and guest editors, in recent years there has been a notable increase in contributions from American and European scholars. We would like to encourage this trend.

From ***CJNR* Goes Online: An e-Journal at Last!**
by Laurie N. Gottlieb (*CJNR* 2003, Vol. 35 N° 1, 3–5)

To ignore anything more than 5 years old is, to my mind, to engage in a sort of ageism of knowledge — discarding the old to create an illusion of the new. Knowledge must be rooted in the work of our predecessors and be built on solid foundations. How else can it advance?

There is no fast and easy way to circumscribe the time and energy required to develop in-depth knowledge in a given field of practice. Specialized, in-depth knowledge is acquired through years of study and experience in the skills of inquiry.

We need to carefully consider the practice of limiting our literature reviews to the last 5 years. If we fail to stop and think about what we are doing and why we are doing it, we risk taking nursing science backward instead of forward. We risk re-inventing the wheel, or at best spinning our wheels. We run the risk of unwittingly promoting ageism of knowledge, and in so doing planting trees with very shallow roots. A "best before" date may apply to food purchases. Surely it has no place in scholarship.

From **Ageism of Knowledge: Outdated Research**
by Laurie N. Gottlieb (*CJNR* 2003, Vol. 35 N° 3, 3–6)

The challenges faced in Toronto were not that dissimilar to those faced in Hong Kong. The deadly SARS epidemic exposed the inner workings of the health-care and related systems, and much was found wanting. The various systems proved vulnerable and lacking the capacity and flexibility necessary to adapt quickly and efficiently to a situation that was unpredictable and constantly changing.

Those who lived the SARS experience need to join forces and seize the initiative to create a new way of doing research, one that transcends borders. The challenge for the international nursing scientific community is to begin talking to our nursing and health-care colleagues now, in order to determine the role that nurse scientists will play in future times of crisis. We need to develop a model for working together as a scientific community in order to meet the next health-care challenge brought about by our connected world and the realities of globalization. The health, recovery, and well-being of so many depend on it.

From **Lessons from SARS: Challenges for the International Nursing Research Community**
by Laurie N. Gottlieb, Judith Shamian, and Sophia Chan
(*CJNR* 2004, Vol. 36 N° 1, 3–7)

Nurses have never wavered in their support for the principles of the *Canada Health Act* despite the incredibly harsh conditions under which they have laboured.

The past decade has been brutal to nursing. The system under which nurses work has not been as generous, supportive, committed, and loyal to them as nurses have been to it.

And yet despite the deplorable working conditions under which they care for patients and their families, nurses have remained steadfast in their support of a single-tiered, nationally funded health-care system. The question is why. Are nurses masochists? Angels? Paralyzed? Why have nursing organizations not advocated for a return to privately funded health care?

The answer may be found in nursing's ethos of caring. Caring has been nursing's banner, and, for many, caring and nursing are synonymous.

In 1970 the slogan Nurses Care; Physicians Cure was created to distinguish nursing from medicine. This was a time when nursing was seeking its own identity. It was an unfortunate slogan inasmuch as it sent the erroneous message that only nurses care. The reality is that the majority of those who choose a career in one of the many helping professions do so because they are dedicated and committed to people in need. They want to contribute to the betterment of humanity. Nurses care. Doctors care. Other health professionals care. However, there are many models of caring and many ways of expressing caring. The different models of caring may explain why one health-care profession supports a single-tiered system while another supports a two-tiered system.

Drawing on the analogy of different family structures and ways of functioning, Dr. Lakoff describes two basic family forms to represent two approaches to moral and political action: the Nurturant Parent Model and the Strict Father Model. The two models, based on different worldviews, give rise to different moral systems and different modes of reasoning and discourse, and lead to very different ways of acting. The Nurturant Parent Model stresses social responsibility, social and individual ends, and individual rights and freedoms, whereas the Strict Father Model stresses survival of the fittest, taking responsibility for oneself, self-reliance, and individual rights over social responsibility.

Nurses generally subscribe to the Nurturant Parent Model, because nurses bear witness to suffering. Nurses are privy to the most intimate aspects of a person's and a family's life. Nurses know the hardships endured during illness and how these hardships lead to increased vulnerability when access to affordable care is limited. They know how the vulnerable become more vulnerable, the needy more needy, the despondent more despondent when health care is not fully accessible or affordable.

Within the health-care milieu, nurses are among the strongest advocates of retaining the single-tiered system. However, if the government fails to properly support nursing and to radically reform nurses' working environment, it will find that its most loyal ally has deserted it. Even the Nurturant Parent cannot support a morally bankrupt environment. Without the support of nursing, the demise of the single-tiered system is inevitable. And it is more than the health-care system that will be lost. Canadians' sense of identity and this country's moral compass are also in jeopardy.

From **Nursing's Ethos of Caring and Its Support for a Single-Tiered Health-Care System**
by Laurie N. Gottlieb (*CJNR* 2004, Vol. 36 N° 3, 3–5)

What…makes scholarship Canadian? What purpose or purposes does the label "Canadian" serve? How can academic nationalism, if you will, be a positive force in moving the discipline of nursing forward?

The real [questions] for us and for you are whether national distinctions serve the interests of science and the extent to which research reporting advances or undermines the pursuit of cultural competence and better care for nursing's clients. All of these issues need to be probed.

In the meantime, we encourage you to begin thinking more broadly about the role of nationality and culture in the research enterprise. Ask yourself, your students, and your colleagues what exactly is meant when the label "Canadian" is used in your scholarly endeavours. Proud nationalism can be a great positive force, but open-mindedness and intellectual curiosity about the world beyond and how others see it are essential parts of the nurse scholar's toolkit in any country or culture.

From **Made in Canada?**
In Search of a National Research Identity
by Sean P. Clarke and Laurie N. Gottlieb
(*CJNR* 2004, Vol. 36 N° 4, 3–6)

Open access refers to the products of scientific and medical research (usually meaning published articles) being made available, free of charge, to everyone. First floated some 10 years ago in reaction to escalating subscription rates, open access has gone from an idea to a movement. The open-access movement was born of the Information Age and the Internet. It holds that information should be available to the widest possible audience rather than just to the elite and the privileged.

In an ideal world who could be against open access? There is consensus that open access would indeed be a great thing if only it worked. But it presents many problems. At the heart of the issue are two questions: Who will pay? and How will standards be maintained?

From **Open Access: A Hot Topic in the Publishing World**
by Laurie N. Gottlieb (*CJNR* 2005, Vol. 37 Nº 2, 5–8)

For everyone involved, publication is a big step — sometimes a hurdle — in the research process. Much is at stake. Continued funding, scholarships, positive annual reviews, and even promotions can be contingent on having the right number and mix of publications on one's CV. No wonder publishing causes so much anxiety. In my role as Associate Editor and as a peer reviewer for *CJNR* and a number of other journals over the years, I've noticed a few patterns in what influences whether a manuscript gets accepted. Indeed the process of getting a paper into print isn't as secretive or obscure as it might seem.

One of the most preventable forms of rejection could be called "not our cup of tea," and it occurs when a manuscript is just inappropriate for the journal to which it has been submitted.

The second form of rejection might be called "too much development required" (or, less charitably, "not even close"). Editors are generally looking for work that can be brought up to an acceptable level of quality with one rewrite, followed perhaps by one set of revisions.

"Fatally flawed" is the third type of rejection. This category includes submissions that are turned down because of fundamental problems in study design that weaken or invalidate the conclusions.

The most discouraging reason why manuscripts are turned down might be called "and so?" (or, less politely, "so what?"). Bottom line: the "message" is unclear.

For you and for us, few things are as depressing as rejection letters and nothing is as uplifting as receiving (or sending) an acceptance letter and seeing your ideas in print. A little extra work on the basics can really pay off.

From **Advice to Authors:**
The "Big 4" Reasons Behind Manuscript Rejection
by Sean P. Clarke (*CJNR* 2005, Vol. 37 Nº 3, 5–9)

The impact factor was never intended as a measure of the quality of an individual researcher's work. It is widely assumed that if a scholar publishes in high-impact journals, then his or her work must be of superior quality. Remember, the impact factor concerns the impact of the journal, *not* an individual article.

It is generally recognized that we do need criteria for assessing the importance of researchers' work. We must ask whether the impact factors of the journals in which nursing scholars publish are necessarily the best measure of the quality of scholarly output.

Surely impact on science encompasses more than just the venues in the periodical literature where articles land, and surely the contribution of nursing scholarship extends beyond a work's influence on other publications — to include direct and indirect influences on the quality of health care. Nursing has an opportunity to lead by developing and testing new ways of assessing impact and influence, as an alternative to blindly following disciplines that, for a variety of reasons, have unquestioningly adopted the impact factor to the exclusion of other measures and considerations. Let us hope that researchers and leaders in academic nursing take up this challenge — and quickly.

From **Impact Factors and the Law of Unintended Consequences**
by Laurie N. Gottlieb and Sean P. Clarke
(*CJNR* 2005, Vol. 37 N° 4, 5–10)

While *CJNR* is an independent, academic journal not affiliated with a professional association, the rift between several professional associations and their official journals should be of concern to all. This rift is indicative of a fault line in a system that has been in place for almost a century, a system whose purpose has been to safeguard the role of professions within society and to ensure the highest standards of professionalism.

For some time now, there has been growing scepticism about the ability of professional associations to monitor themselves. New structures have been created to serve as "watchdogs." …[committees have been formed] to develop guidelines for improving the quality of scientific papers and to ensure that authors and editors meet the highest standards of ethical conduct. They stand on guard for signs of interference with editorial independence or violations of the principles of scientific publishing.

Until the issues eroding professionalism are better understood and a new social contract between professions and society is drawn up, we can expect to see more rifts between professional associations and their journals. These rifts should be seen as symptoms of serious malfunctioning. During this period of breakdown and transition, as we await the emergence of a new system, we must be prepared to defend the integrity of our professions and to safeguard the public good. We all have a role to play.

From **Conflicts Between Professional Associations and Their Journals Strike at the Heart of Professionalism**
by Laurie N. Gottlieb (*CJNR* 2006, Vol. 38 N° 2, 3–6)

This editorial is a departure for me inasmuch as I have decided to devote much of it to reprinting authorship guidelines set forth by the International Committee of Medical Journal Editors (ICMJE). My decision to do so stems from a growing concern about the practice of assigning authorship of a manuscript to those whose contribution is limited or even questionable. Many nursing authors, knowingly or unknowingly, may be engaging in practices that are commonplace in other disciplines without questioning whether they are indeed ethical.

Each field develops its own practices [for assessing authorship] based on the nature and type of scholarship inherent in the discipline, its historical system of knowledge development, and the pressures and rewards from its various constituencies.

There is a growing belief among editors of nursing journals that some authors do not merit authorship, given the nature and extent of their contribution.

From **ICMJE Guidelines for Assigning Authorship and Acknowledging Contributions**
by Laurie N. Gottlieb (*CJNR* 2006, Vol. 38 N° 3, 5–8)

Tongue firmly in cheek, we can talk about three roles that reviewers tend to assume — diviner, goalie, and coach. All reviews are useful to us as editors in some respect, but their contributions are distinct.

The first reviewer category is the diviner. He or she has expertise that the editors usually do not, either in the subject matter or in the methods described in a paper. The diviner arrives at a judgement — "thumbs up" or "thumbs down" (worthy of publication or not) and may be more or less cryptic about the basis for that assessment.

The second role played by many (perhaps most) reviewers is that of goalie, trying to keep poor scholarly work out of the literature and holding high the bar for scientific publication. While diviners tend to get a global "feel" for a paper and make their assessments of suitability from there, goalies tend to be more rule-based.

The third role that reviewers assume is that of coach, helping both the author and the editor to ensure that only the best possible version of a manuscript (including the best science possible) appears in print.

In the end, if we are not prepared to be coaches, or have little time to write coaching reviews, some blend of the diviner and goalie roles usually produces reviews that are the most useful for editors. We tend to let many aspects of peer review drift into the background, because we see reviewing and receiving reviews as an imperfect but inescapable part of life as a scientist. But all of us involved in the process really need to read about, reflect on, talk about, and write about peer review and its successes and shortcomings. This will not only improve the process at individual journals and in nursing as a whole, but also, in the long run, help to create a system that gives us the kinds of reviews we ourselves would want to receive.

From **Reviewing Peer Review:**
The Three Reviewers You Meet at Submission Time
by Sean P. Clarke (*CJNR* 2006, Vol. 38 N° 4, 5–9)

It has taken a mere 17 years to develop this critical mass of nurse scholars who have already made an unmistakable impact on the nursing profession and on health care. Although the Canadian nursing community built these successes, not all will remember the battles that were fought to arrive at this point. Those of us who were around in the early days never imagined how quickly the seeds of change, once planted, would take root and produce this amazing growth.

We are at a critical juncture. If we compromise quality and lower our standards, we run the risk of endangering the reputation of nursing as a serious science and, more importantly, providing poor science for the practice of nursing. We must stand on guard in order to protect what has already been built and determine the conditions that have to be in place to train first-rate nurse scientists. In the coming decade, we will have to go from strength to strength, not weakness to weakness. It is time for us to pause, take stock of our successes, and reflect on current trends so that nursing as a discipline can continue to celebrate excellence.

From **Canadian Nursing Scholarship:**
A Time to Celebrate, a Time to Stand Guard
by Laurie N. Gottlieb (*CJNR* 2007, Vol. 39 N° 1, 5–10)

We think of our reviewers as partners. As editors we rely heavily on their assessments and evaluations in our deliberations on what will be published in the pages of *CJNR*. This means that we share responsibility with our reviewers for what appears in print. We draw on their expertise to assess the conceptual basis and scientific merit of a research study and to ensure the integrity of what we publish. The feedback and direction that their critiques provide us and our authors lead to improved manuscripts. As we have stated in *CJNR*'s editorial pages over the years, through their comments to editors and authors, reviewers make essential contributions to the development of science, particularly nursing science.

Our reviewers, and those who review for other scholarly journals, subscribe to an ethos of sharing: They are willing to give of their time and knowledge because they know this is the right thing to do for the community of scholars and readers.

We hear from readers, and see for ourselves, that the research contributions are more sophisticated and impressive with each successive volume of the Journal. This is not only a reflection of the maturation of the Canadian nursing research community, but also a tribute to our reviewers.

From **A Salute to Our Reviewers:**
Partners in the Scientific Endeavour
by Laurie N. Gottlieb and Sean P. Clarke (*CJNR* 2007, Vol. 39 N° 4, 5–9)

There are words and acts in scholarly publishing that are considered unethical, immoral, and in some cases even illegal. When such breaches of conduct occur in scientific publishing, they challenge the moral order of the scientific community by undermining the integrity of the literature and violating the rights of others — colleagues, subjects, readers, the public. When I think of such acts in the academy and in the publishing world, the ones that immediately spring to mind are plagiarism, duplication, cheating, misrepresentation, fabrication, and falsification of data… And every day new acts are added to the list. One of the most recent to make it onto editors' lists of offences is self-plagiarism. I have trouble adding it to mine.

Where is the violation or crime? What is being stolen, and from whom? What fraud is being committed? What is the nature of the misconduct?

In dealing with self-plagiarism, we at *CJNR* choose to steer a course of transparency and disclosure. We rely on a spirit of partnership with our authors — putting stock in their competence and their commitment to responsible authorship — on the conscientiousness of our reviewers, and on our own wits to help ensure the integrity of both the literature and scientific practice. In short, we choose common sense and reasonable accommodation.

From **Self-Plagiarism: Some Common Sense,**
Some Reasonable Accommodation — Please!
by Laurie N. Gottlieb (*CJNR* 2008, Vol. 40 N° 2, 5–9)

As we write this editorial we cannot help but reflect on how much has happened in the past 6 weeks. In the autumn of 2008 we stand in a familiar place, with some continuity, many changes (some of which promise to be dramatic), and a nagging feeling that a profound and transformative shift in our societies is imminent. In Canada we have re-elected a minority government. In the United States a charismatic new president is preparing to take the helm, promising a dramatically different new era in American politics. We are now well into what threatens to be a deep and painful world economic crisis.

Every society in the West is confronting what health economists call the "iron triangle" of cost, access, and quality, meaning that it is difficult, if not impossible, to either change or hold constant any one of the three without affecting the other two.... Can we have infinite resources for health promotion, cutting-edge medical technology, happy, healthy, fulfilled health professionals, and patients equipped with all the tools they need to take control of their health care...? Will we be able to meet the demands for a "full service" health-care system without raising taxes? Will there be growing disparities, in terms of service access, between those who can afford to pay and those who cannot?

Keeping silent is no longer an option.... We must raise issues in public and in private, form coalitions with other health professionals, work with our professional associations and demand that they become players at the table, and ensure that the issues receive thoughtful attention by organizing and getting involved at the grassroots.

Researchers must show, with facts and specific details, how nurses make important ideas come to life in health-care delivery: cost-effective, high-quality care provided by teams that include patients and families and a balanced approach to the use of technology, one that recognizes both the positive contributions and the limitations of technology. Data in hand, nurses and nurse scholars can show how care at its best focuses on helping patients and their families pass safely through our networks of professionals and agencies — and, to the greatest extent possible, on their own terms.

This is a time to get involved, to be proactive, to seek solutions and influence new health policies. This is nursing's time to make its mark. Keeping the welfare of patients and the well-being of society front and centre in our actions as citizens, nurses, and researchers is more likely to result in viable, fair solutions than trusting others to take up the charge or leaving developments to fate and chance.

From **Influencing Health Policy for the Imminent Health-Care Crisis: A Task for Informed Citizens, Proactive Nurses, and Committed Researchers**
by Sean P. Clarke and Laurie N. Gottlieb (*CJNR* 2008, Vol. 40 N° 4, 5–9)

CJNR 2009, Vol. 41 N° 1, 73–83

Highlights From Discourses Published in Volumes 31–40

What is apparent in both the study and the application of research utilization principles and methods is that it is a social process.

With the accumulation of more evidence on research utilization, we need to recognize our theoretical and methodological blind spots and move from taking comfort in the certainties derived from simplistic reductionist approaches to acknowledging the assumptions, biases, and weaknesses that characterize most of our scientific investigations. The uncertainties of research utilization may make us feel overwhelmed by the complexity and messiness of the job; however, other disciplines are beginning to report unintended consequences of successful innovation and the potentially destabilizing impact that "decontextualized" change can have on local communities.

Variously described as an innovation, new idea, new technology, research finding, and, most recently, evidence, that which gets put into practice has to stand up to scrutiny.

It would seem that health care (including nursing) is entering a period of intense activity around research utilization methods and practices. We need to take account of existing research findings but acknowledge the theoretical and methodological blind spots. Our new endeavours must offer us the ability to integrate scientifically derived knowledge with personal experience and patient preferences in ways that are rigorous, holistic, and theoretically coherent.... Having mapped out these areas, we must now move on to embrace the complexities of the wider context and how our relationships within that context influence our ability to respond to innovations. Finally, we must face more fundamental questions, concerning whether we can or should entertain the possibility of workers and clients themselves developing that capacity to decide what innovations should be introduced, how, and for what purpose!

From **Research Utilization: Current Issues, Questions, and Debates**
by Alison Kitson (*CJNR* 1999, Vol. 31 N° 1, 13–22)

Without trivializing the continuing impact of severe mental disorders, it is probably fair to say that, because of access to appropriate care, many severely mentally ill adults can now anticipate more satisfying, "normal" lives with reasonable control over their symptoms.

From **The Biopsychosocial Perspective in Psychiatric Nursing: Myth or Future Reality?**
by Linda Chafetz and Nicole Ricard (*CJNR* 1999, Vol. 31 N° 2, 17–23)

Although the language becomes cumbersome at times, I have tried to avoid the term "non-pharmacological" when I really mean behavioural and environmental interventions. I try to avoid implying that pharmacological interventions are the gold standard for pain relief and that we must choose one kind of intervention over the other. I have argued that environmental and behavioural strategies provide the foundational substrate for neonatal pain management to which pharmacological therapy is additive or synergistic…

Nevertheless, as much as we pride ourselves on our avoidance of the dualistic mind/body trap, with respect to pain treatment our professional literature reflects the physical/psychological dualism and the pharmacological idolatry in the field of pain.

We must acknowledge that the language of pain, like the experience of pain, has a high degree of plasticity. The terms we use to describe pain will evolve over time to reflect the social and scientific conceptions of cultural groups at any specific point, with acknowledgement of historical ways of thinking. However, we must strive to continually make these conceptions explicit, so that the assumptions will be instructive and not simply a source of bias.

From **Relieving Pain: What's in a Name?**
by Linda S. Franck (*CJNR* 2000, Vol. 31 N° 4, 9–16)

During the past 30 years the nature of physicians' directives has changed dramatically, as has medical technology. Much experiential clinical learning in nursing is undescribed because of the social misunderstanding that nurses just "apply" well-established medical knowledge under the direct supervision of doctors. Yet many areas of nursing practice have developed new and uncharted knowledge, of both the delegated and undelegated kind.

Nurses bring a rich experiential wisdom to their thinking. Much of that wisdom is poorly articulated and misunderstood. All three modes of philosophical thinking are needed to do justice to the concerns and goals central to nursing. We need critical powers to evaluate practice, theory, and research. We need creative and edifying philosophies to create an adequate vision for the goals of nursing practice. Finally, we need articulation research and thinking to describe what we know and do not know in our practice.

From **Links Between Philosophy, Theory, Practice, and Research**
by Patricia Benner (*CJNR* 2000, Vol. 32 N° 2, 7–13)

Have we arrived in Kansas yet? If the destination of chronic illness research has been an explication of the complexity and richness of chronic illness as experienced over time within social and personal contexts, the answer is no. The constructions of chronic illness to date have provided only a snapshot of the chronic illness experience, because they have limited the breadth and depth of investigations in this field of study. The hope of nurse researchers is that the findings will make a difference to the care and health of those with chronic illness. In order to reach this destination, nurse researchers in the next decade must be prepared to take into account the fluid, contextually based, individual experiences in living with chronic illness. They must be prepared to refrain from assuming that the traditional constructions of chronic illness are representative of the totality of the chronic illness experience. This will require creativity in our methodological strategies, courage in our interpretive claims, and a commitment to more in-depth and multilayered representations of what the complexity of chronic illness entails.

From **"Are We in Kansas Yet, Toto?"**
The Construction of Chronic Illness in Research
by Barbara L. Paterson (*CJNR* 2000, Vol. 32 Nº 3, 11–17)

Nursing's voice must be heard among the voices of social scientists, women, and communities calling for public policy and social action to address violence and abuse. This can happen only if the public is aware that violence is woven into the conceptual fabric of nursing practice. Nursing's presence in the interdisciplinary and intersectoral work that addresses violence must shift from that of supporting cast to leading role.

From **A Call to Focus Our**
"Passion for Substance" on Family Violence
by Colleen Varcoe and Judith Wuest (*CJNR* 2001, Vol. 32 Nº 4, 11–19)

Economics has had the dubious distinction of being termed the "dismal science," and its application in health care has often pitted clinicians against economists in a struggle to lay claim to the mantle of patient advocacy. Practically speaking, economics provides a framework for the allocation of resources, in this case nursing care, among competing ends and the costs, both financial and non-financial, of allocation decisions. The economics question facing nursing is not what the value of nursing care *is* (i.e., costing out nursing services for the sake of determining its costs) but *how* to allocate this valuable resource to best meet the health-care needs of our patients and the population.

From **Nursing's Valued Resources:**
Critical Issues in Economics and Nursing Care
by Julie Sochalski (*CJNR* 2001, Vol. 33 Nº 1, 11–18)

While [commissioned government reports on home care have been] crafted to reflect the notion that home care is for the good of the individual, the documents have as their fundamental precepts a concern with government spending on health; home-care management as a gendered activity, and the expectation that women will take on the role of caregiver; and the ideology of one's individual responsibility for oneself. Furthermore, the home-care discourse is based on deep-seated assumptions about home and family, for example that we all have homes with family and friends close at hand to provide a nurturing environment and that resources are in place (bedding, laundry facilities, etc.) to make home care a reality. In other words, the notion of home care is entrenched in a particular meaning of "home" and constructed from a particular social location: the privileged middle class. Most importantly, it represents an off-loading of responsibility from the state to the individual and "family," even in those instances where "home-care services" are supposedly provided. As I point out elsewhere, the home-care movement must be understood in the context of societal and health-care ideologies that stress individual and family responsibility…and that are enmeshed in the notion that personal misfortunes (as well as personal successes) are *individually* produced.

From **The Politics of Home Care: Where Is "Home"?**
by Joan M. Anderson (*CJNR* 2001, Vol. 33 N° 2, 5–10)

Many consider that the continuous cycles of over- and under-supply of health human resources worldwide reflect inadequate projection methods for estimating future requirements for expanding health systems and/or a failure to consider the evidence supplied by labour market trends. HHRP in most countries has been poorly conceptualized, intermittent, uneven in quality, profession-specific in nature, lacking in vision, and lacking in data upon which to base sound decisions. To ensure efficiency and effectiveness, planning activities should be needs-based, responsive to a changing system, and outcomes-directed.

From **Where To From Here?**
by Linda O'Brien-Pallas (*CJNR* 2001, Vol. 33 N° 4, 3–14)

The topic of coping covers a vast landscape, but to date it has been investigated like a tourist who has time only for a helicopter excursion and therefore never gets a close-up look at the fauna and flora. Coping researchers have barely penetrated the diverse ways in which people come to terms with the alarms, transitions, and setbacks of life. This is partly owing to the fact that coping has been ill-defined, its measurement has preceded its understanding, and the contingencies affecting the forms it takes are poorly comprehended. In the future, depth should take priority over breadth, and a more dynamic process orientation should replace fruitless study of the relations between isolated bits of coping and the outcomes of interest. Instead of searching for evidence that certain strands of coping have adaptive value, we need to ask how clusters and sequences of coping foster progress towards the goals people strive to attain.

From **Coping Research: The Road Ahead**
by Benjamin H. Gottlieb (*CJNR* 2001, Vol. 34 N° 1, 13–27)

Within a relational ethic, we want to give relationship between people primary consideration. We want to acknowledge and give attention to the space between us. Let me take the rather simple hyphen, the hyphen that connects the nurse and the patient as in nurse-patient relationship. When we focus our attention on the relation itself, it might be more useful to move away from the short horizontal line of the hyphen (nurse-patient) and create two vertical lines (nurse | | patient) to give renewed attention to this space. The vertical lines provide a space that stirs us to contemplate the interconnection of human life. Note that the vertical lines (nurse | .. | patient relationship) give more attention to the individuality and separateness of each person in the relationship.

From **Ethical Challenges of the 21st Century: Attending to Relations**
by Vangie Bergum (*CJNR* 2002, Vol. 34 N° 2, 9–15)

The real question is: does participation in treatment decision-making at time of diagnosis really improve one's chances of survival?

Why is it so important that we address this question? Because there is an underlying assumption that the answer to the question is "yes."

If important options that could maximize survival are not available in our health-care system, why study patient participation? In more and more cases, there is no real choice — defined as availability of evidence-based interventions — because resources, including nursing resources, are severely limited. In spite of this we create the illusion that there is a choice. Whether this illusion really helps people facing life-threatening illnesses to deal with their disease and treatment remains to be seen.

We have an illusion that we are "in control," but are we really? Ethics and decision-making at the individual level are becoming less relevant as targets of study, while the same topics at the system level are becoming increasingly relevant.

From **Ethics and Decision-Making: Lessons From the "Cancer Wars"**
by Lesley F. Degner (*CJNR* 2002, Vol. 34 N° 3, 9–13)

Over the past decade, research has succeeded in clarifying some of the mechanisms that underlie the risk for developing and reinforcing substance abuse. Powerful natural recovery processes have been observed, supporting the use of opportunistic, brief interventions in settings where substance abuse is often encountered, such as the frontline. The nursing professional seems exquisitely positioned to engage in effective yet brief intervention for substance-abuse disorders encountered in such settings.

From **Nursing Research and Alcohol Problems: Learning From Recent History?**
by Maurice Dongier and Thomas G. Brown
(*CJNR* 2003, Vol. 35 N° 1, 13–22)

Research has explored and substantiated culture and gender as a determinant of health. Considerably less progress has been made, however, in incorporating this knowledge into the design of health interventions. What is the basis for this omission? Perhaps it is related to culture and gender being considered "non-modifiable" risk factors. Many researchers acknowledge the influence of these factors but believe that little can, or should, be done to modify them.

From **Incorporating Culture and Gender Into Multiple Intervention Programs** (Guest Editorial and Discourse)
by Judy Mill and Nancy Edwards (*CJNR* 2003, Vol. 35 N° 2, 9–14)

Are we living at a time when words beginning with the letter "e" are pre-eminent in health-care discourse? Four words in particular come to mind, three of which are *effectiveness, efficacy,* and *efficiency*. On close inspection, these words all have the same Latin root, "effectus." Webster's dictionary provides eight definitions for the noun *effect*, the first being "something that is produced by an agency or cause; result; consequence"… Other definitions connote purpose or intent and the power to produce results. Note that these definitions are neutral or value-free; that is, the "something that is produced" could be either positive or negative, intended or unintended. However, when *effect* is used in the adjectival form, it is no longer neutral but takes on a positive value. In the context of health care, *effective* is applied to something that produces an expected effect under everyday conditions, *efficacious* refers to something capable of achieving a desired end or purpose under ideal conditions (often in the context of randomized clinical trials…), and *efficient* implies skilful accomplishment of a purpose with little waste of effort or resources…

What, then, is nursing care effectiveness?... It is about the power or strength of nursing care to produce intended and desired health outcomes for patients, families, and communities… We need evidence that professional nurses are effective agents in producing desired outcomes through systems of care delivery and processes of care and by their presence and discrete actions or interventions.

From **Nursing Care Effectiveness: Here to Stay** (Guest Editorial and Discourse)
by Sandra LeFort (*CJNR* 2003, Vol. 35 N° 3, 7–16)

Unfortunately, it seems that a reduction in disturbed behaviour has become the preferred outcome for quality of care and health services research in long-term care. Is this good enough?… Much more attention needs to be focused on conceptualizing the quality of daily life and quality of the moment in the cognitively impaired elderly population.

Because of the aging of our population and the resulting increase in the number of people who are cognitively impaired, more people will have parents and grandparents with cognitive impairments and will insist that their lives be lived as fully as possible. Even without this reality, however, I think the opportunity to be creative and to bring innovative approaches to understanding behaviour and to testing different ways of being with and engaging these people will become irresistible to some of our best researchers.

From **Making Moments Matter**
by Dorothy Pringle (*CJNR* 2003, Vol. 35 N° 4, 7–13)

Continuity is a goal to be pursued in primary care. However, policymakers must appreciate the fact that continuity of care means considerably more than simply ensuring that each person is able to register with a family physician. Flexibility of care venue, team continuity, and the use of integrating information technology are all areas of innovation in primary care that offer an opportunity to place current concepts of continuity into a broader policy context.

From **Reflections on Continuity in Contemporary Canadian Primary Care**
by Sam Shortt (*CJNR* 2004, Vol. 36 N° 2, 7–10)

By pressing for the exposure of situated vulnerabilities, I hope to open an inclusive discourse on diversity that sees discrimination and social injustice not as the prerogative of those assigned to certain categories but as germane to all. No one is exempt from the discourse on diversity. Nor is anyone immune to the experience of marginalization, dehumanization, and human suffering.

A postcolonial feminist humanism holds out hope for the opening up of a discursive space for diverse voices, resistances, and praxis that might move us towards inclusivity and social justice.

From **The Conundrums of Binary Categories: Critical Inquiry Through the Lens of Postcolonial Feminist Humanism**
by Joan M. Anderson (*CJNR* 2004, Vol. 36 N° 4, 11–16)

Rural health research…has been concerned more with access, regardless of how services are funded, and should offer more opportunities for international exchange. Rural health research means different things to different folks. Those accustomed to thinking about research in terms of randomized clinical trials, or at least in terms of a quasi-experimental design, in which an intervention is assessed for its effect on outcomes, may be surprised to learn of the large body of funded research that makes little or no use of such methods.

In contrast, much of the rural health research currently funded in the United States is undertaken not to discover effective clinical interventions but to discover effective policy interventions. Those who labour in this vineyard have fashioned their research portfolios to address how rural is different, why rural is different, and, in most cases, whether the differences merit a policy intervention.

From **Rural Health Research: Building Capacity and Influencing Policy in the United States and Canada**
by David Hartley (*CJNR* 2005, Vol. 37 N° 1, 7–13)

Until recently, palliative care tended to concentrate on the needs of cancer patients and their families, focusing on the terminal stages of a person's life. However, the field is being challenged to provide high-quality care to a wider range of patients, receiving care in a variety of settings, with more complex symptoms and co-morbidities, at earlier stages of their illness.

The attention given to the patient's comfort, complex symptoms, and confusing feelings, as well as difficult family dynamics, is what makes palliative care effective. It is impossible to be an expert palliative care nurse and skim over the patient's concerns, minimize distress, or ignore minor difficulties. Indeed, it is the nurse's detailed attention to the small aspects of a patient's physical, emotional, and spiritual state that makes a difference.

From **Directions in Palliative Care Nursing Research: Impeccable Care, Timing, and Complexity**
by Linda J. Kristjanson (*CJNR* 2005, Vol. 37 N° 2, 13–20)

Much remains to be unmasked; we have to make transparent the complexities of these intersections and how they are *played out in everyday life to determine women's health.* We might assume we know what "race" means, but how can we use the concept as an analytic category in trying to comprehend the social determinants of women's health? What are the *processes* by which *race* is played out in everyday life that makes it worthy of mention, and how do these processes intersect with class and gender?

Let me be swift in pointing out that it is not only people of colour who are racialized. The processes of racialization apply to everyone. Or we might assume that people from some "ethnic groups" will go home from hospital to an extended-family situation when, in fact, they may have no one to help them out at home.

Nurses have a social and moral responsibility to conduct research that is inclusive of all of Canada's populations. However, we must conduct this research in ways that do not reproduce racialized categories but that, instead, challenge the categories and assumptions that result in the demeaning of people.

From **Reflections on the Social Determinants of Women's Health – Exploring Intersections: Does Racialization Matter?**
by Joan M. Anderson (*CJNR* 2006, Vol. 38 N° 1, 7–14)

What if the forms of research and restoration that we need to do in order to build a safer, more sustainable health system for all are not the forms of science and knowledge initiatives that are consistently rewarded in our academic lives? If nurse researchers have to struggle to get the respect and recognition for their work in citizen science that corresponds to their efforts, will they answer the call for this difficult work in the backcountry of modern health care?

From **Field Notes From Research and Restoration in the Backcountry of Modern Health Care**
by Patricia Marck (*CJNR* 2006, Vol. 38 N° 2, 11–23)

In Canada and the United States and all around the world there are glaring disparities in the health of women of colour compared to white women. This reality is well known, as is the reality of interpersonal violence for a large proportion of women. Yet these two intersecting issues are seldom considered together, in spite of the documentation of violent victimization among women of colour and IPV as a risk factor for many conditions.

As health-care interventions for domestic violence are developed and tested…, it is imperative that they be tested specifically among different racial, ethnic, and cultural groups, or we may end up increasing rather than decreasing the health disparities for abused women of colour.

From **A Further Celebration of Nursing Research in Violence**
(Guest Editorial and Discourse)
by Jacquelyn C. Campbell and Angela Henderson
(*CJNR* 2006, Vol. 38 N° 4, 11–26)

If nursing information systems continue to restrict nurses' tasks, there is a risk that nurses will resist using them, as they offer so little support to the more complex functions of knowledge utilization and knowledge development. Since nurses who devote a considerable amount of time to documenting their practice feel increasingly burdened with information management, it seems more appropriate to develop information systems that support nurses in their decision-making and other functions, where timely access to knowledge is crucial.

From **Nursing Informatics:**
Developing Knowledge for Nursing Practice
by Luc Mathieu (*CJNR* 2007, Vol. 39 N° 1, 15–19)

Nursing has its own cultural history with respect to pain. It is a history that bears heavily on both the science of pain and the application of that science in everyday practice. As one of the quintessential areas of nursing care, nursing has long been associated with comfort and support for the sick and suffering.

If we apply the virtue script to pain care, we find the widespread idea that the patient is best served by a kind and attentive nurse, one who helps the patient to voice his or her feelings, supports families, and puts energy and sensitivity into determining the meaning of the illness and the pain for the patient. This is the tenet of patient-centred care. Of course all of these principles are central to good practice, but what concerns me is what is missing from this model of excellent nursing. Where is the science?

Pain management is a science, and one in which nurses are key. The virtue script may have served nurses and their patients well in the past, but in the field of pain, as in so many other domains of care, we need to move beyond angels and practise as knowledgeable scientific and compassionate professionals.

From **When Caring Is Not Enough:**
Understanding the Science of Pain
by Sioban Nelson (*CJNR* 2007, Vol. 39 N° 2, 9–12)

Place can impact on many of the health risks we are exposed to, the types of disease that confront us, and the health services that are available to us — important factors in the study of population health. The time is right for nurse researchers to consider some of the health implications of geography.

From **The Importance of Geography and Health in Nursing Research** (Guest Editorial and Discourse)
by Shirley M. Solberg and Christine Way
(*CJNR* 2007, Vol. 39 Nº 3, 13–18)

Until governments recognize home care as a major component of the health-care system, and until they embrace an integrated continuing care model that incorporates a continuing-relationship approach, the needs of persons with dementia and their family caregivers will remain unmet. As a result, costs to the health-care system will increase, especially if family members are unable to continue in their caregiving role. There is a narrow window of time in which to address these issues. We must act now.

From **Looming Dementia Care Crisis: Canada Needs an Integrated Model of Continuing Care Now!**
by Dorothy A. Forbes and Anne Neufeld
(*CJNR* 2008, Vol. 40 Nº 1, 9–16)

Because nursing is a practical profession, there is always room for improvement, which, in turn, should increase its contribution to patient well-being and health. Such a development, however, cannot be supported solely by a research approach that focuses on enhanced understanding of the perceptions and experiences of nurses and patients. There is also a profound need for evaluative and experimental research to enhance knowledge about what works in practice and its impact on patient outcomes — that is, the effectiveness of nursing interventions… In discourse terms, it is time for a shift.

From **A Descriptive Feast But an Evaluative Famine: Implementation Research in Nursing**
by Lars Wallin (*CJNR* 2008, Vol. 40 Nº 2, 17–23)

Studies with patients who have become expert in everyday self-care decision-making reveal that they do not achieve that expertise through compliance with recommendations or adherence to standardized approaches. Rather, those who attain expertise figure out at some point along the way that it is their life that will be lived and they must become the ultimate authority on that life.

From **Chronic Disease Management: What Is the Concept?**
by Sally Thorne (*CJNR* 2008, Vol. 40 Nº 3, 7–14)

Landmark Articles
From Volumes 31–40

Des articles-jalons
tirés des volumes 31 à 40

CJNR 2009, Vol. 41 N° 1, 86–107

Résumé

Les infirmières canadiennes face à la difficulté de mettre en pratique les valeurs qui leur sont chères

Brenda Beagan et Carolyn Ells

Les chercheuses ont mené des entretiens qualitatifs auprès de 20 infirmières d'une ville canadienne dans le but d'analyser leur expérience morale au travail. Elles ont demandé à celles-ci d'indiquer ce qu'elles valorisaient dans leur vie professionnelle et de préciser en quoi leur travail leur permettait de mettre leurs propres valeurs en pratique. Les répondantes sont quasi unanimes à évoquer leur adhésion à des valeurs comme l'aide, la sollicitude, le besoin d'être utile à la société, la relation axée sur le patient, la défense des droits, l'intégrité professionnelle, les soins holistiques et la volonté de transmettre des connaissances qui permettront aux patients de se prendre en main. Elles relèvent les difficultés et les frustrations qu'elles éprouvent lorsqu'elles tentent de mettre ces valeurs en pratique. Les obstacles de nature systémique comprennent notamment les hiérarchies professionnelles, la structure organisationnelle, les problèmes que connaît le système de santé et les dynamiques de pouvoir. Les faire tomber n'est pas une tâche qui appartient aux seules infirmières. Elle nécessitera un éventail de stratégies complexes : changements systémiques; restructuration des relations de pouvoir; et création d'une culture fondée sur l'éthique et propice au respect des valeurs essentielles à la prestation de soins infirmiers de qualité.

Mots clés : éthique, soins infirmiers; vie professionnelle

CJNR 2009, Vol. 41 Nº 1, 86–107

Values That Matter, Barriers That Interfere: The Struggle of Canadian Nurses to Enact Their Values

Brenda Beagan and Carolyn Ells

Qualitative interviews were conducted with 20 nurses in a Canadian city to explore the moral experience of nurses in their working lives. The participants were asked what they valued in their profession and how well their work lives enabled them act on their values. Almost uniformly, they expressed commitment to the values of helping others, caring, making a difference, patient-centredness, advocacy, professional integrity, holistic care, and sharing knowledge for patient empowerment. They identified several challenges and frustrations experienced in attempting to enact these values. System-level challenges included professional hierarchies, organizational structures, issues in the health-care system, and power dynamics. Removing these barriers cannot be left to nurses alone. It requires complex, wide-ranging strategies: system change, power restructuring, and the creation of ethical climates and cultures that support values that are essential to good patient care.

Keywords: ethics, nursing; decision-making, ethical; moral distress; burnout, professional

Attention to ethical practice in health care has been dominated by medical ethics, which has meant a tendency to focus on highly charged medical situations — what Varcoe and colleagues (2004) call "big 'E' ethical issues" (p. 317). The ethical situations that arise in nurses' everyday practice are often dismissed, and they are not identified as ethical concerns by researchers, theorists, or nurses themselves (Cohen & Erickson, 2006; Smith & Godfrey, 2002).

Distinctions made by Andrew Jameton (1984) regarding challenges in nurses' ethical experiences are still apt. Nurses can experience uncertainty about the ethical aspects of a situation, experience conflict between relevant ethical values or responsibilities, and experience ethical distress when something prevents them from acting ethically. According to the Canadian Nurses Association (CNA) (2003), ethical distress occurs when "a decision is made regarding what one believes to be the right course of action, but barriers prevent the nurse from carrying out or completing the action" (p. 3). Such barriers can be individual, interpersonal, or institutional (Cohen & Erickson, 2006; Hamric, 2000; Torjuul & Sorlie, 2006).

Originally published in CJNR 2007, Vol. 39 Nº 4, 36–57

After studying hospital nurses for more than 10 years, Chambliss (1996) concludes that ethical concerns in nursing are primarily systemic and structural, transcending the moral practices or commitments of the individual nurse. A persistent problem is interprofessional conflict as nurses try to do what they believe should be done in the face of counter-directives by others (cf. Storch, Rodney, Pauly, Brown, & Starzmoski, 2002). In a study with critical care nurses, Gutierrez (2005) found that nurses who were excluded from patient care decision-making perceived their work as devalued. Lacking a sense of autonomy, they felt powerless and constrained in ethical decision-making. Chambliss points out that ethical distress is not individual: "Remove a nurse with an ethical problem from the hospital, replace her, and her replacement will encounter the same problem" (p. 91). Confirming consistency across studies, Redman and Fry (2000), in their systematic analysis of nurses' ethical conflicts, conclude that most of these arise from institutional constraints against rather than uncertainty about the right course of action.

In Canada, Varcoe and colleagues (2004) studied the ethical experiences and needs of nurses on the west coast. They conclude that ethical practice in nursing is utterly contextual. Participants struggled to enact their personal and professional values — to do "good" — in the face of conflicting values and institutional constraints. They described being caught between physicians and patients; caught by the medical emphasis on technology and cure, at the expense of care; and caught by the need to document and account for their work, discounting those aspects of care that were not quantifiable. In the context of the dominant ideologies of scarcity and the need for efficiency, the nurses learned to ration their time and their care, which left them wondering if they were doing the right thing. Many participants were troubled by the belief that they were not practising ethically: "As one said, 'It's everything I can do, but it isn't enough.' This inability to 'do good' and 'do enough'…gave rise to profound moral distress" (p. 320).

Unresolved ethical distress is, clearly, linked to burnout (Severinsson, 2003; Sundin-Huard & Fahy, 1999), as well as to nurses' leaving their posts or leaving the profession (Corley, 1995, 2002). When nurses undergo intensive professional training, they not only acquire skills unique to their profession and specialized knowledge, but also assimilate the attitudes, values, and beliefs of their profession (Thompson, Melia, & Boyd, 2000). This process of professional socialization continues throughout one's career, sometimes reinforcing values and attitudes, sometimes transforming them in the context of practice (Cohen & Erickson, 2006; Lindh, Severinsson, & Berg, 2007). Juthberg, Eriksson, Norberg, and Sundin (2007) suggest that nurses unwittingly "deaden" their consciences, compromising their values in order to get along in interprofessional environments. The *Code of Ethics* for nurses in Canada identifies core values as follows: provision of safe, competent, and ethical care; promotion of health and well-being; respect for choice and autonomy; advocacy for respectful and dignified treatment of all persons; observance of confidentiality; upholding of justice; observance of accountability; and advocacy for quality practice environments (CNA, 2002, p. 8). If Canadian nurses do in fact hold these values and are prevented from enacting them in daily practice, then ethical distress is a likely outcome.

In contrast to previous studies that have asked nurses about their experiences related to ethical concerns, the current study did not predetermine the ethicality of experiences, nor did it predetermine categories of ethical uncertainty, conflict, or distress. Rather, we asked nurses about their values, and about how those values were or were not supported in their daily practice. Because of our broad focus on values, nurses had room to discuss issues they might not have identified as ethical, particularly as "big 'E' ethical" (Varcoe et al., 2004). This approach enabled us to unearth everyday ethical tensions, which are more subtle than ethical dilemmas (Cohen & Erickson, 2006). We took ethical tensions to include not only ethical distress (where barriers prevent one from doing the right thing) but also those routine feelings of simply being torn between conflicting values (Cohen & Erickson, 2006) or competing value sets (e.g., whether to be a "good nurse" or a "good co-worker") or uncertainty about ethical aspects of a situation. These feelings create a tension — a mental strain — that implicates one's values and the culpability of one's conduct and character. What one nurse defines as an ethical issue another might not. We wanted to explore the intersections among values, practices, and ethics, regardless of whether or not an individual nurse saw the issue as ethical in nature.

This article reports on a qualitative study with 20 nurses in Halifax, Nova Scotia, Canada, addressing four questions: *How do nurses view the core values of their profession? To what extent do they find themselves able to enact those values in practice? What barriers to acting on those values do nurses identify? What ethical tensions arise when there are barriers to acting on core values?*

Methods

Following university research ethics approval, we recruited nurse participants through posters, announcements in newsletters and circulars, snowball sampling, and recruitment letters sent to nurses in the Halifax metropolitan area. Those who were interested in participating contacted the research team. Several more nurses expressed interest than we were able to interview. In selecting participants, we strove for diversity in race, gender, age, and years of nursing experience. Volunteers took part in a one-on-one semi-structured qualitative interview following a guide that was developed from the literature as well as from discussions among the research team. The interviews drew upon the ethnographic tradition (DePoy & Gitlin, 2005). They were intended to elicit rich descriptions of participants' perceptions and experiences so that their accounts could be analyzed in relation to those of other participants as well as in relation to discourses on ethical practice and nursing values. In the interviews, participants were asked about the values they believed to be inherent to the profession when they entered it, how those perceptions may have changed over time, and their experiences with trying to act on those values in their day-to-day work.

In total, 20 nurses were interviewed by a trained research assistant who was not a nurse. The demographics of the participants are listed in Table 1. Each nurse met with the interviewer at a time and location

Table 1 *Demographics*

	#
Sex	
Male	2
Female	18
Ethnicity	
Caucasian	14
Racialized minority	6
Practice setting	
Community	6
Hospital	14
Years in practice	
< 5	3
5–9	2
10–14	1
15–19	2
20+	12
Age	
25–35	3
36–45	6
46–55	5
56–65	3
Not provided	3

convenient for the nurse. Consent was obtained. Interviews lasted approximately 1 hour and were audiotaped with permission. The tapes were transcribed verbatim and the transcripts were coded inductively using AtlasTi qualitative data analysis software.

In accordance with standard qualitative practice, themes were generated through in-depth examination of the transcripts. In an inductive and iterative process, data were read in depth and labels (codes) were applied to words, phrases, and concepts used time after time by participants. Text segments were compared within and across transcripts to refine coding. Codes were compared, clustered, and sorted until sufficiently distinct and comprehensive themes were generated and defined (Boyatzis, 1998; Luborsky, 1994). Further analysis followed common techniques in qualitative research, including memoing and thematic interpretation (Coffey & Atkinson, 1996). The findings reported here are drawn particularly from responses to questions about professional values, but the transcripts were also searched for instances in which participants spoke implicitly about values that guided their practice or about situations in which they were or were not able to act in accordance with their values.

One research assistant coded all of the data for internal consistency. She was trained in the use of the software and developed and used a codebook. Codes were refined through weekly meetings of the primary researcher and other research assistants. Participants received a descriptive feedback report based on all the interviews and confirmed the findings of the research team.

Findings

Values That Matter

Nurses expressed their values when speaking about their motivations for practising nursing, the reasons why they had initially chosen the profession, and the reasons why they had remained in the profession despite some challenges, as well as what they thought makes a "good nurse." They were fairly consistent in the values they expressed and often conveyed a deep commitment to those values. The key values identified were helping others, caring and compassion, making a difference, patient-centredness, advocacy, professional integrity, holistic care, and sharing knowledge for patient empowerment.

The value of ***helping others*** was raised frequently during the interviews. The nurses spoke about their desire to "help," about the importance of being in a "helping profession," and about nursing in order to "help others." Many identified the desire to help others as their primary reason for choosing nursing as a career and for finding it "fulfilling and satisfying." Helping was viewed as distinct from caring and empowering.

It was seen as *doing for* the patient and as central to the provision of assistance.

Caring and compassion, also described as empathy, were tied closely to the value of helping others. Yet some participants drew a clear distinction between these two values, noting that helping others can take place without compassion. Compassion can be understood as an emotional connection to the suffering of others. Caring or compassionate action involves understanding the other, then choosing to act in his or her best interests. Some participants referred to a selflessness in caring that nurses expect of themselves and each other:

> *A good nurse is able to be compassionate and holds someone's hand or hugs them without having to be [told]. It should come naturally. You should be intuitive enough to know what the person needs at that moment in time.*

One participant said that nurses should be willing not only to care but to care specifically for strangers.

Most participants explained that their choice of nursing as a career was closely linked to ***making a difference,*** a value held dear. One nurse spoke broadly of "wanting to make a difference and making it a better world." Others spoke of going the extra mile. For instance:

> *A good nurse should have the understanding that that person is at a very vulnerable place in their life and you have the ability to — in some way, shape, or form — touch that person's life, and whether they remember you or don't remember you they'll probably remember that it wasn't as bad as they had feared it would be.*

The words used to describe ***patient-centredness*** differed, but the description always included the right of patients to have a say in their own care. Some nurses described an evolution in patient-centred care: a gradual shift away from doing *for* the patient towards a team approach — doing *with* the patient — so as to provide the best care possible. The core of this value seemed to be respect for the individuality and knowledge of the patient: "We're giving back part of the care to the patients — what does *this* patient want? — whereas before everybody got the same thing." Participants noted that nursing care should accommodate the distinctiveness and individual needs of each patient.

Patient ***advocacy*** was a strongly held value. It was identified as "one of the primary responsibilities of a nurse" and as an integral part of a nurse's standard of care. Its importance stems from nurses' intimate knowledge of their patients: "You certainly have the ability to advocate on their behalf, because you're the one who knows them the best — you're with them all the time." This value lies in a deep-seated belief that nurses ought to use their knowledge of a patient to act in his or her best interests. One participant described a situation in which a nurse's failure to advocate — to insist on a second opinion — led to a patient's death. The participant considered this an inexcusable abandonment of the patient. Another participant said that nurses can play a role as health advocates on a larger scale, at the level of the health-care system; she described this as an "exciting opportunity," one she clearly thought nurses ought to embrace.

Participants valued ***integrity*** in both personal and professional terms, describing it as doing what you are "supposed to do," "stand[ing] up for what you believe," "doing the right thing," and not going "over the line." What had drawn one participant into the nursing profession was the integrity of his preceptors, who were "meticulous about their charting or their care [to] make sure it's done as per protocol" because "they wanted to be the best nurses possible." Some participants linked integrity to a strong commitment to accountability:

> *It's the code of conduct for nurses. They have a responsibility to maintain standards. Accountability is one of them. If you did something wrong, own up to it… If you've made a medication error…you'll have to suffer the consequences but at least you know in your mind that you've done the right thing.*

A willingness to provide ***holistic care*** was frequently named as an essential value in nursing practice. Participants described holism as a relationship with the whole patient:

> *I could easily just carry out the orders that the doctor has written, [but] I have a choice within my practice to try to explore and further that relationship with the patient, explore what else I can do to help the person… You don't look at just what's in front of you. You always look at the whole picture. That's holistic care.*

Participants ascribed considerable importance to their profession-specific knowledge, naming their expertise yet also insisting on the importance of ***sharing knowledge for patient empowerment***: "Knowledge is power, and you empower people by giving the knowledge to them." One nurse elaborated:

> *I value knowledge because I like knowing as much as I can about what I'm doing and being able to impart that to the people that I am taking care of, so that they can further themselves or take advantage of it [my knowledge] or take responsibility for themselves.*

The value here is the manner in which knowledge is wielded — shared with patients rather than used by nurses to reinforce their own authority.

Challenges and Frustrations

In describing the values that mattered most in their everyday work, the nurses revealed numerous challenges and frustrations. This section focuses on the emotional impact of the nurses' experiences, while the next identifies *why* some of these challenges arose. The inability to make a difference, or sustain patient-centredness, and conflicts between the values of patients and those of colleagues were repeatedly cited as emotional frustrations and challenges. For some nurses, the emotional toll of their inability to enact deeply held values was burnout and detachment, which in turn compromised their ability to enact other values such as caring, compassion, and helping. Many of the participants became profoundly disillusioned when they found that they were unable to do what they had entered nursing to do.

Inability to make a difference. Participants faced significant obstacles to enacting their desire to make a difference in patients' lives, or to alter the course of their patients' care when they knew the care being provided was not what the patient wanted. Several participants came to realize that making a difference was never as easy as it seemed:

> *You go in really wanting to change everything and then you can't even move forward an inch sometimes. I think maybe in my heart, not in the front of my brain, I thought everything would be wonderful. But it's not like that. It's hard work.*

Values in conflict. Several nurses spoke about the difficulty of enacting patient-centred care when their values came into conflict with those of the patient. This challenges the notion of empowering patients by sharing expert knowledge:

> *Sometimes there's a dichotomy between what I know is best for you or what medically is best for you and what you choose to do. I'm a firm believer in giving somebody education to make the choices, but sometimes it's hard to [reconcile] their not doing the right thing. "Why can't you take your medication?" I think that's one of the biggest ethical challenges.*

Some participants spoke of nurses unintentionally and perhaps unwittingly imposing their own values, especially in the case of a nurse believing strongly that a particular course of action is in the patient's best interests. When this is not what the patient wants, the value of patient-centred care is compromised.

Challenges to professional integrity arose because of differences in values or practices among colleagues. When they worked with people who had different perceptions of what constitutes professional behaviour, or of what constitutes an acceptable standard for fulfilling one's duties, nurses were torn between collegiality and professional integrity:

> *If you don't adhere to the standards of practice, then you shouldn't be in nursing. If you start down the slippery slope, it never stops. If you make that decision not to do proper patient care…if you do it once, you're willing to do it again. I don't feel that people get to a level in their professional life where they're pulled up and reported to the College for a one-off incident. It's a pattern.*

One participant said that nurses about to begin a new job should be advised "to look at the vision and the philosophy of the nurses that you'll be working with so that you know that it's congruent with your own beliefs before you actually start the job." Her warning suggests that incongruent ethical stances may be a source of considerable day-to-day tension.

Unenacted values take an emotional toll. While acknowledging that the reality of their workplaces was often different from what they had expected, participants were quick to state that their values had not changed. One participant said, "My values didn't change, but sure enough there is frustration." Some nurses cited the emotional toll taken by routinely having difficulty enacting one's professional values. Many participants spoke of a drain of energy, which some described as burnout. The constant giving in a profession that tends to give very little in return led some participants to move to a less demanding practice setting or from full-time to part-time work. Such changes allowed them to work in environments where they could provide care in ways that did not leave them drained of energy and detached from their work: "You give and you give and you give all day. We have to replenish that energy. That's human nature."

Emotional detachment from the constant giving of themselves seemed inevitable to the nurses, vital to the preservation of their own health and well-being. The participants felt that, in order to function in their work (and in their lives), they had to detach themselves emotionally and mentally from their work, the politics of their profession, and their patients. One participant stated that pediatric nurses cannot become involved with their patients beyond a superficial level, adding that to become detached one has to be more professional and less sympathetic. A coronary care nurse made a similar claim, adding that attending bereavement services for patients is a signal that the nurse has become too attached. While none of the participants was specifically asked to articulate *why* it was so important not to become "too attached" to patients, there was a suggestion that one must maintain emotional control in order "to cope" or to do one's job competently:

> *I try to remain as detached as I can to get my work done, but I still want [my patient] to feel that…I'm really there for her and I'm feeling it as much as I can, helping her out. You know, I don't want to dissolve into a slobbering mess. That's not going to help anybody either.*

Ironically, while participants expressed the view that burnout and detachment can have negative consequences for patients, these responses also compromise caring, helping, and compassion — the very nursing values that many participants cherished. Detachment, while protective, becomes a barrier to experiencing compassion, a deeply held value. One participant commented that nurses who are more detached in their approach are rarely thanked by patients and are rarely acknowledged as helping or as making a difference.

Not surprisingly, several nurses reported "relentless" and profound disillusionment upon finding themselves routinely unable to enact their core values: "I found my values were being challenged all the time because I wasn't able to give what I thought I wanted to give, and that was a daily frustration." One nurse expressed this frustration particularly well:

> *I want to care for my patients more than just in the way of giving out medications, washing them up for the day, or filling these tests out. It's just relentless, and that is where I am caught. What I want to do for my patient is always second, and I can't seem to get my head around not being able to do that all the time. I've contemplated a lot about switching professions, just for the mere fact of not being able to carry out the things that I want to do for my patients.*

Barriers That Interfere

Participants identified a number of challenges to their ability to enact nursing values in their everyday work. Key barriers identified were hierarchies within health care, workplace structures and policies, and the priorities of the health-care system.

Interprofessional hierarchies within the health-care system were a frequently identified source of frustration and ethical tension, though for the most part those nurses who worked within a team found their colleagues and other health professionals to be very supportive. The workplace conflicts most often discussed were those with physicians, due to the subordinate status of nurses in the health-care hierarchy:

> *I do butt heads with the physicians… As a nurse you can advocate, but if they really feel that [the patient] needs that medication, they're the ones with the higher credentials…so they're the ones that are going to make the decisions.*

One participant commented that the nurse "follows doctors' orders… initiates treatment…and that's your job." For some participants, unquestioning compliance directly contradicted their core values of patient-centredness, helping, and professional integrity:

> *I knew that I wouldn't have the ability to make all the decisions that I wanted to make. I wouldn't have the control. It's not an independent profession, no matter what the academics might say. I knew I wouldn't have the autonomy. I just didn't know, when I graduated, how much that would mean to me. What I see as important for my patient and what their doctor sees as important can be two very divergent things. And it can be frustrating, because I don't have the power to diagnose, I don't have the power to prescribe.*

At the time of the interview this participant was in the process of leaving the profession. Several other participants had seriously contemplated leaving as well. In contrast, some of the nurses expressed relief that the responsibility for medical care did not fall to them; they were, as one put it, "freed" by the scope of their practice — the physicians "are the ones ultimately responsible."

Apart from the lack of autonomy, some participants argued that physicians are simply ignorant about the work that nurses do, the extent of nursing education, and the scope of nursing practice: "We work with some physicians who have no appreciation of nursing, don't know that nurses have their own code of conduct, their own standards of practice… That's very infuriating." Furthermore, the participants reported that some physicians do not provide an opportunity for nurses to be heard and do not tolerate being questioned by nurses:

> *Some physicians will not accept [questioning]. They don't like their authority to be challenged… I know a couple in particular who would not listen to any patients, and even for me to talk to them it wouldn't make any difference.*

This lack of acknowledgement was draining for some participants, who felt they had no place in patient care: "I'm just nobody."

One of the underlying tensions between nurses and physicians apparently stemmed from a difference in professional values. Participants spoke of nurses as focused on care and of physicians as focused on cure, sometimes at the expense of the patient's overall well-being. Related to this difference in focus, some participants identified an epistemological conflict between nurses and physicians, grounded in the valuing of very different kinds of knowledge. Some participants spoke of nurses' ways of knowing being dismissed and evidence-based practice being favoured over "gut feelings," "instinct," and nurses' experiential knowledge. Thus holistic care requiring the experiential knowledge of nurses, gained through ongoing contact with patients, is compromised in a medically dominated system. The conflict between professions in terms of values was a struggle for the nurses; the interprofessional hierarchy constituted a barrier to their acting in accordance with their values.

Intraprofessional hierarchies and organizational structures. Intraprofessional hierarchies and the organization of the workplace caused tension for the nurses. Several participants described tensions surrounding differences in professional training. Diploma-trained nurses described feeling "diminished," held back, and pressured by management to obtain a degree. One nurse stated:

> *You would get these people who because they have their master's or their bachelor's...would have this holier-than-thou attitude...who maybe had only been there 2 or 3 years. What happened to [the value of] experience?*

Other reasons given for tensions related to workplace structure included an apparent disjuncture between frontline staff and management. A common complaint was that managers were sheltered from the realities of frontline work and failed to seek frontline input into decision-making. Some managers had little clinical experience, or no background in the speciality, and therefore were unfamiliar with the issues confronted by the nurses under their supervision and were distanced from the realities of trying to enact nursing values.

Workplace policies and practices were another source of ethical tension. Participants spoke of nurses sometimes needing to or choosing to circumvent the rules, which created areas of tension. Some cited the presence of "unwritten rules." Lack of clarity about parameters caused one participant to move to an area of nursing where everything was "black and white," with no room for guesswork. For such participants, routine policies and practices got in the way of enacting values, leaving nurses torn between obeying the rules and acting with integrity.

For some participants, in contrast, adhering to policies afforded a measure of protection, guarding them against personal responsibility and liability:

> *It's sort of like a standard set of care you have to follow. It's quite regiment[ed]. If you don't follow it precisely and everything is okay, that's fine. But if you ever didn't follow it precisely and something went wrong, huge, huge litigation... The policies are very restrictive in some ways, but in other ways they're to protect the patients and...to protect us, so even though they're a bit regiment[ed], they're there for a reason.*

These participants appeared to resolve any ethical tensions between practice and values by deferring to the rules.

Failings of the health-care system. The health-care system was often cited as a constant source of frustration and tension because of reduced staffing and lack of funding for quality care. Some participants suggested that, while all health-care workers feel the pressure of constraints on the system, because of nurses' direct contact with patients 24 hours a day, they feel the lack of time and resources as a distinctively *ethical* tension: They are unable to provide the kind of care that compelled them to go into nursing in the first place. One nurse described the situation in a graphic way that also reveals some personal distancing from the diminished care provided:

> *In the hospital years ago we used to [give] a lot more personal care to people... They stay[ed] longer, so you [had] to give them their bedside care, physical care. But now...if they [the nurses] give you a bowl of water you're lucky!*

Most participants felt that they simply did not have the time to provide emotional support to patients. This was an increasing source of tension for them. One nurse explained that there was no time "to hold somebody's hand when they're crying and that sort of thing," which frustrated her ability to enact the value of holistic, patient-centred care. Decreased staffing was seen as a direct cause of increased workload and time constraints:

> *In terms of cuts...it's across the board. Every place I've worked, you see it in nursing. It makes it harder because oftentimes you don't have the resources to always do the right thing to the extent you want to do it. My frustrations come from just so much more I want to do and I can't do it.*

Many participants felt they were unable to provide the best possible care when exhausted from working overtime. Clearly, they believed that their professional integrity was compromised.

One nurse suggested that cutbacks to cleaning, kitchen, and clerical staff had resulted in those support functions being relegated to nurses while, at the same time, their paperwork had increased. One participant was "irked" by having to account for every activity in order to justify staffing levels: "Are we actually measuring this so we can be staffed? How do you measure emotional support? ...that's ridiculous." Another participant spoke of nursing as having become a "paper profession" rather than a "people profession," with nurses having less and less time to perform the caring tasks they see as central to their profession.

Time pressures and stretching oneself too thin served to raise the discomfort level, but it was when these factors led to decreased patient care that distinctly ethical tensions arose. One nurse explained that where once patients were discharged to home-care services, they were now discharged into the care of neighbours or family members, regardless of their caregiving abilities:

> *You need them to do it. You teach them — how much can they learn in 2 hours…? Somewhere there's somebody suffering, but what can you do? There's no resources, no money — that's what they have to have to get assistance; they're saying there's no money.*

The ethical tensions arose from an inability to express compassion by providing quality care. For some participants, unmet needs seemed limitless and all they could to do was focus on the task at hand. One participant described nurses as "policing" each other so that no one raised patients' expectations by providing care beyond what was deemed feasible:

> *Things were quiet one evening and I was going around rubbing people's backs, while the rest of the staff were totally appalled that I would do something like that, because "these people are going to expect that tomorrow night." And I said, "Well, that's your problem."*

For nurses who had entered the profession to help people, make a difference, or show compassion, the lack of resources to routinely enact these values gave rise to ethical tensions, which could in turn lead to profound disillusionment and detachment.

Summary

The values that mattered most to the participants were clear: helping, caring, making a difference, patient-centredness, advocacy, professional integrity, holistic care, and sharing knowledge for patient empowerment. In attempting to enact these values in their work, the nurses met with frustration and challenges, including the inability to make a difference and conflicting values, leading to emotional detachment, disillusionment, and burnout. The participants identified a number of systemic barriers to their ability to enact their values. These included interprofessional hierarchies; different professional epistemologies, values, and approaches to caring; intraprofessional hierarchies; workplace structures and policies; and the priorities of the health-care system with their accompanying time pressures and reduced quality of care. One participant pointed out that nurses can have difficulty even recognizing the day-to-day ethical challenges:

> *I think my biggest challenge with this [the interview] was trying to rediscover…how I've been ethically challenged throughout my practice. And it's very difficult, but I know in my heart of hearts that I'm ethically challenged 10 times more than I even recognize.*

Discussion

The findings suggest consistency among nurses regarding the core values of their profession, as well as the enduring nature of these values despite barriers to their enactment in the workplace. Further, without prompting about the substance of their values, the nurses described the core values articulated in the CNA's *Code of Ethics for Registered Nurses* (2002). This finding confirms the relevance of the *Code of Ethics* for Canadian nurses. Yet confidence in one's fundamental values and the support of one's professional association for those values are no guarantee that one will be able to enact them in the workplace. Indeed the findings indicate that Canadian nurses face significant constraints in enacting their values, resulting in ethical distress.

Our findings echo those of previous research suggesting that system-level issues impede nurses' everyday work (Chambliss, 1996; Health Canada, 2002; Poncet et al., 2007; Tadd et al., 2006; Varcoe et al., 2004), causing or exacerbating ethical distress (Corley, 2002; Gutierrez, 2005; Hamric, 2000; Millette, 1994; Pask, 2005; Redman & Fry, 2000; Storch et al., 2002; Varcoe et al., 2004). The priorities of the health-care system or of its institutions result in nurses having little say in the care of their patients; understaffing; severe constraints on nurses' time, such that they believe they are fulfilling only a fraction of their ethical mandate; demands that nurses fulfil auxiliary roles despite their inability to fulfil what they see as their primary role; the abandonment of holistic patient care under pressure for early discharge; and limited patient access to diagnostic and treatment interventions. Further, the participants appeared to believe that removal of system-level barriers cannot be left to nurses alone (Chambliss, 1996; Health Canada, 2002; Tadd et al., 2006), as nurses function in a context of multiple players, realities, values, and goals. The ethical environment of Canadian nursing consists of social, political, economic, and institutional forces; regulatory bodies; and multiple health professions with different aims, values, and educational priorities. As health care becomes infused with corporate ideologies, assumptions about scarcity and the need to maximize efficiency form barriers to the enactment of core nursing values (CNA, 2002).

Collaborative, wide-ranging, multifaceted initiatives are needed to generate system change, restructure power, and build ethical climates and cultures that support values that are essential to good care. Such collaboration seems unattainable when nurses' ethical practices are hampered by inter- and intraprofessional differences in power, values, and knowledge and a mutual lack of understanding with respect to professional skills and abilities. Nonetheless, a commission appointed by Health Canada (2002) produced 51 recommendations for improving the working lives of

Canadian nurses; these address workload, leadership, education, violence and abuse, nurses' health, accreditation, human resources, research, and government. A comprehensive set of initiatives based on the recommendations has yet to be accepted and implemented.

In the meantime, there are practical steps that nurses and nursing leaders can take to alleviate ethical distress. They can create organizational environments that foster ethical reflection. Certain types of collaboration with other health professionals (Juthberg et al., 2007) and with nursing colleagues can cause nurses to compromise their values. This can mean "having to deaden one's conscience in order to uphold one's identity as a 'good' health care professional" (Juthberg et al., 2007, p. 339). This deadening can continue as long as everyday activity precludes time to reflect. Reflection results in the need to find justification for one's actions or inactions.

All of this suggests one immediate strategy for enhancing ethical practice even in untenable environments: the creation of opportunities for collegial discussion of nursing values. Such opportunities could take the form of continuing education courses, or could be as simple as a series of brown-bag lunches (Andrews, 2004; Cohen & Erickson, 2006; Lindh et al., 2007; Storch et al., 2002). The point is to provide mutual support for ethical questioning. Among nurses, discussion groups would focus on the kind of reflection that is needed to reverse deadening of conscience. The groups would have to be carefully facilitated, so as not to become mired in discussion that normalizes and therefore reinforces the compromising of ethical values. Facilitation by an outsider, such as a pastoral care specialist or an ethicist, might serve to promote the questioning of taken-for-granted practices. Discussions would need to be guided by critical questions such as What *should* happen in such situations? What would it take to make that happen? The immediate implication for bedside nurses might be to challenge ethical "slippage," supporting one another to find ways to enact one's professional values. This approach could also foster the development of a collective voice at the local level, which is critical since no individual can break down institutional and system-level barriers alone (Buchman & Porock, 2005).

Such ongoing discussion could also serve another, related purpose. Our findings indicate that being hindered from acting on compassion causes ethical distress. At the same time, acting compassionately and altruistically can lead to burnout and detachment, given the magnitude of patient need (cf. Abendroth & Flannery, 2006; Gutierrez, 2005). Safe places where nurses can meet regularly to discuss the ethical values that underpin their work may help to guide those who tend to cross the line into excessive empathy while also validating and affirming the importance of compassion for those who have come to see giving patients a back rub as violating practice norms. Detachment from caring and compassion denies a core nursing value, a value that motivates many nurses to continue working.

Ideally such discussions of values and ethics would take place among bedside nurses and nurse managers, since different work situations can result in very different values and in ethical conflict (Carney, 2006; Guiterrez, 2005). Similarly, it would be ideal for nurses to converse with other health professionals, especially physicians, to enhance understanding of each other's values and professional ethics as well as the causes of ethical distress in different professions (Torjuul & Sorlie, 2006). We believe, however, that it is too soon to initiate this step. Nurse managers and physicians are among the sources of nurses' ethical distress. Given existing power relations, it is critical that bedside nurses have safe places to talk with each other, to reinforce everyday ethical values in practice. At this point it may be more useful for nurses to converse with other allied health professions who also experience power differentials with physicians and managers.

Educational settings are the ideal site for interprofessional ethics education. Such learning should extend beyond the classroom to clinical rotations. At the same time, ethics education must be pragmatic — it is futile for nurses to learn ethical principles if they see no way to put them into action (Andrews, 2004). A pragmatic ethics education would emphasize contextual realities, including naming the power relations that affect everyday practice, such as nurse-physician relations. It would teach students to consider a range of possible responses when faced with resource limitations that hinder them from acting on their values, to talk with each other about the realities as well as the ideals of practice (Lindh et al., 2007), and to become active in professional organizations that provide a collective voice for change (Buchman & Porock, 2005). In clinical settings, nurse leaders and seasoned nurses need to demonstrate for students a willingness to speak out, to ask critical questions that lead to collective questioning of institutional barriers to ethical practice (Cohen & Erickson, 2006).

Finally, research is needed to assess the effects of interventions, such as those outlined above, for enhancing nurses' ability to act ethically. Nurse leaders and administrators may be able to persuade hospitals and other health-care facilities to fund such research by linking ethical work environments with nurse retention and the potential for improved care. At a time of nursing shortages across the country, many of the participants in this study were contemplating leaving the profession, working fewer hours, or transferring to a less demanding work environment (cf. Health Canada, 2002; Millette, 1994). Cherishing the values and ideals of nursing but unable to provide the kind of care they consider integral to nursing, some nurses cope by removing themselves from the very workplaces and settings where they aspire to make a difference. Their departure signals a lack of moral will on the part of the health-care system, health professionals, and society.

Limitations

Although the participants represented a variety of work settings and demographics, the study explored the experiences of one sample of nurses in one eastern Canadian city. While a study of this nature seeks depth of description and analysis, rather than generalizability across sites, it would be interesting to explore the ethical experiences of nurses in other settings. It is nonetheless intriguing to note the similarities between our findings and those of two other Canadian studies, one on the east coast (Gaudine & Thorne, 2000) and one on the west coast (Varcoe et al., 2004). Moreover, Gaudine and Beaton (2002) found that nurse managers experienced similar ethical distress, feeling powerless and voiceless, torn between the needs of patients, families, and nurses and the needs of the hospital. There is much in our data to suggest that when nurses are unable to enact their professional values, patient care suffers. At the same time, there are hints that some nurses extend themselves in an attempt to cover the gaps. Future research might explore the relationship between nurses' ethical tensions and quality of patient care. Another limitation is the fact that neither the interviewer nor the primary researchers were nurses. While a nurse interviewer might have been better able to relate to the participants, some nurses might have been unwilling to critique aspects of their work to a fellow nurse. Lastly, the study design allowed for only one interview with each participant. Several of the nurses remarked that the interview had caused them to reflect deeply; a follow-up interview may have elicited valuable insights.

Conclusion

The challenge of working in a nursing environment that does not recognize giving a back rub or holding someone's hand as part of the nursing profession, where personal satisfaction from making a difference or fulfilling one's role is rarely experienced, exacts a toll on nurses. The findings of this study draw attention to these concerns. The detailed reports of the participants, delivered with such emotional urgency and distress, should move us to action. It is urgent that the system-level issues that impede nursing work be addressed. One means of doing so may be to create local environments conducive to the discussion of ethical concerns.

References

Abendroth, M., & Flannery, J. (2006). Predicting the risk of compassion fatigue: A study of hospice nurses. *Journal of Hospice and Palliative Nursing, 8*(6), 346–356.

Andrews, D. R. (2004). Fostering ethical competency: An ongoing staff development process that encourages professional growth and staff satisfaction. *Journal of Continuing Education in Nursing, 35*(1), 27–33.

Boyatzis, R. E. (1998). *Transforming qualitative information: Thematic analysis and code development.* Thousand Oaks, CA: Sage.

Buchman, D. E., & Porock, D. (2005). A response to C. Varcoe et al. "Ethical practice in nursing: Working the in-betweens." *Journal of Advanced Nursing, 51*(6), 658–659.

Canadian Nurses Association. (2002). *Code of Ethics for Registered Nurses.* Ottawa: Author.

Canadian Nurses Association. (2003). Ethical distress in healthcare environments. In *Ethics in Practice for Canadian Registered Nurses* (pp. 1–8). [CNA occasional publication.] Ottawa: Author. Retrieved November 13, 2007, from: http://www.cna-nurses.ca.

Carney, M. (2006). Positive and negative outcomes from values and beliefs held by healthcare clinician and non-clinician managers. *Journal of Advanced Nursing, 54*(1), 111–119.

Chambliss, D. F. (1996). *Beyond caring: Hospitals, nurses, and the social organization of ethics.* Chicago: University of Chicago Press.

Coffey, A., & Atkinson, P. (1996). *Making sense of qualitative data: Complementary research strategies.* London: Sage.

Cohen, J. S., & Erickson, J. M. (2006). Ethical dilemmas and moral distress in oncology nursing practice. *Clinical Journal of Oncology Nursing, 10*(6), 775–782.

Corley, M. (1995). Moral distress of critical care nurses. *American Journal of Critical Care, 4,* 280–285.

Corley, M. (2002). Moral distress: A proposed theory and research agenda. *Nursing Ethics, 9*(6), 636–650.

DePoy, E., & Gitlin, L. N. (2005). *Introduction to research: Understanding and applying multiple strategies* (3rd ed.). St. Louis: Elsevier.

Gaudine, A. P., & Beaton, M. R. (2002). Employed to go against one's values: Nurse managers' accounts of ethical conflict with their organizations. *Canadian Journal of Nursing Research, 34*(2), 17–34.

Gaudine, A. P., & Thorne, L. (2000). Ethical conflict in professionals: Nurses' accounts of ethical conflict with organizations. *Research in Ethical Issues in Organizations, 2,* 41–58.

Gutierrez, K. M. (2005). Critical care nurses' perceptions of and responses to moral distress. *Dimensions of Critical Care Nursing, 24*(5), 229–241.

Hamric, A. B. (2000). Moral distress in everyday ethics. *Nursing Outlook, 48,* 199–201.

Health Canada. (2002). *Our health, our future: Creating quality workplaces for Canadian nurses.* Final report of the Canadian Nursing Advisory Committee. Ottawa: Author.

Jameton, A. (1984). *Nursing practice: The ethical issues.* Englewood Cliffs, NJ: Prentice-Hall.

Juthberg, C., Eriksson, S., Norberg, A., & Sundin, K. (2007). Perceptions of conscience in relation to stress of conscience. *Nursing Ethics, 14*(3), 329–343.

Lindh, I. B., Severinsson, E., & Berg, A. (2007). Moral responsibility: A relational way of being. *Nursing Ethics, 14*(2), 129–140.

Luborsky, M. R. (1994). The identification and analysis of themes and patterns. In J. F. Gubrium & A. Sankar (Eds.), *Qualitative methods in aging research* (pp. 189–210). Thousand Oaks, CA: Sage.

Millette, B. E. (1994). Using Gilligan's framework to analyze nurses' stories of moral choices. *Western Journal of Nursing Research, 16,* 660–674.

Pask, E. J. (2005). Self-sacrifice, self-transcendence and nurses' professional self. *Nursing Philosophy, 6,* 247–254.

Poncet, M.C., Toullic, P., Papazian, L., Kentish-Barnes, N., Timsit, J.F., Pochard, F., et al. (2007). Burnout syndrome in critical care nursing staff. *American Journal of Respirology and Critical Care Medicine, 175,* 698–704.

Redman, B. K., & Fry, S. T. (2000). Nurses' ethical conflicts: What is really known about them? *Nursing Ethics, 7,* 360–367.

Severinsson, E. (2003). Moral stress and burnout: Qualitative content analysis. *Nursing and Health Sciences, 5*(1), 59–66.

Smith K.V., & Godfrey N. S. (2002). Being a good nurse and doing the right thing: A qualitative study. *Nursing Ethics, 9,* 301–322.

Storch, J. L, Rodney, P., Pauly, B., Brown, H., & Starzmoski, R. (2002). Listening to nurses' moral voices: Building a quality health care environment. *Canadian Journal of Nursing Leadership, 15*(4), 7–16.

Sundin-Huard, D., & Fahy, K. (1999). Moral distress, advocacy and burnout: Theorising the relationships. *International Journal of Nursing Practice, 5*(1), 8–13.

Tadd, W., Clarke, A., Lloyd, L., Leino-Kilpi, H., Strandell, C., Lemonidou, C., et al. (2006). The value of nurses' codes: European nurses' views. *Nursing Ethics, 13*(4), 376–393.

Thompson, I. E., Melia, K. M., & Boyd, K. M. (2000). *Nursing ethics* (4th ed.). New York: Churchill Livingstone.

Torjuul, K., & Sorlie, V. (2006). Nursing is different than medicine: Ethical difficulties in the process of care in surgical units. *Journal of Advanced Nursing, 56*(4), 404–413.

Varcoe, C., Doane, G., Pauly, B., Rodney, P., Storch, J.L., Mahoney, K., et al. (2004). Ethical practice in nursing: Working the in-betweens. *Journal of Advanced Nursing, 45*(3), 316–325.

Acknowledgements

This study was funded by the Social Sciences and Humanities Research Council of Canada.

We wish to thank the nurses who were interviewed for the study, Andrea D'Sylva and Zofia Kuma-Tan for their research assistance, the College of Registered Nurses of Nova Scotia for its recruitment assistance, and the Social Sciences and Humanities Research Council of Canada for its financial support. Drs. Sue Campbell, Joan Evans, Joan Harbison, and Donna Meagher-Stewart were members of the larger research team.

Brenda Beagan, PhD, is Associate Professor, School of Occupational Therapy, Dalhousie University, Halifax, Nova Scotia, Canada. Carolyn Ells, PhD, is Assistant Professor of Medicine and Member of the Biomedical Ethics Unit, McGill University, and Clinical Ethicist, Sir Mortimer B. Davis Jewish General Hospital, Montreal, Quebec, Canada.

2009 update: *Brenda Beagan is Tier II Canada Research Chair, Women's Health, Dalhousie University. Carolyn Ells is Associate Professor of Medicine, McGill University; her other positions/affiliations are unchanged.*

CJNR 2009, Vol. 41 Nº 1, 108–126

Résumé

Une violence insidieuse : le racisme tel que vécu par les adolescents au Nouveau-Brunswick

Cynthia Baker, Manju Varma et Connie Tanaka

L'objectif de la recherche était de décrire la nature du racisme tel que vécu par des adolescents affirmant être victimes de ségrégation dans la province du Nouveau-Brunswick, au Canada, ainsi que leur réaction face aux incidents de racisme perçu. Une méthodologie qualitative fondée sur un paradigme constructiviste a été utilisée dans le cadre de cette étude. Des entrevues en profondeur ont été menées auprès d'adolescents non blancs qui ont été victimes de racisme et auprès des parents de ces victimes. Bien que la recherche ait été initiée en réponse à une campagne publicitaire intensive portant sur la violence raciale chez les adolescents, les résultats indiquent que les incidents de racisme sont un phénomène connu des participants. Ces derniers décrivent un problème insidieux mais aussi persistant auquel ils ont dû faire face lorsqu'ils ont commencé à fréquenter l'école publique. Les injures constituent la forme de racisme la plus répandue et font partie de la plupart des incidents décrits. Même si les symboles d'autorité les qualifient d'inoffensives, les injures semblent produire des effets à long terme sur les personnes ciblées. Selon les résultats, les réactions des participants face au racisme comportent trois phases : l'éclatement de l'univers, la résistance en spirale et le désengagement. Les résultats révèlent que les infirmières œuvrant en milieu scolaire doivent traiter des questions ayant trait au racisme avec les enfants et les adolescents.

CJNR 2009, Vol. 41 N° 1, 108–126

Sticks and Stones: Racism as Experienced by Adolescents in New Brunswick

Cynthia Baker, Manju Varma, and Connie Tanaka

The purpose of the study was to describe both the nature of racism as experienced by adolescent self-described victims in the province of New Brunswick, Canada, and their response to the perceived racist incidents. A qualitative methodology based on the constructivist paradigm was used. In-depth interviews were conducted with non-White adolescent victims of racism and with parents of victims. Although the study was initiated in response to an eruption of publicity about teenage racial violence, the findings indicate that racist incidents were not a new phenomenon for the participants. They described a low-key but long-term problem that had begun when they entered the public school system. Name-calling was by far the most common form of racism identified, and it played a part in most of the other incidents described; dismissed as harmless by authority figures, it appeared to have long-term consequences for its targets. The participants' response to racism was found to have 3 phases: splintered universe, spiralling resistance, and disengagement. The results suggest that nurses working in the field of school health should address issues of racism among children and adolescents.

Over the last three decades, changes in Canada's immigration policy have transformed its ethnic composition. Although the proportion of the population not born in Canada has remained stable, the percentage from non-European countries has increased dramatically (Badet, 1993). The resulting increase in visible ethnic diversity has given racism greater public salience. There has also been a growing recognition among health-care professionals that racism is a determinant of health as well as a significant social issue. Stress related to racist incidents has been associated with a wide variety of physical and emotional health problems (Rollock & Gordon, 2000).

Of particular concern has been increased interethnic conflict among adolescents. Most investigations of this problem have been conducted in metropolitan centres with large immigrant communities. A number of reported incidents of racially motivated violence targeting non-White youths in the province of New Brunswick prompted a study of the problem in a different social context, since, unlike some areas of Canada, New Brunswick has a relatively homogeneous population (Badet, 1993).

Originally published in CJNR 2001, Vol. 33 N° 3, 87–105

The purpose of this study was to describe the nature of racism from the perspective of adolescent victims living in areas of limited ethnic diversity, as well as their responses to racist incidents. It was undertaken as a first step in a larger project designed to promote sensitive institutional responses to the needs of young victims of racism. The specific questions examined were: *What is the nature of racism as experienced by self-described adolescent victims in the province of New Brunswick? How do self-described adolescent victims of racism respond to perceived racist incidents?*

Background

Definitions of racism focus on three central attributes: assignment to a racial group based on physical characteristics, associated inferiority or superiority of designated racial groups, and policies or behaviours that differentially affect the self-esteem and life chances of members of a racial group (Green, 1995; Rollock & Gordon, 2000). Scholars differ in the extent to which they believe racism should be studied individually or structurally (Rollock & Gordon, 2000). Institutional racism is differentiated from individual racism. The former exists when institutions grant fewer rights to a given racial/ethnic group or limit the opportunities of that group to exercise its rights (Green, 1995). The health effects of both individual and institutional racism have been documented. At the individual level, racism has been linked to general emotional well-being (Vrana & Rollock, 1996, 1998), psychophysiology (Clark, Anderson, Clark, & Williams, 1999), and restrictions on lifestyle options (Rollock & Gordon, 2000). Perceived institutional racism has been linked to mental health (Hendryx & Ahern, 1997).

Although nurses have investigated cross-cultural relationships, they have given racism little attention as a distinct phenomenon, tending instead to see it as part of cultural differences. The few nursing studies of the phenomenon that have been done have focused on racism among caregivers. Bonaparte's (1979) investigation of nurses' attitudes towards culturally different clients suggests that ego defensiveness and closed-mindedness play a part. Similarly, racism is among the problems identified in Béguin Stockli's 1997 study of problematic issues in the care of refugees and other asylum-seekers in Switzerland (cited in Shaha, 1998). Shaha explicitly set out to determine whether patients in a Swiss hospital encountered everyday racism. Her findings, however, are ambiguous. Green (1995) also focused directly on racism. She developed a scale to measure perceived racism among African-American women in the United States. Nursing studies support findings that racism impacts on the delivery of health care.

Racism and its effects have been studied in children. Racial prejudice has been found to be distressingly common among children (Bigler & Liben, 1993; Doyle & Aboud, 1995). Despite a popular conception that prejudice is learned as people become adults, it is reported that children as young as 5 years possess perceptual and attitudinal biases. White children in particular have been found to express prejudice towards Blacks and Natives (Corenblum & Annis, 1993). Studies of the effects of racism on young people have found it to be related to poor emotional health (Tatum, 1992), low academic achievement (Harrell, 2000), and lack of hope for the future (Murray & Clark, 1990).

As noted, most investigations of the impact of racism on adolescents have been conducted in metropolitan centres where victims are numerous enough to form large groups. Little is known about the experience of racism among non-White youths dispersed in small numbers throughout a region of limited ethnic diversity.

Methodology

The study used a qualitative methodology based on a constructivist research paradigm in which realities are considered to be "apprehendable in the form of multiple intangible mental constructions" (Guba & Lincoln, 1994, p. 10). The research process is inductive and is guided by a relativist ontology. Findings are constructed through the interactions of the investigator and participants (Appleton & King, 1997). Data collection involves both a hermeneutic and a dialectical approach (Lincoln & Guba, 2000). Hermeneutics is concerned with the interpretation of texts and is used to understand the way people experience their world and their place in it (Carpenter, 1999). Interviews with participants are transcribed into a "field text," which is read and reread as the investigators categorize it and seek patterns of meaningful connection (Carpenter, 1999). This involves a hermeneutic circle of interpretation, in which the investigators move back and forth between understanding the parts of the text in light of their global view of the phenomenon and understanding their global view in light of their interpretation of its parts (Allen & Jensen, 1990; Carpenter, 1999). Interpretations of the text are checked with participants and with counterparts until consensus is achieved (Lincoln & Guba, 1985, 2000).

Dialectic logic sees oppositions and contradictions as fruitful of new and better syntheses (Appleton & King, 1997). A dialectical process guides constructivist inquiry on several levels. Investigators seek divergent views or experiences through purposive sampling and through flexible interview schedules. They also contrast divergent views or experiences when analyzing the data in order to achieve a better understanding of the phenomenon (Appleton & King, 1997; Guba & Lincoln, 1994).

Sampling

Interviews were conducted with a sample of 25 adolescent self-described victims of racism and 14 parents of perceived victims. Sampling was purposive. In order to ensure some geographical variation, the sample was selected from the four areas of the province with the most ethnic diversity: the cities of Moncton, Fredericton, and Saint John and the region of Richibucto/Miramichi. Board members of multicultural associations in each of the four areas as well as personnel of band offices (administrative units) of four First Nations reserves assisted investigators by recruiting participants. A number of participants also referred others. During the recruitment process, participants were given a form describing the study. Selection criteria were that the subject be between 15 and 19 years of age and believe he or she had been the target of racism. In addition, an effort was made to balance the ratio of male to female respondents and to achieve even distribution among the four geographic areas. Parents of perceived victims were interviewed in order to gather additional information on the adolescents' experiences of racism. They provided triangulation of data (Atkinson & Hammersley, 1994) in that their observations and experiences echoed what the young people were articulating.

The adolescents were a mix of first-generation Canadians and youths from communities with long roots in the province. The former group included two participants whose parents had emigrated from Africa and two whose parents had emigrated from the West Indies. The latter were either members of one of New Brunswick's two First Nations communities, the Mi'kmaq and the Malaseet, or members of an indigenous community of Blacks. The Mi'kmaq and the Malaseet have inhabited the Atlantic region for more than two thousand years (Whitehead, 1991) and in New Brunswick number approximately 15,000 (New Brunswick Family Policy Secretariat, 1995). The Mi'kmaq participants were mostly from rural reserves in the Richibucto/Miramichi region, whereas the Malaseet participants were from the St. Mary's reserve in Fredericton. The indigenous people of colour in the province are descendants of British Empire Loyalists from New York State and are estimated to number 3,500.[1] They live mainly in Fredericton and Saint John. Natives and indigenous people of colour are the two largest visible-minority groups in the province. Eight adolescents identified themselves as

---

[1] Estimates from PRUDE Inc. (Pride of Race, Unity, Dignity, Education), Saint John.

members of the indigenous Black community and 13 as either Mi'kmaq or Malaseet.

Data Collection and Analysis

To enhance consistency, only one member of the research team conducted the interviews. The interviewer took care to establish rapport with the respondents in order to gather data of depth. The interview schedule consisted of 10 broad, open-ended questions. It was used flexibly to collect as much information as possible about racist incidents and the participants' response to them; for instance, one question asked adolescents to describe their first racist incident. Parents were asked the same 10 questions about their child's racist experiences. To ensure a dialectical process, the interviewer sought to clarify the respondents' statements and explored alternative constructions with them. Interviews were audiotaped and transcribed. A brief socio-demographic questionnaire was administered to obtain an overview of the sample (Table 1).

Following the inductive methodology of the constructivist paradigm, data analysis was begun during data collection. It involved Lincoln and Guba's (1985) steps of unitizing, categorizing, and pattern-seeking. In the first step, the transcribed interviews were broken down into units of data. In the second step, units were brought together into provisional categories. The constant comparative method of data analysis was used, whereby researchers constantly compare data sets to redefine units and to develop and refine categories (Lincoln & Guba, 1985). Thus, as new units of data were assigned to categories, they were continuously compared with previously identified units. Finally, patterns were sought as categories were reassembled into a construction of the experiences being examined. In doing this, the investigators moved back and forth between the categorized data and the original field text. Memo writing was used to describe emerging patterns in the data and to reflect on relationships among categories (Appleton & King, 1997; Lincoln & Guba, 1985).

To enhance the credibility of the study, those affected by the phenomenon under investigation were asked to contribute to its design and to the emerging analysis, in several ways. A panel of parents of self-described victims of racism initially guided investigators in developing the study questions and suggesting ways of recruiting participants. Emergent findings were discussed first with a focus group of adolescents and parents, later with individual respondents, and finally with the original panel of parents. An audit decision trail was kept to enhance dependability. Two investigators unitized and categorized data separately and then compared and contrasted analyses until consensus was achieved. Throughout this process, the emerging categories and constructions were discussed with the investigator who conducted the interviews.

Table 1 ***Adolescent Participants***

	Age	Gender	Ethnic Background of Parents
Moncton	18	F	Indigenous Black (from Saint John)
	17	F	Indigenous Black (from Nova Scotia)
	19	M	Indigenous Black (from Nova Scotia)
	16	F	West Indian Black
	18	F	African Black (from Zaire)
Fredericton	15	F	Malaseet
	15	M	Malaseet
	20	F	Malaseet
	17	M	Malaseet
	17	F	Malaseet
	19	M	Indigenous Black
Saint John	19	M	Indigenous Black
	17	F	Indigenous Black
	19	F	American Black
	18	M	Indigenous Black
	19	M	Indigenous Black
	19	M	Jamaican Black
Richibucto/Miramichi	18	M	Mi'kmaq
	15	M	Mi'kmaq
	18	F	Mi'kmaq
	19	F	Mi'kmaq
	18	M	Mi'kmaq
	15	M	Mi'kmaq
	15	M	Mi'kmaq
	19	F	Mi'kmaq

Ethical Considerations

Participants signed a consent form that described the project and guaranteed confidentiality and anonymity. The study was approved by the Université de Moncton ethics committee before data collection was begun.

Findings

The inductive nature of the methodology quickly revealed that the primary concern of both adolescent and parent respondents was not the highly publicized episodes of racial violence that had prompted the study. Rather, it was the stress of dealing with a long-term but low-key racist environment. They framed racism as a life-long burden, not a recent phenomenon. One mother summed up this view succinctly: "People sometimes need bad actions like we had lately here in Moncton to see that something wrong is going on, because what just boiled over was not new; it has been going on for ages." Furthermore, racism was a cumulative experience for the adolescents, and their response to it was an evolving one. In presenting the findings, the nature of the racist incidents experienced by the adolescents will be described first, followed by the participants' evolving response to racism.

The Face of Racism

The nature of the racism experienced by the adolescents was strikingly similar regardless of their background or geographic location. Furthermore, the perceptions of parents mirrored the accounts of the adolescents. By far the most common problem identified was name-calling. Although the specific racial slurs varied, every adolescent interviewed had been exposed to a considerable amount of this type of verbal abuse. Name-calling also played a role in most of the other types of racist incidents described.

The second most frequent form of racism reported was either threat of or actual physical violence on the part of peers. This was both an individual and a collective phenomenon. In their early years at school, participants had been "shoved," "pushed," and "punched" by individual name-callers. As the participants grew older, these situations sometimes involved groups of young people or members of particular teen groups ("the hillbilly crowd," "the skinheads," "the skaters"). Several had received written threats, often accompanied by swastikas. For example, one girl received a note "with all kinds of Nazi symbols" and the message "niggers must die," and another discovered "Squaw you're next" written on her school locker.

Even though many participants singled out a particular teacher, principal, or policeman as having gone out of their way to support them, the third most frequently identified problem was unfair treatment by authority figures. All the youths described instances in which they believed they had been subjected to injustice because of racism. These instances typically involved the participant's having responded to name-calling by fighting back. For example, a Black youth in Saint John who had been charged following a fight with a skinhead over racial slurs said, "The cop looked at me straight in the face. I couldn't believe what he says: 'Does your father have a criminal background?' My father could have been a *priest!*"

As a result of such experiences, both the adolescents and the parents were convinced that non-White youths are constantly at risk of unfair treatment because of racial stereotyping. One mother said, "I tell my kids, you can be in a crowd of a hundred White people — if something happens they will come and single you out and nobody will stand up for you except those few minority kids who are your friends." This theme was revisited frequently during the interviews.

Since schooling holds a dominant position in the lives of youths, it is not surprising that school was the key arena for racist experiences. Most participants vividly recalled their first brush with racism, and the majority of these incidents occurred at school, often in the very early years. A Mi'kmaq participant described his initial reaction to attending school off the reserve: "I didn't really prepare myself for that [racial taunting] — all those people who don't really like us in the White world."

As the children grew older, the arena for racist experiences extended to malls, streets, parks, restaurants, bars, and dances. Incidents in these areas, however, were sporadic and as a result often caught them completely off guard. One youth described an incident at a mall: "This guy approached me and said, 'Hey, nigger.' I turned around and I thought I was hearing things. 'Are you talking to me?' And he goes, 'I hate niggers.... Nigger, you're not listening to me. I kill niggers'." The cumulative effect of these intermittent experiences left respondents with the perception that racism can surface anywhere at any time in the community.

Evolving Response to Racism

The participants' response to racist incidents involved a synergistic and negative process that compounded the effects of racism on them. Two covert factors driving this process surfaced from the data. Both involved a significant dichotomy in understandings between participants and members of the mainstream society. Before outlining phases in participants' changing response to racism, we will describe this dichotomy. The first covert factor involved incompatible views of the meaning of racist name-calling, the second an historic versus episodic understanding of individual racist incidents.

Meaning of name-calling. Participants considered racial taunts to be both highly wounding and unequivocal evidence of racism. Racist names brought to the surface a sense that people were imposing on them an inalterable and discredited social identity because they were visibly different. For instance, a Moncton girl said she had been walking by a busy coffee shop when an old man came up to her and said, "Hey, you black bitch, do you want to fuck?" She said of the incident, "It really made me realize, like, Oh my God, I'm Black and people notice it." In contrast, authority figures consistently discounted the importance of racial slurs, seeing name-calling as something all children do and all children have to put up with. One young participant said he was told by a school principal, "Being called a nigger is no different from being called a geek or a nerd." For the youth, however, it was completely different. He explained why: "When I was a kid I wasn't aware of being Black. I was just me. And when it really hit home was being called 'nigger'."

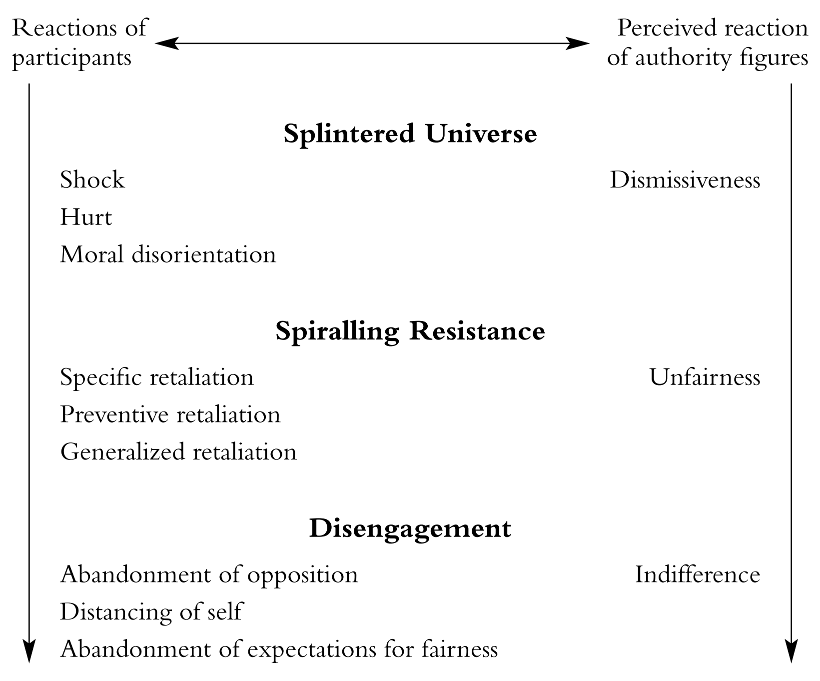
Historic versus episodic understandings. Participants' descriptions of specific racist incidents indicate that they perceived the episode through the lens of their personal, accumulated experiences of racism. Their reaction to each individual act of racism was part of a life-long battle against the imposition of a socially discredited identity. Their accounts emphasized the event that had triggered their reaction, which usually was derogatory, racist name-calling. Authority figures responded to the retaliatory behaviour rather than to the triggering event, and the participants usually ended up being punished as a result. For example, one youth reported that while he was boarding the school bus another boy called out, "Hey, black boy." He responded, "Don't call me that," and kept on walking, but the boy taunted him again, with "nigger," so our participant, as he put it, "started flipping out." The bus driver pulled over, put him off the bus, and reported to his parent that he had "started everything." The bus driver judged the youth's violent reaction as the problem. Our participant, however, felt he had been the victim: the name-calling was another cut in the life-long wound of racism, and he was fighting a collective force of experienced racism. In these situations, authority figures witnessed an individual reaction (episodic understanding of the incident), whereas our participants were responding to just one more instance of harassment (historic understanding of the incident).

From Splintered Universe to Disengagement

Three phases were identified in participants' evolving response to racism. We term the first phase "splintered universe," the second "spiralling resistance," and the third "disengagement" (Figure 1). On the one hand, the response process involved gradual changes in how they reacted to specific incidents; on the other hand, it incorporated changes in how they perceived the reaction of authority figures to racism.

Splintered universe. This occurred when participants first encountered negative racial comments from other children. As noted above, the encounters often occurred very early in their schooling, sometimes on their first day of school. Their initial reaction was one of shock. A Mi'kmaq participant explained: "I wasn't used to it — it wasn't done to me before." For many, an element of the shock was the discovery that they were visibly different from their peers. One participant said, "I'd never seen myself any different from anyone else before, and then all of a sudden I was." Their lack of awareness of being visibly different prior to these early name-calling incidents may be due to the limited ethnic diversity in the region.

Figure 1 ***From Splintered Universe to Disengagement***



Shock quickly gave way to hurt. Most of the youths and some of the parents had asked authority figures to intervene, but these people had a very different understanding of the meaning of name-calling. Teachers and principals downplayed or dismissed racist taunts with comments such as, "well, it's only names." One Black youth in Saint John said, "I was always told one way or another that I didn't feel the way I thought I felt and [that] I didn't hear that the way I thought I'd heard it." The result was moral disorientation. The message in the name-calling was that the visibly different person was irreversibly inferior, or as one participant put it, "a second-class citizen." And the message in the dismissive institutional response was that their distress was unimportant. In other words, the harm they were being done, which in their eyes was morally wrong, was being condoned by the authority figures in the moral social order. A mother spoke of having to go and retrieve her child from underneath a sink in the school bathroom: "His hands were wrapped around the pipes and he refused to come out. The kids had been calling him 'nigger'…when he tried to tell the teacher, she said, 'It's not an issue'."

As their world splintered, many of the participants wished they were White. For instance, a Mi'kmaq participant said she had thought at the time, "I bet you if I was White I'd have all the friends I need but I had no friends because I'm Indian." Similarly, a Black youth said, "I remember going home at night and praying to God that I would wake up in the morning and be White like other kids."

Spiralling resistance. Sooner or later most participants fell into a pattern of spiralling resistance, attacking first those who attacked them and then any potential threat. As racist incidents accumulated in their lives, they increasingly interpreted individual episodes from the perspective of their history of racist experiences. The first development in this phase was direct retaliation against anyone responsible for an act of racial harassment. For instance, a participant explained that when she was called names like "little squaw" and "wagon burner" she began to "punch them out…I learned after a while, you know, they're going to say something to me, I'm going to say something right back." Another said, "I just couldn't take it no more and I'd got a little bit bigger, so I just went after them."

The youths (and many of their parents as well) believed that this type of retaliation had been an effective strategy in the short run. One girl said, "I just stopped crying and started beating people up, and that's why it stopped." Another participant said, "I used to be called names.… I stood up to them, that's when they left me alone." Perhaps because fighting back appeared to be effective, many of our participants began to adopt a preventive form of retaliation, such as attempting to circumvent racist situations with verbal threats: "I told them, 'You call me names and what's going to happen is I'm going to explode and I'm going to fight.' I said, 'I'll kick all your asses' — and they smartened up!"

Finally, many advanced to a generalized form of retaliation whereby any hint of racism towards themselves or actual racism towards someone else provoked a violent reaction, because it was viewed in the context of their long-term experience. An incident described by a Moncton youth who had been suspended from school following a fight will serve to illustrate this. He had been reacting to a racist comment directed not at him but at another Black student: "She got her test back. It was… something on the test like 'niggers,' 'I hate niggers.' Of course, the teacher is not going to put that on the test! It was a skinhead in the class. He laughed about it, thought it was a big funny! So I approached him…so I got in a fight."

Authority figures, applying an episodic understanding of these incidents, punished the youths for retaliating. To the participants, applying a historic understanding of the experience, this was unfair. They felt they had been defending themselves against racist victimization and the instigators were not being reprimanded. One youth explained: "The teachers, they were always thinking that I had provoked it all. They used to say, 'Well, you must have done something for him to start going on like that,' and I would be the one in trouble. They wouldn't do anything to the kid who was calling me names." A young girl who had been sent for counselling because of her behaviour said of the counsellor, "She would say, 'So…what did you do to agitate the kid to call you that name?' How am I supposed to agitate a name like that?"

Disengagement. The third phase is one of less external disruption but may feature internal difficulties, as it involves loss of hope and connection with society. Overt acts of opposition are abandoned, as resistance seems more and more futile. Participants realized that although fighting back might help them win battles against racism, they were losing the war. One said, "I just learned no matter how many times I would get all raged up and hurt somebody would be calling me names again, so it wasn't working." Another commented that fighting "didn't…get me anywhere really, even though it got me to get them to stop calling the names."

Instead of retaliating, many of our participants began to distance themselves emotionally from racist attacks. One way they did this was by defining racism as reflecting negatively on the racist rather than on them. A Mi'kmaq youth said, for instance, "I think people that make fun of us it's because they're not educated and they don't know they're ignorant." Another way they distanced themselves was by developing a protective social wariness so as never to be caught off guard and therefore hurt by a racist remark. A young participant, surprised by a racial slur one evening outside a nightclub, said, "It made me understand that there's a lot of ignorant people out there and it might happen again and it might not happen again, but, you know, don't let your guard down completely." Another explained, "I've learned not to trust Whites."

During this last phase, our participants dropped their expectations for an equitable society, seeing low-key racism as interwoven throughout the community and a permanent feature of it. Many stated that they had come to realize that racism will never go away. Parents also believed this. A mother said, "When I was going to elementary school I got called names every day, so what I'm really trying to say is that we have never really been without racism…it's here, it's been here, and it always will be here." At this stage, therefore, there was no longer any expectation that authority figures would intervene fairly or effectively when racism surfaced. The participants understood institutional reactions to racist incidents as reflective of a fundamental social indifference to the issue. This attitude is illustrated by the comment of a mother who went to a member of the school board with a racist note her daughter had received at school: "He looked at it briefly, 3 seconds, and 'Oh, that's terrible; oh, we'll deal with this.' So instead of dealing with this they were painting the walls [to remove racist graffiti]."

Discussion

Sticks and stones may break my bones but names will never hurt me. These words, often used to soothe hurt feelings, reflect the widespread belief that name-calling is essentially harmless. Because of our focus on the subjective experience of racism, we did not investigate the attitudes of people who downplayed racial taunts. The comments of the participants suggest that authority figures truly considered such behaviour to be innocuous. The analysis indicates that, on the contrary, their dismissal of name-calling represented a tacit endorsement of racism and was at the root of a long, cumulative process. When our young participants first encountered racist taunting they began to feel distinct from others, and when their complaints were downplayed they began to understand their reality as different from that of others. Hall, Stevens, and Meleis (1994) identify this differentiation from the mainstream as an integral component of marginalization. In many respects, the synergistic impact of racist incidents on the adolescents in the present study can be understood as a process of marginalization as conceptualized by these authors.

Margins are defined as the periphery-determining aspects of persons, social networks, communities, and environments. Marginalization is the process by which persons are peripheralized on the basis of identities, associations, experiences, and environments (Hall, Stevens, & Meleis, 1994). Contemporary scholarship treats race as a social construction and discusses racialized identities in terms of a "socially constructed otherness" (Ladson-Billings, 2000, p. 262). Our young participants' historic understanding of racist experiences caused them to vigorously resist the imposition by their peers of a socially constructed "otherness." This, in turn, merely compounded their peripheralization. When authority figures intervened in their attempts to thwart racism, they saw a single, unconnected event. Although the punishment meted out might have fitted the actual behaviour, it was at odds with the reasons for the behaviour and therefore tended to heighten the sense of peripheralization. The youths experienced the powerlessness and silencing that Hall, Stevens, and Meleis (1994) identify as key components of marginalization. Parents fared no better in their attempts to stem the tide that was pushing the youths out from the mainstream. Most had complained to the school about racial taunts and threats, on behalf of their children, but felt that their concerns were put aside.

A recent study of sexual harassment in the lives of schoolgirls reports similar reactions on the part of authority figures. The girls' complaints were dismissed, and when they fought back they were the ones punished, not the perpetrators (Berman, McKenna, Traher Arnold, Taylor, & MacQuarrie, 2000). Sexism and racism among young people appear to have produced the same silencing of victims and to have received the same tacit endorsement by the social order. There are some important differences, however, in the experiences of the two groups of adolescents. Sexist and demeaning remarks were often tolerated by the girls in that study. The investigators report as well that the girls often discounted sexual harassment as just fun-making. In discussing the implications of their findings, they propose that nurses teach adolescent girls to recognize and name the everyday violence that they encounter. In marked contrast, the harassment faced by the youths in the present study was clearly named by the victims as racism, and it provoked a highly charged reaction from them. In fact, participants argued that it was members of the dominant group who failed to recognize and name the incidents as racism: "It's very easy for White people to say racism doesn't exist, because they've never experienced it."

Such comments reflect the broad perspective that many theorists on race have associated with marginalization and otherness (Ladson-Billings, 2000). In 1903 Cora Du Bois identified "the double consciousness" of Black Americans who understood the perspective of both those at the margin and those in the mainstream (Du Bois, 1953). Hall, Stevens, and Meleis (1994) link this perspectival advantage to the power inherent in marginalization, noting that those at the margins understand, by necessity, the way of thinking of those at the centre while the converse is seldom true.

Another difference between the adolescents in this study and those who participated in the study by Berman et al. (2000) is the reflectiveness characterizing the last stage of their response to racism. They came to see racism as an inevitable feature of their social landscape, and redirected their resistance from external opposition to internal psychic work to avoid internalizing a stigmatized identity. Hall, Stevens, and Meleis (1994) describe the reflectiveness of marginalized people as conscious introspection in order to understand and compensate for the inner conflict caused by their peripheralization.

Racism is not typically defined by nurses as falling within the domain of nursing practice. The discipline, however, places an emphasis on health promotion and illness prevention. Racism is an unsolicited and unwarranted form of violence (Dobbins & Skillings, 2000) that threatens physical, psychological, social, functional, and spiritual well-being (Harrell, 2000). A recent review of racism-related stress concluded that "the evidence is compelling and growing that racism is pathogenic with respect to a variety of physical and mental health outcomes" (Harrell, 2000, p. 48). Certainly, the marginalization experienced by our young participants as a result of low-grade racism had health consequences for them. All three phases of their response to racist incidents involved distress, but emotional anguish was especially evident during the first phase, when they began to encounter name-calling. The subsequent phase of spiralling resistance affected their functional well-being, since their response to racism during this period tended to impact on their school performance; some avoided going to school, some were frequently sent out of class, and several were suspended for extended periods. During the disengagement phase, their inability to trust those in the dominant group had implications for their social well-being.

Chopoorian's seminal work in re-conceptualizing the environment as a focus for nursing interventions (Chopoorian, 1986) is relevant in considering the nursing implications of these findings. This view of environment incorporates social, economic, and political relationships that impact on health and well-being. Nurses are challenged to direct their interventions at changing the status quo and attempting to resolve social problems. Although findings of qualitative studies are inherently provisional and incomplete, data from the present study suggest that two aspects of the social environment may well have affected the well-being of the participants: the authorities' dismissal of racist name-calling, and their episodic as opposed to historic understanding of conflicts between White and non-White youths. Previous research on racism provides further support for nursing interventions concerning such incidents. Researchers have found that the subjective experience of racism is commonly disbelieved or doubted by members of mainstream society (Essed, 1991; Harrell, 2000), that generally the victim's perception of racism is accurate (Taylor, Wright, & Porter, 1994), and, finally, that others' resistance to validating the reality of a racist incident increases the stress experienced by the victim and thus the potential damage (Essed, 1991; Harrell, 2000).

As members of the school health team, public health nurses can play a key role in influencing attitudes and policy development related to racism in schools, a central element in the social environment of young people. Participants in this study proposed a range of solutions to the dichotomy of understandings of racist incidents in the school environment. We believe their suggestions provide a strategic place for nursing interventions to begin. First and foremost, the participants argued, members of the dominant group must acknowledge the racism inherent in name-calling. As one youth said, the first step is "to admit there is racism there." They argued as well for public condemnation of racial taunting and expressed the view that the school should take a formal stand by developing and implementing written policies specifying the consequences of such behaviour. Finally, they expressed the view that authority figures should always assess and take into account the triggering role of racist taunts and prior racist experiences when intervening in conflicts between White and non-White youths.

References

Allen, M., & Jensen, L. (1990). Hermeneutic inquiry: Meaning and scope. *Western Journal of Nursing Research, 12*(2), 241–253.

Appleton, J., & King, L. (1997). Constructivism: A naturalistic methodology for nursing inquiry. *Advances in Nursing Science, 20*(2), 13–22.

Atkinson, P., & Hammersley, M. (1994). Ethnography and participant observation. In N. Denzin & S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 248–261). Thousand Oaks, CA: Sage.

Badet, J. (1993). Canada's immigrants: Recent trends. *Canadian Social Trends, 29,* 8–11.

Berman, H., McKenna, K., Traher Arnold, C., Taylor, G., & MacQuarrie, B. (2000). Sexual harassment: Everyday violence in the lives of girls and women. *Advances in Nursing Science, 22*(4), 32–46.

Bigler, R., & Liben, L. (1993). A cognitive-developmental approach to racial stereotyping and reconstructive memory in Euro-American children. *Child Development, 64,* 1507–1519.

Bonaparte, B. (1979). Ego-defensiveness, open-closed mindedness and nurses' attitudes toward culturally different patients. *Nursing Research, 28,* 166–172.

Carpenter, D. (1999). Phenomenology as method. In H. Streubert & D.Carpenter (Eds.), *Qualitative research in nursing* (pp. 43–62). Philadelphia: Lippincott.

Chopoorian, T. (1986). Reconceptualizing the environment. In P. Moccia (Ed.), *New approaches to theory development.* New York: National League for Nursing.

Clark, R., Anderson, N., Clark, V., & Williams, D. (1999). Racism as a stressor for African Americans: A biopsychosocial model. *American Psychologist, 54,* 806–816.

Corenblum, B., & Annis, R. (1993). Development of racial identity in minority and majority children: An effect discrepancy model. *Canadian Journal of Behavioural Science, 25,* 499–521.

Dobbins, J., & Skillings, J. (2000). Racism as a clinical syndrome. *American Journal of Orthopsychiatry, 70*(1), 14–27.

Doyle, A., & Aboud, F. (1995). A longitudinal study of White children's racial prejudice as a social cognitive development. *Merrill-Palmer Quarterly, 41,* 210–229.

Du Bois, W. (1953). The souls of Black folk. New York: Fawcett (original work published in 1903).

Essed, P. (1991). *Understanding everyday racism: An interdisciplinary theory.* Newbury Park, CA: Sage.

Green, N. (1995). Development of the Perceptions of Racism scale. *Image, 27*(2), 141–146.

Guba, E., & Lincoln, Y. (1994). Competing paradigms in qualitative research. In N. Denzin & Y. Lincoln (Eds.), *Handbook of qualitative research* (pp. 105–117). London: Sage.

Hall, J., Stevens, P., & Meleis, A. (1994). Marginalization: A guiding concept for valuing diversity in nursing knowledge development. *Advances in Nursing Science, 16*(4), 23–41.

Harrell, S. (2000). A conceptualization of racism-related stress. *American Journal of Orthopsychiatry, 79*(1), 42–57.

Hendryx, M., & Ahern, M. (1997). Mental health functioning and community problems. *Journal of Community Psychology, 25,* 147–157.

Ladson-Billings, G. (2000). Racialized discourses and ethnic epistemologies. *Handbook of qualitative research, 2nd Ed.* (pp. 257–277). London: Sage.

Lincoln, Y., & Guba, E. (1985). *Naturalistic inquiry.* London: Sage.

Lincoln, Y., & Guba, E. (2000). Paradigmatic controversies, contradictions, and emerging confluences. In N. Denzin & Y. Lincoln (Eds.), *Handbook of qualitative research,* 2nd ed. (pp. 163–188). London: Sage.

Murray, C., & Clark, R. (1990). Targets of racism. *American School Board Journal, 177*(6), 22–25.

New Brunswick Family Policy Secretariat. (1995). *Foundations for the future: A proposed framework for family policy in New Brunswick.* Fredericton: Government of New Brunswick.

Rollock, D., & Gordon, E. (2000). Racism and mental health. *Journal of Orthopsychiatry, 70*(1), 5–13.

Shaha, M. (1998). Racism and its implications in ethical-moral reasoning on nursing practices: A tentative approach to a largely unexplored topic. *Nursing Ethics, 5*(2), 139–146.

Tatum, B. (1992). Talking about race; learning about racism: The application of racial identity development theory in the classroom. *Harvard Educational Review, 62*(1), 1–24.

Taylor, D., Wright, S., & Porter, L. (1994). Dimensions of perceived discrimination: The personal/group discrimination discrepancy. In M. Zanna & J. Olson (Eds.), *The psychology of prejudice: The Ontario Symposium* (Vol. 7, pp. 233–255). Hillsdale, NJ: Erlbaum.

Vrana, S., & Rollock, D. (1996). The social context of emotion: Effects of ethnicity and authority/peer status on the emotional response of African American college students. *Personality and Social Psychology Bulletin, 22,* 297–306.

Vrana, S., & Rollock, D. (1998). Physiological responses to a minimal social encounter: Effects of gender, ethnicity and social context. *Psychophysiology, 33,* 462–469.

Whitehead, R. (1991). *The old man told us.* Halifax: Nimbus.

Acknowledgements

This project was funded by the Department of Canadian Heritage.

Cynthia Baker, PhD, is director of nursing at the Université de Moncton, New Brunswick, Canada. Manju Varma, PhD, teaches at Mount Allison University, Sackville, New Brunswick. Connie Tanaka is co-ordinator of the New Brunswick Cross Cultural Health Council.

2009 update: *Cynthia Baker is Director, School of Nursing, and Associate Dean, Faculty of Health Sciences, Queen's University, Kingston, Ontario, Canada. Manju Varma-Joshi is with the Department of Canadian Heritage and is President of Diversity Matters, a consulting company.*

CJNR 2009, Vol. 41 N° 1, 128–143

Résumé

L'importance du *lieu* dans le secteur des soins infirmiers communautaires

Amy Bender, Laurie Clune et Sepali Guruge

Quand un emplacement géographique acquiert un sens, il devient un lieu. Les auteures examinent l'importance de ce constat du point de vue de la géographie et de l'expérience vécue. Elles étendent le concept actuel de géographie des soins infirmiers aux soins infirmiers communautaires, s'intéressant aux complexités de cette sphère d'exercice et à des travaux de recherche souvent passés inaperçus. Elles explorent la notion de lieu au sein du foyer et de la collectivité, touchant aux dimensions structurelles et spatiales qui définissent la relation thérapeutique. Les auteures recensent les travaux en géographie de la santé et proposent une analyse de leurs implications pour la pratique et la recherche en santé communautaire. Elles invitent les infirmières de ce secteur à se pencher sur ces questions en s'attardant à des dimensions comme le pouvoir de l'infirmière, le rôle des lieux marginalisés comme déterminant de la santé et les meilleures approches en matière de soins destinés aux clients de milieux sociaux diversifiés.

Mots clés : géographie de la santé, géographie des soins infirmiers, lieu, soins infirmiers communautaires, relation thérapeutique

CJNR 2009, Vol. 41 Nº 1, 128–143

Considering *Place* in Community Health Nursing

Amy Bender, Laurie Clune,
and Sepali Guruge

When a geographic location is assigned meaning, it becomes a *place.* The authors argue that place matters as both geographical location and lived experience. They extend the current conceptualization of nursing geography to encompass community health nursing and address intricacies of community nursing practice and research that often go unnoticed. They do so by exploring the notion of *place* in home and community, including the structural/spatial dimensions of the nurse-client relationship. The authors review the health geography literatures, then discuss the implications for practice and research in community health. They invite community health nurses to critically examine their practice and research with reference to such issues as the power of the nurse, marginalized places as determinants of health, and how best to care for clients living in diverse community settings.

Keywords: health geography, nursing geography, place, community nursing, nurse-client relationships, therapeutic landscapes, post-asylum geography

The discipline of geography has moved beyond mapping the physical earth to include social, cultural, historic, political, economic, and physical features that together create the context of human life (Cutchin, 2005). While nursing researchers have given much attention to the effects of environment on health, they have paid less attention to the places where nurse-client relationships exist and how those places shape such relationships. This article originated in conversations among the three of us as doctoral students with an interest in space and place in community nursing. We hope it will raise awareness about the complexity of relationships in community nursing practice, an area steeped in geographical implications. In terms of the dynamics between nurses and clients in community work, we argue that place matters — as geographical location and lived experience, as demarcation of space, and as site of meaning creation. Like a growing number of nursing scholars, we believe that nursing research and practice benefit from a thoughtful examination of health geography, a sub-discipline of geography. Our understanding of place in nursing has been shaped by the work of several authors, most notably Gavin Andrews (2002, 2003a, 2003b, 2004) and Joan Liaschenko (1994, 1997, 2001) and their call for an exploration of how nursing affects, and is affected by, the spaces and places in which care is provided.

Originally published in CJNR 2007, Vol. 39 Nº 3, 20–35

Andrews and Liaschenko shed particular light on the notions of location, environment, and the moral geography of nursing.

Our aim in this article is to extend the ideas presented in nursing geography to community health nursing. We believe that when nurses think and talk about how they navigate actual geographic places, they are articulating an aspect of community practice that is important to the nature of the work but often goes unnoticed in health-care discourses. Specifically, we suggest that health geography can be used to critically examine community nursing research and practice. Such a perspective can highlight issues of marginalization and vulnerability not only in how clients belong (or are assigned) to certain diagnostic, economic, racialized, or gendered groups, but also in the places of community practice. It can also highlight issues of power and proximity in the nurse-client relationship.

We present our argument in two sections: a brief review of the health geography literature, and considerations for community health nursing provoked by the review.

A Brief Review of the Health Geography Literature

The philosopher Edward Casey (2001) sets *place* apart from *space*, arguing that each addresses a different aspect of our spatial lives. He suggests that space is disembodied and abstract while place is a bodily orientation, yet both are inseparably related and ever shifting. Casey (1993) suggests that "there is no being except being in place. Put the other way around, there is no utterly placeless existing…" (p. 313). With this concept in mind, in this article we adopt the following definition of place: "an operational 'living' construct which 'matters' as opposed to being a passive 'container' in which things are simply recorded" (Kearns & Moon, 2002, p. 609). A geographical location matters when people attach meaning to it through their own understandings and experiences, their own social, cultural, and economic circumstances. Different people coming together in the same place at the same time will experience the place in distinct ways, and the same person can experience a place differently at different points in time.

A closer look at places reveals things about them. Physical structures suggest underlying social structures and other invisible divisions. For example, well-maintained houses may be associated with wealth and cramped, rundown houses with poverty. However, in many cases the physical structure reveals little about the place or may lead one to draw inaccurate conclusions; for example, a person's place of residence may not be what she or he considers home. Hence, places shape social meanings and social meanings, in part, shape places.

Health geography has emerged as an area of human geography, a subdiscipline that critiques traditional notions of geography as purely objectivist spatial science. Health geographers study people and places in relation to health issues. They explicitly address people *in place,* calling on the philosophical traditions of phenomenology, symbolic interactionism, and existentialism (Andrews, 2003a). They use two particular approaches to human geography: the humanist focus on individual agency in the experience of place, and the cultural focus, which examines cultural impacts on the construction of places, and, conversely, the creation of culture by places. Out of these traditions emerge questions about people's sense of place and placelessness, or the feeling of being out of place, and the structural (social, political, and economic) aspects of place (Andrews, 2004) — all of which influence health.

Next we will briefly review four subsets of health geography: infectious disease, therapeutic landscapes, post-asylum, and nursing. All of these geographic perspectives are valuable in thinking about community health nursing, particularly health-related meanings of the places in which we community nurses work and how we occupy these places with our clients.

Infectious Disease Geography

Health geography, historically known as medical geography, initially focused on infectious disease (Andrews, 2002). This primarily epidemiological concern for the mapping of disease still dominates common understandings of public health (Andrews, 2004; Frohlich, Corin, & Potvin, 2001; Rosenberg, 1998). Public health, as one avenue of community health, has origins in the connecting of geographical characteristics to disease outcomes, using prevalence and incidence rates to generate knowledge about the distribution and determinants of disease across populations in order to identify and isolate risk factors (Frohlich et al., 2001). One such disease is HIV/AIDS, which is generally studied according to rates of spread by location, underlying causes, modes of diffusion, including behaviours of risk groups, and socio-economic conditions of the locations where risk-taking occurs (Andrews, 2004; Rosenberg, 1998). Accounts of HIV infection have tended to omit the influence of cultural aspects of places on people's health choices and, conversely, the influence of individuals' choices on social and cultural norms regarding HIV. This is an important consideration given that, as pointed out by Gesler (1992), both physical environment and culture are integral dimensions of health.

The stigma of contagiousness is one social dimension of infections that has influenced their management and treatment. Examples of stigmatized illnesses are leprosy, the plague, cholera (Gesler, 1992), and tuberculosis (Draus, 2004). Considerations of place are implicated in the goal of protecting society from such diseases. Isolation, quarantine, and colonization occur through the construction of places such as hospitals, sanatoriums, and asylums in order to contain the disease as well as its victims. People deemed "diseased" are removed from everyday life so that society is safeguarded and can continue to function (Gesler, 1992). However, these means of protecting society can serve to stigmatize those who have been removed from it.

Therapeutic Landscapes

Health geographers' exploration of therapeutic landscapes — landscapes associated with treatment or healing (Gesler, 1992) — parallels nursing scholars' concern for environment as one of the metaparadigms of nursing (Thorne et al., 1998). Both the natural world, such as the countryside or mineral springs, and the built environment, including the design of buildings and rooms (Gesler, 1992), have been studied in this sub-discipline of geography, not only as physical settings but as places with supposedly therapeutic effects on the people in them. The concept of therapeutic landscape suggests that places can be part of the healing process (Gesler, 1992). However, geographic landscapes may not be intrinsically therapeutic (Conradson, 2005). Although there may be landscapes of treatment, healing, or even respite, the notion of *therapeutic* remains subjective; that is, inhabitants' experiences of and interactions with a place must be considered, and in this sense landscape has a subjective as well as a relational outcome (Conradson, 2005; Gastaldo, Khanlou, & Andrews, 2004).

Beyond the *therapeutic* landscape, there are ordinary, everyday places that contribute to or detract from healthy living (Andrews & Kearns, 2005; Wilson, 2003). For example, Wakefield and McMullan (2005) present a case study of Hamilton, Ontario, a steel-manufacturing city, as an everyday geography. They point out that while there are places that are typically understood as healthy, there are also those that are deemed unhealthy, unpopular, on the margins of society, and therefore stigmatized, and that these places also affect one's well-being.

Therapeutic landscapes have power, and so does the published research about them. This research tends to be conducted in Western countries and based on biomedical understandings of health (Gesler, 1992) that have ethnic and racialized underpinnings (Delaney, 2002; Wilson, 2003). Furthermore, therapeutic landscape research tends to be focused on extraordinary events in people's lives (e.g., visiting a spa or summer camp), to the exclusion of everyday geographies and non-Western conceptualizations of place (Wilson, 2003). Wilson's study of the relationship of Aboriginal people with the land addresses this gap, highlighting the complex link between the land and health and between the spiritual and social aspects of place.

Post-Asylum Geography

Gone are the days of the asylum in the sense of problematic long-term mass housing and custodial care of people with mental illness. In its long shadow has come a movement towards deinstitutionalization, a phenomenon marked by a significant shift of psychiatric care from the hospital to the community (Dear & Wolch, 1987; Philo, 2000). This is the focus of inquiry for post-asylum geographers, who examine places other than hospitals as settings for mental health care. Questions addressed can include how those living with mental health problems occupy places; how they are sheltered, cared for, and assisted in such "post-asylum" locations (Philo). Pinfold (2000), for example, looks at how deinstitutionalized groups are supported in the community; she explores the roles, positions, and therapeutic benefits resulting from "socio-spatial networking in the community" (p. 201). The places inhabited and described by Pinfold's research participants tend to be marginalized — places that keep them separated from society even outside of the hospital's physical walls.

Nursing Geography

The growing body of what is characterized as *nursing geography* literature informs our understanding of the interplay between nursing, space, and place (Andrews, 2004; Carolan, Andrews, & Hodnett, 2006). In the general nursing literature, the term *place* is ambiguous. It is often used metaphorically, but metaphors for place do not incorporate geographic elements (Andrews & Moon, 2005). In nursing geography, place and space constitute and are constituted by the everyday world of nursing, and there are multiple ways in which questions of place and space are taken up in nursing scholarship: the importance of health-care settings and how they are socially constructed; the relationship between moral agency and place in nursing care; and the spatial dynamics between nurses and their clients in the health-care places of hospital and, to some extent, home (Andrews, 2003a; Ekman, Skott, & Norberg, 2001; Liaschenko, 1997, 2000; Malone, 2003; Peter, 2002). Carolan et al. (2006) identify the nurse-client relationship as an important element in nursing geography in terms of the healing nature of places, questions of situatedness, and nurses' social location in the context of gender and power.

Community Health Nursing and *Place*

The areas of health geography reviewed above have particular relevance for community health nursing. The infectious disease perspective calls to mind the work of present-day TB nurses, who provide care in a range of physical locations such as homes, workplaces, coffee shops, parks, and shelters. Although they no longer work in sanatoriums, the obligation to protect society from infectious disease remains central to their practice. This obligation is complicated by the need to navigate multiple places of care.

The concept of therapeutic landscape fits well into discussions of the concept of community. We may ask, for example, how a sense of community affects clients' healing processes. Critiques in this area of health geography that move away from "therapeutic" language are also useful. "Street nursing," a sub-specialty of community nursing, is one example of a practice in which nurses and their clients occupy everyday geographies that are unpopular, considered unhealthy, and stigmatized by their association with homelessness and poverty. Additionally, community nurses often provide care to Aboriginal and other racialized people, and are therefore challenged to understand multiple cultural meanings of the relationship between health and place, beyond Western notions of what is therapeutic.

Debates surrounding post-institutional mental health care in post-asylum geography resemble those found in community health. For example, the social-structural concerns in mental health care centre on risk assessment, coercion versus civil liberties, resource limitations, and development of appropriate supports throughout the course of illness and health (Pinfold, 2000). These concerns are shared by nurses working in other areas of community health such as communicable diseases or healthy-baby programs. In writing about community health nursing, Chalmers, Bramadat, and Andrusyszyn (1998) argue that simply moving clients from hospitals to community settings does little to address health needs unless the structure of the health-care system becomes more community-focused. Post-asylum geographers raise questions about not only the places where care is provided but how those places shape care. Moreover, post-asylum geographers highlight the troublesome question of place for community nurses who work with marginalized people in marginalized places.

Ideas from nursing geography are explored here with particular attention to place, space, and the nurse-client relationship in community work. Community health nursing takes various forms: home care, public health, outpost, street, or parish nursing. Differences in location of care and clientele define the type of care provided within these forms, and the nurse-client relationship varies across a range of job descriptions, tasks, and program mandates. The Canadian Home Care Association (2003) defines home care as a range of services that help clients to live at home and that often prevent, delay, or substitute for hospital care. Public health nursing is distinct from home care in that it is directed towards population-health promotion in "diverse settings…and with diverse partners, to meet the health needs of specific populations" (Community Health Nurses Association of Canada, 2003, p. 3). While home care and public health nursing, along with other nursing specialties, are organizationally distinct, their values and care situations often overlap. Community nurses integrate personal and clinical understandings of people's health and illness into their care. Care begins with the general assumption that the nurse is a guest in the client's place, whereas the hospital is often perceived, by both health professionals and clients, as the health professional's place. Home is "a place offering a wider view of the patient's life, disease, illness and suffering" (Liaschenko, 1997, p. 50). It is a private place, a haven of physical and emotional well-being that shelters individuals from public scrutiny and surveillance, a place from which they can prohibit unwanted outsiders. Even in situations where home is a site of fear, abuse, exploitation, and/or isolation, it is understood by many as a personal and private domain.

Nurses' work in the home is usually organized by, and in the direct interest of, the client, not the nurse. Yet once the nurse enters, the home's privacy is challenged and the client's ability to restrict public surveillance is compromised. Clients may feel uncomfortable acquiescing to a stranger, albeit a professional one, in their homes. Likewise, the nurse's sense of a controlled workspace is altered, along with her/his sense of power, authority, and control. This altering of positions serves to blur the boundaries between the personal and the professional and therefore can create spaces that engender more egalitarian partnerships between nurses and their clients (McGarry, 2003; Peter, 2002; Spiers, 2002). Liaschenko (1994) makes three points about nurse-client relationships in the home that allude to this personal/professional blurring: nurses have the authority to perform regulated acts in places other than the hospital, the nurse's role in the home involves surveillance, and the private versus public spaces of the home must be considered.

Care in community health nursing is not restricted to the home but also occurs in places such as schools, community centres, and drop-in clinics. Unlike hospital and home-care nurses, community health nurses observe and engage with people in the broader community context of their daily lives. *Context* implies not only the physical setting but also social, political, and cultural settings that entail moral ambiguities and responsibilities for nurses. For example, a community's physical boundaries are usually defined for a specific public purpose, often to separate one subpopulation from another. Areas of different social, economic, and ethnic groups often have more subtle boundaries, expressed colloquially as "the other side of the tracks," "a neighbourhood too rich for my blood," "gay village," "subsidized housing," "inner city," "Chinatown," or "Little Italy." Such labels often determine how the inhabitants of an area are perceived and judged. Nurses working in these neighbourhoods may see their clients through these generalized and often stigmatizing labels. Certainly these dimensions of place complicate the nature and quality of nurse-client relationships in community settings, relationships in which nurses must deal with issues of stigma and prejudice about their clients as well as the location of their care, and even themselves. We believe that addressing such problematic attitudes about marginalized people *and places* is part of the responsibility of community nurses.

The discourse on community health nursing has popularized the notion of community as a "plurality of persons" (Smith-Campbell, 1999) rather than a physical setting. In the concept of community-as-client, the whole community, rather than individuals, is seen as the recipient of care. Community-as-client has been used as a theoretical framework for studies of caring in public health (Rafael, 2000; Smith-Campbell, 1999), nurses' perceptions of their work (Reutter & Ford, 1996), and client competence and empowerment (Courtney, Ballard, Fauver, Gariota, & Holland, 1996; Reutter & Ford, 1996). Community-as-client, however, has not gone without critical analysis. Attributing client characteristics to a community serves to remove the physical geography of communities from theory, although it remains a pragmatic aspect of practice. St. John (1998) found that community-as-client may not be useful for community nurses. Her research participants did not describe the community as an entity receiving nursing care; they used the language of geography, networking, resources, and target groups, most often describing community as a place. Schroeder and Gadow (2002) reached similar conclusions; they point out that community-as-client ignores obvious, significant differences between an individual and a community. Community-as-client has been pivotal in reorienting community nursing practice towards the broader social-determinants-of-health perspective. But abandoning the geographic aspects of community may contribute to a homogenized view of clients, where they are grouped into general categories such as "high risk," which often have negative connotations. In viewing community as a geographical setting, we seek to understand the nurse-client relationships that exist therein and the ethical questions that arise out of such relationships.

Non-institutional places of care affect the moral agency of the individuals involved — from nurses and clients to family members and other health-care workers — in similar yet distinct ways. Liaschenko (1994,

2000) invokes ethical issues of place and space in her articulation of the moral geography of home care, which refers to the nature and quality of the nurse-client relationship in sustaining clients in the setting of their choice, such as the home. Whether it be hospital, home, or other location, the place itself can enhance or diminish the power of the individual (Peter, 2002), which in turn can positively or negatively affect the care provided. McGarry (2003) discusses the balancing of power between nurse and client, which can be partially understood by viewing the nurse as a guest in the client's home. In McGarry's study of community nursing, the location, as well as the longevity and structure of relationships, was a source of both satisfaction and tension for nurses. This raises the question of how close to or distant from (both spatial conditions) one another nurses and clients feel.

The spatio-structural dimensions of nursing relationships have been explored, implicating them as a kind of geography in themselves. Liaschenko's (1997) and Malone's (2003) moral explorations of nursing relationships focus on how spatial and structural concerns affect nurses' proximity to their clients. According to Liaschenko, the nurse-client relationship is inherently spatial, because it comprises the relative physical, social, and psycho-emotional positions of nurse and client and the practical circumstances that bring them together. Liaschenko points out that relationships have local/intimate as well as global/structural dimensions. The former involve the nurse and client in close proximity, while the latter are the social, cultural, and political aspects of a place that bear on the moral work of nurses.

Malone (2003) expands on Liaschenko's ideas by explicating proximal and distal nursing. She conceptualizes proximity as "nested proximities" — physical, narrative, and moral. Physical proximity is direct bodily contact between nurse and client and is the nest for narrative proximity, which involves the nurse listening to the client's story, engaging with the client as a person beyond the illness. Finally, moral proximity is nested within both physical and narrative proximity: being physically and narratively close to clients, nurses are in the moral position of bearing witness to distress and suffering. Malone proposes that it is more difficult to stay close to patients in hospitals; nurses are forced, by structural factors such as staff shortages and lack of time, to practise distal nursing. In fact, the practice of proximal nursing in hospitals becomes "a powerful form of spatial resistance" (p. 2324) that emphasizes the relational and context-bound situations of nursing care. Similar structural factors exist in organizations such as home-care agencies, community care access centres, and public health departments. Community nurses, too, may be pushed into distal nursing by structural factors such as the staffing policies of community organizations, regardless of their close personal involvement with clients in the private setting of the home.

As Malpas (2003) points out, however, proximity does not disappear with distance; rather, the character of proximity shifts. Nurses adjust psychologically and emotionally according to the physical and social structures within which they work and within which their clients live. Nurses may create distance while remaining physically close to their community clients. This can happen when they witness inequity, oppression, poverty, abuse, or discrimination or where the setting of care causes anxiety about their personal safety. As Peter and Liaschenko (2004) explain, "nurses may want to flee [from such situations], but their place in the system, both geographically and politically, prevents it" (p. 222). Proximity and distance are, thus, subjectively experienced by both nurse and client. Nurses and clients must negotiate proximity, particularly in home and community settings, as part of the nurse-client relationship. This negotiation requires that nurses and clients make choices about their closeness to one another, which may become problematic when examined with an awareness of place.

Purkis (1996) points out that when we move about in places we "read possibilities into space" (p. 109). She expands on the notion of proximity by suggesting that nurses choose how close to or distant from clients they will be. Their choices are based on who their clients are, their unique life circumstances, the specific health situation, and the geographical, sociopolitical, and cultural places in which nursing is carried out. The choices call for self-awareness, self-knowledge, an ability to set boundaries, and empathic understanding. Choices regarding proximity are part of nurses' obligation to continually re-examine their power as professionals.

Implications and Conclusions

Viewing *place* through the various geographical lenses we have presented raises ethical questions for community health nursing practice and research. We now offer three general reflections about such questions. First, unpopular and unhealthy community places in which care and everyday life happen raise concerns of social justice. Second, the social and cultural location of nurses as professionals, practitioners, and researchers raises questions of power. Third, community nurses can increase their awareness of their choices about proximity to clients and ask themselves whether they are practising proximal or distal nursing, through critical self, peer, and supervisory reflection and feedback.

Place is not neutral, and it must be considered in community practice and research. We invite nurses to critically examine issues such as the power of the nurse, marginalization and oppression as profound determinants of health, and how best to care for those experiencing such conditions or how best to include them in research studies. This examination begins with the unpacking of assumptions about the places in which we work and the ways in which we take our power for granted in our relationships with clients. It includes a consideration of the places and conditions of people's lives and how we engage with them in these places. Community nursing means thinking about how place matters in our clients' lives and asking them, perhaps directly, about the meanings that particular places hold for them. It involves a questioning of our understanding of notions such as *guest* and reflecting on our presence in our clients' places. Are we simply guests in clients' homes? How do we overtly and subtly exercise our authority as we make decisions in clients' homes? How do the places in which we find ourselves working affect our choices about how close we get to clients? Do our choices about proximity contribute to healing and well-being, or do they inadvertently reinforce clients' feelings of displacement?

Peter and Liaschenko (2004) argue that nurses cannot sustain proximity without adequate resources and good working conditions. What community resources and working conditions support nurses' critical reflection on their proximity to complex and often troubling client situations? Peter and Liaschenko suggest that dialogue, a way for nurses to theorize their practice, is one avenue for such reflection and that it ought to occur among nurses, administrators, and policy-makers so that discussions of nurse-client proximity take place at all levels. How might community health organizations foster and promote this dialogue?

As nursing geography continues to develop, we need more research that explicitly addresses place and its relationship to community nursing. Such research ought to begin with the explicit assumption that place is not neutral, particularly in community work. We need not only research *on* places, but also research *in* places, in order to incorporate more interpretive, embodied understandings of place in the community setting of nursing care (Parr, 1998). This includes a critical examination of nursing relationships (including researcher-participant relationships) *with* and *in* places.

By reflecting on community nursing *in* place, we will view our relationships as care providers and researchers in new ways. Nurses can tend to become comfortable with and complacent about our benevolent power. We like to think that we are good listeners who respect boundaries, that we are compassionate and caring people who communicate effectively. However, through such complacency we may inadvertently be resigning ourselves to distal nursing. By examining the places of our relationships with clients, we are forced to also examine our participation in them. We need to become aware of our prejudices about the places in which we work, of the value judgements we make about, for example, supposedly high-risk neighbourhoods or the cleanliness, noisiness, comfort, and even tidiness of our clients' homes. It is our responsibility, as practitioners and researchers, to be aware of aspects of place and how they may play out in the situations and concerns of each of our clients or research participants.

References

Andrews, G. J. (2002). Towards a more place-sensitive nursing research: An invitation to medical and health geography. *Nursing Inquiry, 9,* 221–238.

Andrews, G. J. (2003a). Locating a geography of nursing: Space, place and the progress of geographical thought. *Nursing Philosophy, 4,* 231–248.

Andrews, G. J. (2003b). Nightingale's geography. *Nursing Inquiry, 10,* 270–274.

Andrews, G. J. (2004). (Re)thinking the dynamic between healthcare and place: Therapeutic geographies in treatment and care. *Area, 36,* 307–318.

Andrews, G. J., & Kearns, R. A. (2005). Everyday health histories and the making of place: The case of an English coastal town. *Social Science and Medicine, 60*(12), 2697–2713.

Andrews, G. J., & Moon, G. (2005). Space, place, and the evidence base. Part I: An introduction to health geography. *Worldviews on Evidence-Based Nursing, 2,* 55–62.

Canadian Home Care Association. (2003). *Portraits of home care: A picture of progress and innovation.* Ottawa: Author.

Carolan, M., Andrews, G., & Hodnett, E. (2006). Writing place: A comparison of nursing research and health geography. *Nursing Inquiry, 13*(3), 203–219.

Casey, E. S. (1993). *Getting back into place: Toward a renewed understanding of the place-world.* Bloomington: Indiana University Press.

Casey, E. S. (2001). On *habitus* and place: Responding to my critics. *Annals of the Association of American Geographers, 91*(4), 716–723.

Chalmers, K. I., Bramadat, I. J., & Andrusyszyn, M. (1998). The changing environment of community health practice and education: Perceptions of staff nurses, administrators, and educators. *Journal of Nursing Education, 37*(3), 109–117.

Community Health Nurses' Association of Canada. (2003). *Canadian community-health nursing standards of practice.* Retrieved January 10, 2004, from www.communityhealthnursescanada.org.

Conradson, D. (2005). Landscape, care and the relational self: Therapeutic encounters in rural England. *Health and Place, 11,* 337–348.

Courtney, R., Ballard, E., Fauver, S., Gariota, M., & Holland, L. (1996). The partnership model: Working with individuals, families, and communities toward a new vision of health. *Public Health Nursing, 13*(3), 177–186.

Cutchin, M. P. (2005). Spaces for inquiry into the role of place for older people's care. *Journal of Clinical Nursing, 14,* 121–129.

Dear, M., & Wolch, J. (1987). *Landscape of despair: From deinstitutionalization to homelessness.* Princeton, NJ: Princeton University Press.

Delaney, D. (2002). The space that race makes. *Professional Geographer, 54*(1), 6–14.

Draus, P. (2004). *Consumed in the city: Observing tuberculosis at century's end.* Philadelphia: Temple University Press.

Ekman, I., Skott, C., & Norberg, A. (2001). A place of one's own: The meaning of lived experience as narrated by an elderly woman with severe chronic heart failure. A case-study. *Scandinavian Journal of Caring Sciences, 15,* 60–65.

Frohlich, K., Corin, E., & Potvin, L. (2001). A theoretical proposal for the relationship between context and disease. *Sociology of Health and Illness, 23*(6), 776–797.

Gastaldo, D., Khanlou, N., & Andrews, G. (2004). Therapeutic landscapes of the mind: Theorizing some intersections between health geography, health promotion and immigration studies. *Critical Public Health, 14*(2), 157–176.

Gesler, W. (1992). Therapeutic landscapes: Medical issues in light of the new cultural geography. *Social Science and Medicine, 34*(7), 735–746.

Kearns, R. A., & Moon, G. (2002). From medical to health geography: Novelty, place and theory after a decade of change. *Health and Place, 26*(5), 605–625.

Liaschenko, J. (1994). The moral geography of home care. *Advances in Nursing Science, 17*(2), 16–26.

Liaschenko, J. (1997). Ethics and the geography of the nurse-patient relationship: Spatial vulnerabilities and gendered space. *Scholarly Inquiry for Nursing Practice: An International Journal, 11*(1), 45–59.

Liaschenko, J. (2000). The moral geography of care work. *Home Care Provider, 5*(4), 126–128.

Liaschenko, J. (2001). Nursing work, housekeeping issues, and the moral geography of home care. In D. N. Weisstub, D. C. Thomasma, S. Gauthier, & G. F. Tomossy (Eds.), *Aging: Caring for our elders* (pp. 123–136). Dordrecht: Kluwer Academic.

Malone, R. (2003). Distal nursing. *Social Science and Medicine, 56,* 2317–2326.

Malpas, J. (2003). Bio-medical Topoi – The dominance of space, the recalcitrance of place, and the making of persons. *Social Science and Medicine, 56,* 2343–2351.

McGarry, J. (2003). The essence of "community" within community nursing: A district nursing perspective. *Health and Social Care in the Community, 11*(5), 423–430.

Parr, H. (1998). The politics of methodology in "post-medical geography": Mental health research and the interview. *Health and Place, 4*(4), 341–353.

Peter, E. (2002). The history of nursing in the home: Revealing the significance of place in the expression of moral agency. *Nursing Inquiry, 9*(2), 65–72.

Peter, E., & Liaschenko, J. (2004). The perils of proximity: A spatiotemporal analysis of moral distress and moral ambiguity. *Nursing Inquiry, 11*(4), 218–225.

Philo, C. (2000). Post-asylum geographies: An introduction. *Health and Place, 6,* 135–136.

Pinfold, V. (2000). "Building up safe havens…all around the world": Users' experiences of living in the community with mental health problems. *Health and Place, 6,* 201–212.

Purkis, M. E. (1996). Nursing in quality space: Technologies governing experiences of care. *Nursing Inquiry, 3,* 101–111.

Rafael, A. R. F. (2000). Watson's philosophy, science, and theory of human caring as a conceptual framework for guiding community health nursing practice. *Advances in Nursing Science, 23*(2), 34–49.

Reutter, L. I., & Ford, J. S. (1996). Perceptions of public health nursing: Views from the field. *Journal of Advanced Nursing, 24,* 7–15.

Rosenberg, M. W. (1998). Medical or health geography? Populations, peoples and places. *International Journal of Population Geography, 4,* 211–226.

Schroeder, C., & Gadow, S. (2000). An advocacy approach to ethics and community health. In E. T. Anderson & J. McFarlane (Eds.), *Community as partner: Theory and practice in nursing* (3rd ed.) (pp. 78–91). Philadelphia: Lippincott, Williams & Wilkins.

Smith-Campbell, B. (1999). A case study on expanding the concept of caring from individuals to communities. *Public Health Nursing, 16*(6), 405–411.

Spiers, J. (2002). The interpersonal contexts of negotiating care in home care nurse-patient interactions. *Qualitative Health Research, 12*(8), 1033–1057.

St. John, W. (1998). Just what do we mean by community? Conceptualizations from the field. *Health and Social Care in the Community, 6*(2), 63–70.

Thorne, S., Canam, C., Dahinten, S., Hall, W., Henderson, A., & Reimer Kirkham, S. (1998). Nursing's metaparadigm concepts: Disimpacting the debates. *Journal of Advanced Nursing, 27*(6), 1257–1268.

Wakefield, S., & McMullan, C. (2005). Healing in places of decline: (Re)imagining everyday landscapes in Hamilton, Ontario. *Health and Place, 11,* 299–312.

Wilson, K. (2003). Therapeutic landscapes and First Nations peoples: An exploration of culture, health and place. *Health and Place, 9,* 83–93.

Acknowledgements

The authors gratefully acknowledge the guidance of Dr. Gavin Andrews during initial conversations on the topic. Amy Bender wishes to thank Dr. Elizabeth Peter for her support in doctoral work related to ideas presented in this article. Laurie Clune received a publication grant from the Faculty of Community Services, Ryerson University.

Amy Bender, RN, MN, is a PhD candidate and Lecturer, Lawrence S. Bloomberg Faculty of Nursing, University of Toronto, Ontario, Canada. Laurie Clune, RN, MEd, is a PhD student and Assistant Professor, Faculty of Community Services, Ryerson University, Toronto. Sepali Guruge, RN, PhD, is Associate Professor, Faculty of Community Services, Ryerson University.

2009 update: *Amy Bender is to undertake postdoctoral work addressing the intersections of infectious diseases, mental health, and global health, while continuing to teach in the Faculty of Nursing, University of Toronto. Laurie Clune is Professor, Daphne Cockwell School of Nursing, Ryerson University, and is set to begin postdoctoral work at the Institute for Work and Health, Toronto. Sepali Guruge is Associate Professor and CIHR New Investigator, Daphne Cockwell School of Nursing; her research focuses on immigrant women's health and violence against women throughout the migration process.*

CJNR 2009, Vol. 41 N° 1, 144–165

Résumé

Analyse descriptive des expériences vécues par les réfugiées victimes de violence en temps de guerre

**Helene Berman, Estella Rosa Irías Girón
et Antonia Ponce Marroquín**

Même si les femmes se retrouvent rarement sur la ligne de front en temps de guerre, elles en subissent néanmoins les conséquences de façon disproportionnée, comme c'est le cas dans plusieurs autres sphères de la vie contemporaine. Celles qui ont connu la guerre sont nombreuses à avoir subi la torture ou été témoins d'actes de torture ou de meurtre infligés à des proches et à des amis. Le recours au viol ainsi qu'à d'autres formes de torture sexuelle est un fait attesté par de nombreux témoignages. Les femmes forcées de fuir leur foyer et leur pays se voient souvent obligées de se séparer de leur conjoint, de leurs enfants et des autres membres de leur famille. Le nombre de réfugiés et de déplacés ne cesse de croître en raison de l'ampleur même des conflits dans le monde : on estime que les femmes en représentent plus de la moitié. La présente étude avait pour but de décrire l'expérience de réfugiées qui ont été victimes de violence dans le cadre d'une guerre. Huit thèmes se dégagent des données recueillies : la transformation d'une vie à jamais; de nouvelles conceptions de la normalité; un sentiment de peur permanent; la perte d'identité; l'impression de vivre à cheval entre les cultures; la place de la femme au Canada; le sentiment de porter un lourd fardeau — le rôle central des enfants; l'indifférence des intervenants de la santé. Les auteures examinent les implications de l'étude pour la recherche et la pratique, soulignant les limites des approches individualisées suivies en Occident.

Mots clés : réfugiées, femmes, guerre, violence, santé

CJNR 2009, Vol. 41 Nº 1, 144–165

A Narrative Study of Refugee Women Who Have Experienced Violence in the Context of War

Helene Berman, Estella Rosa Irías Girón, and Antonia Ponce Marroquín

Although women are rarely on the frontlines of battle, as in many other realms of contemporary life they bear a disproportionate burden of the consequences of war. Many have experienced torture firsthand or been witnesses to the torture or killing of family, friends, and loved ones. The use of rape and other forms of sexual torture has been well documented. For those who are forced to flee their homes and countries, separation from spouses, children, and other family members is common. Because of the sheer magnitude of global conflict, the number of refugees and displaced persons throughout the world has risen exponentially. It has been estimated that women constitute more than half of the world's refugee population. The purpose of this narrative study was to examine the experiences of refugee women who experienced violence in the context of war. Data analysis revealed 8 themes: lives forever changed, new notions of normality, a pervasive sense of fear, selves obscured, living among and between cultures, a woman's place in Canada, bearing heavy burdens — the centrality of children, and an uncaring system of care. Implications for research and practice, including limitations associated with individualized Western approaches, are discussed.

Keywords: refugees, women, war, violence, trauma, narrative, health

Introduction

Although women are rarely on the frontlines of battle, as in many other realms of contemporary life they bear a disproportionate burden of the consequences of war. Many have experienced torture firsthand or been witnesses to the torture or killing of family, friends, and loved ones. The use of rape and other forms of sexual torture has been well documented (Bourke, 2006; Drumbl, 2000; Hynes, 2004; Liebling, 2003; Moussa, 1998; Nikolic-Ristanovic, 2000; Young, 1997). For those who are forced to flee their homes and countries, separation from spouses, children, and other family members is common. Because of the sheer magnitude of global conflict, the number of refugees and displaced persons throughout the world has risen exponentially. It has been estimated that women constitute more than half of the world's refugee population, a scenario that has led Apfelbaum (2000) to suggest that we live in an *era of uprooting*.

Originally published in CJNR 2006, Vol. 38 Nº 4, 32–53

For refugee women, the usual responsibility to care for, protect, and nurture their families never stops. Despite the premigration atrocities they may have endured, they are still expected to carry out their "mothering." The disproportionate burden carried by refugee women, and the unique challenges they face, have received growing attention in recent years. However, theoretical understanding remains sparse and few programs have been developed that are responsive to the needs of these women. The purpose of this narrative study was to investigate the experiences of refugee women who have lived through violence in the context of war before migrating to Canada. Three research questions were addressed: *What experiences of premigration trauma have immigrant and refugee women had before arriving in Canada? How do premigration experiences influence current everyday life among refugee and immigrant women? What do refugee and immigrant women perceive as helpful or unhelpful in their interactions with health and social service providers?* It was expected that the knowledge gained from this study could be used to offer recommendations for the provision of nursing care to refugee women that takes into account the intersecting realities of their lives.

The Policy Context for Refugee Women in Canada

In order to understand the sociopolitical status of refugee women in Canada, it is worth considering key documents that have informed policy and legislation over the past decade. Two papers, *Not Just Numbers* (1997) and *Building on a Strong Foundation for the Twenty-First Century: New Directions for Immigration and Refugee Policy and Legislation* (Citizenship and Immigration Canada, 1998), provided the framework for the passage of the *Immigration and Refugee Protection Act* (IRPA) (2001). With an emphasis on "human capital," the expectations and requirements for entry into Canada stipulated within these reports and by the IRPA are extremely restrictive. Entry would be granted only to those individuals who have high levels of formal education, are capable of supporting themselves or resettling in 12 months (in the case of refugees), speak at least one official language or have the ability to learn it quickly, are relatively young, are in excellent health, and exhibit the ability to adapt quickly and successfully to Canadian culture. Notably absent is attention to emotional trauma, imposed isolation, lack of a supportive social network, sexism, racism, and ethnocentrism. In a critique of *Not Just Numbers,* Arat-Koc (2000) observes that the paper is "a product of anti-immigrant, anti-refugee, and racist sentiments" (p. 18), especially with respect to newcomers from non-traditional source countries. Arat-Koc asserts that the report's recommendations overlook the most disadvantaged group of immigrants and refugees, namely poor women and women of colour, and, moreover, that the document lacks a gender-based analysis in its recommendations and "fails to acknowledge and address existing bias and discrimination against women in the immigration and refugee system" (p. 18).

Women and children are among those most adversely affected by these guidelines. Many refugee women have limited access to formal education, language courses, jobs that might provide them with needed skills, and financial resources. The fact that women are often victims of rape and other forms of intimate partner violence, while a large number of children suffer malnutrition and other health problems in the refugee camps, though well established, is essentially ignored in these documents. Finally, the *New Directions* recommendation to dissolve the Live-In Caregiver Designated Class, "the one predominantly female immigration stream," and incorporate it into the Temporarily Highly Skilled Foreign Workers Class seems to be an attempt to leave more space for a male-centred flow of human capital (Hyndman, 2000, p. 9). These facts make the report's stipulations not only controversial but unrealistic. Despite significant concerns with current policies, several positive initiatives have been undertaken in an effort to include women's needs and voices in the international agenda. For example, the Canadian Immigration and Refugee Board's decision to adopt the *Guidelines on Women Refugee Claimants Fearing Gender-Related Persecution* in 1993 represents an important effort to acknowledge the lived realities of refugee women. As well, the proposed policy direction that the Family Class criteria be broadened to include persons in common-law and same-sex relationships is commendable. However, we need more inclusive criteria that "explicitly recognize women's rights as human rights and incorporate human rights abuses directed at women and children including sexual violence, domestic violence, and sex slavery" (Arat-Koc, 2000, p. 22). In the absence of explicit recognition of the distinct forms of abuse experienced by women and children, the net effect is policy that privileges men over women and that relegates the needs and welfare of women and children to the fringes of immigration and citizenship legislation.

Literature Review

This literature review examines research that is relevant to an understanding of the experiences of refugee women. It includes studies related to premigration experiences, including rape and other forms of sexual torture carried out in the context of war, and postmigration experiences and resettlement. The review is a result of database searches in the fields of nursing, sociology, anthropology, and psychology. Because much of the current knowledge regarding the responses of refugee women to wartime trauma is derived from research using the concept of posttraumatic stress disorder (PTSD), several critical issues are identified.

Premigration Experiences

Before coming to Canada, refugee women are typically exposed, directly or indirectly, to a range of premigration atrocities. During the war in Bosnia, many women knew that their husbands were being beaten and tortured while held in concentration camps; although they did not witness the beatings, they saw the aftermath — the physical and emotional scars — and were deeply traumatized, and forever changed, by the events (Weine et al., 2004; White-Earnshaw & Misgeld, 1996). Similar experiences have been described in research with women from Mozambique (Sideris, 2003), Iraq (Laban, Gernaat, Komproe, Van der Tweel, & De Jong, 2005), Ethiopia (Fenta, Hyman, & Noh, 2004), and El Salvador (Zentgraf, 2002).

Many refugee women spend months or even years in refugee camps in their own or neighbouring countries. Although women in these camps are safe from the bombing and gunfire, they often experience sexual or physical abuse, lack of food, inadequate health care, isolation, and severe emotional trauma (Cardozo, Talley, & Crawford, 2006). Commenting on refugee camps, Crisp (2001) notes the lack of funding from the United Nations High Commission for Refugees and the failure to promote sustainability and development in these communities, thus promoting a cycle of dependency for the aid recipients. Shanks and Schull (2000) write about the occurrence of gender-based violence in refugee camps, asserting that the perpetrators of violence are often the peacekeepers, who have coerced women to engage in sexual activity in return for food (Black, 1998; Hynes, 2004).

Much of the research related to the experiences of women exposed to war has focused on the incidence of PTSD. In their study of the patterns of psychological distress among Salvadoran women refugees, Bowen and colleagues (1992) found that more than 50% of the participants exhibited PTSD symptoms, including recurrent and intrusive recollections, dreams, flashbacks, and intense feelings associated with the event; 41% met the diagnostic criteria for PTSD. The authors conclude that "there may be a high incidence of PTSD among the general population in El Salvador, with particularly traumatic effects on women" (p. 271). Similarly, Eytan and colleagues (2004) report that, among a sample of Kosovar refugees, 23.5% suffered from PTSD, with higher rates among females.

With respect to women refugees in the host countries, PTSD may be exacerbated by "long-standing conditions of social illegitimacy, powerlessness and violence" (Farias, 1991, p. 179). When the stress of alienation is coupled with family disruption, unemployment, inability to speak either official language of the host country, and lack of social support, women may experience "a sense of personal disarray" (p. 186). These findings are supported by those of Gafner and Benson (2001), who report that PTSD hampers the ability of Central American refugees to integrate into the host society.

Sexual torture, assault, and rape in warfare. Rape and other forms of sexual violence against women occur in times of war and peace. In warfare, however, the brutality and acceptability of rape are escalated by the fact that "in the eyes of the rapist, the woman is the enemy" (Nikolic-Ristanovic, 2000, p. 48). In a study conducted in Sierra Leone, women in 94% of the households surveyed had experienced wartime "rape, torture, and/or sexual slavery" (Hynes, 2004). The use of rape as a weapon of war has also been clearly documented in studies with refugees from the Balkans (Nikolic-Ristanovic, 2000) and Mozambique (Sideris, 2003).

The way in which women experience wartime rape is exacerbated by the patriarchal values ingrained in society and amplified by what Hynes (2004) calls the "culture of war." Sideris (2003) observes that gender discourses tend to lay the main responsibility for sexual integrity on women as the bearers of culture. For example, after the mass rape of women in Rwanda, the combined pressure of Roman Catholic values and social norms dictating that children of militiamen be rejected and considered "lixo" (rubbish) resulted in women giving birth in secret and abandoning their babies (Sideris, 2003).

According to Nikolic-Ristanovic (2000), during wartime "women's bodies become a battlefield where men communicate their rage to other men, because women's bodies have been the implicit political battlefields all along" (p. 63). Aron, Corne, Fursland, and Zelwer (1991) discuss the sociopolitical context of sexual abuse with respect to Guatemalan and Salvadoran refugee women. They delineate the differences between institutionalized (wartime) and non-institutionalized (peacetime) sexual assault. In state terrorism, sexual violence and rape are gender-specific and are seen as a means of annihilating the political opposition. Rape becomes a normal act, carried out to gain social control on behalf of the collectivity. The assailants are not punished because their acts are considered to be politically motivated. The authors note that, not surprisingly, refugee women often avoid speaking about sexual torture and rape for fear of losing whatever support they might have, not being believed, or, ironically, being blamed.

The shortcomings of the international human rights laws and their failure to adequately protect women's rights have been addressed by numerous human rights advocates (Copelon, 1999; Malone, 1996; Pratt & Fletcher, 1994; Walton-Roberts, 2004). In recent years, efforts have been made to have rape included as a form of torture in the Tribunal

Statute under the Geneva Conventions and in the United Nations Torture Convention more explicitly. To date, rape has been mostly implied or very broadly presented in the legislation, and the only article in the Statute that explicitly identifies rape as a crime is Crimes against Humanity, Article 5 (Copelon, 1999). While Canada has shown some leadership by recognizing gender-based persecution and using gender guidelines since 1993, the devastating physical and psychological consequences of rape need to be included in the legislation.

Postmigration Resettlement

Many researchers have described the multiple losses that refugees face following migration to a new country. Prominent among these are the loss of homeland, loss of family members, loss of language, and loss of culture and its values (Forbes Martin, 2004; Jiwani, 2001; Momartin, Silove, Manicavasagar, & Steel, 2004; Warriner, 2004). Zabaleta (2003) writes of the suffering among refugee women who have lost their professional and personal identity, exacerbated by government policies that effectively restrict them to housekeeping and childrearing activities.

Resettlement is considered particularly stressful for women who have been separated from their families (Franz, 2003). Simich (2003) explores the supportive roles that the extended family can play in refugees' resettlement and notes that the ability to re-establish social networks and shared cultural experiences is critical. According to Beiser (1999), changing gender roles within the family heightens the sense of marginalization and depression among refugee women.

Seu (2003) conceptualizes the barriers to successful adjustment as either societal or individual. The societal barriers include racial, sexual, and cultural discrimination. Seu observes that xenophobia, cynicism, and the stereotyping of refugees are often internalized among citizens of host countries. From Seu's perspective, derogatory labelling and treatment of refugees is a defensive mechanism by which citizens avoid social responsibility for human rights abuses and express feelings of righteous indignation.

Culture shock and the relegation to minority-group status contribute to women's isolation and sense of displacement. The language barrier constitutes another significant impediment for refugee women and is one of the main obstacles to finding employment (Warriner, 2004). Language programs for newcomers in Canada are largely underfunded, and where courses are available refugee women who have suffered trauma may experience memory and concentration problems, making the task of learning a new language exceedingly difficult (Warriner, 2004).

Underemployment is another significant stressor in the lives of refugee women (Beiser, 1999). In her research with Bosnian refugee women, Franz (2003) found that many accepted low-paying, low-skill jobs so as not to "upstage" their husbands; in this way, traditional gender roles were reinforced and sustained. In research with women from El Salvador, Zentgraf (2002) observed that work outside the home is not new to many refugee women and often gives them confidence and a sense of autonomy.

In sum, refugee women who have experienced violence in the context of war face a multitude of premigration and postmigration challenges. While much of the research related to this population has focused on the incidence of PTSD, several researchers have questioned the validity and relevance of the PTSD construct with respect to refugees from non-Western countries (Bracken, 1998; Friedman & Jaranson, 1994; Muecke, 1992). According to these researchers, PTSD is a diagnostic label established among individuals from Western societies who had experienced trauma and subsequently applied to refugees from non-Western countries. While they admit that all individuals display some similar symptoms, Friedman and Jaranson (1994) point out that "ethno cultural differences in the expression of traumatic stress may not conform to the diagnostic criteria for PTSD" (p. 215). Thus, the ethnocentricity and narrowness inherent in the PTSD model might affect our ability to fully comprehend the meaning of trauma in the lives of refugee women. Further, Salis Gross (2004) argues that the concept of trauma is often threatening to refugees, as the acceptance of the trauma discourse may undermine their experiences as victims of human rights violations, forcing them to accept a label in order to achieve legal status in the host country.

Research Methods

A narrative research design was used to address the research questions. Although narrative research embraces many theoretical approaches, several assumptions are shared. One of these is consensus on the pervasive nature of stories and storytelling. Under this assumption, human beings are storytelling organisms who, individually and socially, lead storied lives. Although storytelling has historically been accorded a marginal position in research, it has emerged as an approach with considerable potential (Berman, 2000; Dossa, 2004).

All of the women took part in an individual interview, conducted in an informal manner that encouraged dialogue and reflection. Thus, the semi-structured interview guide developed for this research was used flexibly and consisted of open-ended questions on aspects of the women's lives before, during, and after migration to Canada. The interviews were conducted by two of the authors in either English or

Spanish. The Spanish interviews were translated using the "back translation" method. All interviews were audiotaped and transcribed verbatim. The interviews lasted approximately 2 hours and were conducted at a location chosen by the participants, usually in a quiet room in their place of residence. Ethics approval was obtained from the Health Sciences Human Subjects Review Board of the University of Western Ontario prior to data collection.

Data were analyzed using methods suggested by Mishler (1986) and Riessman (1993). These entailed re-transcribing sections of text that appeared to take a narrative form, thus establishing the boundaries of the narratives; reduction to the core narrative; and analysis of the core narrative. A qualitative computer program was used in the coding and sorting of data. By attending to the context and content of the narratives, we attempted to create a "conversational space" through reflexive listening and reading. Our challenge was to listen to the voices of the women in ways that allowed us to capture their "lived realities" while simultaneously understanding how these realities are shaped by dominant social and political systems.

Upon completion of the interviews, all participants were invited to attend a focus group during which emerging themes were shared, discussed, and revised. Six of the women took part in this process. In addition, an invitational community forum was held with health and social service providers, community stakeholders, policy-makers, and most of the study participants.

Sample

Sample size was determined according to the criterion of saturation, meaning that that sampling was discontinued when no new themes emerged from the interviews. The final sample consisted of nine women: three from Bosnia, three from Guatemala, two from El Salvador, and one from Chile. The women from Central and South America had arrived in Canada during the 1980s, those from Bosnia in the 1990s. One participant had not completed high school, six had undergraduate degrees, and one had postgraduate university education. All of the women had respected professions before arriving in Canada. Included were two teachers, one doctor, one psychologist, one clerk, one nurse, and one artist. None of the women were able to practise their profession in Canada as their academic credentials and professional experiences were not recognized or validated. Four women returned to school and earned new degrees. The others, after years of being underemployed and holding low-paying jobs, managed to achieve what they considered a respectable lifestyle. Some were still trying to gain social acceptance and a sense of belonging within Canadian society.

Findings

The women described traumatic experiences that included both direct and indirect exposure to violence. It was evident that their experiences of pain and suffering were shared equally, regardless of whom the trauma was directed at. For these women, life would never be the same. In this presentation of the findings, all names are pseudonyms.

Violence of War in the Lives of Women

Before coming to Canada, all of the Central and South American participants had been involved in various forms of social action. Their efforts included the seemingly innocuous activity of participating in labour unions, literacy programs, teachers' associations, and health reforms. However, in the social and political context of their countries, such activities targeted them as subversives. Paula, a participant from El Salvador, recalled an incident involving her husband, a teacher. He had attended a teachers' union meeting to plan activities for the school year when helicopters began to encircle the region. The army captured 40 teachers, including Paula's husband, and took them to a clandestine jail where they were imprisoned and tortured for 15 days. Later, the army destroyed their home and burned most of their belongings. According to Paula, people in the city who were in any way associated with human rights organizations were viewed as a threat and forced underground. The outcome of being found was typically persecution and/or death.

Virtually all of the women acknowledged that, in addition to the violence of war per se, other forms of violence — physical, sexual, and/or emotional — became an integral part of their lives. Many stated that they knew women who had been raped or that they had been sexually abused themselves. Although the incidents occurred long before, in some cases as much as 20 years, their accounts were clear and detailed. One woman described an incident in Guatemala when she was 15 years old:

> *[The soldiers] yelled at me and forced me out of the shower. They did not allow me to get dressed and with the butt of their bayonets were pushing me. They made me give them a tour of the house as they ransacked it and then took me naked out of the house… I yelled at the maid to ask for help, but she fled. The neighbours closed their doors and I felt so scared and infinitesimal. I was almost 16 years old.*

Miriam recalled an incident in Chile when soldiers prodded her and a group of women anally using electrical wires while swearing and threatening to "screw" them. Some of the women were physically assaulted and others verbally harassed about the "firmness and appearance" of their "butts."

Frequently, the women's homes were invaded by strangers who would interrogate them and raid their homes before leaving. Raquel recognized this tactic as a form of torture. She described an incident during which soldiers invaded and ransacked her house while interrogating her about her husband. After they left, Raquel began to comprehend the enormity of the danger she and her husband were in, firmly believing that they would face torture, and possibly death, if they did not escape.

Lives forever changed. In many instances the wars were perceived to have begun very rapidly and the women's lives were changed suddenly and dramatically. Ariana, from Bosnia, recalled that, without apparent warning, she "woke up in a war, where everybody was trapped in their houses and the entire town was surrounded." Mira, also from Bosnia, had not believed that war in Sarajevo was imminent when she was forced to flee with her two children to Vienna, where they sought refugee status. Her husband stayed behind and fought with the Muslims, although he was not Muslim. Mira did not hear from him for three years. After the war, her family managed to come to Canada, where their lives were once again "turned upside down."

The women described how they were changed emotionally as a result of physical trauma, and noted that these changes, in turn, affected their physical health and well-being. One of the Bosnian women said that her menstrual periods stopped, which she attributed to shock, fear, and stress. After the war, she was unable to conceive a child. Excessive weight loss, malnutrition, and loss of hair and teeth were also described by the women.

All participants shared a deep sense of helplessness knowing that their loved ones were being tortured or were suffering in concentration camps or jail. They described the profound impact that this had on them, stating that witnessing violence was as devastating as having violence inflicted upon themselves:

> *I saw my cousin be shot at his face. His eyes were open. They shot him on his face! I had a disbelief and questioned why at his face? People that were killed were all neighbours and friends.*

A woman who had described her husband's experience of torture and violence while in prison explained that soldiers would take some prisoners outside and stage "mock executions" to instil fear among the others.

The women often had difficulty, not surprisingly, remembering and recounting their stories, either laughing nervously or crying as they reflected on their past. The profound way in which war had altered their lives was particularly evident in the words of one woman: "War changed people, changed minds, changed everything."

New notions of normality. Although most of the women were able to recall life in "better times," they stated that once war began it became a defining feature of everyday life. Witnessing and experiencing violence became commonplace and "normal." It became routine to be followed by the "authorities," to encounter armed soldiers and war machinery in the streets, and to hear the sound of gunfire sporadically both near and distant. The black market flourished, inflation was rampant, and long queues for water, milk, bread, or meat became the norm. According to the participants, the most disturbing aspect of this situation, and a somewhat eerie one, was that it came to represent the usual state of affairs. One woman told of a time when she would hear grenades going off, one at a time, and because the sound was so familiar to her, she knew they came in threes. After the three grenades went off, she would get out her broom and sweep the sidewalk — just as one might clean up any other debris from the streets.

Over time, the toll on the women's health and well-being became evident. Deprived of electricity, water, and basic medication in the refugee and concentration camps, they developed a variety of infectious diseases. Despite the hardships, the women expressed gratitude that they and their families were alive, even if separated.

Arrival in a New Country: The Influence of War on Everyday Life

The women were asked how their premigration experiences influenced their everyday lives in Canada, upon their arrival and at present. Although they came from different countries, and in different decades, their stories contained many similarities. For all, the sudden nature of their flight and their uprooting and displacement, both geographically and emotionally, were central to the shaping of their lives.

Pervasive sense of fear. Despite the fact that they were now geographically far removed from war, many of the women continued to fear for their own safety and that of their loved ones, some of whom remained in their homelands. The fear was intensified by the Canadian social and political landscape. As refugees, all of the women were required to provide proof of persecution, something that was not always possible. Thus, many lived for years in fear of deportation. As well, they feared being unable to provide for their children, as they seldom had money, jobs, or support networks.

The women expressed fear of being misunderstood, combined with a distrust of people: "I am afraid of talking or disclosing to medical doctors for fear of having a medical record that later could be used against me." The women from Bosnia spoke of being betrayed by friends and neighbours during the war, explaining that they now found it difficult to establish trusting relationships, which contributed to their marked sense of isolation.

Selves obscured. Frequently the women reported a loss of the sense of self and identity. The physical and emotional pain they had endured, combined with being in a new country with an unfamiliar language and culture, changed these women. In some cases, they commented that they no longer recognized themselves.

The loss of the lives they had known before coming to Canada had different meanings for the women. Sonia had been a physician in Guatemala but was unable to practise medicine in Canada:

> *It affects my life, as I do not practise medicine, that for so many years I stayed home and I did not have a status in Canada, certainly all those losses, especially the family and friends that I lost, had an impact on my life and has an impact on my children as well.*

Paula added that the loss of her former life greatly affected her everyday life:

> *I've spent a lot of time living in denial. I was here in Canada, but my mind was somewhere else, and I didn't want to be here.*

Raquel continued to question her decision to come to Canada, a country that from her perspective was not particularly welcoming. Paula found herself "constantly thinking about El Salvador, wanting to be there" and stated that she has suffered from depression in recent years. Julia came from El Salvador. She explained that her husband became an alcoholic to "lessen the pain and enable him to talk about everything that happened." After he stopped drinking he was no longer able to talk openly about his trauma and, after several years in Canada, they divorced.

Among and between cultures. Relocation was a difficult process for all the women. After arriving in Canada they encountered numerous barriers. Some commented that they would never fully identify with Canadian life. Most said that their home represented the quintessence of their culture. It was there that they preserved their customs, habits, values, and traditional way of life. As Paula said, "We live in our own world in our house."

Many women expressed discontent with the roles they had to accept, especially during their first years of resettlement. Domesticity characterized their daily lives, a stark contrast to the professional lives they had had in their countries of origin. Paula recalled being isolated in the home for 12 years due to family responsibilities and her husband's uncertain legal status. Similarly, one of the Bosnian women, who had been a prominent fashion designer in her country, was dependent on social assistance despite her concerted efforts to find employment. Every woman told a story of marginalization and seclusion, which deeply affected their lives. Although they were dedicated to their families, the fact that their roles had been restricted to those of mother and wife left them discouraged, pessimistic, and in some cases depressed.

At the time of the interviews, some of the women had been in Canada for almost 20 years. While they recognized Canada as their home, this reality was always associated with a degree of tension and ambivalence. They praised what they viewed as a Canadian valuing of freedom and security but stressed that they would never consider themselves entirely Canadian. Moreover, they criticized what they viewed as racist and xenophobic attitudes and Canada's failure to give racialized communities the recognition and respect they deserve.

New Roots and Old Connections: Facilitating the Transition to Life in a New Country

The women were asked to discuss what had and had not been helpful to them after their arrival in Canada. In their responses, the positive and negative frequently overlapped. The women reported that programs or services that were intended to be helpful were often delivered in such a way that they were in fact unhelpful. All of the women spoke about the importance of having their basic needs met and reconnecting with family members who had arrived before them. Dolores considered herself fortunate because she had relatives already here. Sonia noted that the most difficult aspect of resettlement was having no one with whom to talk about her experiences. Although she found a physician whom she viewed as trustworthy, she was never asked by him, or anyone else, why she was in Canada. These intangible aspects of life seemed to be much more important to the women than material comforts.

A woman's place in Canada. Several women spoke about the availability of services for women, particularly for women who are experiencing abuse. When asked what was helpful to her, Julia spoke about the greater value placed on women here, as compared to Latin America. "Your life as a woman has worth. We do have support." While some women spoke about services for refugee and immigrant women, others had little knowledge of such services. Fatima, a Bosnian woman, spoke about the lack of violence-related services for women in Bosnia:

> *We don't have so many services [in Bosnia]…a man could beat up his wife and kids and there is no place where they would be really protected, or if he got drunk or something.… Nobody would really bother to help out, only that embarrassment from some neighbours or workplace, but there were no services like this that you could call the police or if you feel threatened in every way. That is something that they [Canadians] have and we [Bosnians] didn't have.*

Several women expressed frustration with their financial dependence on their husbands. Their lack of confidence was reinforced by the discrimination they endured and the low status accorded to them as refugee women. Although they were aware that they possessed many skills, the fact that their skills were not recognized made them withdrawn, bitter, and voiceless.

Bearing heavy burdens: The centrality of the children. The participants viewed the academic success of their children as validation for their sacrifices, making them feel that they had not suffered in vain. Although the children did not participate in the study, it appeared that their mothers' expectations of them imposed tremendous responsibility on them. As well, several participants shared their concerns about their children not being accepted socially. One woman from El Salvador spoke about the prejudice her children faced at school, with classmates calling them "Native Indians." Mira had lived with her children in three countries over a relatively short period. She said her children were having a difficult time adjusting to the Canadian education system:

> *When we came here, it was a new language. He [her son] didn't know a word, but having experience from being a stranger in another country, he really gave his best to learn English. But then he lost his working habits here, moving to different schools. I think kids go through changes we are not aware of, not at all. I never, ever thought about my son, how he is coping in his classroom, before I went to teachers' college, when I realized I am the only one among all these people who think I am stupid and ignorant because my English was not as good as theirs.*

An uncaring system of "care." Encounters with health-care providers were varied. While a few women told of helpful and compassionate responses, many described attitudes they perceived as condescending, patronizing, and demeaning. These concerns were raised by the women from Central America who arrived in the 1980s as well as by the Eastern European women who had migrated more recently. Several of the Central American women commented that, in their view, resettlement assistance has not changed significantly over the years and health and social service professionals continue to lack understanding of the complex circumstances of refugee women. Some described explicit instances of hostility, racism, or other forms of violence. All indicated that, generally, health professionals showed little interest in learning about what had happened to them, and two participants noted that, in response to their efforts to speak openly with their physicians, they were given antidepressant medication.

Two women told of sexual assaults by physicians during prenatal visits. Paula recounted an incident several years after her arrival. A physician at a walk-in clinic touched her inappropriately during her first prenatal visit. Too stunned and distressed to do anything at the time, Paula later told her husband what had occurred and subsequently returned to the clinic to inform the chief medical officer. Paula did not know if any action was ever taken against the doctor, but continued to feel a profound sense of violation. Another participant told of a similar experience with a gynecologist. Although she called for her husband, who had been forced to leave the room but was able to stop the abuse as it was occurring, no formal action was ever taken against the physician. In both cases, the women lacked the language skills necessary to articulate what had occurred, as well as information regarding their legal rights; formal action was simply not an option. The women were left with feelings of profound shame and anger that remained with them.

Discussion

The women who participated in this research thoughtfully and sensitively shared stories about their lives, how they were shaped by violence in the context of war, and about their efforts to establish themselves and their families in a new and unfamiliar country. Although the interviews often evoked deeply painful memories, the women repeatedly commented that they welcomed the opportunity to talk. Their need to tell, to bear witness to the horrors of war, is not surprising. Aron (1992) discusses the beneficial effects of *testimonio* for people who have suffered trauma under state-sponsored terrorism. According to Aron, testimonio "validates personal experience as a basis for truth and knowledge, and personal morality as a standard for public virtue" (p. 176).

In this study, the narrative interviews provided a vehicle for denouncing the sexual violence perpetrated against the women. Upon completion of the study, a follow-up invitational forum was held. It was attended by most of the women who participated in the research as well as community leaders, public health nurses, social service providers, and policy-makers. The forum served as a "safe space" for the women. They made a public plea for punishment of the perpetrators and called for the establishment of sustainable programs that are responsive to their distinct needs. In *The Blue Room*, Agger (1994) writes about the healing effects of testimony: "private shame can be transformed to political dignity, providing a source of knowledge about the methods of the dictatorship, while healing the wounds inflicted through these methods" (p. 10).

Several of the women in this study spoke about depression. The tendency to medicalize and individualize the "narratives of suffering" is discussed from a critical medical anthropological perspective by Eastmond (2000). According to Eastmond, refugees' responses are best analyzed in their own terms and interpretation, situated in the local cultural context of their experience. Like Aron (1992), Eastmond believes that refugee women need to go through the cathartic experience of telling their stories (testimonio) as part of the "meaning-making" process. Further, she asserts that the tendency to label refugee women as "traumatized," and thus to stigmatize them, diverts their attention from the "more multifaceted definitions of their problems" (p. 81), ultimately hindering the process of healing. She implores health providers to approach human suffering from both clinical and anthropological perspectives in order to broaden their understanding of the refugees' experiences. This approach contrasts with deeply entrenched Western-based scientific models, which often are unable to yield comprehensive understanding of the needs and concerns of refugee women.

Many of the participants in the study displayed a sense of resignation, saying that they were "just surviving." The refugee women who arrived several decades ago and those with non-transferable occupational skills were more likely to be isolated in their homes, "stuck" on social assistance, or relegated to unskilled jobs. Although the women had come to Canada with valuable skills, their credentials were not recognized and they found themselves de-skilled and with few prospects. A Guatemalan woman who had been a teacher in her home country reported that, in a private conversation, her ESL teacher had implied that newcomers — refugees in particular — were expected to become manual labourers. As lack of language proficiency was identified as a major barrier to employment, the women realized that they had to make Herculean efforts to overcome the obstacles they encountered every day. Other barriers identified by the women were poor housing, poor health status, lack of proper access to health care and counselling, isolation, rejection, racism and other forms of violence, culture shock, and powerlessness.

The women in the study were cut off from their traditional support systems, from family, friends, and a sense of community, and they had all experienced trauma, directly or indirectly. They felt uprooted, confused, and disconnected. While a few of the women seemed satisfied with the quality of services they received upon arriving, most expressed dissatisfaction with the services provided to them. The general feeling was that, instead of mutually agreeing upon a plan of action, health and service providers assumed the role of "expert" and decided what was in the best interests of the women. The women were disheartened by what they perceived as the patronizing attitudes of service providers, and most expressed the need for greater understanding.

The findings from this research have implications for all health providers. Undoubtedly, the premigration and postmigration experiences of women refugees deeply affect their physical and emotional health and can have a significant impact on the resettlement process. Many challenges in developing programs for refugee women have been identified. Much of the literature on existing programs is based on American programs that place the emphasis on health and well-being from a biomedical perspective. Many of these programs lack a holistic thrust and instead focus on the physical health of refugees, prioritizing vaccinations and parasite screening (Ford, 1995; Kennedy, Seymour, & Hummel, 1999).

One challenge addressed by both Goodburn (1994) and DeSantis (1997) is the fear and mistrust of refugees who have experienced persecution at the hands of untrustworthy officials. Health providers who rely on a foundation of trust in the relationship face challenges in establishing programs for this group. Most notably, refugees may be reluctant to approach the health-care worker with their specific needs. Therefore, developing trust must be a priority in caring for refugees, whether at the individual or the community level.

We need comprehensive approaches that include examination of societal, institutional, and individual factors that impact on health. The trauma of migration, racism, marginalization, and exclusion, and the dynamics of violence should be considered in tandem with assessment of the health needs of refugee women. Efforts to reduce the women's sense of isolation should be promoted through active outreach strategies and the deployment of public health or community nurses. Fluency in the person's language is a necessity, as is knowledge about the community's social and historical experiences. The unique and very challenging circumstances of refugee women have prompted a movement towards contextualized care. Such care takes into account the intersectionalities of oppression and includes a comprehensive analysis of gender, class, culture, and the political environment (Adams & Assefi, 2002; Atlani & Rousseau, 2000; Gasser, Dresden, Keeny, & Warren, 2000; Guruge & Khanlou, 2004; Jiwani, 2001; Sidieris, 2003; Whittaker, Hardy, Lewis, & Buchan, 2005).

One limitation of this research concerns the nature of the sample. As a group of well-educated women, the participants possessed resources and opportunities that would not be shared by refugee women with less education. Thus, research with refugee women from more varied socioeconomic backgrounds would yield more comprehensive understandings. Another limitation is the inclusion of women who had arrived in Canada during two distinct periods. Finally, it might be argued that the inclusion of women from different ethnocultural backgrounds was a limitation. However, we are reluctant to advocate ethnospecific research because of the tendencies in both scholarly and popular media to reinforce unwarranted stereotypes (Dossa, 2004; Jiwani, 2001).

The stories told by the women who participated in this research are just a beginning. From their position in the margins of society, these courageous women do not need nurses or other health professionals to tell them how they should live, or to individualize their problems and deflect attention from the larger social, cultural, and structural barriers they face. Nor do they need medication to lessen the pain. Rather, they need social spaces and networks that can sustain the element of struggle and a belief in the possibilities for change; they need jobs and people to whom they can talk openly and honestly, without fear of retribution or judgement.

References

Adams, K., & Assefi, N. (2002). Primary care refugee medicine: General principles in the postimmigration care of Somali women. *Primary Care Update for Ob/Gyns, 9*(6), 210–217.

Agger, I. (1994). *The blue room: Trauma and testimony among refugee women. A psycho-social exploration.* London: Zed Books.

Apfelbaum, E. R. (2000). And now what, after such tribulations? Memory and dislocation in the era of uprooting. *American Psychologist, 55,* 1008–1013.

Arat-Koc, S. (2000). NAC's response to the Immigration Legislative Review Report "Not Just Numbers: A Canadian Framework for Future Immigration." *Canadian Woman Studies/Cahiers des Femmes, 19*(3), 18–23.

Aron, A. (1992). Testimonio: A bridge between psychotherapy and sociotherapy. In E. Cole, O. Espin, & E. Binghamton Rothblum (Eds.), *Refugee women and their mental health: Shattered societies, shattered lives* (pp. 173–189). New York: Harrington Park Press.

Aron, A., Corne, S., Fursland, A., & Zelwer, B. (1991). The gender-specific terror of El Salvador and Guatemala: Post-traumatic stress disorder in Central American refugee women. *Women's Studies International Forum, 14*(1/2), 37–47.

Atlani, M., & Rousseau, C. (2000). The politics of culture in humanitarian aid to women refugees who have experienced sexual violence. *Transcultural Psychiatry, 37*(3), 435–449.

Beiser, M. (1999). *Strangers at the gate: The Boat People's first ten years in Canada.* Toronto: University of Toronto Press.

Berman, H. (2000). The relevance of narrative research with children who witness war and children who witness woman abuse. *Journal of Aggression, Maltreatment and Trauma, 3*(1), 107–125.

Black, M. (1998). Girls and war: An extra vulnerability. *People and the Planet,* 7(3), 24–25.

Bourke, J. (2006). War and violence. *Thesis Eleven, 86*(1), 23–38.

Bowen, D. J., Carscadden, L., Beighle, K., & Fleming, I. (1992). Post-traumatic stress disorder among Salvadoran women: Empirical evidence and description of treatment. *Women and Society. Special Issue: Refugee Women and Their Mental Health: Shattered Society, Shattered Lives II, 13*(3), 267–280.

Bracken, P. J. (1998). Hidden agendas: Deconstructing post-traumatic stress disorder. In D. Summerfield et al. (Eds.), *Rethinking the trauma of war.* London: SCF.

Cardozo, B. L., Talley, L., & Crawford, C. (2004). Karenni refugees living in Thai-Burmese border camps: Traumatic experiences, mental health outcomes, and social functioning. *Social Science and Medicine, 58*(12), 2637–2644.

Citizenship and Immigration Canada. (1998). *Building on a strong foundation for the twentieth century: New directions for immigration and refugee policy and legislation.* Ottawa: Minister for Public Works and Services Canada.

Copelon, R. (1995). Gendered war crimes: Reconceptualizing rape in time of war. In J. Peters & A. Wolper (Eds.), *Women's rights, human rights: International feminist perspectives.* New York and London: Routledge.

Copelon, R. (1999). Surfacing gender: Reengraving the crimes against women in humanitarian law. In N. Dombrowski (Ed.), *Women and war in the twentieth century: Enlisted with or without consent.* New York and London: Garland.

Crisp, J. (2001). Mind the gap! UNHCR, humanitarian assistance and the development process. *International Migration Review, 35*(1), 168–191.

DeSantis, L. (1997). Building healthy communities for immigrants and refugees. *Journal of Transcultural Nursing, 9*(1), 20–31.

Dossa, P. (2004). *Politics and poetics of migration: Narratives of Iranian women from the diaspora.* Toronto: Canadian Scholars' Press.

Drumbl, M. (2000). Punishment goes global: International criminal law, conflict zones, and gender inequality. *Canadian Woman Studies, 19*(4), 22.

Eastmond, M. (2000). Refugees and health: Ethnographic approaches. In F. L. Ahearn Jr. (Ed.), *Psychosocial wellness of refugees: Issues in qualitative and quantitative research.* New York and Oxford: Berghahn Books.

Eytan, A., Gex-Fabry, M., Toscani, L., Derro, L., Loutan, L., & Bovier, P. (2004). Determinants of post-conflict symptoms in Albanian Kosovars. *Journal of Nervous and Mental Disease, 192*(10), 664–671.

Farias, P. J. (1991). Emotional distress and its sociopolitical correlates in Salvadoran refugees: Analysis of a clinical sample. *Culture, Medicine and Psychiatry, 15*(2), 167–192.

Fenta, H., Hyman, I., & Noh, S. (2004). Determinants of depression among Ethiopian immigrants and refugees in Toronto. *Journal of Nervous and Mental Disease, 192*(5), 363–372.

Forbes Martin, S. (2004). *Refugee women,* 2nd ed. Lanham, MD: Lexington.

Ford, M. (1995). Innovations in refugee health care. *Caring: The National Association for Home Care Magazine, 14*(12), 32–35.

Franz, B. (2003). Bosnian refugee women in (re)settlement: Gender relations and social mobility. *Feminist Review, 73,* 86.

Friedman, M., & Jaranson, J. (1994). The applicability of the posttraumatic stress disorder concept to refugees. In A. J. Marsella, T. Bornemann, S. Ekblad, & J. Orley (Eds.), *Amidst peril and pain: The mental health and well-being of the world's refugees.* Washington: American Psychological Association.

Gafner, G., & Benson, S. (2001). Indirect ego-strengthening in treating PTSD in immigrants from Central America. *Contemporary Hypnosis, 18*(3), 135–144.

Gasser, N., Dresden, E., Keeny, G., & Warren, N. (2000). Status of women and infants in complex humanitarian emergencies. *Journal of Midwifery and Women's Health, 49,* 7–13.

Goodburn, A. (1994). A place of greater safety. *Nursing Times, 90*(24), 46–48.

Guruge, S., & Khanlou, N. (2004). Intersectionalities of influence: Researching the health of immigrant and refugee women. *CJNR, 36*(3), 2–47.

Hyndman, J. (2000). Gender and Canadian immigration policy: A current snapshot. *Canadian Woman Studies, 19*(3), 7–10.

Hynes, H. P. (2004). On the battlefield of women's bodies: An overview of the harm of war to women. *Women's Studies International Forum, 27*(5/6), 431–445.

Jiwani, Y. (2001). *Intersecting inequalities: Immigrant women of colour, violence, and health care.* Vancouver: FREDA Centre. Available online: http://www.harbour.sfu.ca/freda/pdf/inequal.pdf

Kennedy, J., Seymour, D. J., & Hummel, B. J. (1999). A comprehensive refugee health screening program. *Public Health Reports, 114*(September/October), 469–477.

Laban, C., Gernaat, H., Komproe, I., van der Tweel, I., & de Jong, J. (2005). Postmigration living problems and common psychiatric disorders in Iraqi asylum seekers in the Netherlands. *Journal of Nervous and Mental Disease, 193*(12), 825–832.

Liebling, H. (2003). Women's war experiences: Sexual violence and torture during civil war years in Luwero. *Impact, 4,* 22.

Malone, L. A. (1996). Beyond Bosnia and *In re Kasinga:* A feminist perspective on recent developments in protecting women from sexual violence. *Boston University Law Journal, 14,* 319–341.

Mishler, E. (1986). The analysis of interview-narratives. In T. R. Sarbin (Ed.), *Narrative psychology: The storied nature of human conduct* (pp. 233–255). New York: Praeger.

Momartin, S., Silove, D., Manicavasagar, V., & Steel, Z. (2004). Complicated grief in Bosnian refugees: Associations with posttraumatic stress disorder and depression. *Comprehensive Psychiatry, 45,* 475–482.

Moussa, H. (1998). Violence against refugee women: Gender oppression, Canadian policy and the international struggle for human rights. *Resources for Feminist Research, 26*(3/4), 79.

Muecke, M. (1992). New paradigms for refugee health problems. *Social Science and Medicine, 35*(4), 515–523.

Nikolic-Ristanovic, V. (Ed.). (2000). *Women, violence, and war: Wartime victimization of refugees in the Balkans.* Budapest and New York: Central European University Press.

Not just numbers: A Canadian framework for future immigration. (1998). Ottawa: Government of Canada.

Pratt, K. M., & Fletcher, L. E. (1994). The case for international prosecutions of rape and gender-based violence in the former Yugoslavia. *Berkeley's Women Law Journal, 9,* 77–103.

Riessman, C. K. (1993). *Narrative analysis.* Newbury Park, CA: Sage.

Salis Gross, C. (2004). Struggling with imaginaries of trauma and trust: The refugee experience in Switzerland. *Culture, Medicine and Psychiatry, 28*(2), 151–167.

Seu, B. I. (2003). The woman with the baby: Exploring narratives of female refugees. *Feminist Review, 73,* 158–165.

Shanks, L., & Schull, M. J. (2000). Rape in war: The humanitarian response. *Canadian Medical Association Journal, 163*(9), 1152–1156.

Sideris, T. (2003). War, gender and culture: Mozambican women refugees. *Social Science and Medicine, 56*(4), 713–724.

Simich, (2003). Negotiating boundaries of refugee resettlement: A study of settlement patterns and social support. *Negotiating Boundaries in a Globalizing World, 40*(5), 575–591.

Walton-Roberts, M. (2004). Rescaling citizenship: Gendering Canadian immigration policy. *Political Geography*, *23*(3), 265.

Warriner, D. S. (2004). Multiple literacies and identities: The experience of two women refugees. *Women's Studies Quarterly, 32*(1/2), 179–195.

Weine, S., Muzurovic, N., Kulauzovic, Y., Besic, S., Lezic, A., & Mujagic, A. (2004). Family consequences of refugee trauma. *Family Process, 43*(2), 147–160.

Whittaker, S., Hardy, G., Lewis, K., & Buchan, L. (2005). An exploration of psychological well-being with young Somali refugee and asylum-seeker women. *Clinical Child Psychology and Psychiatry, 10*(2), 177–196.

Young, M.Y. (1997). Bearing witness to the unspeakable. *Women and Therapy, 20*(1), 23–25.

Zabaleta, M. R. (2003). Exile. *Feminist Review, 73,* 19–38.

Zentgraf, K. M. (2002). Immigration and women's empowerment: Salvadorans in Los Angeles. *Gender and Society, 16*(5), 625–646.

Acknowledgements

This research was supported in part by a grant from the Centre for Research on Violence Against Women and Children.

The authors would like to thank the women who shared their stories, research assistants Liana Voia, Sarah Derby, and Susana Caxaj, and the anonymous reviewers for their helpful insights.

Helene Berman, RN, PhD, is Associate Professor, School of Nursing, and Scotiabank Chair, Centre for Research and Education on Violence Against Women and Children, University of Western Ontario, London, Ontario, Canada. Estella Rosa Irías Girón, MD, MSW, is Volunteer and Crisis Line Coordinator, Sexual Assault Centre London, and Woman's Support Worker, Native Family Healing Services, At^losha, London. Antonia Ponce Marroquín is Woman Abuse Counsellor, Changing Ways, London.

2009 update: *Helene Berman's positions are unchanged. Estella Rosa Irías Girón is Volunteer and Crisis Line Coordinator, Sexual Assault Centre London. Antonia Ponce Marroquín is a Counsellor at Women's Community House, a shelter for women who have left abusive relationships.*

CJNR 2009, Vol. 41 N° 1, 166–191

Résumé

Les discours influençant les perceptions des infirmières à l'égard des patients autochtones

Annette J. Browne

Cette étude explore les discours sociaux et professionnels ayant une influence sur les connaissances et les présupposés des infirmières à l'égard des patients autochtones. Elle est fondée sur un modèle d'investigation ethnographique, des entrevues en profondeur et l'observation des participants. Les données ont été recueillies au cours d'une immersion de neuf mois effectuée par l'auteure dans un hôpital de taille moyenne, situé dans l'Ouest canadien. Trente-cinq participants ont été recrutés grâce à un sondage par choix raisonné, soit des infirmières, des patientes autochtones hospitalisées et des informateurs clés spécialisés en santé des Autochtones. Les résultats indiquent que les perceptions des infirmières à l'égard de leurs patientes autochtones sont façonnées par le chevauchement de trois discours : un discours concernant la culture, un discours professionnel sur l'égalitarisme et un discours populaire sur les peuples autochtones. Ils révèlent que les présupposés culturels sont entrelardés des stéréotypes entretenus par la société dominante et sont parfois présentés comme des faits même lorsqu'ils contredisent les idéaux égalitaires du locuteur. Les conclusions de l'étude mettent en lumière la nécessité de concevoir des stratégies pour stimuler chez les infirmières une réflexion critique sur la culture, le cadre sociopolitique qui détermine les rapports dans le milieu de la santé et, dans une perspective plus large, les discours sociaux ayant une influence sur leurs attitudes.

Mots clés : peuples autochtones, femmes autochtones, Canada, perceptions des infirmières, culture

CJNR 2009, Vol. 41 N° 1, 166–191

Discourses Influencing Nurses' Perceptions of First Nations Patients

Annette J. Browne

This study explores the social and professional discourses that influence nurses' knowledge and assumptions about First Nations patients. Through the use of an ethnographic design, in-depth interviewing, and participant observation, data were collected over a 9-month period of immersion in a midsized hospital located in western Canada. Purposive sampling was used to recruit 35 participants: nurses, First Nations women who were patients in the hospital, and key informants with expertise in Aboriginal health. The findings indicate that 3 overlapping discourses were shaping nurses' perspectives concerning the First Nations women they encountered: discourses about culture, professional discourses of egalitarianism, and popularized discourses about Aboriginal peoples. Cultural assumptions were intertwined with dominant social stereotypes and were sometimes expressed as fact even when they conflicted with egalitarian ideals. Conclusions highlight the need for strategies to help nurses think more critically about their understandings of culture, the sociopolitical context of health-care encounters, and the wider social discourses that influence the perspectives of nurses.

Keywords: Aboriginal peoples, indigenous people, First Nations, First Nations women, Canada, provider-patient relations, nurses' attitudes, culture, colonialism, cultural safety

Health care involving Aboriginal peoples[1] in Canada continues to unfold against a backdrop of colonial relations[2] that shape access to health care, health-care experiences, and health outcomes. Despite significant

---

[1] The term "Aboriginal peoples" refers generally to the indigenous inhabitants of Canada, including First Nations, Métis, and Inuit peoples (Royal Commission on Aboriginal Peoples, 1996, p. xii). These three groups reflect "organic political and cultural entities that stem historically from the original peoples of North America, rather than collections of individuals united by so-called 'racial' characteristics" (p. xii). Specifically, the term First Nation replaces the term Indian, Inuit replaces the term Eskimo, and Métis refers to people of mixed European and Aboriginal ancestry. The labels "Native" and "Indian," however, continue to be used in federal legislation and policy (e.g., the *Indian Act*), statistical reports, and public discourses. In 2001, 1.3 million people, or 4.4% of the total Canadian population, reported Aboriginal ancestry (Statistics Canada, 2003).

In this paper, the term "Aboriginal peoples" is used to refer generally to the diverse groups within Canada. First Nations is used more specifically to refer to the participants in the study who identified as First Nations.

[2] Kelm (1998) discusses colonization from a historical perspective as the "sociocultural dislocation, the establishment of external political control and economic dispossession,

Originally published in CJNR 2005, Vol. 37 N° 4, 62–87

improvements in recent years, the health of Aboriginal peoples continues to lag behind that of the overall Canadian population on virtually every measure (Canadian Institute for Health Information [CIHI], 2004). Scholars across all sectors of Aboriginal health research concur that persistent disparities in health and social status are entrenched in the history of relations between Aboriginal peoples and the nation-state (Adelson, 2005; Dion Stout, Kipling, & Stout, 2001; Kelm, 1998).

In Canada, O'Neil's (1989) hallmark study of health-care encounters involving Inuit patients and Western care providers has been highly influential in drawing attention to the political context of patient-provider relations. By situating individual patient-provider interactions in the internal colonial context of health-care provision in northern Canada, O'Neil demonstrates how paternalism, power differences, and cultural misunderstandings are shaped by wider sociopolitical issues. O'Neil argues further that the tendency of Western nurses and doctors to "bracket out" the sociopolitical context of health-care encounters stems from their professional socialization and their predominantly middle-class values.

Most of the research on health-care encounters involving Canadian Aboriginal patients subsequent to the publication of O'Neil's (1989) work has been conducted from the perspective of patients (Baker & Daigle, 2000; Browne, 1995; Browne & Fiske, 2001; O'Neil; Sherley-Spiers, 1989). For example, Browne and Fiske (2001) found that some women were acutely aware of their gendered stereotyping as First Nations women by health-care providers. Findings from this and other studies demonstrate the need to locate the micropolitics of health care within sociopolitical and historic contexts. Research conducted from the vantage point of patients is critical to improving the provision of services. Such research shows that it is equally important to explore how it is that health professionals come to hold the knowledge and assumptions that

---

the provision of low-level social services, and finally, the creation of ideological formulations around race and skin colour" (p. xix). In the current context, LaRocque (1993) defines colonization from an Aboriginal perspective as the "loss of lands, resources, and self-direction and…the severe disturbance of cultural ways and values" (p. 73). It should be kept in mind, however, that colonizing forces did not operate as a single, uniform trajectory of subjugation — oppositional voices and resistance also existed: "The processes of power inherent in colonization [are]…diffuse, dialectical, and subject to competing positions both from within the society of the colonizers and from the colonized" (Kelm, 1998, p. xviii). Further, Furniss (1999) argues that what characterizes colonial culture in Canada is "not merely the presence of racist discourses" but also the distinctions drawn between Aboriginal and non-Aboriginal peoples through the assignment of "difference — negative, neutral or positive — or through the denial of difference.…These alternating tendencies toward…assertion and denial of indigenous differences are central dynamics within colonial discourses and practices" (p. 13).

shape their views of particular patients or patient groups. The present study takes up this challenge by exploring the social and professional discourses that influence nurses' knowledge and assumptions about the First Nations patients they encounter in hospital.

Several concepts central to this paper require defining at the outset. Discourse can be defined as a "coherent way of describing and categorizing the social world" through patterns of "words, figures of speech, concepts, values, and symbols" (Lupton, 1994, p. 18) or as a "domain of language-use that is characterised by common ways of talking and thinking about an issue (for example, the discourses of medicine)" (Germov, 1998, p. 341). Further, "it is through discourse that social reality comes into being" (Escobar, 1997, p. 85).

The notion of "dominant culture" is also central to this paper. Furniss (1999), a Canadian anthropologist, describes dominant culture as a "deeply rooted set of understandings" that is experienced as a "set of common-sense, taken-for-granted truths" about individuals, society, and social relationships (p. 14). This does not imply that there is a unitary dominant culture, that all people subscribe to dominant cultural assumptions, or that these assumptions are static or fixed. However, various kinds of dominant cultural assumptions infuse many aspects of everyday life — through the media, schoolbooks, public interest debates, and everyday conversations. They shift and change according to one's life context, the local issues of which they are a part, and current political and economic contexts. Hence the "different life experiences of individuals, conditioned not only by their individual biographies but also by their varied positions within structures of inequality…give rise to different perceptions" that challenge the legitimacy of a dominant culture (p. 14–15).

The concept of culture also requires close analysis. In nursing and health care, culture is commonly understood as "a template or blueprint for human behaviour, grounded in the values, beliefs, norms, and practices of a particular group that are learned or shared" (Reimer Kirkham & Anderson, 2002, p. 4). Several nurse researchers have written extensively on the limitations of this perspective, arguing that culture is much more complex[3] than is typically assumed (see, e.g., Allen, 1999; Anderson, 1998; Anderson & Reimer Kirkham, 1999; Culley, 1996; Doane & Varcoe, 2005; Meleis & Im, 1999; Reimer Kirkham et al., 2002). Allen argues that culture cannot be reduced to a set of fixed, identifiable characteristics or traits attributable to members of a particular ethnocultural group. Culture can, however, be understood as a shifting, changing, relational process that is lived within and among groups and

---

[3] As Margaret Lock (1993) points out, "culture" is "one of the two or three most complicated words in the English language" (p. 144).

people, and therefore as deeply enmeshed in power relations and in economic, political, and historical contexts (Anderson & Reimer Kirkham, 1999; Doane & Varcoe, 2005; Stephenson, 1999). The scholars cited above point to the problems that can arise when health-care providers are taught to watch for particular cultural traits or cultural differences, arguing that notions of difference are always set against presumed (dominant) cultural norms. This practice tends to reinforce ideas about "us and them," "normal and different," "typical" or "Other."[4] Despite an increasing number of critiques in nursing and health care, culture continues to be viewed as synonymous with "difference," without a full appreciation of how these differences can reflect widely held stereotypes. Compounded by the propensity to view culture as equivalent to ethnicity or nationality, culture tends to be seen as relevant only to people who differ from the dominant group. It is in this context that ideas about culture have the potential to become problematic in nursing.

Social Determinants of Aboriginal Women's Health

In Canada, the complex history of colonial politics, policies, and practices has resulted in profound social and cultural disruption within many Aboriginal communities, marginalization of many Aboriginal people in terms of the wage economy and mainstream political processes, and the forced economic dependence of many Aboriginal peoples on the nation-state (Kelm, 1998; Waldram, Herring, & Young, 1995). The regulation of Aboriginal peoples' lives through social policies embedded in the *Indian Act,* the restrictions placed on Aboriginal self-government, land claims, and the economic development of Aboriginal communities are vestiges of the colonial past (Armitage, 1995) that, in turn, shape life opportunities, economic conditions, and the overall health and social status of individuals, families, and communities. According to leading scholars in Aboriginal health,

> Despite public recognition of past injustices committed against Aboriginal peoples in this country, marginalization and prejudice remain very much present in the daily lives of many community members. While the effects of this marginalization make themselves manifest in any number of ways, few are more telling than statistics that place

---

[4] Othering refers to the projection of assumed cultural characteristics, differences, or identities onto members of particular groups. Othering is also a process through which we construct our own identities in reference to Others (Varcoe & McCormick, 2007). By identifying individuals or groups as Other, one magnifies and reinforces projections of apparent differences from oneself (Johnson et al., 2004). As Ahmad (1993) explains, by "defining the Other (usually as inferior) one implicitly defines oneself against that definition (usually as normal or superior)" (p. 18).

> Canada's Aboriginal population far below their non-Aboriginal counterparts in the United Nations Human Development Index. (Dion Stout et al., 2001, p. 12)

The colonial legacy of subordination of Aboriginal peoples has resulted in multiple jeopardy for many Aboriginal women, who face personal and institutional discrimination and disadvantage on the basis of race, gender, and class (Browne & Fiske, 2001; LaRocque, 1996; Native Women's Association of Canada [NWAC], 2002). Despite improvements in recent years, health and social status indicators continue to demonstrate large discrepancies between Aboriginal and other Canadian women (CIHI, 2004; Dion Stout et al., 2001). For example, age-standardized mortality rates from all causes for Aboriginal women are substantially higher than those for other women. Life expectancy for Aboriginal women is 76.2 years, versus 81.0 years for non-Aboriginal women (NWAC, 2002). The incidence of low income among Aboriginal women is more than twice that among the general female population (42.7% vs. 20.3%) (Dion Stout et al., 2001), and the economic situation for Aboriginal lone mothers is even more grave (NWAC, 2002). The current crisis caused by extremely high rates of HIV among Aboriginal women is one of the most devastating manifestations of the cumulative effects of poverty, dispossession, powerlessness, and despair (Health Canada, 2002; Spittal & Schechter, 2001). These social and health inequities cannot be glossed over as lifestyle or cultural issues; they are manifestations of the complex interplay of historical, social, political, and economic determinants of health status and access to health care.

Colonizing Assumptions About Aboriginal Women

To explain how the marginalization of Aboriginal women was rationalized in the past, scholars are drawing attention to the ways in which colonial images were used to manipulate public opinion. For example, images of Aboriginal women as dissolute, neglectful, and irresponsible helped government officials in the past to justify the extreme levels of poverty and ill health in many Aboriginal communities, creating misrepresentations that "blamed First Nations women for their lot in life and justified state intervention" (Stevenson, 1999, p. 66). Colonizing images of Aboriginal women as irresponsible and incompetent contributed to the "inferiorization of Aboriginal motherhood" and fuelled the widespread practice in the 1960s and 1970s of placing Aboriginal children in non-Aboriginal foster homes (Fiske, 1993, p. 20). More recently, public awareness campaigns portraying fetal alcohol syndrome as a primarily Aboriginal health problem have been criticized for perpetuating the public and professional perception of Aboriginal women as negligent and uncaring (Tait, 2000a, 2000b). Negative images from the past endure today as stereotypes (Eisenberg, 1998; Green, 1995; Gunn Allen, 1995; Newhouse, 2004; Stevenson, 1999; Tait, 2000b). As social tensions continue to rise in the competition for diminishing economic resources, misinformation about Aboriginal peoples is becoming even more visible, as issues related to land claims, rights, and entitlements are debated in public venues (Furniss, 1999). An editorial in a major Canadian newspaper serves to illustrate these public discourses:

> It's called a culture of entitlement and a whole lot of Canada's aboriginals have it real bad. Those who suffer from this energy sapping affliction almost always grow lethargic and passive.... Even the label "First Nations" speaks of entitlement, as though all others are second in line... The truth is, however impolitic it may be to say it, pandering to Native Indians has become a virtual industry in this country. (Yaffe, 2002, p. A14)

This is not an isolated diatribe. Furniss (1997/98, 1999), Dunk (1991), Newhouse (2004), and Ponting (1997, 2001) document the extent to which assumptions about Aboriginal peoples as wards of the state are expressed matter of factly in the media and in everyday conversation as popularized public viewpoints. These dominant cultural discourses — generated in the wider social world — can also shape the perspectives of health-care providers, and the knowledge and assumptions they hold about the patients they encounter in the clinical setting.

Research Methods

In this paper I discuss one aspect of the findings of a larger study exploring the sociopolitical context of health-care encounters between nurses and First Nations women. Specifically, it focuses on the wider social discourses that were found to influence nurses' interpretive perspectives. "Interpretive perspectives" refers to the various types of knowledge, assumptions, and experiences that shape nurses' understandings of their patients. Elsewhere, I discuss how these perspectives affected nurses' interactions with patients and their practices with regard to patients (Browne, 2003). Because of the need to limit the scope of the paper, the perspectives of the First Nations patients are also reported elsewhere (Browne, 2003).

Using an ethnographic design and in-depth interviewing and participant observation, data were collected over a 9-month period of immersion in a midsized hospital located in a western Canadian city. Aboriginal peoples comprised 9% of the city's population, compared to an average of 3% in other cities in the same province (Statistics Canada, 2003). Because of these demographic characteristics, this particular hospital setting was well suited to the exploration of health-care encounters between nurses and First Nations women.

Theoretical Perspectives Informing the Study

The study was informed by an emerging body of inquiry in nursing scholarship that draws on postcolonial theoretical perspectives (Anderson, 2000, 2002, 2004; Anderson et al., 2003; Browne & Smye, 2002; Browne, Smye, & Varcoe, 2005; Doane & Varcoe, 2005; Reimer Kirkham & Anderson, 2002; Varcoe & McCormick, 2007). Postcolonial theories can be understood as forming a body of critical perspectives that share a political and social concern about the legacy of colonialism, and how this legacy shapes relations at the individual, institutional, and societal levels (Young, 2001). As McConaghy (2000) explains, "the term postcolonial does not refer to a period of time, that is, the period of history after colonialism. Rather, the post in postcolonial refers to a notion of both working against and beyond colonialism.... Postcolonial therefore refers to issues of power, rather than time" (p. 268). Of central concern in postcolonial scholarship are analyses that shed light on how conceptions of race, racialization, and culture are constructed in particular sociopolitical contexts and shape contemporary social life, including relations in health care (Anderson, 2004). Exploration of these issues is particularly relevant in the Canadian context, where historically established relations of power, authority, and paternalism continue to shape health-care policies and practices concerning Aboriginal peoples (Adelson, 2005; Browne et al., 2005; Kelm, 1998; O'Neil, 1989; Waldram et al., 1995). In applying postcolonial theoretical perspectives, the goal is to use theory not as "the container into which the data must be poured" (Lather, 1991, p. 62), but rather as an interpretive lens through which to analyze the findings (Sandelowski & Barroso, 2003; Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004).

The Participants

Purposive sampling was used to recruit a total of 35 participants. These included 14 registered nurses (RNs) and two licensed practical nurses (LPNs) who worked at the hospital, 14 First Nations women who were their patients in the hospital, and the Native liaison worker employed at the hospital. The nurses were recruited by inviting those who were assigned to care for First Nations women (in addition to their other patients) to participate in the observations and interviews. After a significant proportion of the data had been collected and analyzed, four key informants with expertise in Aboriginal health were invited to discuss aspects of the data and to provide feedback on the preliminary themes. These included two RNs and a community health representative, all of whom worked in a nearby reserve community, and a health administrator responsible for First Nations health care in the region. Each of the key informants self-identified as First Nations. All of the participants were women.

Among the hospital nurses (*n* = 16), six had been employed at the hospital for between 15 and 25 years, eight for between 5 and 10 years, and two for less than 2 years. Two held baccalaureate degrees, three were in the process of completing BSN degrees, and the remainder were diploma-prepared. All worked either full time or nearly full time. The majority were experienced clinicians: on average, they had 16.5 years of nursing experience (range 2–25 years). Their average age was 43.8 years (range 25–58 years). All but two had lived and worked in this city or in the vicinity for several years (range 3–30+ years). Four self-identified as First Nations and the remainder as Euro-Canadian.[5] To protect anonymity, particularly for the two LPN participants, the term "nurse" is used to refer to both RNs and LPNs except where specific distinctions are required.

Data Collection

The study was approved by a university and hospital ethics board. The nurses and the First Nations women they were assigned to care for provided written informed consent before participating in interviews or the participant observation components. All data were collected by the principal investigator with the exception of data collected in three interviews conducted by two trained research assistants.

Participant observation involved the researcher's accompanying RNs during day and night shifts as they provided care to a variety of patients, including First Nations women. Observations were conducted on medical-surgical, renal, and postpartum units in order to ensure maximum variation, among both nurses and patients, in terms of different areas within the hospital. Participant observation provided the researcher with an opportunity to observe the patterns of interactions between nurses and patients, listen unobtrusively, and engage in dialogue with nurses and patients. Observation was essential to developing insights into the contextual factors that informed nurses' perspectives, the institutional context, and the challenges faced by the nurses as they provided

---

[5] Although "white" is the more common colloquial term used in Canada to distinguish non-Aboriginal peoples, Furniss (1999) states that Euro-Canadian is "the accepted term in formal academic discourse to refer to the dominant segment of Canadian society" (p. xi). Extending Furniss's rationale, I draw on Frankenberg's (1993) conceptualization of white (in this case, as synonymous with Euro-Canadian) to signal "a location of structural advantage, of race privilege…a 'standpoint', a place from which white people look at ourselves, at others, and at society" (p. 1).

care to various patients. Observational data were recorded as field notes. Field notes also contained reflexive analyses on how the researcher's professional, social, and ethnocultural positioning may have influenced the research process and the dynamics of her interactions with participants.

Because the data were collected over a period of 9 months, I had numerous opportunities to connect with nurses informally during coffee or lunch breaks or during shift reports. During the observational sessions, I remained in the role of researcher and did not participate as a practising nurse. However, as a clinician I often alerted nurses to changes in patients' status and assisted nurses with non-clinical tasks. In relation to patients, I often brought tea, ice chips, or snacks if permitted, helped to adjust their bedding or their position in bed, or discussed the health-related concerns they raised. In these ways, I assisted the nurses and patients as needed but did not get involved in the practice of clinical nursing per se. Nonetheless, on several occasions nurses asked my opinion as they engaged in clinical decision-making, and I responded based on my clinical expertise.

In ethnographic research, it is important that the researcher reflect on the extent to which his or her presence affects the process of data collection. During the observational sessions in this study, I noted that the nurses did not seem to be spending extra time talking or lingering with patients, or making special efforts to connect with them beyond what was required during routine care, because of the hectic pace and the volume of their work. In other words, the nurses seemed not to alter their pace or manner of interacting with patients or each other on account of my presence. In fact, most of the nurses' encounters with patients occurred during brief, almost fleeting, moments as they rushed from patient to patient. Often, it was when they were not at the bedside — for example, when they were at the nurses' station, at the charting desk, or in medication and supply rooms — that nurses would spend a few moments reflecting on the process of providing care. On a few occasions nurses who felt particularly overburdened and pressed for time asked me to defer the observational session to a subsequent shift. On other occasions they commented on how "easy" it was to have me shadow them. Although it is never possible to definitively determine the authenticity of research participants' behaviours, the use of a variety of data-collection methods (for example, participant observation and individual interviews) provided a more comprehensive portrayal of nurses' encounters with patients than would be possible with any single data-collection method (Silverman, 1998; Thorne et al., 2004).

In-depth interviews were conducted with nurses who participated in observational sessions, in order to explore their experiences and perspectives in relation to the First Nations women they cared for in hospital. The majority of nurses chose to be interviewed on their days off and at a location other than the hospital (e.g., in the researcher's office). The interview guide included open-ended, broad "trigger" questions (intended to stimulate discussion) (Spradley, 1979). First, nurses were asked what it was like to work in the hospital and to describe the range of patients they encountered in their work. As the interview progressed, they were asked to describe their experiences caring for the First Nations women they encountered as patients. Throughout the interview, nurses were asked to ground their discussion in examples and to reflect on situations that they found particularly positive and those that were more challenging. Additional questions were formulated during the interview in response to nurses' accounts. Since the interviews took place some days after the observational sessions, questions specific to the observational sessions were also posed. This created an opportunity to ground the interview in the context of nurses' everyday practice. Follow-up interviews were conducted to clarify and verify information discussed in the initial ones. All interviews were audiotaped and transcribed verbatim.

Data Analysis

An interpretive thematic analysis was completed using processes described for qualitatively derived data (Sandelowski, 1995; Thorne et al., 2004). Coding and analysis was facilitated by the use of NVivo, a computer program for organizing, contrasting, and comparing qualitative data. Consistent with interpretive inquiry, data analysis was an iterative process of moving back and forth between the data as they were collected and coded. As data were continually gathered, interviews and field notes were read repeatedly to identify recurring and contradictory patterns in the data, preliminary concepts and themes, and possible linkages to theory. Concepts and themes were developed and used to categorize and code the data. As more data were collected and coded, categories were collapsed, expanded, modified, and refined. All data were coded by the author; in addition, interview transcripts were independently coded by two trained research assistants in order to identify similarities and differences. Discrepancies in coding served to identify areas for further exploration and led to further refinement of the coding categories. In the final stages, the analysis shifted to a more theoretical level of conceptualizing the ideas and themes expressed in the data (Sandelowski & Barroso, 2003).

Scientific quality and trustworthiness of the analysis were assessed through triangulation of multiple data sources (Thorne et al., 2004). Observational data contributed to the validity of findings by providing a form of triangulation that created a context within which to interpret the interview data — and vice versa. Relevance and credibility of the data were evaluated by reviewing the emerging analysis with several of the hospital nurses and the four key informants, who provided feedback on the ways in which the preliminary themes resonated with their perspectives or experiences. Throughout the study, reflexive analyses were recorded in field notes as a way of critiquing how the researcher's assumptions, values, and perspectives influenced the research process and interpretation of findings (Emerson, Fretz, & Shaw, 1995; Harding, 1987). At all stages of the study, an auditable decision trail of analytical and interpretive pathways was maintained.

Findings

Nurses and other health-care providers are influenced by a variety of theoretical and ideological perspectives garnered through their educational programs, accumulated professional experience, popularized public discourses, and societal experiences. Nurses thus draw upon a range of interpretive perspectives as they provide care to an increasingly diverse spectrum of patients. In this study, three overlapping discourses seemed to be shaping the nurses' interpretive perspectives and their understanding of the First Nations women they encountered: (a) discourses about culture, (b) professional discourses about egalitarianism, and (c) popularized discourses about Aboriginal peoples. While these discourses are discussed separately in the analysis that follows, they were not mutually exclusive; rather, they intersected to form complex and often contradictory interpretive perspectives. Consistent with interpretive inquiry, I interwove literature with the findings in order to form linkages between the empirical data and relevant theoretical perspectives (Sandelowski & Barroso, 2003; Thorne et al., 2004).

Discourses About Culture

The nurses were well aware that attending to issues of culture is an essential component of quality nursing care, and culture figured strongly in many aspects of their discussions. They stressed the importance of developing a better understanding of their patients' cultural backgrounds and saw "cross-cultural training" as a means of improving their practice:

> *[We are] getting better... The more we're learning about different cultures and having the cross-cultural classes in the nursing schools...experience helps; working with different cultures...helps a lot too.*

Several nurses discussed cross-cultural training as a means of developing a non-judgemental approach in their practice:

> *One of the things they teach you in nursing is to be non-judgemental. You can't help somebody if you're busy judging them for what they're doing. It's the same with Native people. You can't help them if you're judgemental in the way you approach them…. And a lot of that is non-verbal, non-spoken.*

A common belief in health care is that more cross-cultural training is needed, to help providers move beyond their judgements about certain patients. The nurses who felt they were not offered enough cross-cultural training opportunities described their work with some First Nations patients as "more challenging." One nurse described a commitment to treating all patients equally despite her sense of having to work from a deficit position in terms of cultural knowledge:

> *Everybody has cultural beliefs and practices that you have to take into consideration. So that's always a challenge — and more of a challenge for me, because I didn't have any training in those things.*

In an attempt to elicit cultural information from patients, nurses used an open-ended item on the hospital's admission form asking about "cultural practices":

> *Whenever a patient comes onto the ward, we do a complete history…and we talk to them about cultural and religious practices and how they feel the hospitalization will impact on that… Most people do respond, and say there are no issues.*

The purpose of the "cultural practices" item is to focus attention on issues of culture, the implication being that cultural information can be efficiently and easily elicited from patients. Consistent with prevailing conceptualizations of culture in health care, such institutional practices reinforce the notion of culture as something readily identifiable and easily addressed during routine health care (Allen, 1999). It is not the intent behind the item that is problematic but, rather, the *effect* of the item in reinforcing the notion of culture as quite narrowly defined in relation to the values, beliefs, and practices that are inherent to particular groups of people. When culture is represented in this way, it tends to be thought of as existing outside of power relations, or outside of people's social or economic circumstances (Doane & Varcoe, 2005). As the findings continued to show, narrow conceptualizations of culture can, paradoxically, reinforce the stereotyping of people who belong to particular ethnocultural groups — in this case Aboriginal patients.

As nurses discussed the diverse patients they encountered in the hospital, including First Nations women, they struggled to speak sensitively about the social problems affecting some of their patients. One nurse grappled to find the appropriate phrasing:

> *I find with Native people, just the way their culture is, I think you get a lot more social things that you need to deal with, a lot of — not necessarily problems but…[pause] What am I thinking of?… [pause] They are very complex socially and you need to look at a lot of things.*

As the interview progressed, this nurse provided some examples of the social issues alluded to above. For example, she commented, "It is in their culture to have a lot of violence, stabbing, alcohol abuse…more than what you see in other cultures." She also reiterated that this "doesn't mean that all Native people are drinking or in violent situations" but that there seemed to be more of those issues in First Nations culture.

Equating social problems with cultural characteristics is not uncommon in health-care discourses. Reflecting a proclivity for culturalist discourses in health care generally, culture is often given as the primary explanation for why certain people or groups experience various health, social, or economic problems (Reimer Kirkham et al., 2002). Culturalist discourses run the risk of shaping the perspectives of health-care providers by conveying the message that social problems such as alcoholism, dependency, and unemployment are largely a reflection of a group's cultural characteristics. They are infused with socially constructed assumptions about cultural essentialism — whereby a group's values, lifestyles, or beliefs are seen as reflecting inherent cultural characteristics. When health-care providers have frequent contact with patients who embody social problems (e.g., alcoholic patients), and when these patients are associated with a particular ethnocultural group, it can be challenging *not* to assume that social problems are culturally based. Because of the relatively narrow conceptualization of culture, the tendency in culturalist discourses is to overlook the broader structural, economic, and historical contexts that shape social and health problems.

Many of the nurses appeared to be strongly influenced by these cultural discourses. For example, a nurse reflecting on a challenging discharge-planning process for a First Nations woman from a reserve community commented: "She didn't take care of any of her own responsibilities [at home]. She didn't look after her own child. Now, I know that is a cultural thing." The tacit linking of maternal irresponsibility[6] with First Nations culture was one of several ways in which culturalist

---

[6] Aboriginal and non-Aboriginal scholars argue that historically mediated images of Aboriginal women as irresponsible mothers persist today as popularized stereotypes (Eisenberg, 1998; Green, 1995; Gunn Allen, 1995; Newhouse, 2004; Stevenson, 1999; Tait, 2000b).

discourses manifested in clinical conversations and reflected negative stereotyping. The limitation of a culturalist perspective lies in its tendency to overlook the socio-economic and historical issues (e.g., violence, poverty, intergenerational trauma) that place certain persons at risk. In a similar vein, culturalist discourses that conflate alcoholism with Aboriginal culture, as manifested in some of the nurses' comments that "quite often in this culture, they drink a lot" further mark Aboriginal peoples as stereotyped, cultural Others. Again, there is the tendency to overlook the socio-economic and historical conditions that can give rise to some people's experiences of poverty or substance use. These narrow understandings of culture, which are pervasive in health care, constrained the nurses' analyses of the wider structural, historical, and social contexts that shape people's lives, life opportunities, and access to the resources for health.

Professional Discourses About Egalitarianism

As the nurses discussed the diverse patients they encountered, they reiterated that they were committed to treating all patients equally. Reflecting a widely held professional discourse about the importance of egalitarianism (Canadian Nurses Association, 2002), many concurred with a sentiment expressed by one of their colleagues: "I treat nobody of a different culture any differently. I treat people equally, all the same."

Consistent with "colour blindness" as an appealing and powerful professional discourse, the principles of egalitarianism assume that all people should be — and in most cases are — treated the same regardless of their social, ethnocultural, or gendered location (Henry, Tator, Mattis, & Rees, 2000). Discourses about egalitarianism convey the message that, generally speaking, health-care systems and institutions are fair and treat people equitably. Many of the nurses expressed this idea, commenting that inequities in relation to Aboriginal patients were a "thing of the past... We're all smarter than that now. That is no longer acceptable."

In some cases the interview process itself served as a catalyst for nurses to reflect critically on the ideals of egalitarianism. Provided with an opportunity to reflect on their experiences, some nurses began to question their own level of awareness:

> *Many people, a lot of times, get categorized. That would probably be the only thing... And I find quite frequently people may jump to the conclusion that if someone [a patient] drinks, they categorize Native people as drinking quite frequently. I guess in one way you can call that a little prejudiced.... But other than that, I don't see people being prejudiced in any way.*

Another nurse stated that materials she was studying in an ethics course helped her to think critically about the precepts of egalitarianism. As she discussed her work with some of the First Nations women who were her patients, she drew distinctions between the need to treat all patients equally and the need to tailor services and care to specific groups, to rectify past injustices and present inequities. This level of analysis contrasted with the responses of some other nurses who expressed the view that "here, everyone is treated equally."

Other nurses pointed to more explicit challenges to egalitarianism operating in health-care encounters. One nurse whose interpretive lens was shaped partly by her experiences as a First Nations woman described her sensitivity to seemingly innocuous comments made on the wards:

> *It's really hard for me to talk about [it]. I think to myself, it shouldn't bother me.... There are comments, not directly about one particular patient but comments in a general sense.... I've heard, just as I'm charting, something like, "Oh, they [Aboriginal patients] get all their medications paid for," "no taxes," and things like that.... And I don't respond to those because this is where I work. I don't need this kind of stress.*

It was not only the First Nations nurses who reflected critically on the notion of "equal treatment for all." One nurse described her colleagues' "feelings" (as she sensed them) about their work with First Nations patients:

> *You get your good and your bad. You get a couple who...don't want to know any more. But most of them are professional enough — if they do have those feelings, they go in and do their jobs and leave. I have seen nothing really overt. I have heard a few comments...I know that the feelings are there.*

Several nurses expressed faith in "professionalism" as the mechanism by which their colleagues would manage their "feelings" towards particular patients. To keep one's biases in check — to "not let it show in your work," in the words of one nurse — was often framed as a professional responsibility:

> *Individuals have individual perceptions, individual biases, depending on how you were brought up, what you experienced in life. You have to make up your mind that you're going to try as much as you can to treat everybody equal. And sometimes it becomes hard. You may generalize. I mean, people generalize all the time. So it's a very individual thing, and in nursing you have to be careful.*

The idea that one can achieve egalitarianism by remaining professional serves to place the responsibility firmly on the shoulders of individuals.

However, focusing on biases as individually held opinions obscures the ways in which individual opinions are actually connected to — and reflections of — much wider social discourses. Wider social discourses can and do exert an influence on nurses' interpretive perspectives, despite personal commitments to the ideals of egalitarianism or professionalism.

Popularized Discourses About Aboriginal Peoples

Awareness of how dominant social views can be given expression through seemingly tolerant democratic discourses helps to explain why some nurses can view "all patients as equal" and, at the same time, view some Aboriginal patients as negative stereotypes. For example, discourses about respect and egalitarianism were sometimes discussed in parallel with constructions of Aboriginal people that reflected popularized negative stereotypes. One nurse described her approach to caring for some patients and the challenges she perceived:

> *I don't approach them [Aboriginal patients] any differently.... I look at them as individuals.... Respect, just show them respect. Have an empathetic attitude. But I also don't let them get away with a lot of what they try and get away with. For example, I find drugs and alcohol are real big problems with First Nations.... It's kind of sad.*

Despite the inherent contradictions in this comment, it is apparent that the critical issue is not the individual beliefs expressed but the extent to which the nurse's thinking is *organized* by racialized assumptions. The image of the "drunken Indian" is one of the most enduring colonizing images pervading Canadian society (Furniss, 1999, p. 107). This stereotype cannot be accounted for as an individually based opinion; rather, it has its origins within the domains of public history, which continue to shape Canadian consciousness.

Canadian social discourses that represent Aboriginal peoples as dependent, as "getting everything for free," or as undeserving recipients of government programs are pervasive in the media, in public debates, and in everyday conversation (Furniss, 1999; Newhouse, 2004; Ponting, 1997). The nurses in this study who were concerned that Aboriginal people "get everything paid for" were reflecting social views expressed more widely. In the absence of strategies or opportunities to think critically about these issues, nurses sometimes drew on powerful dominant discourses to form their understanding of the First Nations patients they encountered in the hospital:

> *I just don't think that throwing large sums of money without any direction or any guidance or any programs helps people who have been sidelined for*

> *a long time. They don't have to pay taxes. They don't have to work. That's how they live. And I think the government precipitates that.*

This view bears a striking resemblance to that expressed in the newspaper editorial cited earlier. In the absence of a broad base of knowledge about the economic and historical issues that have contributed to marginalization from the wage economy, or about the necessity for some communities to rely on government subsidies to maintain a basic standard of living, it can be a challenge to see "dependency" as anything other than a cultural way of life. As one nurse said:

> *The government gives them land, pays for their school. What do they have to do? And that filters right on through to when they come in here [the hospital]. They expect you to give because they are used to having it handed to them.... And as a result they don't have a bottom line, maybe the way you and I would have.*

One of the features of popularized assumptions — particularly in relation to ethnocultural groups — is the way in which they feed into the "us/them" binaries so characteristic of these wider social discourses. Popularized assumptions about Aboriginal peoples tend to portray a self-reliant member of the dominant culture on the one hand and a dependent, irresponsible Other on the other hand. Underlying such constructions is the view that people should be able to overcome social problems, become self-sufficient, and assume personal responsibility for their lifestyles.

These wider social perceptions serve as a lens through which patients' individual circumstances are interpreted. In everyday clinical practice, seemingly innocuous comments can resonate with socially constructed messages. A First Nations nurse recounted her experience caring for an indigent First Nations man who had just been admitted to a ward:

> *He was just covered in dirt from head to toe, so we did what we could and made him comfortable. I felt that everybody was working together. Everybody was doing what was required of them. But then, as we were leaving [the room], somebody made a comment... "There is your argument for land claims." And the conversation kind of turned. Maybe there was something about land claims in the newspapers at the time, because the conversation at the nurses' station turned towards that specifically. You know, "this is where all the money is going" and a general attitude about that. I wanted to cry for that man. I said to them, You can't imagine how this man must feel about himself to allow himself to be that neglected. It doesn't just happen overnight. You know, this is a long process of somebody who feels worthless. This man has nothing to do with land claims. Nothing. He's not going to see a dime. Like I said, they provided*

> *the care, absolutely. But it was afterwards that you could tell there were a lot of bad feelings about the treaties and the land claims.*

As alluded to by the nurse, the assumption expressed in relation to this one patient reflected a much wider range of discourses about Aboriginal rights and entitlements in Canada; comments at the nurses' station thus become part and parcel of the public debate about Aboriginal-state relations. As a microcosm of society, the hospital environment reflects the conversations that are taking place among the general public.

Some nurses spoke from personal experience as First Nations women and focused on the process by which dominant social discourses come into being. As one nurse explained:

> *All over the schoolyard you hear it.... There is that immediate difference between them and us. It's about the things that Natives get, and then, all of a sudden, you are not on the same ground as others. And I think I went through that in high school.*

Some of the non-First Nations nurses also discussed how their experiences living and working in First Nations communities made them aware of the social and historical issues shaping the lives of some patients. One nurse spoke of the perspectives she gained while working in community health:

> *A lot of issues came out. A lot of these women had been abused in the past and it was amazing that they had gotten the strength to decide that they were going to get an education, that they were better than just being put down all the time.*

Certainly, life experiences, social positioning, ethnocultural background, educational preparation, and family upbringing will intersect to shape the kinds of knowledge and perspectives that nurses bring to their practice. The most striking feature in the findings from this study, however, was the extent to which culturalist discourses became intertwined with dominant social stereotypes about Aboriginal peoples and were expressed as fact even as they conflicted with professional discourses about egalitarianism. This illustrates the complex and sometimes contradictory ideologies that can underpin nurses' interpretive perspectives.

Discussion

It is increasingly being recognized that relating to patients on the basis of assumptions and stereotypes can jeopardize the delivery of equitable, effective services (Anderson et al., 2003; Browne & Fiske, 2001; Drevdahl, 1999; Meleis & Im, 1999; Papps & Ramsden, 1996; Reimer Kirkham, 2003; Smedley, Stith, & Nelson, 2002; Sohler, Walmsley, Lubetkin, & Geiger, 2003). Nonetheless, a focus on the attitudes or assumptions of *individual* health-care providers overlooks the fact that attitudes and assumptions are deeply entrenched in dominant culture. Assumptions about Aboriginal peoples or any other group of people do not emerge merely from the misinformed opinions of individual nurses. The participants in this study were not espousing individually based values and assumptions, but were reflecting discourses and assumptions embedded in the dominant society and reinforced through media, institutional policies, and everyday practices (Doane & Varcoe, 2005; Furniss, 1999; Newhouse, 2004).

Nor do nurses intentionally take up these wider social discourses. On the contrary: health-care organizations "are filled with individuals who are deeply committed to their professional work, who are regarded as highly skilled practitioners, who believe themselves to be liberal human beings — and yet they unknowingly, unwittingly contribute to...inequality" (Henry et al., 2000, p. 383). Also, the professional discourses in health care that promote the ideals of egalitarianism are rooted in social and political ideologies (Browne, 2001). Liberalism, as a dominant political ideology, assumes that society is essentially fair and equitable. As Browne (2001) and Doane and Varcoe (2005) argue, liberal ideology has a profound impact on the thinking and practice of nurses and other health-care providers. Liberalism tends to steer attention in nursing away from treating racialization and other forms of inequality as relevant to health care. A recommendation arising from this study, therefore, is that strategies be adopted — in basic nursing education and in programs for practising nurses — to help nurses develop more awareness of how their interpretive perspectives are informed and shaped by wider social discourses. This is no small challenge: with few exceptions, the health and nursing literature in Canada has been silent on issues related to marginalizing and racializing practices (Reimer Kirkham, 2003; Varcoe & McCormick, 2007). Nonetheless, there is a growing body of critical scholarship to draw upon, and student and practising nurses alike will benefit from engaging critically and reflexively with these issues in the context of everyday clinical practice. Only when such steps are taken will nurses develop the critical-thinking skills they need in order to question assumptions, challenge dominant discourses, and engage in critically reflexive practice.

Findings from this study also highlight the problems that can arise when narrow understandings of culture and culturalist discourses are applied to particular patients and groups. A second recommendation is that theoretical frameworks or conceptual models be developed to help nurses move beyond conceptualizing culture as primarily a matter of lifestyles, behaviours, values, or choices. In Canada there is growing interest in one such model, that of "cultural safety"[7] (Anderson et al., 2003; Doane & Varcoe, 2005; Downey, 2003; Reimer Kirkham et al., 2002; Smye & Browne, 2002). The central tenets of cultural safety have particular relevance in practice and education. Used as a framework for prompting critical analyses, cultural safety would encourage nurses to question popular notions of culture and cultural differences, to be more aware of the dominant social assumptions that misrepresent certain people and groups, and to reflect critically on the wider social discourses that inevitably influence nurses' interpretive perspectives and practices. These areas of exploration could be catalysts for critically reflexive practice.

These kinds of critical analyses will require a greater nursing emphasis on the sociopolitical context of health-care encounters as well as the socio-economic and historical circumstances that shape patients' health status, opportunities for health, and access to resources. Increasingly, university nursing programs in Canada are incorporating critical pedagogies into their curricula. These could be expanded to focus on, for example, issues of political economy, the historical process of colonization in Canada, and the role of our sociopolitical landscape in shaping inequities. However, the real challenge will lie in developing strategies for fostering critical analyses at the frontlines of health care — in the busy clinical settings in which nurses work. This will require an infusion of support for resources, time, and strategies for critically oriented continuing education activities.

Critical reflection on the discourses that shape nurses' interpretive perspectives provides a window onto the factors that contribute to inequitable relations in health care. Only when we engage in ongoing critiques of how nursing is influenced by these discourses will we be able to contribute more fully to social justice in the realm of Aboriginal health.

References

Adelson N. (2005). The embodiment of inequity: Health disparities in Aboriginal Canada. *Canadian Journal of Public Health, 96,* 45–61.

Ahmad, W. I. U. (Ed.). (1993). *"Race" and health in contemporary Britain.* Buckingham, UK: Open University Press.

Allen, D. G. (1999). Knowledge, politics, culture, and gender: A discourse perspective. *Canadian Journal of Nursing Research, 30,* 227–234.

---

[7] Originally developed in the New Zealand context to address persistent health and access inequities affecting Maori populations, cultural safety extends the analytical gaze well beyond notions of cultural sensitivity to power inequities, institutional forms of discrimination, and the dynamics of health-care relations in a postcolonial context (Papps & Ramsden, 1996; Ramsden, 1993, 2000, 2002).

Anderson, J. M. (1998). Speaking of illness: Issues of first generation Canadian women — Implications for patient education and counseling. *Patient Education and Counseling, 33,* 197–207.

Anderson, J. M. (2000). Gender, "race," poverty, health and discourses of health reform in the context of globalization: A postcolonial feminist perspective in policy research. *Nursing Inquiry, 7,* 220–229.

Anderson, J. M. (2002). Toward a postcolonial feminist methodology in nursing: Exploring the convergence of postcolonial and black feminist scholarship. *Nurse Researcher: International Journal of Research Methodology in Nursing and Health Care*, *9*(3), 7–27.

Anderson, J. M. (2004). Lessons from a postcolonial-feminist perspective: Suffering and a path to healing. *Nursing Inquiry, 11,* 238–246.

Anderson, J., Perry, J., Blue, C., Browne, A., Henderson, A., Khan, K., et al. (2003). "Re-writing" cultural safety within the postcolonial and postnational feminist project: Towards new epistemologies of healing. *Advances in Nursing Science, 26,* 196–214.

Anderson, J. M., & Reimer Kirkham, S. (1999). Discourses on health: A critical perspective. In H. Coward & P. Ratanakul (Eds.), *A cross-cultural dialogue on health care ethics* (pp. 47–67). Waterloo, ON: Wilfrid Laurier University Press.

Armitage, A. (1995). *Comparing the policy of Aboriginal assimilation: Australia, Canada, and New Zealand.* Vancouver: University of British Columbia Press.

Baker, C., & Daigle, M. C. (2000). Cross-cultural hospital care as experienced by Mi'kmaq clients. *Western Journal of Nursing Research, 22,* 8–28.

Browne, A. J. (1995). The meaning of respect: A First Nations perspective. *Canadian Journal of Nursing Research, 27*(4), 95–109.

Browne, A. J. (2001). The influence of liberal political ideology on nursing science. *Nursing Inquiry, 8,* 118–129.

Browne, A. J. (2003). *First Nations women and health care services: The sociopolitical context of encounters with nurses.* Unpublished doctoral dissertation, University of British Columbia, Vancouver.

Browne, A. J., & Fiske, J. (2001). First Nations women's encounters with mainstream health care services. *Western Journal of Nursing Research, 23,* 126–147.

Browne, A. J., & Smye, V. (2002). A postcolonial analysis of health care discourses addressing Aboriginal women. *Nurse Researcher: International Journal of Research Methodology in Nursing and Health Care, 9*(3), 28–41.

Browne, A. J., Smye, V., & Varcoe, C. (2005). The relevance of postcolonial theoretical perspectives to research in Aboriginal health. *Canadian Journal of Nursing Research, 37*(4), 17–37.

Canadian Institute for Health Information. (2004). *Improving the health of Canadians.* Ottawa: Author.

Canadian Nurses Association. (2002). *Code of Ethics for Registered Nurses.* Ottawa: Author.

Culley, L. A. (1996). A critique of multiculturalism in health care: The challenge for nurse education. *Journal of Advanced Nursing, 23,* 564–570.

Dion Stout, M., Kipling, G. D., & Stout, R. (2001). *Aboriginal women's health research: Synthesis Project final report.* Ottawa: Centres of Excellence for Women's Health, Health Canada.

Doane, G. H., & Varcoe, C. (2005). *Family nursing as relational inquiry: Developing health-promoting practice*. Philadelphia: Lippincott, Willams & Wilkins.

Downey, B. (2003). Inaugural international indigenous nurses and midwives caucus. *Aboriginal Nurse* (December). Retrieved October 7, 2005, from http://www.findarticles.com/p/articles/mi_qa3911/is_200312/ai_n9332304.

Drevdahl, D. (1999). Sailing beyond: Nursing theory and the person. *Advances in Nursing Science, 21,* 1–13.

Dunk, T. (1991). *It's a working man's town: Male working-class culture in northwestern Ontario*. Montreal: McGill-Queen's University Press.

Eisenberg, A. (1998). Domination and political representation in Canada. In V. Strong-Boag, S. Grace, A. Eisenberg, & J. Anderson (Eds.), *Painting the maple: Essays on race, gender, and the construction of Canada* (pp. 37–52). Vancouver: University of British Columbia Press.

Emerson, R., Fretz, R., & Shaw, L. (1995). *Writing ethnographic fieldnotes.* Chicago: University of Chicago Press.

Escobar, A. (1997). The making and unmaking of the Third World through development. In M. Rahnema & V. Bawtree (Eds.), *The post-development reader* (pp. 85–93). Halifax: Fernwood.

Fiske, J. (1993). Child of the state, mother of the nation: Aboriginal women and the ideology of motherhood. *Culture, 13,* 17–35.

Frankenberg, R. (1993). *White women, race matters: The social construction of whiteness.* Minneapolis: University of Minnesota Press.

Furniss, E. (1997/98). Pioneers, progress, and the myth of the frontier: The landscape of public history in rural British Columbia. *BC Studies, 115/116,* 7–41.

Furniss, E. (1999). *The burden of history: Colonialism and the frontier myth in a rural Canadian community.* Vancouver: University of British Columbia Press.

Germov, J. (1998). *Second opinion: An introduction to health sociology.* New York: Oxford University Press.

Green, R. (1995). Culture and gender in Indian America. In M. Andersen & P. H. Collins (Eds.), *Race, class, and gender: An anthology,* 2nd ed. (pp. 547–555). New York: Wadsworth.

Gunn Allen, P. (1995). Angry women are building: Issues and struggles facing American Indian women today. In M. Andersen & P. H. Collins (Eds.), *Race, class, and gender: An anthology,* 2nd ed. (pp. 32–36). New York: Wadsworth.

Harding, S. (Ed.). (1987). *Feminism and methodology: Social science issues.* Bloomington: Indiana University Press.

Health Canada. (2002). *HIV/AIDS Epi Update.* Centre of Infectious Disease Prevention and Control. Retrieved October 25, 2002, from http://www.hc-sc.gc.ca/pphbdgspsp/publicat/epiu-aepi/hiv-vih/aborig-e.html

Henry, F., Tator, C., Mattis, W., & Rees, R. (2000). *The colour of democracy: Racism in Canadian society,* 2nd ed. Toronto: Harcourt Brace.

Johnson, J. L., Bottorff, J. L., Browne, A. J., Grewal, S., Hilton, A., & Clarke, H. (2004). Othering experiences in health care. *Health Communication, 16,* 253–271.

Kelm, M. (1998). *Colonizing bodies: Aboriginal health and healing in British Columbia 1900–50.* Vancouver: University of British Columbia Press.

LaRocque, E. D. (1993). Violence in Aboriginal communities. In *The path to healing: Royal Commission on Aboriginal peoples* (pp. 72–89). Ottawa: Canada Communications Group.

LaRocque, E. D. (1996). The colonization of a Native woman scholar. In C. Miller & P. Chuchryk (Eds.), *Women of the First Nations: Power, wisdom, and strength* (pp. 11–17). Winnipeg: University of Manitoba Press.

Lather, P. (1991). *Getting smart: Feminist research and pedagogy within the postmodern.* New York: Routledge.

Lock, M. (1993). Education and self-reflection: Teaching about culture, health and illness. In R. Masi, L. Mensah, & K. McLeod (Eds.), *Health and cultures* (pp. 139–158). Oakville, ON: Mosaic.

Lupton, D. (1994). *Medicine as culture: Illness, disease and the body in Western societies.* London: Sage.

McConaghy, C. (2000). *Rethinking indigenous education: Culturalism, colonialism and the politics of knowing.* Brisbane: Post Pressed.

Meleis, A. I., & Im, E. (1999). Transcending marginalization in knowledge development. *Nursing Inquiry, 6,* 94–102.

Native Women's Association of Canada. (2002, May). *Aboriginal women and health care in Canada.* Retrieved February 15, 2005, from http://www.nwac-hq.org/reports.htm

Newhouse, D. (2004, June). All singing, all dancing, 24/7. In Centre for Research and Information on Canada, *Facing the future: Relations between Aboriginal and non-Aboriginal Canadians* (pp. 11–13). Retrieved February 15, 2005, from http://www.cric.ca/en_re/cahiers/

O'Neil, J. D. (1989). The cultural and political context of patient dissatisfaction in cross-cultural clinical encounters: A Canadian Inuit study. *Medical Anthropology Quarterly, 3,* 325–344.

Papps, E., & Ramsden, I. (1996). Cultural safety in nursing: The New Zealand experience. *International Journal for Quality in Health Care, 8,* 491–497.

Ponting, J. R. (1997). *First Nations in Canada: Perspectives on opportunity, empowerment, and self-determination.* Toronto: McGraw-Hill Ryerson.

Ponting, J. R. (2001). Racism and resistance. In D. Glenday & A. Duffy (Eds.), *Canadian society: Meeting the challenges of the twenty-first century* (pp. 39–69). Don Mills, ON: Oxford University Press.

Ramsden, I. (1993). Kawa Whakaruruhau: Cultural safety in nursing education in Aotearoa, New Zealand. *Nursing Praxis in New Zealand, 8,* 4–10.

Ramsden, I. (2000). Cultural safety/Kawa whakaruruhau ten years on: A personal overview. *Nursing Praxis in New Zealand, 15*(1), 4–12.

Ramsden, I. (2002). *Cultural safety and nursing education in Aotearoa and Te Waipounamu.* Unpublished doctoral dissertation, University of Wellington, New Zealand.

Reimer Kirkham, S. (2003). The politics of belonging and intercultural health care. *Western Journal of Nursing Research, 25,* 762–780.

Reimer Kirkham, S., & Anderson, J. (2002). Postcolonial nursing scholarship: From epistemology to method. *Advances in Nursing Science, 25,* 1–17.

Reimer Kirkham, S., Smye, V., Tang, S., Anderson, J., Browne, A., Coles, R., et al. (2002). Rethinking cultural safety while waiting to do fieldwork:

Methodological implications for nursing research. *Research in Nursing and Health, 25,* 222–232.

Royal Commission on Aboriginal Peoples. (1996). *Report of the Royal Commission on Aboriginal Peoples.* Ottawa: Author.

Sandelowski, M. (1995). Qualitative analysis: What it is and how to begin. *Research in Nursing and Health, 18,* 371–375.

Sandelowski, M., & Barroso, J. (2003). Classifying the findings in qualitative studies. *Qualitative Health Research, 13,* 905–923.

Sherley-Spiers, S. K. (1989). Dakota perceptions of clinical encounters with Western health-care providers. *Native Studies Review, 5,* 41–51.

Silverman, D. (1998). The quality of qualitative health research: The open-ended interview and its alternatives. *Social Sciences in Health: International Journal of Research and Practice, 4,* 104–118.

Smedley, B. D., Stith, A. Y., & Nelson, A. R. (Eds.). (2002). *Unequal treatment: Confronting racial and ethnic disparities in health care.* Washington: Institute of Medicine, National Academies Press.

Smye, V., & Browne, A. J. (2002). "Cultural safety" and the analysis of health policy affecting Aboriginal people. *Nurse Researcher: International Journal of Research Methodology in Nursing and Health Care, 9*(3), 42–56.

Sohler, N., Walmsley, J., Lubetkin, E., & Geiger, H. J. (2003). *The right to equal treatment: An annotated bibliography of studies on racial and ethnic disparities in healthcare, their causes, and related issues.* Boston: Physicians for Human Rights.

Spittal, P. M., & Schecter, M. T. (2001). Injection drug use and despair through the lens of gender. *Canadian Medical Association Journal, 164,* 802–803.

Spradley, J. P. (1979). *The ethnographic interview.* New York: Holt, Rinehart & Winston.

Statistics Canada. (2003). *Aboriginal peoples of Canada: A demographic profile, 2001 census.* Catalogue #96F0030XIE2001007. Ottawa: Author.

Stephenson, P. (1999). Expanding notions of culture for cross-cultural ethics in health and medicine. In H. Coward & P. Ratanakul (Eds.), *A cross-cultural dialogue on health care ethics* (pp. 68–91). Waterloo, ON: Wilfrid Laurier University Press.

Stevenson, W. (1999). Colonialism and First Nations women in Canada. In E. Dua & A. Robertson (Eds.), *Scratching the surface: Canadian anti-racist feminist thought* (pp. 49–82). Toronto: Women's Press.

Tait, C. (2000a). *A study of the service needs of pregnant addicted women in Manitoba.* Winnipeg: Manitoba Health.

Tait, C. (2000b). Aboriginal identity and the construction of fetal alcohol syndrome. In L. J. Kirmayer, M. E. Macdonald, & G. M. Brass (Eds.), *Culture and Mental Health Research Unit report no. 10: The mental health of indigenous peoples* (pp. 95–111). Montreal: McGill University.

Thorne, S., Reimer Kirkham, S., & O'Flynn-Magee, K. (2004). The analytic challenge to interpretive description. *International Journal of Qualitative Methods, 3*(1). Retrieved September 1, 2004, from http://www.ualberta.ca/~iiqm/backissues/3_1/ html/thorneetal.html

Varcoe, C., & McCormick, J. (2007). Racing around the classroom margins: Race, racism and teaching nursing. In L. E. Young & B. L. Paterson (Eds.), *Teaching nursing: Developing a student-centered learning environment* (pp. 437–466). Philadelphia: Lippincott Williams & Wilkins.

Waldram, J. B., Herring A., & Young T. K. (1995). *Aboriginal health in Canada: Historical, cultural, and epidemiological perspectives.* Toronto: University of Toronto Press.

Yaffe, B. (2002, July 23). Attitude ensures Natives remain an underclass. *Vancouver Sun,* p. A14.

Young, R. J. C. (2001). *Postcolonialism: An historical introduction.* Oxford: Blackwell.

Acknowledgements

Funding for this study was provided by the Canadian Institutes of Health Research.

I would like to thank Joan Anderson, Madeleine Dion Stout, John O'Neil, and Sally Thorne for sharing their expertise. Discussions with Colleen Varcoe about issues raised in this paper were instrumental in strengthening the arguments. Many thanks to Vicki Smye, who helped me refine the final version. Thanks also to Judy Lynam, Sheryl Reimer Kirkham, and the anonymous reviewers for their valuable feedback on earlier drafts.

Annette J. Browne, PhD, RN, is Associate Professor, New Investigator, Canadian Institutes of Health Research, and Scholar, Michael Smith Foundation for Health Research, School of Nursing, University of British Columbia, Vancouver, Canada.

2009 update: *Annette J. Browne's positions/affiliations are unchanged. Her research remains focused on addressing issues of equity and social justice in nursing practice and health services research.*

CJNR 2009, Vol. 41 N° 1, 193–203

The Costs and Effects of Addressing the Needs of Vulnerable Populations: Results of 10 Years of Research

Gina Browne, Jacqueline Roberts,
Carolyn Byrne, Amiram Gafni, Robin Weir,
and Basanti Majumdar

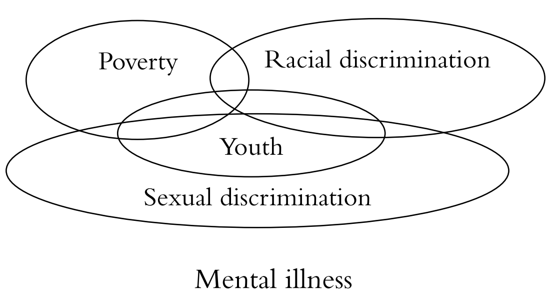
Concepts of Vulnerability

Vulnerability in an individual implies "inequality" in the person's biological characteristics (age, gender, genetic endowment), personal resources (cognitive, emotional, intellectual), and/or environmental supports (social, material, cultural). While biological characteristics cannot be modified, personal resources and environmental supports can, and to considerable economic effect (Browne, Roberts, et al., 1999).

Within an individual, aspects of vulnerability intersect, as shown in Figure 1, and can be synergistic and cumulative, such as "young gay Asian man with HIV/AIDS who is on social assistance."

In a vulnerability index (Rogers, 1997), vulnerability is the net result of an interaction between personal resources and environmental supports, both of which, along with genetic endowment, are determinants of health and therefore of expenditures on health services. Figures 2 and 3

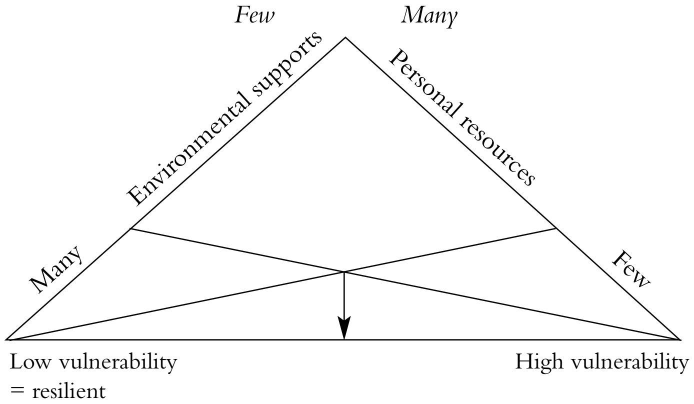
Figure 1 *Intersection of Spaces of Vulnerability*



Source: Delore & Hubert, 2000.

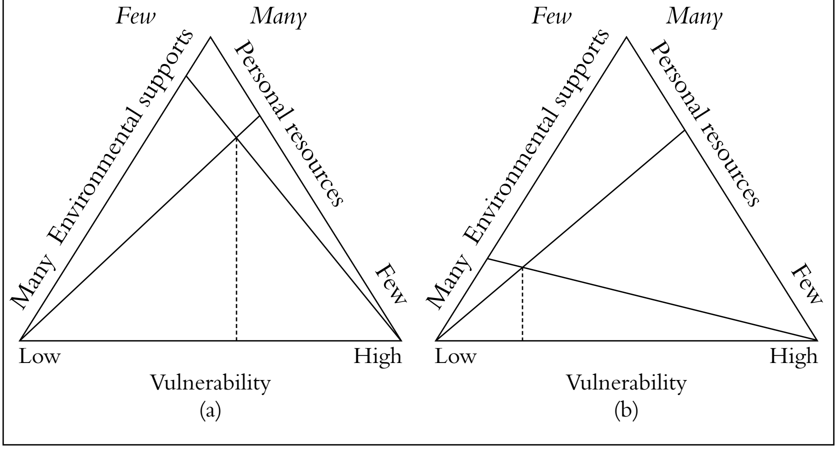
Originally published as a Translating Research feature in CJNR 2001, Vol. 33 N° 1, 65–76

Figure 2 ***Concept of Vulnerability***



Source: Rogers, 1997.

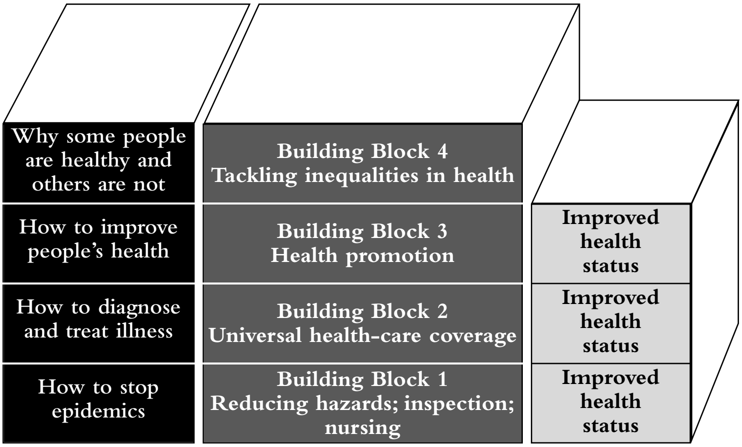
Figure 3 ***Degrees of Vulnerability***



show that even if personal resources hold constant, variations in the individual's environmental supports can greatly alter their degree of vulnerability, and thus also their use of services. Furthermore, insured medical services may not meet all of the sources of vulnerability.

The work of the System-Linked Research Unit on Health and Social Service Utilization at McMaster University in Hamilton, Ontario,

Figure 4 ***Building Blocks of Health Policy***



Source: Glouberman, 2001.

Canada, addresses such health inequalities and documents the reasons why some people with a particular disease or condition are healthier and less costly to the system than others (see Glouberman's [2001] fourth building block of health policy in Figure 4).

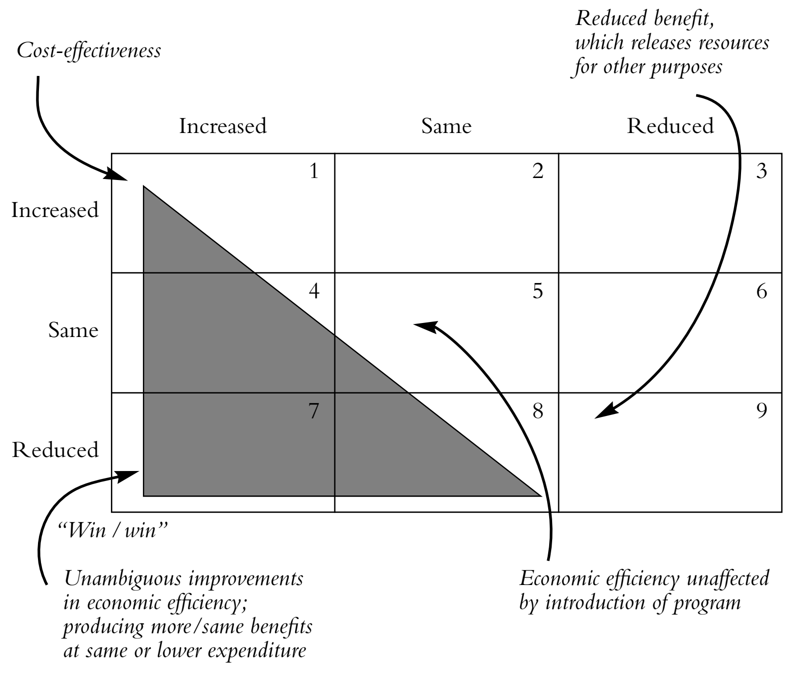
We will attempt in this article to briefly summarize 10 years of research on the results and costs of efforts to reduce inequalities in a variety of vulnerable populations. We argue that, in a system of national health insurance, measures to reduce inequalities will pay for themselves within a year, and that health-care costs can be reduced by simply helping people to get the services they require. The most expensive services we now provide are those that are *not* tailored to people's needs (vulnerabilities).

Evaluation of Costs and Effects

Although the literature contains many evaluations of programs seeking to achieve improved outcomes for vulnerable populations, few of these outcomes studies include measures of costs. The work of the System-Linked Research Unit and its community partners — service providers for the regions of Halton and Hamilton-Wentworth — can make a significant contribution to our understanding of this issue.

As depicted in Figure 5, the economic evaluation of health-care programs yields nine possible outcomes (the more favourable ones are high-

Figure 5 ***Economic Evaluation of Health-Care Programs***



lighted by shading) (Birch & Gafni, 1996). In outcome 1, increased health benefits are achieved through increased expenditures on resources. Cost-effectiveness results when increased benefits are achieved through increased expenditures, typically among marginalized populations with low access to services. The outcome is also favourable when increased benefits are achieved through the use of one approach over another at equivalent cost. Outcome 7 represents a "win/win" situation, or unambiguous improvements in economic efficiency, when more benefits are achieved at lower cost, especially in populations who consume many uncoordinated services. Outcome 8 represents a situation of alternative health programs achieving the same effect. However, some approaches are associated with lower expenditures from a societal perspective. Often, studies that find no difference in the effects of two approaches miss the real effect: reduced use of services with one of the approaches. Outcomes 7 and 8 are superior to the more frequently encountered outcome 9, where funding cuts are accompanied by a potential reduction in benefits. In these two outcomes, resources are released for use in other areas (Birch & Gafni, 1996).

This approach can be used to classify the main effects and costs of comparable community health interventions. It can also be used to classify the recipients of various health interventions according to degree of beneficial results, as well as the expenditures necessary to achieve these results. Within national health insurance systems, people tend to use whatever services are available, even if they are not necessarily appropriate (Browne et al., 1995).

Finally, it has been found that investments in one sector can achieve savings in another — such as recreation provided by the voluntary sector resulting in savings to the publicly funded health, social, and corrections systems (Browne et al., 2000; Browne, Byrne, et al., 1999; Browne, Bryne, Roberts, Gafni, & Whittaker, 2001; Browne, Roberts, et al., 1999). (Nonetheless, agencies should be compensated for savings they generate elsewhere [Browne et al., 1995]).

Research Production and Utilization

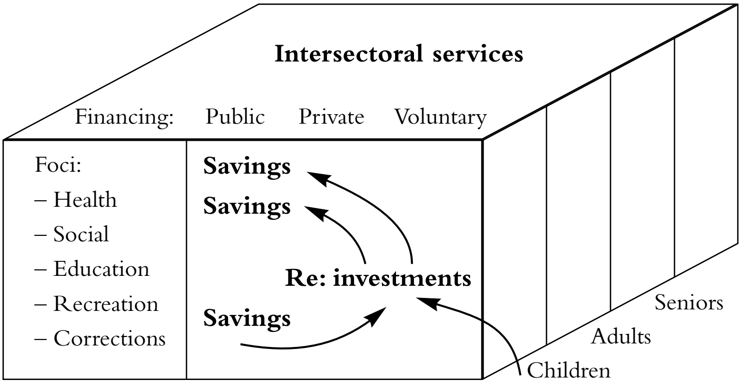
Over the past 10 years, the System-Linked Research Unit has been studying how improved health and cost containment might be achieved by providing community-based services to people with some health problems and exhibiting many signs of vulnerability (Browne, Roberts, et al., 1999). With the active participation of our community partners, the Unit's investigators have conducted studies on a variety of samples, settings, sectors, and services in an effort to reduce inequalities. The findings are relevant for the participating agencies and, since they have been involved, dissemination of the findings is easy. At the same time, agencies are more likely to use their own relevant information once it is made understandable.

What we have found is both simple and profound: that helping people to find the means to feel better and function more effectively costs no more, in a system of national health insurance, than doing nothing.

Why? Because people who are hurting will usually try to find a remedy, yet the services they use are not necessarily the ones that will solve their problem. A piecemeal approach to helping them can be expensive and still fail to identify the cause of the problem (Browne et al., 1994). Even a trained professional will have difficulty sorting out the differences among a person's condition (say, severe diabetes), circumstance (recent job loss), challenges (depression), and context (a child in trouble with the law).

Savings can be achieved not because an effective service is cheap, but because making people healthier and better able to cope with their life circumstances results in savings elsewhere. The greatest cost savings in

Figure 6 ***Societal Savings Resulting from Strategic Investments***



health care tend to accrue among those people who are high users of the health-care system.

What may seem unlikely on the surface — better health outcomes for the same amount of money or less — actually makes perfect sense. Consider someone who has a chronic illness, lives alone, and is having trouble coping. If there is no concerted effort made to help this person with problem-solving and adjustment to his or her particular circumstances, the individual will likely spend a great deal of time seeking assistance from a variety of insured services. We compared two groups of people with chronic illness, poor adjustment, and poor problem-solving ability. One group received counselling and support and the other group were left to their own devices. The group who struggled with poor coping skills on their own were half as well adjusted and cost the health system 10 times as much as the other group ($40,000 vs. $4,000/person per year) (Roberts et al., 1995).

We found similar patterns in other areas. Some studies found improved outcomes for higher expenditures, but these were in areas in which the clients were members of an under-served group such as a minority population (Majumdar, Browne, Roberts, MacLean, & Carpio, 1995), family caregivers of individuals losing their mental capacities to a condition such as Alzheimer disease (Milne, Sacco, Centinski, Browne, & Roberts, 1994), or persons with chronic schizophrenia living in municipal lodges (Byrne et al., 1999).

The System-Linked Research Unit received core funding from the Ontario Ministry of Health and raised funds for specific projects from other sources, including the federal government. We approached the comparative costing of services on a much broader scale than usual. We looked at not just the cost of providing the service to achieve a certain outcome, but also the other services the person accessed in trying to cope with their particular condition or problem. We used an inventory to track direct and indirect costs, including the frequency of their visits to the doctor or hospital, the medications they used, and whether they were on social assistance (Browne, Arpin, Corey, Fitch, & Gafni, 1990).

One study looked at a program for screening seniors over 75 years of age and living alone and then treating those who were suffering from loneliness and isolation. The study found that those who received support showed some social/emotional improvement and consumed less than one third the health-care resources of the untreated group (Hay et al., 1998).

Another study found that people who attended a clinic for chronic pain increased their ability to live with their pain and, when compared to an equivalent group who did not attend a pain clinic, generated a proportionate decrease in costs associated with use of other health services (Weir, Browne, Tunks, Gafni, & Roberts, 1992).

In yet another study, clients treated at a mental health clinic were found to have similar states of mental health as clients who were referred to the clinic but did not use the service, yet clinic users consumed fewer other health-care services by far (Emond & Browne, 1992).

The research also taught us a great deal about the kinds of services that produce improved health at the same or lower cost. Our current health-care system is geared to offering services one provider at a time, one problem at a time, and on demand. The System-Linked Research Unit has found the most successful strategies to be those that are:

- cooperative and cross-sectoral, linking physical health care to social services, mental health services, and other services
- comprehensive and holistic (rather than disease-by-disease), treating the whole person or the whole family in context
- proactive, reaching out to those who are unlikely to find the help they need on their own.

The services that produced improved health outcomes were not necessarily medical services (Browne et al., 1995). Some were delivered in a doctor's office, but others were provided by a nurse in the person's home (Roberts et al., 1999), or by a volunteer at a seniors' centre, or by a therapist at a mental health clinic, or by a children's recreation coach at a neighbourhood park (Browne, Byrne, et al., 1999), or by a psychologist in a school.

Canadians are proud and protective of their health-care system, and so they should be. We would argue, however, that investments in non-medical services that support health and well-being would take pressure off the health-care system and help the medical community do what it does best.

One suggestion would be to invest in more social workers for hospital emergency rooms. Emergency doctors do not have the time to determine what is troubling people who arrive in the middle of the night; their job is to deal with medical crises. Yet someone who is battling cancer may go to the emergency room mainly because they are frightened and alone. A home assessment, arranged by a social worker, for community counselling and support services could make a major difference to that person's recovery. Based on our research, a community service such as this would pay for itself through cost savings elsewhere in the system. However, we have to give the hospitals and community agencies the funding they need to provide the services that will save money for the system as a whole (Browne et al., 1994).

The cost savings we found were not always in the health-care budget, but they often were. People who had been relying heavily on health services used fewer of them, or fewer expensive ones, when their needs were not met appropriately. Sometimes, the savings were in social services, or in the tax system when people became well enough to return to work (Browne et al., 2000).

Another of our studies looked at a program for very troubled adolescents provided by an alliance of health, social, and educational service providers in a school setting. It compared the cost of the program to the cost of hospital and specialist care for teens who were waiting for admission to the program. Over the same period, the latter group had poorer emotional health and twice the cost ($10,000/person per year) of the students enrolled in the program (Pallister, Browne, Roberts, Byrne, & Gafni, 1995).

A study of single parents on social assistance found that those who were offered a coordinated package of services — child care and recreation for their children, job training, and visits by a public health nurse — were more likely to leave welfare for work than those offered one piece of the package or those left to fend for themselves (Browne et al., in press). The package cost no more than the piecemeal services consumed by those left to fend for themselves and was associated with a $300,000 savings in social assistance payments within 1 year for every 100 mothers served. Recreation for the children paid for itself in reduced use of professional and probationary services as well as resulting in mental health benefits for their mothers (Browne et al., 2000). A number of municipalities in the province of Ontario are improving their services to families on social assistance, based on these findings.

The most serious barrier to the delivery of cooperative, holistic, proactive community-based services is separate funding of the various sectors.

Ways must be found to reward alliances among the health, social, education, recreation, and corrections sectors.

We are not saying that developing these strategies and alliances will be easy. We are saying that innovative, intersectoral approaches have the potential to save precious public resources, not only in health care but across publicly funded systems, and at the same time to improve the quality of people's lives.

In summary, our work demonstrates that community-based services are more effective and less expensive when they are proactive, comprehensive, and aimed at reducing the inequalities in coping capacity and social resources that result in ill health.

The System-Linked Research Unit is currently testing, via randomized trials, the value of augmenting homemaking services with a nurse assessment. It is hypothesized that clients who receive the assessment will show less deterioration and use of services (Markle-Reid et al., 2000; Weir et al., 1998). The added cost would be made up by decreased use of other services.

Another trial is underway to test the value of home care versus use of nurse clinicians in a shopping mall. It is hypothesized that clients who attend the mall clinics will demonstrate improved health status and that the cost of this approach will be one quarter that of home care (Van DeVelde-Coke, McGlashan, Browne, Gafni, & Roberts, 2000).

Both of the hypotheses in ongoing studies would be examples of a "win/win" outcome from an economic perspective.

References

Birch, S., & Gafni, A. (1996). Prevalence and correlates of family dysfunction and poor adjustment to chronic illness in specialty clinics. *Journal of Clinical Epidemiology, 43*(4), 373–383.

Browne, G., Arpin, K., Corey, P., Fitch, M., & Gafni, A. (1990). Individual correlates of health dervice utilization and the cost of poor adjustment to chronic illness. *Medical Care, 28*(1), 43–58.

Browne, G., Byrne, C., Roberts, J., Gafni, A., Watt, S., Haldane, S., et al. (1999). Benefiting all the beneficiaries of social assistance: The 2-year effects and expense of subsidized versus non-subsidized quality child care and recreation. *National Academies of Practice Forum: Issues in Interdisciplinary Care, 1*(2), 131–141.

Browne, G., Byrne, C., Roberts, J., Gafni, A., & Whittaker, S. (2001). When the bough breaks: Provider-initiated comprehensive care is more effective and less expensive for sole-support parents on social assistance. *Social Science and Medicine. 53*(12), 1697–1710.

Browne, G., Roberts, J., Gafni, A., Byrne, C., Weir, R., Majumdar, B., et al. (1999). Economic evaluations of community-based care: Lessons from twelve studies in Ontario. *Journal of Evaluation and Clinical Practice, 5*(4), 387–385.

Browne, G., Roberts, J., Gafni, A., Weir, R., Watt, S., & Byrne, C. (1995). More effective and less expensive. Part I: Lessons from 5 studies examining community approaches to care. *Health Policy, 34*(2), 95–112.

Browne, G., Roberts, J., Watt, S., Gafni, A., Stockwell, M., & Alcock, S. (1994). Community rehabilitation: Strategies outcomes expenditures. *Canadian Journal of Rehabilitation, 8*(1), 9–22.

Browne, G., Roulston, J., Ewart, B., Schuster, M., Edward, J., & Boily, L. (2000). Investments in comprehensive programming: Services for children and single-parent mothers on welfare pay for themselves within one year. In *Our children's future: Child care policy in Canada* (pp. 334–346). Toronto: University of Toronto Press.

Byrne, C., Brown, B., Voorberg, N., Schofield, R., Browne, G., Gafni, A., et al. (1999). Health education or empowerment education with individuals with a serious persistent psychiatric disability. *Psychiatric Rehabilitation Journal, 22*(4), 368–380.

Delore, F., & Hubert, M. (2000). Revisiting the concept of "vulnerability." *Social Science and Medicine, 50*(11), 1557–1570.

Emond, A., & Browne, G. (1992). *Prognosis and cases of clients referred to a community mental health clinic.* Working Paper 91-11. Hamilton, ON: System-Linked Research Unit on Health and Social Service Utilization, McMaster University.

Glouberman, S. (2001, January 22). *The four building blocks of the health policy edifice.* Presentation by Sholom Glouberman, Kunin-Lunenfeld Applied Research Unit. (ICES Presentation, Sheraton Hotel.)

Hay, W.I., Van Ineveld, C., Browne, G.B., Roberts, J., Bell, B., Mills, M.J., et al. (1998). Prospective care of elderly patients in family practice: Is screening effective? *Canadian Family Physician, 44,* 2677–2687.

Majumdar, B., Browne, G., Roberts, J., MacLean, M., & Carpio, B. (1995). *The effectiveness and efficiency of cultural sensitivity training for providers of health care services on provider attitudes: Client access to health care services and health outcomes. Final report.* Hamilton, ON: McMaster University.

Markle-Reid, M., Weir, R., Browne, G., Shadwick, S., Roberts, J., & Gafni, A. (2000). *The effects and expense of augmenting homemaking services with nursing services for the frail elderly home-care population* (funded by Canadian Health Services Research Foundation, 2000–2002).

Milne, C., Sacco, C., Centinski, G., Browne, G., & Roberts, J. (1994). Correlates of well-being among caregivers of cognitively impaired relatives. *Canadian Journal of Nursing Research, 26*(1), 27–39.

Pallister, R., Browne, G., Roberts, J., Byrne, C., & Gafni, A. (in collaboration with Dalton, D., McDonald, R., Filice, U., Bradley, C., & Lyons, L.). (1995). *The potential for more effective, less expensive approaches to adolescent mental health: A description of Halton Cooperative Mental Health Program Strategies with "usual" care.* Working Paper 95-1. Hamilton, ON: System-Linked Research Unit on Health and Social Service Utilization, McMaster University.

Roberts, J.G., Browne, G., Milne, C., Spooner, L., Gafni, A., Drummond-Young, M., et al. (1999). Problem solving counselling for caregivers of cognitively impaired: Effective for whom? *Nursing Research, 48*(3), 162–172.

Roberts, J., Browne, G., Streiner, D., Gafni, A., Pallister, R., & Hoxby, H. (1995). The effectiveness and efficiency of health care promotion in specialty clinic care. *Medical Care, 33*(9), 892–905.

Rogers, A.C. (1997). Vulnerability, health and health care. *Journal of Advanced Nursing, 26*(1), 65–72.

Van DeVelde-Coke, S., McGlashan, S., Browne, G., Gafni, A., & Roberts, J. (2000). *The effectiveness and efficiency of providing home care visits in nursing clinics vs. the traditional home setting* (funded by Canadian Health Services Research Foundation, 2000–2001).

Weir, R., Browne, G., Byrne, C., Roberts, J., Gafni, A., Thompson, A., et al. (1998). The efficacy and efficiency of the Quick Response Program: A randomized controlled trial. *Canadian Journal on Aging, 17*(3), 272–295.

Gina Browne, PhD, RN, is Founder and Director, System-Linked Research Unit on Health and Social Service Utilization, McMaster University, Hamilton, Ontario, Canada. Jacqueline Roberts, BScN, MSc, is with the School of Nursing, the Department of Clinical Epidemiology and Biostatistics, and the System-Linked Research Unit on Health and Social Service Utilization, McMaster University. Carolyn Byrne, PhD, RN, is Associate Professor and Past Chair, BScN Program, School of Nursing, McMaster University, and Associate Member, Hamilton-Wentworth Teaching Health Unit. Amiram Gafni, PhD, is with the Department of Clinical Epidemiology and Biostatistics, the System-Linked Research Unit on Health and Social Service Utilization, and the Centre for Health Economics and Policy Analysis, McMaster University. Robin Weir, PhD, RN, is Professor, School of Nursing, McMaster University, and Clinical Associate, Chedoke-McMaster Hospitals Pain Clinic. Basanti Majumdar, PhD, RN, is Associate Professor, School of Nursing and Centre for International Health, McMaster University.

2009 update: *Gina Browne is Professor, School of Nursing and Department of Clinical Epidemiology and Biostatistics, and Member, Ontario Training Centre in Health Services and Policy Research, McMaster University; her other positions/affiliations are unchanged. Jacqueline Roberts is Professor Emeritus, School of Nursing, Department of Clinical Epidemiology and Biostatistics, and System-Linked Research Unit on Health and Social Service Utilization, McMaster University. Carolyn Byrne is Professor and Founding Dean of Health Sciences, University of Ontario Institute of Technology, Oshawa. Amiram Gafni is Professor, Centre for Health Economics and Policy Analysis, Department of Clinical Epidemiology and Biostatistics, McMaster University. Robin Weir is Professor Emeritus, School of Nursing, McMaster University. Basanti Majumdar is Professor, School of Nursing and Department of Family Medicine, Member, Centre for International Health, and Associate Member, Institute of Globalization, McMaster University.*

CJNR 2009, Vol. 41 N° 1, 204–217

Résumé

Transformer l'espoir : L'espoir chez les personnes âgées en soins palliatifs

Wendy Duggleby et Karen Wright

L'espoir est important pour les patients en soins palliatifs; toutefois, le processus qui permet à ces patients de continuer à vivre et à espérer est inconnu. Cette étude théorique à base empirique décrit les processus qui permettent aux patients en soins palliatifs de continuer à espérer. Seize entrevues ont été menées auprès de 10 patients recevant des soins palliatifs à domicile (moyenne d'âge 75 ans) auxquels on a posé des questions ouvertes. Les participants définissent l'espoir comme les attentes qu'ils ont, par exemple, de ne pas souffrir d'avantage et de mourir paisiblement. Ils décrivent leur principale préoccupation comme étant de vouloir « vivre et continuer à espérer » et ils y arrivent grâce au processus social fondamental de la transformation de l'espoir, ce qui implique d'accepter la « vie comme elle est », chercher du sens et procéder à une réévaluation positive. Les résultats de cette étude serviront de fondement à des recherches futures et à l'élaboration d'interventions visant à susciter l'espoir chez les patients âgés en soins palliatifs.

Mots clés: soins palliatifs, personnes âgées, espoir

CJNR 2009, Vol. 41 Nº 1, 204–217

Transforming Hope: How Elderly Palliative Patients Live With Hope

Wendy Duggleby and Karen Wright

Hope is important to palliative patients; however, the process by which these patients live with hope is unknown. The purpose of this study was to describe, using a grounded theory approach, the processes by which palliative patients live with hope. Sixteen interviews were conducted with 10 home-care palliative patients (mean age 75 years) in their homes using open-ended questions. The participants defined their hope as expectations such as not suffering more and having a peaceful death. They described their main concern as wanting to "live with hope" and they achieved this through the basic social process of transforming hope. Transforming hope involved acknowledging "life the way it is," searching for meaning, and positive reappraisal. The results of this study provide a foundation for future research and the development of interventions to engender hope in older palliative patients.

Keywords: palliative, elderly, hope, qualitative research

Introduction

The alleviation of suffering at the end of life is considered a realistic goal for all health-care professionals (Lindholm & Erickson, 1993). Palliative patients describe their suffering in terms of multiple physical, psychological, and social losses (Daneault et al., 2004). They describe hope as the ability to endure and cope with their suffering (Duggleby, 2000). For patients with incurable cancer, hope is important for a meaningful life and a peaceful death (Benzein, Norberg, & Saveman, 2001).

Several studies of hope in palliative care patients have found that it is very important to these individuals (Benzein et al., 2001; Buckley & Herth, 2004; Duggleby, 2000; Duggleby & Wright, 2004; Hall, 1990; Herth, 1990). However, we do not know how palliative patients maintain their hope in the context of multiple losses. A grounded theory qualitative approach to uncovering the processes by which older palliative care patients maintain their hope may lead to the development of strategies for fostering hope in this population. By increasing hope we may be able to contribute to patients' quality of life (Herth, 2000), which is a goal of end-of-life care (Carstairs & Beaudoin, 2002).

Originally published in CJNR 2005, Vol. 37 Nº 2, 70–84

The purpose of this study was to describe the processes by which older palliative home-care patients with advanced cancer live with hope. Specific strategies used by the participants to foster the hope identified in this study are described elsewhere (Duggleby & Wright, 2004).

Background

Although several studies have been conducted on hope in patients with cancer and chronic diseases, very few have focused on the hope experience of terminally ill patients (Duggleby, 2001). Two studies examined nurses' perceptions of how they fostered hope in palliative patients (Cutcliffe, 1995; Herth, 1995), though it is unknown whether their perceived means of fostering hope were actually effective. Another study examined nurses' perceptions of the hope experience of palliative cancer patients (Benzein et al., 2001; Benzein & Saveman, 1998). Nurses' views of the patients' hope experience may not be accurate, however, as health-care professionals often view the hope of terminally ill patients as a form of denial or false reality (Perakyla, 1991).

Interviews conducted with palliative patients suggest that they define hope as an inner resource and as a coping mechanism essential for their quality of life (Benzein et al., 2001; Buckley & Herth, 2004; Flemming, 1997; Hall, 1990; Herth, 1990). The patients hoped for the avoidance of suffering, a peaceful death, and life after death. Some patients also hoped for a better life for their families. The focus of hope in palliative patients is different from that in other patient populations. Medical/surgical patients (Cameron, 1993; Perakyla, 1991), stroke patients (Bays, 2001), and patients with chronic pain (Howell, 1994) focus their hope on getting better and living longer. The fact that palliative patients define hope differently suggests that their processes of hope may also differ from those of other patient populations.

Research examining the focus of hope for palliative patients has identified strategies that foster hope for these individuals. Such strategies include good symptom control, the setting of short-term goals, faith/spirituality, positive outlook, and connectedness. However, it is not known when and how patients use these strategies. Moreover, the methodological approaches used to examine hope in the studies conducted so far have not allowed for the description of the processes associated with hope. These limitations suggest the need for exploratory research into the processes of hope in the palliative population, in order to facilitate the development of theoretically based frameworks for future hope interventions.

Methods

A qualitative, grounded theory approach (Glaser, 1992, 2001) was used to identify the processes of the hope experience for older palliative home-care patients with advanced cancer. The greatest contribution of grounded theory is in areas in which little research has been done and few adequate theories exist to explain or predict a group's behaviour (Chenitz & Swanson, 1986). It is "a very useful method to understand what is going on in a substantive area and how to explain and interpret it" (Glaser, 1978, p. 3). Specific interventions are more likely to emerge from the data when grounded theory is used as a methodological approach to studying hope (Cutcliffe & Grant, 2001).

Procedure

The study was approved by an Institutional Ethical Review Board. The palliative care coordinator in the health region identified potential participants based on the following criteria: male or female over the age of 65; diagnosed with cancer; receiving palliative home-care services from a rural Canadian health region; English-speaking; Palliative Performance Scale score of at least 30% overall; PPS score of at least 60% for consciousness level; and consent to participate. The PPS was used as a screening tool in order to exclude those who were unable to physically or cognitively participate. It is a reliable and valid measure of functional performance, progressive decline, and confusion in palliative patients (Virik & Glare, 2002).

When potential participants agreed to take part in the study, the research assistant contacted them to describe the study and arrange to meet them in their homes at their convenience. The research assistant (RN-RA) was an experienced palliative home-care nurse trained in obtaining consent and in data collection. At the first visit before data collection, the RN-RA obtained written informed consent.

Data collection entailed a demographic form, face-to-face individual interviews, and information from the patient's chart. The participants also completed the Herth Hope Index (HHI) and the Edmonton Symptom Assessment Scale (ESAS) to describe levels of hope and symptom intensity, respectively. The HHI has been found to be a reliable measure of hope in terminally ill patients (Herth, 1992). It consists of a 12-item, four-point Likert scale with a summative score; higher summative scores denote greater hope. The ESAS consists of nine reliable and valid numerical rating scales of symptom intensity (Chang, Hwang, & Feureman, 2000); higher scores denote greater intensity.

Open-ended audiotaped interviews ranging from 15 to 60 minutes in duration were conducted in the homes of the participants. Questions were asked that invited participants to: describe hope, identify the things that gave them hope, specify the things that increased or decreased hope, and describe what others could do to foster hope.

In addition, field notes were taken on the setting, the non-verbal behaviours of participants, and the interactions of participants with others such as family members and with the environment.

Data Analysis

Each interview was transcribed verbatim. The transcription was then checked for accuracy by the RN-RA who had conducted the interview. Consistent with grounded theory methods, data analysis was carried out concurrently with data collection. Interview data were examined line by line using the constant comparative approach of grounded theory. From the transcripts, codes were identified using the participant's language as much as possible. Then the codes were grouped together to identify processes and underlying patterns. Coding occurred at three levels using Glaser's (2001) approach: open, selective, and theoretical. Open coding was completed when the main concern and basic social process were identified. Selective coding was focused on the basic social process and subprocesses. In theoretical coding, the relationships between substantive codes were conceptualized. The researchers used selective sampling of the literature throughout the analysis to help them fill in the missing pieces in the emerging theory. They used memoing to preserve ideas that came up throughout the data analysis with regard to the emerging theory.

Scientific rigour in qualitative research is judged on the basis of credibility, auditability, fittingness, and confirmability (Marcus & Liehr, 1998). In this study the audiotapes were transcribed verbatim and the participant's language was used in coding, categorizing, and theory writing to establish credibility. Credibility of the findings was also established by confirming the results with the participants whenever possible. Auditability was achieved by keeping raw data, field notes, and memos, ensuring an audit trail. Fittingness of the data was ensured by grounding theoretical observations in the data, and through cross coding and categorization of data. As well, the principal investigator and the co-investigator independently coded selected transcripts throughout the study and then compared the results.

Results

Sample

Ten participants were interviewed in their homes, located in a rural prairie community in Canada. Purposive sampling was used to select participants of different genders, various ages, and with different types of cancer. Unsuccessful attempts were made to recruit patients who had low hope scores and high symptom scores. Once data analysis revealed the basic social process (BSP) present in the data, theoretical sampling was used to select interviewees who would inform the facets and dimensions of the BSP.

Five (50%) of the participants were female and five (50%) male. The age of the participants ranged from 65 to 85 years with a mean age of 75 years. All participants were Caucasian and had been diagnosed with various types of cancer as well as secondary conditions such as kidney disease, arthritis, or heart conditions. The average number of years of education was 10.70 (range: 8–16 years). The majority of participants were married (70%; 30% widowed) and lived with their spouse (70%; 30% lived alone). All participants identified a religious preference, with 80% being Protestant and 20% Catholic. Mean HHI scores were 42.7/48 (range: 34–48), indicating high levels of hope, and ESAS scores were low (mean: 2.21), indicating minimal levels of symptom intensity.

Whenever possible, participants were interviewed twice, in order to have them review their transcript and to explore the concepts highlighted in the first interview. A total of 16 interviews were completed. Six participants reviewed their transcript. Four could not be re-interviewed because of physical symptoms ($n = 3$) or death ($n = 1$).

Main Concern: Living With Hope

From the analysis of transcribed interview data a main concern and a core category were identified. Glaser (2001) describes the main concern as the main preoccupation of the participants. In the present study, participants described their main concern as wishing to "live with hope" in spite of multiple losses with respect to function, independence, relationships, goals, and a longer life. The participants said it was important for them to "live life," "keep on going," and "live day by day." When asked what happens if one does not have hope, one participant said: "I guess if you don't have any hope, I would say you just slowly wither away. I would almost think, if you don't have any hope, then you have nothing for the future or even for the present." Another said: "You can't live without hope."

Core Category: Transforming Hope

In grounded theory, the main concern is continually resolved through a core category, which "organizes and explains most of the variation in how the main concern is resolved" (Glaser, 2001, p. 199). In order to live with hope, the participants described the basic social process of transforming hope. Hope was dynamic: "Well, it changes, that's for sure." The participants had made a conscious decision to change or transform their hope: "What you can do is you can make it tougher in your mind or you can make it easier in your mind."

Through the process of transforming hope, new patterns of hope emerged. These were apparent in the participants' ways of defining hope as a future expectation — "something you hope will happen." They defined their future in terms of minutes, hours, and days and also in terms of their families. For example, they described their hope in terms of "not suffering more," "living life to the fullest in the little time I have left," a peaceful death, life after death, and "hope for a better life in the future" for their family. This differed from their previous patterns of hope, which for some participants included being cured of cancer, living longer, and achieving long-term goals.

The process of transforming hope was facilitated by controlled symptoms, supportive relationships, and spirituality. For example, the participants said that uncontrolled symptoms made it difficult for them to think about the future: "If you feel really in pain and down in the dumps, it's pretty hard to think about how far you're going to go." Supportive relationships were those in which friends and family members provided comfort and hope: "It's comfort from friends, from relatives, and the hope they are giving me." Spirituality fostered hope by providing a framework for understanding what was happening to them and a source of strength in terms of hope: "I think without God I don't have any hope at all. He certainly does provide a spot, or a garden, for our thoughts."

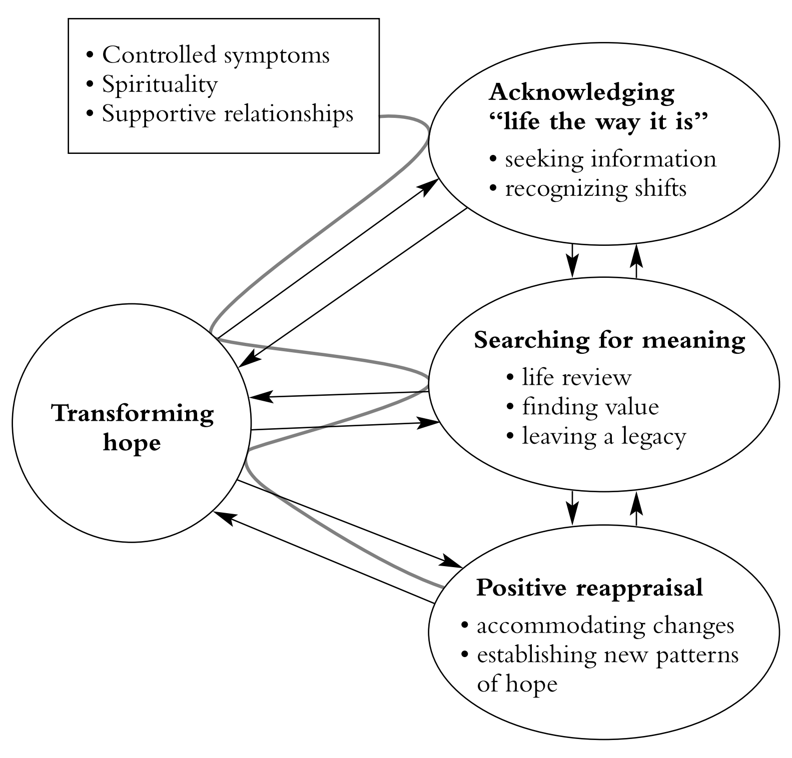
The participants described the sub-processes of transforming hope as acknowledging "life the way it is," searching for meaning, and positive reappraisal. Figure 1 illustrates the basic social process of transforming hope and its sub-processes. Although the figure appears to be linear, the processes are dynamic and interrelated.

Acknowledging "Life the Way It Is"

The participants began the process of transforming hope by acknowledging the changes that had occurred in their lives. Acknowledging "life the way it is" is the recognition that previous expectations and hopes are no longer viable. Two ways of acknowledging "life the way it is" were seeking information and recognizing the shift from what was to what is. One participant expressed the importance of seeking information: "If you don't know the good and the bad, or the pros and the cons, how can you decide on anything?" In this regard, the participants appreciated receiving honest information from nurses and doctors.

In order to accept the change from what was to what is, the participants had to come to terms with their losses, to acknowledge the impracticality of making holiday travel plans, for example, or the fact that they

Figure 1 ***Transforming Hope***



would not be present for the birth of a grandchild. One participant said: "I had things I wanted to do, things that we haven't done yet that I am not going to get around to doing… We had our retirement hopes…it changes, that's for sure." For other participants the process entailed their acknowledging that they had incurable cancer: "You have to accept the fact that you've got it…and if you don't accept that, you're suffering more the way you feel and your own feelings than you are with the disease that's killing you… [You have to] make up your mind that this is the way it is and this is life the way it is."

Searching for Meaning

Participants described searching for meaning as reflecting on and finding value in their lives: "I think you stop then and take a look at yourself…what you have accomplished. I think it all helps us in life, at least to keep hope." Finding meaning and value in their lives was also related to leaving a legacy, something of value. Participants described a legacy as living on even when they were no longer alive: "It contributes to your hope to know that those will live on." This legacy was described as letters, gifts, contributions related to their careers, and, for some, their children and grandchildren. By finding meaning in their lives, the participants were able to view what was happening to them in a positive way.

Positive Reappraisal

By acknowledging their current situation and finding meaning and value in their lives, the participants were able to engage in positive reappraisal, and through reappraisal of their situation, expectations, and goals they were able to change their hope. Positive reappraisal was a process of accommodating life changes and establishing new patterns of hope. One participant said: "I've had to change my outlook on that now. I'll find something else to do, and when that happens I guess that's the way you change your hope and you just have to keep on going."

Discussion

The findings of this study are an emerging theory of hope within the context of the study participants. Glaser (1978, 1992) suggests that an emerging theory can contribute to the development of a formal grounded theory with broader scope and applicability. Elements of "transforming hope" may therefore contribute to the development of a hope theory for older palliative care patients.

The findings of this study are both similar to and different from those of other empirical work. The main concern of the participants, living with hope, was similar to that of the 11 palliative care patients in Benzein et al.'s (2001) study, who described "living in hope." In that study, the concept was described as reconciliation between life and death, whereby the participants were prepared for death in both practical and emotional ways. The dynamic nature of hope and the transformed focus of hope identified in the present study are also consistent with the findings of other studies (Benzein et al., 2001; Flemming, 1997; Hall, 1990; Herth, 1990). However, none of these studies addressed the transformative processes of hope.

Acknowledging "Life the Way It Is"

Acknowledging "life the way it is" was a process of transforming hope. Only one other study of hope reported palliative patients acknowledging or accepting their life situation. Benzein et al. (2001) describe acceptance as an aspect of reconciliation of life and death. However, they do not discuss how this acceptance influenced the hope of the participants.

Acknowledgement of "life the way it is" does not preclude the use of denial as a protective mechanism. Denial as a coping response may act as a self-protection mechanism for palliative care patients, enabling them to defend themselves from threats and therefore enhancing their perception of control and self-efficacy (Russell, 1993). Hope is situational (Rustoen, Wiklund, Hanestad, & Moum, 1998), so denial could be used as a coping mechanism in one aspect of the participants' lives and acknowledging "life the way it is" in other aspects. The two concepts are not mutually exclusive.

The participants described hard facts as having helped them to acknowledge "life the way it is." It is possible that in this sense the participants were playing the role of a monitor who seeks information and wishes to have a larger part in decision-making. Miller's (1995) "blunters," in contrast, coped by not seeking information. Fallowfield, Jenkins, and Beveridge (2002), in a study with 1,046 palliative care patients, also identified the importance of health-care professionals' providing information; the majority of patients wished to receive as much data as possible, whether positive or negative. Benzein et al. (2001) found that lack of information contributed to uncertainty in palliative care patients. More research is needed to determine whether the method of information delivery has an influence on hope and how the concepts of monitors and blunters are related to the process of information delivery.

Searching for Meaning

The participants described searching for meaning as a sub-process of transforming hope, one aspect of which was life review. The concept of searching for meaning has been described in several hope studies with palliative patients (Benzein et al., 2001; Hall, 1990; Herth, 1990). An emergent theme in the Benzein et al. (2001) study was the patients' description of their lived experience of hope as the will to find meaning; for them, life review fostered reconciliation between life and death. Life review has also been found to be a mechanism for fostering hope among elderly residents of long-term-care facilities (Gaskins & Forte, 1995).

The participants also described the importance of leaving a legacy. Life review is focused on the individual, while leaving a legacy is focused on others. This finding is not reported in other studies of hope in palliative care patients. However, in a study of spirituality among palliative patients, the participants over 71 years of age said it was important to them to have accomplished something, whereas those under 71 did not (Thomas & Retsas, 1999). Therefore, leaving a legacy may be an aspect of searching for meaning that is specific to older palliative care patients. More research is needed to determine whether life review and leaving a legacy are linked to finding meaning and hope in other populations.

Positive Reappraisal

The participants' ability to interpret positively the changes in their lives was fostered by finding meaning in their lives. They described a process of reappraising their situation, expectations, and goals, the sub-processes of which were acknowledging "life the way it is" and finding meaning in life.

None of the published studies of hope among palliative patients describes the process of positive reappraisal. Benzein et al. (2001) describe envisioning a better future and Herth (1990) describes a positive outlook. However, these concepts are different from positive reappraisal, which is a cognitive change in perception of situation, expectations, and goals.

In a study with non-palliative, non-elderly breast cancer patients, Wonghongkul, Moore, Musil, Schneider, and Deimling (2000) found positive appraisal to be significantly associated with hope; with increased use of positive appraisal, hope increased. More research is needed to clarify the concept of positive reappraisal and its relationship to hope in palliative patients.

Transforming Hope

The participants in the present study described the sub-processes of transforming hope as interconnected. For example, without acknowledging their situation, they could not find meaning in their experience or use positive reappraisal of their experience in order to transform hope. All three of the sub-processes appeared to be important in transforming their hope. Transforming hope, as described by these participants, was more than the goal-setting and problem-solving that has been the focus of goal-setting theories of hope (Snyder, 2000; Stotland, 1969). Nekolaichuk and Bruera (1998) suggest that multidimensional models of hope reflect the palliative experience of hope more accurately than current theories of hope. The emerging theory of transforming hope discussed here is not only multidimensional but also adds conceptualization of hope as a transformative process with the three sub-processes. As well, the interrelationship of all the sub-processes and the concepts of symptom control, spirituality, and supportive relationships are not discussed in the palliative care literature.

Limitations

The study had several limitations related to the sample and methodology. The sample was 10 older palliative home-care patients living in rural Canada, so it is possible that category saturation as outlined by Glaser (2001) was not reached. The sample was relatively homogeneous. Palliative home-care patients in different geographic regions, of different ages and ethnicities, and with other religious or non-religious preferences, education levels, and incomes may describe their hope experience differently. As well, the participants had low symptom-intensity scores and high hope scores. The processes could differ for palliative patients with high symptom-intensity and/or low hope scores. Finally, given the increasing need to recognize the care requirements of patients with many end-stage illnesses, future research on hope should be conducted with individuals with diseases other than cancer.

Conclusion

It would be premature to generalize the findings of this study. However, the findings provide an empirical basis for informing our understanding of how palliative patients live with hope, and may serve as a basis from which to extend notions of hope captured in theories described in the literature. The sub-processes identified in the model provide a framework from which to conduct further research and to develop strategies for engendering hope in older palliative patients. The findings underscore the importance for nurses of symptom control and the fostering of spirituality and supportive relationships, as these measures are related to the process and sub-processes of hope. Nurses can also provide older palliative patients with information and can promote and facilitate life review, the leaving of legacies, and finding meaning in life. By actively engaging with older palliative care patients in these ways, nurses can foster hope that "enriches life and empowers individuals to live fully in greater aliveness, awareness and reason" (Fromm, 1968).

References

Bays, C. L. (2001). Older adults' descriptions of hope after a stroke. *Rehabilitation Nursing, 26*(1), 18–20.

Benzein, E., Norberg, A., & Saveman, B. (2001). The meaning of the lived experience of hope in patients with cancer in palliative home care. *Palliative Medicine, 15,* 117–226.

Benzein, E., & Saveman, B. (1998). Nurses' perception of hope in patients with cancer: A palliative care perspective. *Cancer Nursing, 21*(1), 10–16.

Buckley, J., & Herth, K. (2004). Fostering hope in terminally ill patients. *Nursing Standard, 19*(10), 33–41.

Cameron, B. (1993). The nature of comfort to hospitalized medical surgical patients. *Journal of Advanced Nursing, 18*, 424–436.

Carstairs, S., & Beaudoin, B. A. (2002). *Quality end of life care: The right of every Canadian. Final report of the Subcommittee to Update "Of Life and Death."* Ottawa: Standing Senate Committee on Social Affairs, Science and Technology.

Chang, V., Hwang, S., & Feureman, M. (2000). Validation of the Edmonton Symptom Assessment Scale. *Cancer, 88,* 2164–2171.

Chenitz, W., & Swanson, J. (1986). Qualitative research using grounded theory. In W. Chenitz & J. Swanson (Eds.), *From practice to grounded theory: Qualitative research in nursing* (pp. 3–15). Menlo Park, CA: Addison-Wesley.

Cutcliffe, J. R. (1995). How do nurses inspire and instill hope in terminally ill HIV patients? *Journal of Advanced Nursing, 22*(5), 888–895.

Cutcliffe, J. R., & Grant, G. (2001). What are the principles and processes of inspiring hope in cognitively impaired older adults within a continuing care environment? *Journal of Psychiatric and Mental Health Nursing, 8*(5), 427–436.

Daneault, S., Lussier, V., Mongeau, S., Paille, P., Hudson, E., Dion, E., et al. (2004). The nature of suffering and its relief in the terminally ill: A qualitative study. *Journal of Palliative Care, 20*(1), 7–11.

Duggleby, W. (2000). Enduring suffering: A grounded theory analysis of the pain experience of elderly hospice patients with cancer. *Oncology Nursing Forum, 27*(5), 825–830.

Duggleby, W. (2001). Hope at the end of life. *Journal of Hospice and Palliative Nursing, 3*(2), 51–57.

Duggleby, W., & Wright, K. (2004). Elderly palliative care cancer patients' descriptions of hope-fostering strategies. *International Journal of Palliative Nursing, 10*(7), 352–359.

Fallowfield, L., Jenkins, V., & Beveridge, H. (2002). Truth may hurt but deceit hurts more: Communication in palliative care. *Palliative Medicine, 16*(4), 297–303.

Flemming, K. (1997). The imponderable: A search for meaning. The meaning of hope to palliative care cancer patients. *International Journal of Palliative Nursing, 3*(1), 14–18.

Fromm, E. (1968). *The revolution of hope: Toward humanizing technology.* New York: Bantam.

Gaskins, S., & Forte, L. (1995). The meaning of hope: Implications for nursing practice and research. *Journal of Gerontological Nursing, 21*(3), 17–24.

Glaser, B. (1978). *Theoretical sensitivity: Advances in the methodology of grounded theory.* Mill Valley, CA: Sociological Press.

Glaser, B. (1992). *Basics of grounded theory analysis.* Mill Valley, CA: Sociological Press.

Glaser, B. (2001). *The grounded theory perspective: Conceptualization contrasted with description.* Mill Valley, CA: Sociological Press.

Hall, B. (1990). The struggle of the diagnosed terminally ill person to maintain hope. *Nursing Science Quarterly, 4*(3), 177–184.

Herth, K. (1990). Fostering hope in terminally ill people. *Journal of Advanced Nursing, 15*, 1250–1259.

Herth, K. (1992). Abbreviated instrument to measure hope: Development and psychometric evaluation. *Journal of Advanced Nursing, 17*, 1251–1259.

Herth, K. (1995). Engendering hope in the chronically and terminally ill: Nursing interventions. *American Journal of Hospice and Palliative Care, 12*(5), 31–39.

Herth, K. (2000). Enhancing hope in people with a first recurrence of cancer. *Journal of Advanced Nursing, 32*(6), 1431–1441.

Howell, S. (1994). A theoretical model for caring for women with chronic non-malignant pain. *Qualitative Health Research, 4*(1), 94–122.

Lindholm, L., & Erickson, K. (1993). To understand and alleviate suffering in a caring culture. *Journal of Advanced Nursing, 18*, 1354–1361.

Marcus, M., & Liehr, P. (1998). Qualitative approaches to research. In G. LoBiondo-Wood & J. Haber (Eds.), *Nursing research: Methods, critical appraisal and utilization,* 2nd ed. (pp. 215–245). St. Louis: Mosby.

Miller, S. (1995). Monitoring versus blunting styles of coping with cancer influence the information patients want and need about their disease. *Cancer, 76,* 167–177.

Nekolaichuk, C. L., & Bruera, E. (1998). On the nature of hope in palliative care. *Journal of Palliative Care, 14*(1), 36–42.

Perakyla, A. (1991). Hope work in the care of seriously ill patients. *Qualitative Health Research, 1*(4), 407–433.

Russell, G. (1993). The role of denial in clinical practice. *Journal of Advanced Nursing, 18*(6), 938–940.

Rustoen, T., Wiklund, I., Hanestad, B. R., & Moum, T. (1998). Nursing intervention to increase hope and quality of life in newly diagnosed cancer patients. *Cancer Nursing, 21*(4), 235–245.

Snyder, C. (2000). *Handbook of hope: Theory, measures and applications.* San Diego: Academic Press.

Stotland, E. (1969). *The psychology of hope.* San Francisco: Jossey-Bass.

Thomas, J., & Retsas, A. (1999). Transacting self-preservation: A grounded theory of the spiritual dimensions of people with terminal cancer. *International Journal of Nursing Studies, 36*, 191–201.

Virik, K., & Glare, P. (2002). Validation of the Palliative Performance Scale for inpatients admitted to a palliative care unit in Sydney, Australia. *Journal of Palliative Care, 23*(6), 455–457.

Wonghongkul, T., Moore, S. M., Musil, C., Schneider, S., & Deimling, G. (2000). The influence of uncertainty in illness, stress appraisal, and hope on coping in survivors of breast cancer. *Cancer Nursing, 23*(6), 422–429.

Acknowledgements

This study was supported by a President's SSHRC Research Grant from the University of Saskatchewan. The authors would like to thank research assistants Joleen Cherland and Marilee Lowe as well as the patients at Sunrise Health Region Palliative Home Care and their families.

Wendy Duggleby, DSN, RN, AOCN, and Karen Wright, PhD, RN, are Associate Professors, College of Nursing, University of Saskatchewan, Saskatoon, Canada.

2009 update: *Wendy Duggleby (PhD) and Karen Wright are Professors, College of Nursing, University of Saskatchewan. Dr. Duggleby leads the research program Living With Hope, comprising approximately 12 studies on hope.*

Résumé

L'élaboration d'un schéma conceptuel traitant de l'utilisation de la recherche en soins infirmiers

Carole A. Estabrooks

L'intérêt accrue qui est porté dernièrement au domaine de l'utilisation de la recherche, lequel s'appuie souvent sur des notions de pratique reposant sur des preuves, fournit de riches possibilités quant à l'avancement de ce créneau des sciences infirmières. Bien qu'il existe, dans la profession, une documentation étendue sur le sujet, un examen approfondi révèle qu'une grande part de celle-ci est fondée sur des opinions ou des anecdotes et que l'élaboration de théories soutenue et génératrice de programmes, accompagnée de vérifications, a été menée, tout au mieux, de façon sporadique. Cet article présente un schéma conceptuel traitant de l'utilisation de la recherche et propose de mettre l'accent sur certains éléments d'étude d'importance : *les fondements, les synthèses, les politiques et les interventions* scientifiques, historiques et philosophiques visant à promouvoir l'utilisation de la recherche, et *les résultats.* En suivant cette voie, nous pouvons développer des approches différentes en matière de perspectives et de conceptualisation dans ce domaine. En exécutant les études et les programmes mis d'avant dans ce schéma, la profession peut, en collaboration avec les partenaires appropriés, réaliser d'importants progrès dans le domaine des études et de la pratique liées à la diffusion et à l'utilisation de la recherche, et ce à de nombreux paliers du système de santé.

CJNR 2009, Vol. 41 Nº 1, 218–236

Mapping the Research Utilization Field in Nursing

Carole A. Estabrooks

The recent increase in interest in the field of research utilization, often embedded in the notions of evidence-based practice, presents a rich opportunity to advance the field in nursing. While an extensive literature on the subject exists in nursing, close examination reveals that much of it is opinion and anecdotal literature, and that sustained and programmatic theory building and testing in this field has been sporadic at best. This article maps the field of research utilization, proposing that we focus on major areas of inquiry: scientific, historical, and philosophical *foundations, synthesis, determinants, policy, interventions* to increase research utilization, and *outcomes.* In so doing, alternative ways of viewing and conceptualizing this field are possible. In conducting the kinds of studies and supporting the kinds of programs identified in this map, nursing, in collaboration with appropriate partners, can significantly advance the field of research dissemination and utilization studies and practice at many levels in the health system.

The past few years have seen a surge of interest in the field of research utilization. This interest has often focused on the broader field of *evidence-based practice* or *evidence-based decision-making,* of which research utilization is a special subset (Estabrooks, 1998; Stetler et al., 1998). Research utilization is, at its simplest, the use of research to guide practice, and is particularly concerned with the use of research evidence — that is, the findings of scientific studies. In contrast, evidence-based practice includes, or ought to include, a much broader conceptualization of evidence than research evidence alone (Estabrooks, 1998). Organizations such as the Agency for Health Care Policy and Research (AHCPR) in the United States, the global Cochrane Collaboration, and the National Forum on Health (NFH), the National Centre of Excellence, and the Health Evidence Application and Linkage Network (HEALNet) in Canada have increasingly focused attention on how scientific evidence is used at various levels of decision-making in health-care practice.

Not since the large research utilization initiatives of the 1970s has there been such a rich opportunity to advance the field in nursing. Since the first nursing study related to research utilization appeared in the literature (Shore, 1972), a large nursing literature has accumulated on the subject. However, much of it is opinion and anecdotal literature, and it has a number of characteristics that suggest the profession has not yet

Originally published in CJNR 1999, Vol. 31 Nº 1, 53–72

been able to realize sustained initiatives that build and test theory in this area.

First, the literature is seriously limited by a scarcity of discussions at the conceptual level. The last in-depth discussions specifically addressing the nature, structure, and/or function of research utilization in nursing were those by Loomis (1985) and Stetler (1985). Second, there were fewer than 70 research studies published between 1972 and 1998, an average of 2.7 a year, with many years yielding none.[1] This publication pattern is illustrated in Figure 1. Further, an examination of those studies reveals little evidence of sustained programmatic research — it is rare to find either individuals or groups who have published repeatedly in the field.

Third, an explicit description of form and substance in the research utilization field could not be located. Such a description or map, were it available, could be used to visualize the field, to locate studies in it, to assess the potential contribution of a study or set of studies to knowledge development in the area, and to guide basic and applied research programs in the field. The perception by many nursing investigators that

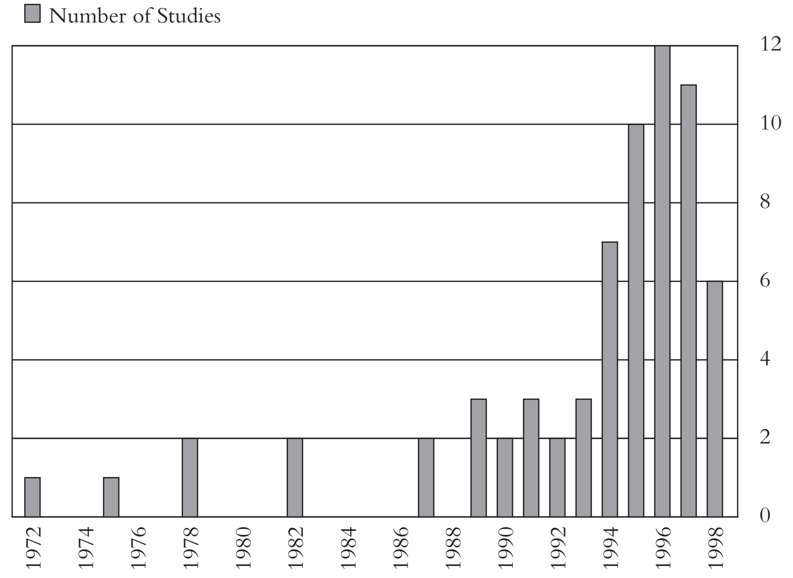
---

[1] While the literature reviewed for this article ranges beyond the nursing literature and has in the past included searches of several databases (e.g., MEDLINE, HSTAR, PSYCHINFO, ABI-INFORM, Dissertation Abstracts, SSCI), the nursing literature reviewed, and to which this statement refers, was examined by using the specific strategies described below. Past searches have also included (a) manual searches of the print version of CINAHL from its beginning to 1982 using the terms *research use, research, research utilization, innovation diffusion,* and *dissemination,* and (b) manual scanning of all reference lists at the end of all retrieved nursing articles. The literature search for this article was undertaken to ensure that all studies were identified. The criteria used to determine whether an article was a study were generous — that is, if authors stated they had done a study and there was any evidence they had measured or intended to measure research utilization (including dissemination, innovation diffusion, adoption, transfer, uptake, or use) or a related dimension (e.g., barriers to research utilization), it was considered a study. Qualitative studies were also counted if they examined research utilization. In conjunction with a reference librarian, the CINAHL database was searched from 1982 through December 1998 using the following terms:

Diffusion of innovation	(subject heading)	
research utilization	(textword)	
Research, nursing	(subject heading-exploded)	OR
and		
transfer, practice or practise	(textwords)	
Research AND transfer	(subject heading and textword)	

Newly retrieved articles were all from 1998; the reference lists of these were manually scanned. Excluded from this count were articles that describe the implementation of a research-based practice on a nursing unit — unless there was an explicit evaluation and some attempt to measure research utilization. These largely anecdotal articles appear primarily in practice journals or research journals targeting clinicians.

Figure 1 ***Research Utilization Studies by Year***



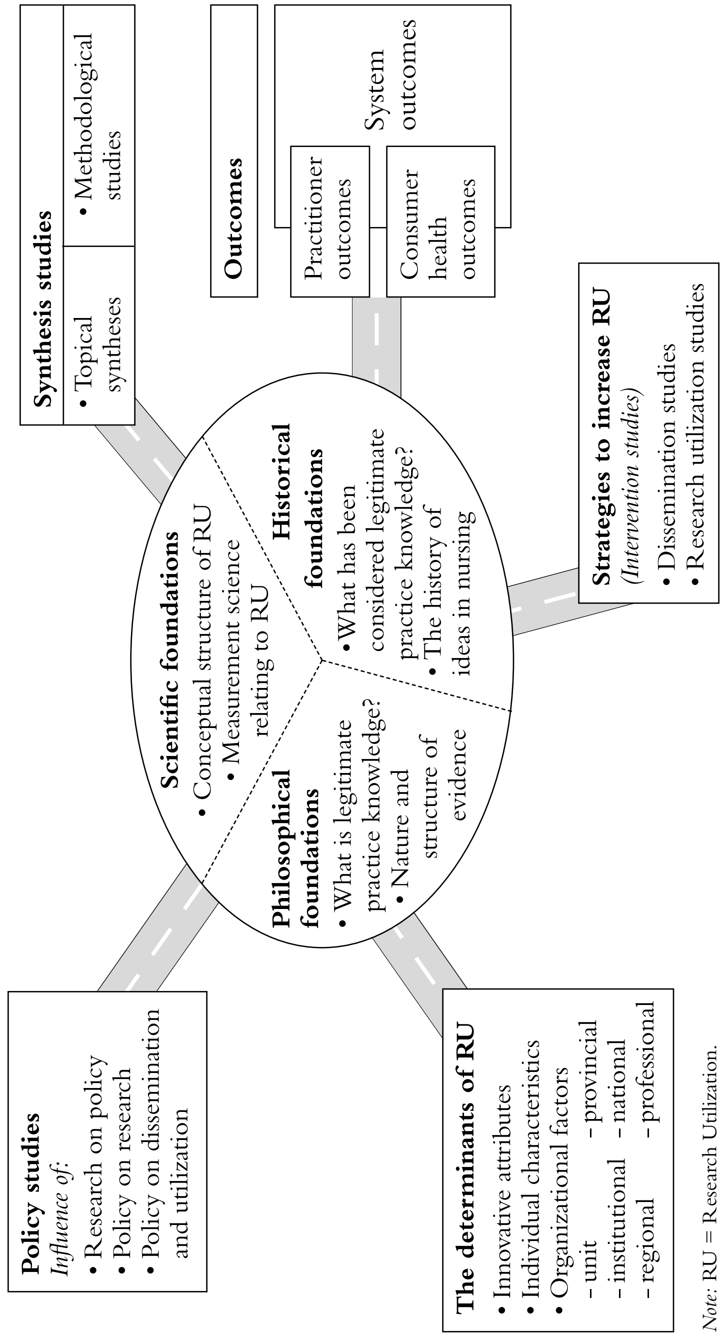
Note: 1998 studies to July 31.

research utilization is exclusively an applied field of study with little or no requirement for basic, foundational studies may in part be responsible for the relatively disorganized state of the field today.

This article proposes such a map, with the goal of clarifying new and more comprehensive approaches to viewing and conceptualizing the research utilization field. A schematic of the map is presented in Figure 2. This schematic attempts to conceptualize research utilization as a field of both basic and applied investigation and as a field in a dynamic and interactive state.

The remaining sections discuss the elements depicted in the figure, beginning with foundational work and progressing through the areas of synthesis, determinants of research utilization, policy, intervention studies to increase research utilization, and outcomes. This article focuses on nurses, and does not address ongoing work in the area of consumer decision-making and consumers' need for and use of research evidence in making health decisions (e.g., Degner et al., 1997; Llewellyn-Thomas, 1997; O'Connor, 1997; O'Connor et al., 1998; Rothert et al., 1997; Sawka et al., 1998).

Figure 2 *Mapping the Field of Research Utilization in Nursing*



Note: RU = Research Utilization.

Foundational Work in the Field

One of the areas most central to sustained advancement in the research utilization field is described in Figure 2 as "foundational work." This foundational work has at least three dimensions: scientific, historical, and philosophical.

Scientific Foundations

Historically, nursing investigators have viewed research utilization as an applied area rather than as a field of inquiry with basic science requirements — that is, as an area of original work itself. Investigators would implement the findings of others' research, develop and apply models of research utilization, and to some extent study influencing factors. In order to advance the research utilization field meaningfully, however, there must be advances in areas such as developing and refining its conceptual structure, developing the measurement science needed to undergird scientific studies, and developing a clear conceptual understanding of the nature and structure of evidence in nursing and of the relationship of research to evidence.

There are no studies or conceptual papers in the nursing literature and only rarely elsewhere (e.g., Dunn, 1983) that directly explore measurement issues. The empirical work in this field is currently plagued with measurement difficulties, which are likely to worsen if we do not explicitly undertake to resolve them. We have little idea of appropriate and relevant measures of research utilization — whether at single or multiple levels. For example, the most common approach to measuring research utilization does not differentiate among the kinds of research utilization, although it is implicitly an instrumental measure (Barta, 1995; Brett, 1987, 1989; Coyle & Sokop, 1990; Michel & Sneed, 1995; Varcoe & Hilton, 1995). If the findings of studies measuring only instrumental research use are used, we will underestimate nurses' overall research use, as we will not have accounted for either conceptual or persuasive use (Estabrooks, 1999b). Furthermore, this approach to measuring instrumental use developed by Brett (1987) is relatively complex, requiring an assessment of the extant user-ready research in the particular area each time it is used, in contrast to a global measure of research use (Estabrooks, 1997, 1999b). Which approach is better? Or does each have an appropriate usage? Are there other approaches that we need to develop?

We require both empirical and conceptual work designed to develop and test emerging mid-range theories on research utilization; the development of these mid-range theories is the overarching goal of activity in this field. In the literature on innovation diffusion, Downs and Mohr (1976) put forward the idea that there was not a single theory of innovation, but that rather different types of innovation require distinct theories. Thirteen years and a considerable amount of research later, Poole and Van De Ven (1989) contended that no single theory can encompass "the complexity and diversity of innovation processes" (p. 638). Other authors in the innovation literature have reached the same conclusion (Damanpour, 1987, 1991; Mohr, 1987; Van De Ven & Rogers, 1988; Wolfe, 1994). While research utilization is not entirely synonymous with innovation diffusion, it is close enough that such advice should be heeded. It is quite likely that as we begin to understand the complexities of the determinants of research utilization and how they behave, different research utilization theories will begin to emerge and be tested.

Historically, nursing investigators have used a fairly limited set of approaches to study this field. Can we expand our repertoire of design approaches and modify our thinking in order to construct densely theoretical studies; studies whose express purposes include theory development and assessment; studies whose reports would include a discussion of where the particular study fits in terms of emerging theories of research utilization in nursing; studies running the gamut from naturalistic to rigid empirical assessment of theory; and studies that help us discover the structure of research utilization, its properties, its predictors, and its contextual variations?

The lack of clarity on the relationship between research utilization and evidence-based practice is also a potentially serious impediment. The current (and, this author believes, erroneous) tendency to equate the two could possibly lead us to rank-order evidence such that we devalue — or, worse, negate — non-scientific evidence. While some recent journal articles in nursing (DiCenso, Cullum, & Ciliska, 1998; Estabrooks, 1998; Kitson, 1997) suggest the need for a debate on the *evidence-based practice* movement, and by implication the nature and structure of evidence, and provide some fodder for this debate, there has not yet been a visible and collective debate on this topic in nursing such as is currently taking place elsewhere — for example, in the *British Medical Journal,* the *Canadian Medical Association Journal,* and the *Journal of Evaluation in Clinical Practice.* In Canada, the NFH published an entire volume on evidence-based decision-making (Evidence-Based Decision Making Working Group, 1997). Additionally, HEALNet has adopted as one of its strategic directions for 1998–2002 the pursuit of a research program on evidence (http://hiru.mcmaster.ca/nce/research.htm). Its work will be influential in determining how evidence is conceptualized, ordered, and ultimately valued in the health-policy environment in Canada. It is a matter of some urgency that nurses too take up a public debate on the nature and structure of evidence — one that develops in print and is voiced where we are gathered.

Historical and Philosophical Foundations

We ought perhaps to be viewing the often neglected areas of historical and philosophical inquiry as primary areas of insight into how we proceed in this complex field. Sound historical inquiry would go a long way in helping us to understand how, for example, nurses as a profession have conceptualized, legitimated, and controlled knowledge for practice and for professionalization. It would enlighten us as to what knowledge we have valued within different social and historical contexts; it would enable us to create a more planned future in the development and use of practice knowledge, including research knowledge; and it would surely expand our thinking in the evidence debate.

While historical examination would assist in laying a foundation for the future, it is to philosophy that we should turn for the debate on what ought to be — that is, what ought we value, create, legitimate, and control? What is and what ought to be the nature of practice knowledge? What parts of that practice knowledge are amenable to the strategies a good research utilization investigator might offer? Encouragingly, small philosophical groups are forming in Canadian nursing graduate programs, and this is where we must hope the seeds will be planted for the epistemological debates that need to occur. Such debates must find their way to basic education curricula in this country if we are to adequately prepare the next generation of practitioners, who will be working not under the shadow of the industrial revolution but rather under the glare of the cybernetic age.

Synthesis Work

Twenty years ago, the most significant problem in research utilization studies was the lack of available studies to utilize (Kreuger, Nelson, & Wolanin, 1978). While we have progressed a great deal, enormous gaps remain in the research that is available to guide nursing practice. There are insufficient synthesized research findings, such as meta-analyses, systematic research effectiveness overviews, and sound integrative literature reviews that would provide clinicians with digestible and readily accessible material.

The Cochrane Collaboration and the AHCPR have spurred a great deal of activity in this area, and in Canada considerable methodological work by nurse investigators is ongoing at McMaster University. However, the set of research methods used in nursing is wide-ranging. We have relatively few randomized clinical trials (RCTs) on which most of the meta-analytic work has been done, and large numbers of descriptive and qualitative studies. If we are to provide the substance that will support research-based nursing interventions, we must hurry on to the demanding methodological work involved in developing appropriate methods with which to synthesize or aggregate non-RCT studies, including qualitative studies.

It is also important to spend some time synthesizing the research utilization work that has been done, so that we have a clearer understanding of the state of affairs. How far have we come? Where are we now? Where do we need to go? Otherwise, we will be vulnerable to random development in the field. It makes little sense to proceed in any but a systematic manner in this field, along the way steering our graduate students and junior investigators in those same systematic directions.

The Determinants of Research Utilization

To date, the work in research utilization in nursing has focused almost exclusively on the determinants of research utilization — those factors, characteristics, and attributes of individuals, organizations, and innovations that influence the use of research. However, despite this focus, after nearly three decades of research the body of descriptive research identifying these determinants is underdeveloped and equivocal.

Individual Determinants

Most of the work to date in nursing has addressed individual determinants of research utilization — that is, those characteristics possessed by the individual that influence their use of research findings in their work. Examples of these factors include: a *positive attitude* to research (Bostrum & Suter, 1993; Champion & Leach, 1989; Lacey, 1994; Rizutto, Bostrum, Suter, & Chenitz, 1994); *autonomy* (Funk, Champagne, Weiss, & Tornquist, 1991; Lacey, 1994; Rodgers, 1994; Walczak, McGuire, Haisfield, & Beezley, 1994); *awareness of agency policy* and *educational level* (Michel & Sneed, 1995); *conference attendance* (Coyle & Sokop, 1990); *cooperativeness and self-efficacy* (Kim & Kim, 1996); *job satisfaction* (Coyle & Sokop, 1990); *involvement in nursing research activities* (Bostrum & Suter, 1993; Pettengill, Gillies, & Clark, 1994); and time spent *reading professional journals* (Barta, 1995; Brett, 1987; Coyle & Sokop, 1990; Kirchoff, 1982). However, when the relatively small body of work on these factors is examined closely, it yields little direction. Study designs and methods vary widely, sample sizes are small, and results tend not to converge on common recommendations (Estabrooks & Floyd, in progress). When the individual determinants that have been studied were rigorously and empirically tested to assess their influence on research utilization behaviour (Estabrooks, 1997, 1999a), only a positive attitude to research, in-service attendance, and the ability to suspend strongly held beliefs remained in structural equation models as significant influencing factors.

Organizational Determinants

Organizational determinants — those characteristics of health-care organizations, of units within those institutions, and of governance structures outside of those institutions that facilitate the dissemination and uptake of research findings — have been addressed to an even lesser extent than have individual determinants. Those organizational determinants that have been looked at include organizational size, administrative support, access to research, and time (Brett, 1987, 1989; Coyle & Sokop, 1990; Dunn, Crichton, Roe, Seers, & Williams, 1998; Funk et al., 1991; Rutledge, Ropka, Greene, Nail, & Mooney, 1997; Varcoe & Hilton, 1995). Other organizational determinants, such as complexity, centralization, presence of a research champion, traditionalism, and organizational slack, have not, for the most part, been addressed in the nursing literature, although others, such as organizational analysts, have studied these characteristics extensively (e.g., Chakarbarti, 1974; Damanpour, 1987, 1988, 1991, 1996; Downs & Mohr, 1976; Fennell, 1984; Kimberley, 1981; Kimberley & Evanisko, 1981; Mohr, 1969).

Perhaps most importantly, there are no published reports of studies whose investigators have examined organizational culture at the local (unit) level, at multiple levels within the organization, or at the Regional Health Authority or Board levels. Unit and institutional culture are undoubtedly significant and multidimensional influences on research utilization behaviours. Elements such as unit norms, unit belief structures, local leadership and influence, rules of engagement, and interactions with other levels of the organization are likely embedded in the broader notion of organizational culture. Additionally, organizational factors such as a supportive administrative structure and adequate time to use research can probably be well understood only within the context of local unit culture. For example, even in a very research-positive climate there may be rules of practice that supersede the will or intent of individuals to use research.

Another dimension of organizational determinants that has received no attention to date in nursing is the influence of institutional structures at the different jurisdictional levels on research utilization behaviour. For example, are there institutional structures in place to support research-based nursing practice at the organizational levels? At regional levels? At provincial or national professional-association levels? At union levels? In educational institutions? If there are, how effective are they? If there are not, how can we expect individual practitioners to be accountable for evidence-based practice?

Attributes of the Innovation

Attributes of the innovation are those characteristics of the research findings and of the clinical phenomenon that influence the uptake of relevant research. For example, the characteristics of the body of research on effective pain management as well as the characteristics of the phenomenon of pain itself will contribute to whether or not nurses make effective use of pain research in their practices. Unfortunately, there is little if any understanding of the influence of attributes of the innovation on nurses' research utilization behaviour.

First, unlike what has been done in other fields, there has been no study of the attributes of the innovation specific to nursing. Second, we do not know to what extent research findings as a product mimic innovations. In nursing, the concepts of innovation diffusion have been readily incorporated into conceptualizations of research utilization as if they were synonymous, but there is little evidence to support this, and little theoretical discussion in this regard. It seems reasonable that some of the attributes of innovations that have been considered to be important are also likely important attributes of nursing research and related clinical phenomena, but it seems equally likely that some are quite different.

Outside of nursing, Rogers (1983, 1995) proposes a list of five innovation attributes — *complexity, relative advantage, compatibility, trialability,* and *observability* — thought to be important to the adoption of innovations. Tornatsky and Klein (1982) report more equivocality in the influence of such attributes than Rogers's work suggests, and others have suggested additional and different attributes (Damanpour, 1988; Dearing & Meyer, 1994; Kimberley, 1987; Van De Ven, 1986). These studies and conceptualizations of innovation attributes in other fields should serve to assist nurses in the conceptualization and study of innovation attributes. In particular, we need to expand our understanding of the parallels between innovation attributes and research attributes and between innovation attributes and the attributes of the clinical phenomenon.

Policy

Few if any studies have been published that address the relationship between nursing research and policy or between policy and research utilization. Policy holds promise as a strategy to facilitate research utilization. It also can function in many institutions as an impediment. The more we know about and understand these processes, the more effective we will be in both the use of policy to improve practice and the use of research to effect policy change. The earlier discussion of institutional structures (under ***Organizational Determinants***) is fundamentally related to questions of policy. Is the current rhetoric (and hence, one could argue, at least the broad policy intent) of evidence-based decision-making in this country tied in meaningful ways to actual policy implementation? What policy instruments have been applied to create an evidence-based decision-making culture? Have these instruments been applied differentially or non-differentially? At what levels have they been applied? Have they been effective? What has been — and what should be — the role of regional boards, employers, professional associations, and labour unions in creating institutional structures that encourage and facilitate research-based practice? What is the profession's capacity to generate policy studies, to influence policy that affects dissemination and uptake of research in the health sector, and to marshal policy expertise among investigators and practitioners?

Strategies to Increase Research Utilization (Intervention Studies)

A second area (in addition to determinants) in which nurse investigators have conducted research is intervention studies (see Figure 2); however, there are few such studies. Examples of those that have been done include the work of Dufault, Bielecki, Collins, and Wiley (1995), who examined the effectiveness of a collaborative research utilization model directed towards the transfer of pain-assessment knowledge to practice; Hodnett et al. (1996), who examined the effectiveness of a marketing strategy geared to increasing nurses' use of intrapartum interventions on patient outcomes; Luker and Kenrick (1992), who evaluated the effectiveness of an "information package" on the management of leg ulcers in the community; Rutledge and Donaldson (1995), who evaluated a 3-year project involving 20 service organizations and nearly 400 nurses in California; and Tranmer, Kisilevsky, and Muir (1995), who evaluated the effectiveness of a nursing research utilization strategy ("developmentally sensitive care") in a neonatal intensive care unit.

Reports such as the above offer beginning evidence about the kinds of strategies that may or may not be useful in getting research used. However, intervention studies designed to examine strategies to increase research utilization are more likely to contribute to knowledge and theory development in this area if they are premised on (a) strong, less equivocal descriptive work (i.e., study of the determinants), (b) reliable outcomes work, and (c) sound theoretical and conceptual foundations. It will be especially difficult to design strong intervention studies until we have well-developed approaches to measuring research utilization.

Outcomes

Intervention studies in this area must be rigorously focused on patient/client health status, and not exclusively on the *intermediate* outcome of research utilization. While we have a great deal of work to do in the area of validly and reliably measuring research utilization — the practitioner outcome of interest in Figure 2 — we also have a considerable amount of work to do in identifying and measuring nurse-sensitive client and system outcomes. Additionally, in light of the discussion thus far, client and system outcomes must be sensitive to research utilization as a predictor variable if we intend to demonstrate that using research to guide nursing practice makes a difference in consumer outcomes. Nurse investigators who have programs in research utilization must begin to work early on with nurse investigators who have expertise in outcomes research.

The measurement of research utilization as a useful outcome is premised on somewhat different assumptions from those sometimes made in intervention studies (e.g., see Hodnett et al., 1996) that eliminate measurement of research utilization (or a research utilization index) as an intermediate variable. These studies directly measure the effect of a specific set of nursing interventions (brought about by a research utilization strategy) on client outcomes and eliminate the measurement of the intermediate outcome, research utilization. It can be argued that the retention of research utilization as an important outcome variable in studies has value beyond the science of those studies. Such value lies in the central relationships of institutional structures, practices, and cultures to the work of nurses. For example, a measure of research utilization in an organization, or on units within that organization, is likely to be an important characteristic or indicator of organizational culture. We can speculate, for example, that it may be a characteristic of the magnet hospital (McClure, Poulin, Sovie, & Wandelt, 1983) and that, as such, its direct measurement is of added value.

Discussion

Mapping a field of inquiry in any domain is a complex undertaking. This first attempt to do so in the field of research utilization is designed to (a) clarify that a field of inquiry exists, (b) clarify that study in this field is best undertaken systematically from both basic and applied perspectives, and (c) encourage collaborative work among investigators. A reasonable next question is: Are there priority areas that we should address? There are many places on the schematic in Figure 2 to legitimately begin for those who are new to the field, and many places to locate one's own work for those already engaged in this area of research.

I began with empirical work that focused on elements of both scientific foundations and determinants, and attempted to develop and test beginning research utilization theory (Estabrooks, 1997, 1999a, 1999b). From that experience, I became convinced that the descriptive and foundational bodies of research are so underdeveloped that we must attend to them with some urgency in order to be able to design sound studies that develop and test strategies to increase research utilization (i.e., intervention studies).

How should we proceed so that our approaches are systematic? Although it is difficult to set priorities for activity in the field, a proposed set of reasonable priorities includes the following:

- develop a more thorough and confident understanding of the determinants of research utilization, with an emphasis on the different levels of organizational determinants, especially local culture, and the interactions of different groups of determinants in different clinical contexts
- conduct foundational studies, both theoretical and empirical, that address, as priorities, the conceptual structure of research utilization and its measurement
- develop a better understanding of individual determinants, with a view to targeting interventions early in educational programs when they are most likely to have an effect, especially if, as we suspect at this stage, these determinants are largely related to attitude, thinking styles, and belief structures
- conduct intervention studies that are informed by descriptive work, by measurement work, and by related outcomes work, taking care to reflect on *the nature and structure of nursing work* when considering different intervention strategies
- build functional partnerships with those individuals and institutions (both within and across disciplines and countries) whose expertise is outside the area of research utilization per se but is central to the advancement of a research utilization agenda — for example, outcomes researchers, policy analysts and experts, political scientists, organizational analysts, clinicians, and clinical investigators.

Two provisos should be added to this discussion. We need to be cognizant of the tendency in the past to study only the utilization of *nursing* research findings. The only plausible reason for restricting study in this area to nursing research seems to be a professional one, intended to advance the legitimization both of nursing as an academic pursuit and of our research. However, nurses need a full repertoire of theoretical and practice knowledge, of which nursing is but one component. Therefore, we should be interested in the use of any and all kinds of research that are relevant to the work of nurses and to better health outcomes for patients and clients. This will require us to work closely with practising nurses and consumers as we develop our understanding of not only what practice knowledge they require, but in what forms they can best use it.

Second, if we are to advance systematic and programmatic study in this field, the profession has considerable work to do to build capacity. The agenda outlined here is ambitious and will require the cooperative work of many individuals and institutions. To date, at least in Canada, we have no readily identifiable centres or programs and very few individuals who espouse expertise in research utilization. While we are aware informally of expertise in some of the sub-areas discussed, we have not often made this explicitly known to potential graduate students or post-doctoral trainees, who are the most likely sources of future capacity. However, because of Canadian funding-agency decisions in recent years to focus more on knowledge dissemination and research transfer and uptake, we have considerable potential to attract and build the needed capacity, as well as to conduct the high-quality studies needed to advance the science of research utilization.

We have an extraordinary window of opportunity that has been opening in Canada since the NFH called for a culture of evidence-based decision-making earlier this decade. We should not squander the opportunity. We should focus on getting on with the agenda — systematically, programmatically, and collaboratively. Doing so could create considerable synergy in this field, setting the stage for observable progress in the decades ahead.

References

Barta, K.M. (1995). Information-seeking, research utilization, and barriers to research utilization of pediatric nurse educators. *Journal of Professional Nursing, 11*(1), 49–57.

Bostrum, J., & Suter, W.N. (1993). Research utilization: Making the link to practice. *Journal of Nursing Staff Development, 9*(1), 28–34.

Brett, J.L.L. (1987). Use of nursing practice research findings. *Nursing Research, 36,* 344–349.

Brett, J.L.L. (1989). Organizational integrative mechanisms and adoption of innovations by nurses. *Nursing Research, 38,* 105–110.

Chakrabarti, A.K. (1974). The role of champion in product innovation. *California Management Review, 17*(2), 58–62.

Champion, V.L., & Leach, A. (1989). Variables related to research utilization in nursing: An empirical investigation. *Journal of Advanced Nursing, 14,* 705–710.

Coyle, L.A., & Sokop, A.G. (1990). Innovation adoption behaviour among nurses. *Nursing Research, 39,* 176–180.

Damanpour, F. (1987). The adoption of technological, administrative, and ancillary innovations: Impact of organizational factors. *Journal of Management, 13,* 675–688.

Damanpour, F. (1988). Innovation type, radicalness, and the adoption process. *Communication Research, 15,* 545–567.

Damanpour, F. (1991). Organizational innovation: A meta-analysis of effects of determinants and moderators. *Academy of Management Journal, 34,* 555–590.

Damanpour, F. (1996). Organizational complexity and innovation: Developing and testing multiple contingency models. *Management Science, 42,* 693–715.

Dearing, J.W., & Meyer, G. (1994). An exploratory tool for predicting adoption decisions. *Science Communication, 16,* 43–57.

Degner, L.F., Kristjanson, L.J., Bowman, D., Sloan, J.A., Carriere, K.C., O'Neil, J., et al. (1997). Information needs and decisional preferences in women with breast cancer. *Journal of the American Medical Association, 277,* 1485–1492.

DiCenso, A., Cullum, N., & Ciliska, D., (1998). Implementing evidence-based nursing: Some misconceptions. *Evidence-Based Nursing, 1,* 38–40.

Downs, G.W., & Mohr, L.B. (1976). Conceptual issues in the study of innovation. *Administrative Science Quarterly, 21,* 700–714.

Dufault, M.A., Bielecki, C., Collins, E., & Wiley, C. (1995). Changing nurses' pain assessment practice: A collaborative research utilization approach. *Journal of Advanced Nursing, 21*, 634–645.

Dunn, V., Crichton, N., Roe, B., Seers, K., & Williams, K. (1998). Using research for practice: A U.K. experience of the BARRIERS scale. *Journal of Advanced Nursing, 27*, 1203-1210.

Dunn, W.N. (1983). Measuring knowledge use. *Knowledge: Creation, Diffusion, Utilization, 5*(1), 120–133.

Estabrooks, C.A. (1997). *Research utilization in nursing: An examination of formal structure and influencing factors.* Unpublished doctoral dissertation, University of Alberta, Edmonton.

Estabrooks, C.A. (1998). Will evidence-based nursing practice make practice perfect? *Canadian Journal of Nursing Research, 30*(1), 15–36.

Estabrooks, C.A. (1999a). Modeling the individual determinants of research utilization. *Western Journal of Nursing Research, 21*(6), 758–772.

Estabrooks, C.A. (1999b). The conceptual structure of research utilization. *Research in Nursing and Health, 22,* 203–216.

Estabrooks, C.A., & Floyd, J.A. (in progress). *A systematic review of the literature addressing individual determinants of research utilization behaviour in nursing.*

Evidence-Based Decision Making Working Group. (1997). *Creating a culture of evidence-based decision making in health.* Ottawa: National Forum on Health.

Fennell, M.L. (1984). Synergy, influence, and information in the adoption of administrative innovations. *Academy of Management Journal, 27,* 113–129.

Funk, S.G., Champagne, R.A., Weiss, R.A., & Tornquist, E.M. (1991). Barriers to using research findings in practice. *Applied Nursing Research, 4*(2), 90–95.

Hodnett, E.D., Kaufman, K., O'Brien-Pallas, L., Chipman, M., Watson-MacDonald, J., & Hunsburger, W. (1996). A strategy to promote research-based nursing care: Effects on childbirth outcomes. *Research in Nursing and Health, 19,* 13–20.

Kim, I., & Kim, M.-I. (1996). The effects of individual and nursing-unit characteristics on willingness to adopt an innovation: A multilevel analysis. *Computers in Nursing, 14,* 183–187.

Kimberley, J.R. (1981). Managerial innovation. In P. Nystrom & W. Starbuck (Eds.), *Handbook of organizational design.* Vol. 1 (pp. 84–104). Oxford: Oxford University Press.

Kimberley, J.R. (1987). Organizational and contextual influences on the diffusion of technological innovation. In J.M. Pennings & A. Buitendam (Eds.), *New technology as innovation: The development and diffusion of microelectronics* (pp. 237–259). Cambridge, MA: Ballinger.

Kimberley, J.R., & Evanisko, M.J. (1981). Organizational innovation: The influence of individual, organizational, and contextual factors on hospital adoption of technological and administrative innovations. *Academy of Management Journal, 24,* 689–713.

Kirchoff, K. (1982). A diffusion survey of coronary precautions. *Nursing Research, 31,* 196–201.

Kitson, A. (1997). Using evidence to demonstrate the value of nursing. *Nursing Standard, 11*(28), 34–39.

Krueger, J.C., Nelson, A., & Wolanin, M.O. (1978). Nursing research: Development, collaboration, and utilization. Germantown, MD: Aspen.

Lacey, E.A. (1994). Research utilization in nursing practice: A pilot study. *Journal of Advanced Nursing, 19,* 987–995.

Llewellyn-Thomas, H.A. (1997). Investigating patients' preferences for different treatment options. *Canadian Journal of Nursing Research, 29,* 45–64.

Loomis, M.E. (1985). Knowledge utilization and research utilization in nursing. *Image: Journal of Nursing Scholarship, 17*(2), 35–39.

Luker, K.A., & Kenrick, M. (1992). An exploratory study of the sources of influence on the clinical decisions of community nurses. *Journal of Advanced Nursing, 17,* 457–466.

McClure, M.L., Poulin, M.A., Sovie, M.D., & Wandelt, M.A. (1983). *Magnet hospitals: Attraction and retention of professional nurses.* Kansas City: American Academy of Nursing.

Michel, Y., & Sneed, N.V. (1995). Dissemination and use of research findings in nursing practice. *Journal of Professional Nursing, 11,* 306–311.

Mohr, L.B. (1969). Determinants of innovation in organizations. *American Political Science Review, 63,* 111–126.

Mohr, L.B. (1987). Innovation theory: An assessment from the vantage point of the new electronic technology in organizations. In J.M. Pennings & A. Buitendam (Eds.), *New technology as innovation: The development and diffusion of microelectronics* (pp. 13–31). Cambridge, MA: Ballinger.

O'Connor, A.M. (1997). Consumer/patient decision support in the new millennium: Where should our research take us? *Canadian Journal of Nursing Research, 29,* 7–11.

O'Connor, A.M., Tugwell, P., Wells, G.A., Elmslie, T., Jolly, E., Hollingworth, G., et al. (1998). Randomized trial of a portable, self-administered decision aid for postmenopausal women considering long-term preventive hormone therapy. *Medical Decision Making, 18,* 295–303.

Pettengill, M.M., Gillies, D.A., & Clark, C.C. (1994). Factors encouraging and discouraging the use of nursing research findings. *Image: Journal of Nursing Scholarship, 26,* 143–147.

Poole, M.S., & Van De Ven, A.H. (1989). Toward a general theory of innovation processes. In A.H. Van De Ven, H.L. Angle, & M.S. Poole (Eds.), *Research on the management of innovation: The Minnesota Studies* (pp. 637–662). New York: Harper & Row.

Rizutto, C., Bostrum, J., Suter, W.N., & Chenitz, W.C. (1994). Predictors of nurses' involvement in research activities. *Western Journal of Nursing Research, 16,* 193–204.

Rodgers, S. (1994). An exploratory study of research utilization by nurses in general medical and surgery wards. *Journal of Advanced Nursing, 20,* 904–911.

Rogers, E.M. (1983). *Diffusion of innovations,* 3rd ed. New York: Free Press.

Rogers, E.M. (1995). *Diffusion of innovations,* 4th ed. New York: Free Press.

Rothert, M.L., Holmes-Rovner, M., Rovner, D., Kroll, J., Breer, L., Talarczyk, G., et al. (1997). An educational intervention as decision support for menopausal women. *Research in Nursing and Health, 20,* 377–387.

Rutledge, D.N., & Donaldson, N.E. (1995). *Journal of Nursing Administration, 25*(10), 12–16.

Rutledge, D.N., Ropka, M., Greene, P.E., Nail, L., & Mooney, K.H. (1997). Barriers to research utilization for oncology staff nurses and nurse managers/clinical nurse specialists. *Oncology Nursing Forum, 25,* 497–506.

Sawka, C.A., Goel., V., Mahut, C.A., Taylor, G.A., Thiel, E.C., O'Connor, A.M., et al. (1998). Development of a patient decision aid for choice of surgical treatment for breast cancer. *Health Expectations, 1,* 23–36.

Shore, H.L. (1972). Adopters and laggards. *Canadian Nurse, 68*(7), 36–39.

Stetler, C.B. (1985). Research utilization: Defining the concept. *Image: Journal of Nursing Scholarship, 17*(2), 40–44.

Stetler, C.B., Brunell, M., Giuliano, K.K., Morsi, D., Prince, L., & Newell-Stokes, V. (1998). Evidence-based practice and the role of nursing leadership. *Journal of Nursing Administration, 28*(7/8), 45–53.

Tornatsky, L.G., & Klein, K.J. (1982). Innovation characteristics and innovation adoption-implementation: A meta-analysis of findings. *IEEE Transactions on Engineering Management, 29,* 28–45.

Tranmer, J.E., Kisilevsky, B.S., & Muir, D.W. (1995). A nursing research utilization strategy for staff nurses in the acute care setting. *Journal of Nursing Administration, 25*(4), 21–29.

Van De Ven, A.H. (1986). Central problems in the management of innovation. *Management Science, 32,* 590–607.

Van De Ven, A.H., & Rogers, E.M. (1988). Innovation and organizations. *Communication Research, 15,* 632–651.

Varcoe, C., & Hilton, A. (1995). Factors influencing acute-care nurses' use of research findings. *Canadian Journal of Nursing Research, 27,* 51–71.

Walczak, J.R., McGuire, D.B., Haisfield, M.E., & Beezley, A. (1994). A survey of research-related activities and perceived barriers to research utilization among professional oncology nurses. *Oncology Nursing Forum, 21,* 710–715.

Wolfe, R.A. (1994). Organizational innovation: Review, critique and suggested research directions. *Journal of Management Studies, 31,* 405–431.

Acknowledgements

The author wishes to acknowledge the thoughtful and lively contributions of the CNA working group on research dissemination and utilization in nursing, the encouragement of colleagues at the Faculty of Nursing, University of Toronto, and Laura Benben at ICES for her assistance with graphics.

Carole A. Estabrooks, RN, PhD, is a Medical Research Council and Alberta Heritage Foundation for Medical Research postdoctoral fellow at the Institute for Clinical Evaluative Sciences in Toronto, Ontario, Canada, and Assistant Professor, Faculty of Nursing, University of Alberta, Edmonton, Canada.

2009 update: *Carole A. Estabrooks is Professor and Canada Research Chair in Knowledge Translation, Faculty of Nursing, University of Alberta.*

CJNR 2009, Vol. 41 N° 1, 238–258

Résumé

Évaluation du programme de prévention du SIDA mené par les infirmières de rue : un pas à la fois

**B. Ann Hilton, Ray Thompson
et Laura Moore-Dempsey**

Le programme de prévention du SIDA mené par les infirmières de rue utilise des infirmières spécialisées en santé communautaire dotées d'une formation spéciale dans le but de promouvoir la prévention du HIV et des MTS auprès d'une clientèle marginale, difficilement atteignable et à risque élevé. Cette démarche s'inscrit dans un effort pour diminuer les problèmes et promouvoir la santé. Des infirmières de rue (n = 17), des pourvoyeurs de soins (n = 30), des représentants d'autres programmes HIV/MTS dans la province canadienne de la Colombie-Britannique (n = 5) et des clients (n = 32) ont été interviewés au cours d'une évaluation dans le but de décrire le travail qu'effectuent les infirmières, les défis qu'elles doivent relever, l'harmonisation de ce programme avec les autres services et l'impact du travail des infirmières. Cet article décrit les effets du travail des infirmières auprès des clients. Les changements sur le plan de l'impact/des résultats indiquaient une progression en matière de niveaux de connaissances et de comportements, et des indicateurs majeurs de santé/maladie. Les effets exercés sur la clientèle incluaient : une meilleure connaissance du HIV/SIDA, de leur propre situation et des options; l'utilisation de fournitures essentielles destinées à réduire les problèmes et à promouvoir la santé; un changement de comportements visant à réduire la transmission de maladies, améliorer la résistance et promouvoir la santé; l'utilisation de ressources d'aide; un sentiment de mieux-être avec eux-mêmes et leur entourage; un sentiment d'être soutenu et d'exercer une influence sur les autres; le sentiment de recevoir plus rapidement de l'attention, face à des problèmes; un meilleur état de santé avec ou sans HIV; l'intégration de changements majeurs en ce qui a trait à l'usage de drogues; et une baisse probable de morbidité et de mortalité. Le programme s'est révélé nettement efficace et ses effets sur la clientèle se sont avérés positifs.

CJNR 2009, Vol. 41 Nº 1, 238–258

Evaluation of the AIDS Prevention Street Nurse Program: One Step at a Time

B. Ann Hilton, Ray Thompson, and Laura Moore-Dempsey

The AIDS Prevention Street Nurse Program uses specially prepared community health nurses to focus on HIV and STD prevention with marginalized, hard-to-reach and high-risk clients within a broader context of harm reduction and health promotion. Street nurses (*n* = 17), service providers (*n* = 30), representatives of other HIV/STD programs in the province of British Columbia, Canada (*n* = 5), and clients (*n* = 32) were interviewed during an evaluation for the purpose of describing the nurses' work, the challenges the nurses' face, the fit of the program with other services, and the impact of the nurses' work. This article describes the impact of the nurses' work on clients. Impact/outcome changes reflected a progression from knowledge to behavioural levels and to major indicators of health/illness. Impact on clients included: knowing more about HIV/AIDS, their own situation, and options; receiving essential supplies to reduce harm and promote health; changing behaviour to reduce disease transmission, improve resistance, and promote health; connecting with help; feeling better about themselves and others; feeling supported; influencing others; receiving earlier attention for problems; being healthier with or without HIV; making major changes in drug use; and likely decreasing morbidity and mortality. The program was found to be clearly effective in making a positive impact on clients.

The AIDS Prevention Street Nurse Program (the Program), an innovation that uses specially prepared community health nurses to work "on the street," was initiated as a pilot project in Vancouver, British Columbia, Canada, in January 1988. Prior to 1988 a smaller, outreach sexually transmitted disease (STD) program was specifically targeted to persons in jail. This was redirected in response to the HIV/AIDS epidemic. In the Program, the nurses work with challenging clients and complex situations in an expanded nursing practice role that includes several delegated medical functions.

Two previous evaluations of the Program (Chan, 1990; Wachtel, 1992) did not, according to the nurses, address areas helpful in informing and influencing their practice. Also, several changes were made to the Program since these were conducted. Both studies used mainly quantitative methods. Chan administered a structured questionnaire to 86 street people and Wachtel primarily analyzed client contact records. The nurses wanted

Originally published in CJNR 2000, Vol. 32 Nº 1, 17–38

to have the nature of their work and its challenges described so that it was visible, and they wanted to have the impact on clients described. As Cohen and Kibel (1993, cited in Julian, Jones, & Deyo, 1995) suggest, in complex, natural environments, traditional evaluation questions related to cause and effect are less important than questions related to impact. Cohen and Kibel define key evaluation questions in terms of understanding the environment in which programs are implemented and tracking progress towards the achievement of specific outcomes.

The goal of the present evaluation was to describe the work of the street nurses and the challenges posed by that work from the perspective of the nurses and others (including clients), and to identify changes resulting from the nurses' work. It was believed that such an analysis would help the street nurses articulate their role and their contributions and identify ways in which the Program might be made more effective. The description of the nurses' work might assist others wishing to offer community outreach services and might help identify gaps in service. This article describes the impact of the nurses' work on clients.

The Program

The primary mandate of the Program is prevention of HIV and STD within a broader context of harm reduction and health promotion, with a focus on the South and Eastside areas of downtown Vancouver. The target populations are marginalized, hard-to-reach, and high-risk street-involved adults and youth; non-street-involved gay, lesbian, bisexual, and transgendered populations; and refugees and immigrants at risk for HIV and STD who may or may not be street-involved. The target population is not homogeneous. The Program also serves as the provincial training site for STD/AIDS outreach programs.

The Program increased from 7.5 street nurses (Full Time Equivalent — FTE), one administrator, and one clerk in 1994; to 8.5 street nurses and two health-care workers in 1995; to 11 street nurses (FTE), two administrators (FTE), two health-care workers (FTE), and two clerks (FTE) in 1998/99.

The nurses and health-care workers go where the clients are, in addition to having established sites of contact such as jails, detoxification centres, clinics, and drop-in centres. Nurses also go door-to-door in single-room occupancy (SRO) hotels and make on-the-street contacts both on foot and via mobile van. The Program is operated by the STD/AIDS Control Division of the British Columbia Centre for Disease Control (BCCDC). Formerly a division of the Ministry of Health, the BCCDC is now part of the Greater Vancouver/Richmond Health Board.

Harm Reduction

The concept of harm reduction embodies beliefs and values that provide direction for social policy, programs, and interventions related to the unintended effects of the use of psychoactive substances (Drucker, 1995; Riley, 1993). Harm reduction has been most often associated with efforts to control the spread of HIV infection among injection drug users (IDUs) and more recently in slowing the rates of hepatitis C infection in the same population (Drucker, 1995).

Beliefs and values surrounding the use of non-medical drugs range from a prohibitionist/abstinence perspective to a legalization/decriminalization-of-drugs perspective (DuPont & Voth, 1995). While most of the recent discourse has focused on the use of illicit drugs, the notion of harm reduction is also applicable to tobacco and alcohol use — for example, driving-under-the-influence laws (Griffin, 1997). Prohibition was the predominant model in the last century until the 1960s when the world saw a proliferation in the availability and use of illicit drugs (DuPont & Voth, 1995). The appearance of the AIDS epidemic among the IDU population in the 1980s raised serious questions about the effectiveness of existing drug policies (Drucker, 1995).

Harm reduction encompasses a range of strategies such as addiction treatment (including methadone maintenance), needle-exchange programs, education in safer drug use and safer sexual practices, and reformation of public policy and drug laws (Drucker, 1995). Nurses in the Program are directly involved in needle exchange and in educational measures directed towards safer drug use and safer sexual behaviour. They are indirectly involved in the referral of clients to addiction treatment programs and in the support of clients in those programs.

Methods

An Evaluation Advisory Committee (EAC) was established comprising representatives of the street nurses, the project coordinator hired for the evaluation, and the evaluators. Both qualitative and quantitative methods were used in this participatory evaluation. Participatory research was deemed appropriate because of its emphasis on collaboration (Erlandson, Harris, Skipper, & Allen, 1993). Qualitative methods are particularly appropriate in responsive evaluation because of their openness and sensitivity to the diverse perspectives of various stakeholders (Patton, 1987). The qualitative methods used in this evaluation included semi-structured interviews and focus groups as well as content analysis of relevant Program documents, such as BCCDC annual reports, for additional information.

Table 1 ***Client Groups Interviewed***

Client Group	**Number**
Female IDUs and sex trade workers	3
Male IDUs	7
Male/transgendered sex trade workers	6
Mobile outreach home-visit client	1
Street youth	6
Bute Street clients	2
Jail	2
Detox client	1
Latino outreach client	1
Francophone client	1
Southeast Asian client	1
Ex-clients	1
Total	32

A series of nominal group-process sessions conducted by the EAC identified key client groups and service providers to be interviewed. Interviews and focus groups were held with four main groups involved with the Program: clients (*n* = 32), street nurses (*n* = 17), other service providers (*n* = 30), and representatives of other HIV/STD programs in the province of British Columbia (*n* = 5) (Table 1). A total of 63 interviews were conducted with 84 individuals; these included 50 individual interviews, four client focus groups, four street nurse focus groups, and five service provider focus groups. Several of the client interviews were conducted in languages other than English.

Clients interviewed were representative of the various target groups of the Program. They were recruited through contacts with the street nurses or approached individually. Clients received a small remuneration for their participation in the study. Interview locations ranged from SROs in the Downtown Eastside to the British Columbia Correctional Centre for Women. In addition, individual interviews were conducted with six street nurses to provide further clarification in several areas. The interviews, which ranged from 30 minutes to 2 hours in length, were taped and transcribed and, if appropriate, translated. All participants were fully informed and gave their written consent. Procedures were approved by the University of British Columbia Ethics Committee.

Interview questions were developed in consultation with the EAC. Client questions that focused on impact included: (1) As a result of your work with the nurses, has anything changed for you? (2) What kinds of things have you learned from the nurses, and what have you done with that information? (3) Has your work with the street nurses changed how or which services, including health-care services, you use? If so, describe the changes.

Interview questions for the street nurses and other providers focused on client changes they believed to be a result of the Program. They were asked for case examples to help describe those changes, in order to obtain both general perspectives and perspectives related to changes in particular clients. The client situations described by the nurses and other providers did not necessarily refer to the same clients who were interviewed.

The transcriptions were read carefully. Although the data were generally segmented by responses to interview questions, any comments in the interviews relating to changes that might have resulted from the nurses' work were included in the analysis of impact. Open coding was used to identify ideas, and further analysis reflected higher order themes. Constant comparative analysis was used to help clarify and refine (Strauss & Corbin, 1990). The team met to discuss the categories and to further refine and define them, as well as to increase the specificity of the codes and to develop higher order themes. Trustworthiness and rigour were supported by clarifying the decision trail (auditability), staying close to the informant's words, using quotations in presenting the results (credibility), discussing themes as they were identified, and supporting evidence with the team and others (fittingness) (Denzin & Lincoln, 1994; Lincoln & Guba, 1985). This process facilitated identification of properties and dimensions and verification of fit.

Findings

To help put the findings on the impact of the nurses' work into context, the themes that emerged on the nature of their work will be identified and briefly described. Further description of the nature of the nurses' work can be found in Hilton, Thompson, and Moore-Dempsey (1999, 2000). All participants contributed to an understanding of the nature of the nurses' work. Reaching marginalized populations at high risk for HIV/STDs focused on the nurses' accessibility, consistency, and flexibility in going where the clients were and establishing contact. Building and maintaining trust, respect, and acceptance focused on the nurses' provision of care in a user-friendly, non-threatening, non-judgemental way. Working towards HIV/AIDS/STD prevention, early detection, treatment, and referral focused on promoting harm reduction within a holistic framework — working with the client's agenda first; educating for harm reduction; testing, monitoring, and contact tracing for HIV/STD, tuberculosis, and pregnancy; providing resources such as needle exchange and condom distribution; and dealing with other care issues such as vein maintenance, wound care, and first aid. Connecting clients with and helping them negotiate the health-care system focused on the nurses' role in providing instrumental and emotional support. The nurses' work also reflected their role in influencing the system and other people to be responsive to the needs of the target population.

Changes Due to the Nurses' Work

Many Program-related changes were identified, but nurses commented on the difficulty of evaluating the impact of their work because of clients being influenced by many powerful factors. To make a significant impact, the Program would have to address core issues such as addictions, poverty, housing, and employment — issues that it could not effectively address in the short term. The nurses also found it difficult to evaluate change because it was impossible for them to know what happened to clients in the long term. As one nurse said, "Did they move out? Did they die? Did they clean up their act? We never know, but it's changing all the time." Nurses also explained that their expectations became more realistic after they had worked in the Program for a while:

> *I'm going to hand out a whole bunch of condoms — that's going to solve the problem? I mean, that's called a finger in a very large dike. There's no way that can happen, because you have to go for a core behaviour change before you're going to get anywhere, and you're not going to get core behaviour change in a short or long period of time... Survival is the biggest thing down there, so AIDS has never taken a big front seat, so in order to be able to offer services you're going to have to deal with what's going on and then get to what it is you need to get to, and that happens over and over and over again with every interaction.*

In spite of these challenges, results of the nurses' work were identified by clients, other service providers, and the nurses themselves. Their work also affected other services and programs. Its impact on clients reflected the theme *taking one step at a time.* Changes occurred both directly and indirectly. Clients were quite clear on how the street nurses' work impacted on them, reflecting a progression from knowledge changes through to behaviour changes related to primary and secondary prevention through to health promotion (Figure 1).

Major areas of nurses' impact on clients were reflected in the following themes: knowing more about HIV/AIDS/STDs, their own situation, and their options; receiving essential supplies to reduce harm and promote health; changing behaviour to reduce disease transmission, improve resistance, and promote health and well-being; connecting with

Figure 1 ***Client Changes Reflecting a Process of Enablement***

Changes in major indicators of morbidity and mortality
↑
Major changes in drug use
↑
Being healthier with or without HIV
↑
Early attention, leading to less severe problems
↑
Influences others
↑
Feels supported
↑
Changes in feelings about themselves and others
↑
Connects with help or care
↑
Changes behaviour, reducing disease transmission,
improving disease resistance, promoting health and well-being
↑
Receives supplies to promote harm reduction
and health promotion
↑
Knows more about HIV and STDs, their own situation, options

help or care; changing feelings about themselves and others; feeling supported; influencing others; receiving earlier attention, thereby reducing the severity of problems; being healthier with or without HIV; making major changes in drug use; and changing indicators likely reflective of decreased morbidity and mortality. Each of these themes will be described using supporting quotes and information.

Knowing more about HIV/AIDS/STDs, their own situation, and their options. As a result of the Program, clients were more aware of and more knowledgeable about HIV/AIDS/STDs, risk behaviours, transmission, prevention, and harm reduction; other health problems and concerns; the availability of resources/services in general and those specific to the individual client; their own health state/situation; and how to care for themselves and make better health-care choices. Because efforts were made to provide services in languages other than English, these changes were noted in clients from diverse cultures. Their new awareness and knowledge helped clients to clarify misconceptions, but they did not necessarily apply all their newly acquired information. Making behavioural or attitudinal changes reflected higher levels of Program impact. Comments from clients included the following:

> *I know my health status: before, I didn't. When I was hustling. Before I got involved with them [street nurses] and got any tests done I had no clue whether I was positive or negative for any disease and now at least I know, and that's definitely a direct result of them.*
>
> *You shouldn't share your water without bleach…they give you a little paper with all this stuff on it and they sit down and talk about it and tell you what not to use…you should always clean before you inject.*

Receiving supplies to reduce harm and promote health. Clients received supplies, such as condoms, bleach, and clean needles, for the prevention and transmission of disease. They also received medicines for the alleviation of discomfort and the promotion of health. These helped promote behavioural change; without them, change was not likely to occur.

In 1997/98 the Program distributed 386,067 needles; in 1999/2000 a projected 407,664 will be distributed (British Columbia Centre for Disease Control [BCCDC], 1998/99). In 1997/98 the return rate of needles exchanged was high, 391,910 — more than were distributed. The street nurses also instituted a bulk needle exchange to better meet the needs of IDUs who require a larger number of needles, partly because these clients were less likely to access exchange locations consistently.

Bulk needle exchanges also make secondary needle exchange possible. Secondary needle exchange occurs when nurses exchange needles for IDU peers unwilling or unable to access the services of street nurses. Other providers saw bulk exchange as a counter-productive strategy, whereas the nurses saw it as an appropriate strategy for increasing the likelihood of IDUs using clean needles each time they injected.

Changing behaviour to reduce disease transmission, improve resistance, and promote health and well-being. Influencing behavioural changes in the marginalized, hard-to-reach population is an important step in preventing and reducing disease transmission and improving health. It is not easy to initiate behavioural changes in this population, yet clients said they did things differently because of the nurses. These behavioural changes were key to reducing disease transmission, increasing resistance, and promoting improvements in health and well-being. Clients changed their habits related to needles, drugs, and condoms. They described themselves as using safer injection techniques more often, using condoms more often, managing wounds more effectively, and using drugs in a less dangerous manner. Clients said they now used new needles "every time," were more careful about sharing needles, and used condoms more consistently. One client said he would "never again" share needles. Another said he had been using condoms incorrectly until seeing the nurse demonstrate proper use. Another stated, "I would never do it without a condom," while another spoke about changing his injection methods. A street youth said, "I cleaned up my act when I learned my HIV status" from the nurse. Although it is not possible to know the number and consistency of these behavioural changes, it was evident that positive changes had come about as a result of the nurses' work and that these changes would lead to a decrease in disease transmission. The street nurses and other service providers corroborated each other's testimony on changes in risk behaviours.

Clients also said they looked after themselves more, had improved diets, and were taking better care of their bodies. They requested information on how to care for themselves. The nurses indicated that clients were making healthier choices, staying on their medications, and following routines. One of the nurses said, "I've seen clients go from living on the streets to being able to find, if not necessarily the best housing, at least some form of housing...and being able to find other options in terms of nutrition and how to feed themselves more adequately."

Connecting with help or care. The nurses also connected clients with resources. Clients had better access to care, increased STD and HIV testing, earlier diagnosis, and access to mainstream services. Reports indicated that street nurse encounters numbered approximately 45,000 annually, of which 8,500 related to clients with STD or HIV (BCCDC, 1999). The Program accounted for 11% of all STD visits in the province (BCCDC, 1997, 1998/99).

Because of the Program, many clients were tested and subsequently treated for HIV and STDs. Of all positive HIV tests in British Columbia (3,101, out of 140,278), the street nurses identified 10% — a clear indication of an effective program facilitating early treatment (BCCDC, 1997, 1998/99). In addition, the Program served to identify other STDs, many of which would have gone undetected for long periods, often leading to further complications. In 1997, 2,040 STD clients were seen in the Program (1,260 males, 767 females, and 13 transgendered persons). Of the 2,010 people screened for STDs, 776 were diagnosed with a variety of STDs, some particularly serious — and the sooner treatment is begun the better, not only for the affected clients but also for those to whom they might transmit. The return-visit rate of clients after testing was excellent, ranging from 76% to 87% at various clinic locations.

The nurses were also effective in helping providers, such as Tuberculosis Control, to locate clients and contacts requiring follow-up. Service providers were very clear about the important role of the nurses in connecting and following up with clients who were hard to locate, those "no one else could find." One of the nurses spoke about a client who had returned, after several years, to be treated for HIV:

> *You are trying to fit them in [to services] so that it would be helpful for them, but they make that decision. They're the ones that initiate that, but they know that you're there for them. It doesn't matter how many times they screw up or whatever happens to them, they can come in and sit down and talk to you and say, "Look, this is what is happening and I'm ready. I think I'm ready to change," and it happens. It's amazing how that happens sometimes. You haven't seen someone for years. Someone I hadn't seen for 8 years who was HIV positive — she was just a young girl, 15, [and she] showed up at the clinic one day and said she remembered me and "I'm ready to do something about being HIV positive, now, what shall I do?" So we must make an impact somewhere for someone to do that and for her to know that she feels really comfortable doing that — no judgements.*

The nurses provided clients with many services besides STD and HIV testing. They effectively addressed counselling and follow-up care, wound and abscess care, and crises such as thoughts of suicide. Clients became connected with mainstream services when they needed them and with health and social service providers that were acceptable to them. Because the nurses helped them negotiate the health-care system, the clients were more likely to receive the care they required. High-priority clients — for example, those with bleeding wounds or showing indicators of endocarditis — received more immediate attention.

Several case studies revealed the nurses' part in making those connections. Many clients would not have accessed care otherwise, or would have taken longer to access care, or would have only reluctantly gone to a clinic or sought out a service. Clients were asked what they would have done had the street nurses not been there. Several indicated that they would not have gone elsewhere: "If I can't see a nurse, well, too bad. I'll take care of it myself." "I'd have nowhere else to turn to get anonymous testing." Others said they would have taken longer to access care, waiting until the situation worsened: "I know I couldn't go to my regular doctor and talk to him or to any of the nurses [in other programs] because they just, like I said, they just look at me as sort of, 'oh, you're an ex-junkie,' you know." "I probably wouldn't go for a pap smear until something felt weird." Others indicated that they would have used other resources, though in some cases only reluctantly: "I can open up with the nurses, but I cannot fully open up with the doctor, the doctor is not the same."

Changing feelings about themselves and others. Clients spoke about how their work with the nurses made them feel better about themselves and others. Gaining trust in marginalized populations is a challenge that must not be underestimated. Once the nurses had gained their trust, clients were more likely to be open to having their health issues, including HIV and STD, identified and dealt with, and more likely to accept and complete recommended treatment. Once trust was established, clients were also more likely to incorporate suggested harm-reduction strategies into their lifestyle.

After working with the street nurses, clients felt more positive about themselves, more trusting of other people, and more valued. They had a greater sense of self-respect and dignity, hope, and belief in themselves. One client said that the nurses "make me feel safe and I trust them... Somebody accepts me for who I am and even though some of my choices and those decisions aren't right, it's still OK." A woman in a correctional facility stated:

> *I'm OK even having HIV. They've given me that strength to believe that I can still be all of who I am with HIV...from nutrition to, like, all the things that go along with HIV and guiding me throughout like that time and you still come back and even so sometimes I wouldn't go there myself. Like, they've come out on the street looking for me. They work to bring me to the doctor. There was times that I had no hope left and stuff like that and they always been there to build me back up to say that things are going to be OK. Like, they do get better from here and at times when I know I need it because sometimes I don't have any hope and I just want to say forget it and I'd rather just be dead and I'd rather just OD and just being there sometimes, yeah, just opens up like more light like a whole new world kind of thing because you can just start again right from where you are and just look at what was going and keep on going.*

In addition to the street nurse, some clients gained trust in others whom they would not have trusted previously. Gaining trust with one street nurse was important, but being able to extend that to other street nurses and other service providers was a significant shift.

> *I didn't trust anybody enough to let them into my life like that. I didn't. I guess because of fear and because I just didn't want them to know too much about me, and then slowly [because the same street nurse was not*

> *in the clinic all the time] for [names another street nurse] to look at and take care of me and assist.*

Feeling supported. Because clients felt accepted and supported, they were able to follow through with plans such as entering alcohol or drug detoxification centres, staying off drugs, commencing methadone maintenance, or going to the hospital for tests. Clients knew the nurses were there if needed. Clients felt accepted, whether or not they were successful in their attempts to change their behaviour. This acceptance influenced their participation in their own health care. A service provider said that when one woman who had been in and out of recovery houses ended up on the street again, the woman felt that the street nurses, unlike others, had not judged her for it. The nurses' unique attitude made her want to go back to them for support and medical care. In several other situations as well, clients said they felt it was acceptable to return to the nurses, but not to others, if the clients had — in their own eyes — failed in some way.

Influencing others. Several clients spoke about influencing others to go for HIV/STD testing and to seek assistance with their health-care needs. They did so through encouragement and support, through volunteering, and through teaching. A Spanish-speaking client said: "I could also accompany them [Spanish-speaking persons]. If one of the nurses could not speak Spanish, I could help translate. I want to help other people to know about the services that the nurses give."

Clients influenced others through one-on-one contact and were clearly proactive in making major system changes. One client was influential in having the street nurses first go to the women's correctional facility. Another client developed an excellent instruction packet for new staff about cocaine: how to prepare it for smoking and how to make a pipe.

Receiving earlier attention, thereby reducing the severity of problems. Early attention to health-care concerns can avert more severe problems. Because of the nurses, infections and abscesses were identified and treated early on. In some cases, endocarditis likely was prevented because of timely intervention. Although some conditions required emergency treatment and hospitalization, others were managed outside of hospital by the nurses, in some cases avoiding more serious problems that would have required hospitalization. Clients said they prevented or minimized problems by "fixing properly," "not tying too tight," and "doing proper vein maintenance." A service provider said:

> *The nurses have circumvented what could have been catastrophes. You see things that if a nurse hadn't gotten on to right away, it could have been a serious problem, and the nurses are more than just nurses. They're part*

> *counsellors... [A client] had slashes going up her arms...and you could see these marks going up...this kid was not aware. She thought it was a bruise. She wasn't really concerned with it at all, and this was a Thursday night...What would have happened if she had not seen a nurse? She could have died. It just could have become that much more serious... I had this kid that had a really bad abscess on the top of her hand and she was on the way to blood poisoning. It took a nurse to say, look, this is bad and you have to come with me.*

Being healthier with or without HIV. Clients, nurses, and other service providers spoke about clients being healthier because of the Program; they were looking after themselves. Service providers commented that they "often see people start to improve health-wise just because they got that contact [with the street nurses] and they've got someone they can ask questions of and someone who can guide them." Even when clients were using drugs, they indicated that they felt healthier. As one nurse said, "One thing that we might have made a difference in is keeping them healthier during the time that they were using, or maybe helped them prevent catching HIV while they were using." Nurses also noted that they were seeing fewer wounds, likely because clients were using better injection methods. One client stated, "I was losing weight because of the dope I did and now I've been clean for a while and I'm gaining my weight back. I'm now riding a bike. I'm healthy."

Making major changes in drug use. Some clients, nurses, and providers linked the Program to major changes in drug-use behaviour. These changes would likely have been greater had sufficient detoxification beds or other addiction services been available, although nurses were working with some clients in home detox. A service provider said:

> *I'd love to say that the outcome of the street nurse program is that people get off the street and move to suburbia...that does happen and we know that, but because most of us work in that area we don't necessarily see those people...a lot of success stories get lost because of where we're situated...people don't necessarily want to come back downtown and say...I'm doing great...Those people might not be in contact with us any more.*

Although this result was not universal, several clients spoke of major changes in their drug use. Some had been clean for a period of time — for example, 3 months off dope; some said the street nurses were instrumental in getting them off drugs. A service provider also made the connection: "One thing we've certainly seen in any number of the patients is perhaps a reduction in drug use, using drugs in a manner that's less dangerous, in a safer manner." The nurses also recounted stories of successful entries to detox and of people who had "gone straight."

Changing indicators likely reflective of decreased morbidity and mortality. From the perspectives of clients, nurses, and service providers, changes in morbidity and mortality were likely, although it is difficult to quantify those outcomes. Clients said they felt better and had less pain and discomfort because of medications they had received through the Program. They also said the Program was responsible for their not getting AIDS. "If it wasn't for this place, I would have AIDS." Nurses likely played a part in reducing the magnitude of the HIV epidemic because of their effectiveness in tracking and testing clients. There were fewer conversions to HIV positive (seroconversion) because clients used condoms and practised safer sex. One service provider was very clear on the incidence of HIV and the positive impact of the Program.

> *What we've seen is a slow decline in [HIV] incidence among men who have sex with men, one of the target populations. We're still seeing new rates of seroconversion, but every year since the program began we've seen a drop in their rates...but we're not down to an elimination of transmission... What we've seen in the street kids is a decline or a levelling in the heterosexually transmitted HIV. I'd say there's been a pretty good impact there... I think the nurses are responsible for reducing one of the major co-factors for transmission, genital ulcer disease...genital ulcer disease is responsible for increasing the transmission of HIV heterosexually sixfold...[the nurses] are bringing a lot of reality testing for people in terms of making...HIV testing much more available... There's a low level of sexually transmitted disease compared to a few years ago.*

Some clients believed they were alive because of the nurses: "If it wasn't for the street nurses, I would probably be dead. I really believe that." "If it wasn't for Street Youth Services and the street nurse I probably would have ended up killing myself that night." Prevention of HIV through harm-reduction strategies results in fewer AIDS cases, and early diagnosis/treatment of HIV considerably extends the period between then and the development of AIDS. Assisting and encouraging clients to take better care of themselves promotes health and prevents disease. Although it is not possible to tease out the influence of the Program from other services and the use of triple-drug therapy, the AIDS mortality rate has decreased considerably since 1992: from 241 in 1992 to 11 in 1997; in addition, reported AIDS cases decreased from 296 in 1993 to 101 in 1998 (BCCDC, 1999), and the HIV-positive rate per 100,000 population decreased from 30.46 in 1987 to 12.09 in 1998.

The Program has also influenced other people, services, and programs. For example, the nurses' observations were important in identifying new outbreaks and epidemics, such as levels of syphilis and hepatitis C, and in influencing studies and program changes at the STD Control Division and the BCCDC. Program workers persuaded others, including key members of the drug-trafficking world, to make changes, changes that could have a direct and positive impact. For example, drug dealers agreed to stop selling drugs to youth in the area, although it is not known whether the agreement was honoured, or for how long.

Discussion

The impact of the Program's street nurses can best be understood in the context of health promotion and the concepts of empowerment and enablement. The *Alma-Ata Declaration* states that health promotion is the process of enabling people to increase their control over and improve their health (World Health Organization, 1978). The *Ottawa Charter for Health Promotion* states that "health promotion is the process of enabling people to increase control over, and to improve, their health...an individual or group must be able to identify and to realize aspirations, to satisfy needs, and to change or cope with the environment" (World Health Organization, Health and Welfare Canada, & Canadian Public Health Association, 1986).

However, as McKnight (1985) states, it is impossible to produce health among the powerless. It is possible only to foster health by transferring tools, authority, budgets, and income to the powerless. Thus the Program had to empower the clients.

The term *empowerment* has been used widely. Though its definition varies, a core set of values and meanings has certainly been agreed upon. To empower is to give official or legal power or authority, to endow with ability, to enable. To enable means to authorize, to empower, or to make possible or effective (Rodwell, 1996). Both words connote the transfer of authority, knowledge, skills, resources, opportunities, and anything else necessary in granting someone the ability to do something they were previously unable to do.

In the context of health promotion, empowerment is a helping process that respects and values individuals and is intended to develop belief in oneself and one's future. At its core, enablement alters the distribution of power, but it also recognizes that power over one's health and well-being originates in self-esteem. Individuals make choices and must accept responsibility for their actions. Thus health-care professionals cannot empower people; people have to empower themselves; what health-care workers *can* do is provide the resources, skills, and opportunities necessary to develop the client's sense of control.

If this transfer of resources, skills, and opportunities is to be fruitful, it must take place in an atmosphere of mutual trust and respect, education and support, participation and commitment (Rodwell, 1996), and power-sharing (Gibson, 1991).

This trust and respect must flow both ways; the power in the caregiver–client relationship must be shared. Health-care professionals need to surrender control or risk fostering dependence. They need to accept the fact that clients will sometimes make decisions counter to what the health-care professional wants for them. In fact, clients may reject their help altogether, and it is their right, as free cognizant human beings, to do so. In such a process, outcomes depend on individual differences; specifically, they depend on the client's growing self-awareness (Labonte, 1989) rather than on the services provided. In other words, the success of the step-by-step process of empowerment (with occasional backsliding) cannot be defined in any single way; it needs to be defined by the people concerned (Rappaport, Swift, & Hess, 1984).

The literature consistently identifies the following concatenation of benefits as outcomes, impact, or products of empowerment: positive self-esteem or self-concept, the ability to set and reach goals, a sense of control over life and change processes, a sense of hope for the future (Rodwell, 1996; Zimmerman & Warschausky, 1998), a sense of connectedness, self-development, social justice (in that people's choices have been respected), and an overall improved quality of life (Gibson, 1991). Gibson also indicates that an empowerment approach minimizes the client's sense of indebtedness.

These instilled or enabled personal attributes engender self-determined, independent health-promoting behaviours (Ellis-Stoll & Popkess-Vawter, 1998; Zimmerman & Warschausky, 1998). They enable individuals to become well and whole, to develop potential, to develop quality of life, or, if necessary, to let go of life (Jones & Meleis, 1993).

Needless to say, groups with the least power tend to be the ones most difficult to empower (Jenkins, 1991). This poses a challenge because it is precisely the most powerless groups, such as the chronically poor and the homeless, who experience the worst health (Rissel, 1994; Winkle & Ward-Chene, 1992).

In the AIDS Prevention Street Nurse Program, the nurses work with a complex and marginalized population, clearly a challenge in enabling positive health changes. However, the results of the evaluation show that the Program has enabled clients to make changes towards preventing HIV/AIDS and STDs, reducing harm, and promoting well-being. The changes reflected increasing levels of application and complexity, from promoting awareness, knowledge, and greater understanding to facilitating behavioural and attitudinal changes, which in turn promoted changes in health, illness, and disease transmission and resistance (see Figure 1).

Within a framework of non-judgemental care, trust, and respect, the nurses assisted and enabled clients to take one step at a time in becoming more aware of their health, factors influencing their health, and how to more effectively look after their health. Clients became connected to appropriate services and health-care providers and dealt with health situations at an earlier, less serious stage. The nurses helped prevent the transmission of HIV/AIDS and STD, and they assisted HIV-positive clients in increasing their longevity. Positive changes in clients' emotional and psychological well-being were also quite evident and reported by clients to be a result of the nurses' work.

At various points in the study, both the nurses and the clients stressed that the Program's benefits progressed through a series of stages, stages that are consistent with the "hierarchy of changes" described by Cohen and Kibel (1993) and consistent with the process of empowerment.

The nurses had to first generate interest and prove "effects"; then consolidate those effects into "gains" — sustained changes in knowledge, skill, attitudes, or behaviours; then get the clients to "buy in" — that is, to commit to implementing a problem-solving approach to their health. The third level in the process is "capacity enhancements" — actual changes in individual or organizational practices that prevent the onset of or reduce the severity of problems. The fourth level is "outcomes," or observable changes in the behaviour of target populations. The fifth and final level is "impacts" — the changes in social indicators reflecting reductions in problems. All of these levels of results were noted in the AIDS Prevention Street Nurse Program.

Though many of the clients seen by the street nurses remained in poor health, they demonstrated a "health within illness" perspective that emphasizes non-physical dimensions of well-being (psychosocial, social, and spiritual) that may increase or strengthen during the experience of an illness or transition (Moch, 1989). These clients grew in self-esteem, in their sense of control and understanding of their illnesses, and in their acceptance of their condition. Clients reported that these perceptions improved their quality of life.

When nursing interventions empower individuals or groups to develop their health potential, the nursing profession contributes significantly to achieving health for all.

However, the findings of this report must be interpreted in the light of limitations evident in the study, primarily due to the pragmatics of conducting such an evaluation. The limitations pertain more to the client group than to the nurses or other providers. Only those clients who consented to participate in the study were heard from directly, through their own input. Because the clients were from a marginalized and difficult-to-reach population, they presented more challenges than usual in having their voices heard. It may be that those who had negative experiences in working with the nurses were not heard from adequately; however, every effort was made to register the variation in voices. Although several efforts were made to include ex-clients, this was not feasible because there was no way of contacting them. In addition, even though the investigators made the best use of the resources that were available, the evaluation had only limited funding. In spite of these limitations, we believe the sample is reasonably representative of the thoughts and concerns of nurses, other providers, and clients.

In conclusion, the results of this evaluation reflect the effectiveness of the AIDS Prevention Street Nurse Program in encouraging clients to take one step at a time towards preventing HIV/AIDS and STDs, reducing harm, and promoting well-being. A single program is not likely to result in significant change at the community level, and should be viewed in terms of its contribution to the achievement of broader community outcomes (Cohen & Kibel, 1993). Many core issues cannot be addressed by programs such as the AIDS Prevention Street Nurse Program. It is just one of many that work with this particular client population. For maximal effectiveness, all parties concerned should take advantage of every opportunity for partnering, coordinating, and collaborating on current and future health-care delivery. The AIDS Prevention Street Nurse Program is identified by the Vancouver/ Richmond Health Board and other user agencies as a good example of partnering and collaborating with clients and with other programs in the downtown areas of Vancouver. It is often cited as an example of successful community collaborating and partnering.

References

British Columbia Centre for Disease Control. (1997). *AIDS update, quarterly report: Third quarter, 1996.* Vancouver: Government of British Columbia, Ministry Responsible for Health and Ministry Responsible for Seniors.

British Columbia Centre for Disease Control. (1998/99). *BC Centre for Disease Control business plan 1998/99.* Vancouver: Author.

British Columbia Centre for Disease Control. (1999). *HIV/AIDS update, year end 1998.* Vancouver: Author.

Chan, S.L. (1990). *Program description, review, and survey of the effectiveness of service provided by the Ministry of Health's Outreach Program.* Master's thesis, University of Victoria, British Columbia.

Cohen, A.Y., & Kibel, B.M. (1993). *The basics of open systems evaluation: A resource paper.* Chapel Hill, NC: Pacific Institute for Research and Evaluation.

Denzin, N., & Lincoln,Y. (Eds.). (1994). *Handbook of qualitative research.* Thousand Oaks, CA: Sage.

Drucker, E. (1995). Harm reduction: A public health strategy. *Current Issues in Public Health, 1,* 64–70. Available online: www.lindesmith.org/library/tlcdruck.html.

DuPont, R., & Voth, E. (1995). Drug legalization, harm reduction, and drug policy. *Annals of Internal Medicine, 123,* 461–465. Available online: www2druginfo.org/orgs/dsi/Legalizit/voth.html.

Ellis-Stoll, C.C., & Popkess-Vawter, S. (1998). A concept analysis on the process of empowerment. *Advances in Nursing Science, 21*(2), 62–68.

Erlandson, D.A., Harris, E.L., Skipper, B.L., & Allen, S.D. (1993). *Doing naturalistic inquiry.* Newbury Park, CA: Sage.

Gibson, C.H. (1991). A concept analysis of empowerment. *Journal of Advanced Nursing, 16,* 354–361.

Griffin, S. (1997). *Do no harm.* Available online: www.realsolutions.org/dono harm.htm.

Hilton, B.A., Thompson, R., & Moore-Dempsey, L. (1999). *Urban outpost nursing – Taking one step at a time: An evaluation of the AIDS Prevention Street Nurse Program.* Unpublished report, University of British Columbia, Vancouver.

Hilton, B.A., Thompson, R., & Moore-Dempsey, L. (2000). *Urban outpost nursing: The nature of the nurses' work in the AIDS Prevention Street Nurse Program.* Unpublished manuscript.

Jenkins, S. (1991). Community wellness: A group empowerment model for rural America. *Journal of Health Care for the Poor and Underserved, 1,* 388–404.

Jones, P.S., & Meleis, A.I. (1993). Health is empowerment. *Advances in Nursing Science, 15*(3), 1–14.

Julian, D.A., Jones, A., & Deyo, D. (1995). Open systems evaluation and the logic model: Program planning and evaluation tools. *Evaluation and Program Planning, 18*(4), 333–341.

Labonte, R. (1989). Community and professional empowerment. *Canadian Nurse, 85*(3), 23–28.

Lincoln, Y., & Guba, E. (1985). *Naturalistic inquiry.* Beverly Hills, CA: Sage.

McKnight, J.L. (1985). Health and empowerment. *Canadian Journal of Public Health, 76*(Suppl), 37–38.

Moch, S.D. (1989). Health within illness: Conceptual evaluation and practice possibilities. *Advances in Nursing Science, 11,* 23–31.

Patton, M.Q. (1987). *How to use qualitative methods in evaluation.* Newbury Park, CA: Sage.

Rappaport, J., Swift, C., & Hess, R. (1984). *Studies in empowerment: Steps toward understanding and action.* New York: Haworth.

Riley, D. (1993). *The Harm Reduction Model: Pragmatic approaches to drug use from the area between intolerance and neglect.* Canadian Centre for Substance Abuse. [Online.] Available: www.ccsa.ca/harmred.htm.

Rissel, C. (1994). Empowerment: The Holy Grail of health promotion. *Health Promotion International, 9*(1), 39–47.

Rodwell, C.M. (1996). An analysis of the concept of empowerment. *Journal of Advanced Nursing, 23,* 305–313.

Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques.* Newbury Park, CA: Sage.

Wachtel, A. (1992). *Street Nurse Program: Final Report – Program assessment and review of the AIDS Prevention Vancouver Street Nurse Outreach Program.* Vancouver: Ministry of Health, Division of STD Control/Social Planning and Research Council of British Columbia.

Winkle, C.R., & Ward-Chene, D.G. (1992). Power, social support and HIV-related service use: The roles of community and homelessness. *Journal of Health and Social Policy, 4,* 47–72.

World Health Organization. (1978). *Alma-Ata Declaration.* Copenhagen: Author.

World Health Organization, Health and Welfare Canada, & Canadian Public Health Association. (1986). *Ottawa Charter for Health Promotion.* Ottawa: Canadian Public Health Association.

Zimmerman, M.A., & Warschausky, S. (1998). Empowerment theory for rehabilitation research: Conceptual and methodological issues. *Rehabilitation Psychology, 43*(1), 3–16.

Acknowledgements

The authors would like to thank the clients, service providers, and street nurses who participated in this evaluation. In addition, the authors would like to thank Caroline Brunt and James Tigchelaar of the Evaluation Advisory Committee, Kylie Hutchinson, Project Coordinator, and Rolly Sidher and Sara Salmon, undergraduate research assistants. The authors also acknowledge the financial support of the British Columbia Centre for Disease Control in carrying out this evaluation.

B. Ann Hilton, RN, PhD, is Professor, School of Nursing, University of British Columbia, Vancouver, Canada. Ray Thompson, RN, MSN, is Assistant Professor, School of Nursing, University of British Columbia. Laura Moore-Dempsey, RN, BScN, was, at the time of the evaluation, Outreach Nursing Administrator, STD/AIDS Control, British Columbia Centre for Disease Control.

2009 update: *B. Ann Hilton is Professor Emerita, School of Nursing, University of British Columbia. Ray Thompson is Assistant Professor Emeritus, School of Nursing, University of British Columbia.*

CJNR 2009, Vol. 41 N° 1, 260–275

Résumé

La divulgation du lesbianisme : le bousculement des a priori

Carol McDonald

Le but de cette enquête interprétative est de favoriser la compréhension de l'expérience que vivent les lesbiennes qui divulguent leur orientation sexuelle. L'étude, fondée sur l'herméneutique gadamérienne et la pensée philosophique féministe, s'inscrit au créneau de la santé des femmes. Selon la perspective féministe de la santé des femmes, l'expérience de la santé est indissociable des expériences quotidiennes de la vie sous toutes ses facettes et est composée des réalités que vit chaque femme sur le plan social, matériel et discursif. L'étude a été réalisée à partir de conversations auxquelles ont participé 15 femmes qui se sont identifiées comme lesbiennes pour les fins de l'enquête, ainsi qu'à partir de témoignages portant sur les femmes dans les médias, et le journal de réflexion de la chercheuse. Les résultats nous font voir de nouveaux points de vue concernant les multiples significations du mot « lesbienne ». Ils invitent vivement le personnel infirmier à considérer les catégories binaires de l'homosexualité et l'hétérosexualité comme des signifiants qui décrivent inadéquatement les réalités vécues par les femmes, à tenir compte des composantes particulières de la vie de chaque femme et à délaisser les a priori hétérosexistes dans le but de réduire l'impact néfaste de l'exclusion sociale, l'isolement, la discrimination et la stigmatisation comme déterminants de la santé.

Mots clés : lesbienne, divulgation, herméneutique, féministe

CJNR 2009, Vol. 41 Nº 1, 260–275

Lesbian Disclosure: Disrupting the Taken for Granted

Carol McDonald

The purpose of this interpretive inquiry was to generate understandings about the experience of lesbian disclosure. The inquiry relied on Gadamerian hermeneutic and feminist philosophical thought and was situated in women's health. In a feminist understanding of women's health, experiences of health are inseparable from the everyday experiences of an embodied life and are constituted within each woman's social, material, and discursive realities. The study was informed by conversations with 15 women who self-identified as lesbian for the purpose of the inquiry, accounts of women in the media, and the researcher's reflective journals. The findings move us towards new understandings about the multiple meanings of "lesbian." They challenge nurses to consider the binary categories of homosexual and heterosexual as inadequate signifiers for the reality of women's lives, to consider the particular arrangements of each woman's life, and to disrupt assumptions of heterosexism in order to reduce the negative impact of social exclusion, isolation, discrimination, and stigmatization as social determinants of health.

Keywords: lesbian, disclosure, heteronormativity, hermeneutics, heterosexism, feminist

Introduction

"The health of a nation, physically and emotionally, can only be as good as the health of its most vulnerable and stigmatized citizens. While culture, class and religion are known to affect how illness may appear and be understood, sexual orientation has been less well researched or understood as a mediator of health and illness." (Forstein, 2003)

In this paper I will report on a study that was intended to open to question our understandings of the interrelationship of lesbian life, the process of disclosure, and experiences of health. In this study the experience of disclosure was understood as central to lesbian life and disclosure was understood as an ongoing process through which a woman makes her lesbian orientation known to herself and to others. The process of disclosure might include overt verbal disclosure, covert or taken-for-granted disclosure, public disclosure, disclosure in relationships, and the decision to withhold disclosure. The breadth of this understanding of disclosure is beyond a temporally located "coming out" event.

Originally published in CJNR 2006, Vol. 38 Nº 1, 42–57

The inquiry was based on an understanding of health that goes beyond a biomedical definition, to the emotional, social, interpersonal, mental, and spiritual realms. Experience of health is not merely the experience of disease or absence of disease from our bodies or our minds. It is increasingly accepted that the social and economic conditions of a person's life influence not only access to health care but the experience of health and illness (Wilkinson & Marmot, 2003). The social determinants of health as identified by the World Health Organization include social and economic realities that construct the environment or context in which a life, including a lesbian life, is lived. Several of these social determinants are particularly important when one considers that the lives of lesbian women are lived in ways that do not conform to the heterosexist social norm. In particular the World Health Organization states that "continuing anxiety, insecurity, low self-esteem, social isolation and lack of control over work and home life have powerful effects on health" (Wilkinson & Marmot, p. 12) and that "social exclusion" resulting from "discrimination and stigmatization" has a deleterious effect on health (p. 16). These threats to health and well-being, constituted in social environments, are particularly significant for the lives of lesbian women as they negotiate their way through a heterosexually determined landscape and face daily decisions regarding the disclosure of their sexual orientation. In addition to the social determinants of health that make up our material world — such as housing, employment, economic realities, social relationships, addiction, means of transport, and circumstances in early life — the experience of health is constituted through the influences of dominant discourses in society that attribute meaning to our lived experiences. The meanings attached to being a lesbian woman in a particular historical context influence the way in which a woman lives her life and the ways in which she and others view her life. It is perhaps these discursive realities that most profoundly affect decisions surrounding disclosure and influence the experience of health and wellness. This conceptualization of social determinants of health — both material and discursive realities — leads one to wonder what it is like for lesbian women to live their lives as a marginalized population in a heterosexist society (Hall, Stevens, & Meleis, 1994; Hitchcock & Wilson, 1992; Misner, Sowell, Phillips, & Harris, 1997; Radonsky & Borders, 1995; Robertson, 1992; Stevens, 1995).

Purpose of the Study

The purpose of the study was to create space for conversations that might generate new understandings of lesbian life as it is lived in a heterosexist society. Disclosure is assumed to be a central and ongoing experience in lesbian life, mediating lesbian identity and dominant heteronormative discourses. It is through disclosure of lesbian orientation that the voice and visibility of lesbian existence come into being. The research question was, then, *What is the experience of disclosure of lesbian orientation in a heteronormative society?*

Self-disclosure of a lesbian orientation is the acquisition of self-knowledge that changes irrevocably how one is situated in the world. This assumption is intended not to support an essentialist belief in a lesbian experience of self-disclosure, but to say that disclosing a lesbian orientation, even to oneself, locates a woman outside of the dominant societal assumptions of heterosexuality.

This experience of being situated outside of heteronormativity raises concerns about the health experiences of lesbian women. The present study was built upon a belief that health is constituted in our experiences of a life lived in a body and in our interpretations of those experiences. Health is constructed as we live our lives in interpersonal relationships, in couples, in communities, and in families. It is enmeshed in our sense of self, our sense of worth, and our sense of belonging; it is embedded in and constituted through our everyday experiences. The experience of living outside of a dominant cultural norm has the potential to affect both one's health and the health care that one receives. It is my assumption that nurses in practice, in education, and in research, as well as other health-care providers, have a limited understanding of the lives of lesbian women and that this lack of understanding compromises the health care that is provided to these women (Mathieson, 1998; Stevens, 1994a, 1994b, 1995).

Background

"All gay people, to one degree or another, travel down the road of coming out to themselves and others about their sexual orientation. The journey lasts a lifetime and is profoundly affected by societal inculcated homophobia." (Scasta, 1998, p. 87)

Disclosure Constructed as Health

The practice literature that addresses lesbian self-disclosure overwhelmingly correlates disclosure with health. Articles that report on research studies (Jordan & Deluty, 1998; Kahn, 1991; Morrow, 1996; Radonsky & Borders, 1995), theoretical articles (Deevey, 1993; Saddul, 1996; Scasta, 1998), and articles that review studies (Taylor, 1999) describe self-disclosure as positively associated with psychological and emotional health and authenticity in relationships. Radonsky and Borders (1995), for example, state unequivocally that "coming out to friends and family…is crucial for self-esteem and self-acceptance" (p. 19). The harmful effects of non-disclosure can include feelings of shame and anxiety, depression, and disrupted interpersonal relationships (Jordan & Deluty, 1998). This picture of disclosure as constitutive of health and well-being is by no means straightforward or uncomplicated. It could be argued that the correlation of disclosure with self-esteem and self-acceptance contributes to a view of non-disclosure as pathological. This is a contentious implication given that the risks of disclosure in a heterosexist society include threats to personal safety, loss of relationships, discrimination in housing, employment, and health care, and irrevocably disrupted family functioning (Gramling, Carr, & McCain, 2000; Radonsky & Borders, 1995; Saddul, 1996; Stevens & Hall, 1988). And so, while self-acceptance and self-esteem are desirable, they are not unconditionally the result of high levels of self-disclosure. The decision whether to disclose is meaningful and understandable in the context of the lives of lesbians, and may even play a role in their mental health. Closely related to this issue is the fact that disclosure has become valorized among some groups of lesbians as exemplifying gay pride and defiance of heteronormative assumptions. This politicization of disclosure, though a reality of lesbian life, is seldom addressed in the literature. The essentializing of disclosure as always the "right thing to do," whether in the name of health or in the name of political ideology, negates the circumstances and experiences of each lesbian life and divests the woman of the opportunity to exercise agency in her own life.

Assumption of Heterosexuality

One cannot understand the experience of disclosure without considering the sociocultural context in which each lesbian life is lived. Heterosexism, which is grounded in the belief that heterosexuality is representative of sexual orientation, fuels the assumption that all women either are or wish to be in sexual/intimate relationships with men. It is a process of oppression through which heterosexual persons are given a privileged position and non-heterosexual persons are considered "other" (Gray et al., 1996).

From a review of the literature it is apparent that there is a pervasive assumption of heterosexuality underlying the health-care structure; the lesbian population is frequently an invisible minority in the health-care system (Hitchcock & Wilson, 1992; Radonsky & Borders, 1995; Robertson, 1992; Stevens, 1995). The assumption of heteronormativity is problematic for women in general and for lesbian women in particular, leaving little space in health care for the reality of lesbian life. The norm of heterosexuality is reflected in sexual and reproductive health-care practices, in demographic forms and interviews, and in the posters and pamphlets found on the walls and on the desks of health services. In research studies published over the past 20 years, lesbian participants report instances of neglect, discrimination, and abuse by health-care providers (Stevens, 1994a, 1994b, 1995) and report that their life experience appears to be poorly understood by those who deliver care (Mathieson, 1998). The experience of being poorly understood is constructed within the dominant discourse of our health-care culture and our society, which presumes heteronormativity.

The work of Stevens and others over the course of a decade indicates that the decision whether to disclose is more complex than the metaphor of being in or out of the closet suggests, and that it must be guided by the particular lived lives of lesbian women. Most recently, Stevens, Tatum, and White (1996) conclude that health-care practices directed towards women should move beyond unexamined categories of identity to consider the particular behaviours that influence the health of each woman.

Methodology

This inquiry relied on Gadamerian hermeneutics and feminist philosophical thought (Butler, 1990, 1991, 1999). Hermeneutics compels us to think about what is at work in our world. Feminist thought creates the space to problematize and historicize gender categories in a way that the male-dominated hermeneutic tradition has not (Butler, 1991; Scott, 1999). Feminist conceptualities thus extend the hermeneutic project of disrupting the taken for granted and opening up possibilities for how we might interpret and understand our world. According to Gadamerian hermeneutics, as we encounter a world and consider how it came to be, we develop an understanding of it and of ourselves as situated in it. Instead of following a set of methodological procedures to capture understandings, we are guided by Gadamerian hermeneutics to "clarify the conditions in which understanding takes place" (Gadamer, 1998, p. 295). "Understanding the lived experience is about understanding the structures and relationships that construct our lived realities, the meanings we create from the context in which we find ourselves" (Ceci, 2000, p. 68).

In hermeneutic inquiry, text is interpreted in such a way that new understandings are generated. The inquiry rests on gathering and accumulating the texts that will inform the interpretation. In the present inquiry, the texts were generated through research conversations with lesbian women, accounts by women in the media, and reflective journaling by the researcher, and the notion of the interview was replaced by that of conversation, as a means of both gathering data and beginning the process of interpretation.

Written informed consent for participation and for audiotaping the conversations was obtained from each participant. The primary texts for the study were generated through conversations between the researcher and the participants. Through conversation, each woman was invited to explore her experience of disclosure of lesbian orientation in order to uncover and generate meanings that the experience held in her life. The purpose of questioning in this hermeneutic inquiry was to stimulate reflection and deeper exploration of the experience. The in-depth exploration produced the meanings and the understandings of a particular experience. In the conversations the women moved beyond describing their experiences, to reflect on the meaning of them (Bergum, 1989), thereby opening up space for new understandings and interpretations of the experience.

The audiotapes of the conversations were transcribed verbatim. The transcripts became the primary data for the study and were used alongside the media accounts of lesbian life and my own reflective journaling. Unlike other approaches to qualitative research, hermeneutic inquiry does not prescribe a procedural, step-by-step method for analysis (Gadamer, 1998). Rather, the researcher "dwells with" the research data, moving between the parts and the whole. This perpetual movement, referred to as the hermeneutic circle, is central to the process of interpretation and understanding. Gadamer defines Heidegger's explication of this reflection or movement between the parts and the whole as an account of the way in which understanding is achieved. Interpretation means following the relationship between particular, shared, experiences and the contexts in which the meanings of these experiences were generated. In the present analysis, the intention was not to recite the experiences of the 15 participants, nor to provide the reader with a set of themes that consistently emerged in the conversations. The interpretations do not stand in for the story of lesbian disclosure, although each interpretation has something to say about that story. Rather, the findings consist of interpretations of what could be transpiring for any lesbian woman and the possible implications of this for her experience of health.

Participants

Conversations were held with 15 women who responded to advertisements for the study posted in women's centres and bookstores and on a university campus in western Canada. Of the participants, some chose to name themselves lesbian and some spoke of being lesbian as central to their identity, giving direction to the journey "a way to have a life." Nine of the participants were in a committed monogamous relationship with another woman; for several of those participants, this was their first lesbian relationship. Six of the participants were not currently partnered. Of the 15 participating women, many had previously been in sexual relationships with men, including having been married to men, and six became mothers during those heterosexual relationships. One woman had previously lived as a man and become a father. One woman became a mother with her female partner. All of the participants had repeatedly faced decisions about disclosure of their orientation.

The participants had, during their lives, spent varying lengths of time in intimate relationships with women. Isis had been out to herself for 29 years. Alex was 49 years old when she sought out a sexual encounter with a woman. Taylor was married to a man for 23 years before she and her two daughters all identified themselves as gay. Jade and Tracey came out to themselves as young women.

The women's ages spanned four decades, ranging from 26 to 56 years. There were no participants in their teens or early twenties. One woman identified her home country as located in Central America; the remainder of the participants identified themselves as of European extraction. Most of the women were employed. Eight had been to university and three were currently students. One woman was a stay-at-home mother. One woman was being supported by social assistance.

Each of the participants had created a life for herself in which intimate/sexual/affectionate relationships with women were valued if not central to the way in which she lived her life. All of the women had passed "under the sign of lesbian" (Butler, 1991, p. 14) and some had chosen to stay and "establish residency there." When one embarks on such a journey, questions of naming and of telling are inevitable. The person has inhabited the terrain.

Findings

The horizons of the study were expanded immediately by the diversity of the women who responded to the call for participants "under the sign of lesbian." A decision was made to include any person who called herself lesbian. I have become familiar, in our culture, with the taken-for-granted meaning of lesbian as a category of sexuality — that is, a woman's object of desire is another woman. Female homosexuality is defined as the manifestation of sexual desire towards a member of one's own sex (*Webster's New Collegiate Dictionary,* 1980). Although all of the women responded to the call for participants as "lesbians," they practised being a lesbian in notably different ways. Many of them had had previous sexual relationships with men and several did not rule out the possibility of relationships with men in the future. Half of the participants were currently in a relationship with a woman and half were not in a relationship.

Several had never had a sexual relationship with a woman. One woman who identified herself as lesbian could also be named transgendered, having previously lived as a man. This group of people standing together as lesbians disrupts the stability of the category. If a lesbian is no longer a woman who manifests sexual desire towards another woman, then what does it mean to say, "I am a lesbian"?

The experiences of women in the world give us some indication of how we might understand disclosure. The possibilities are many, not only for how disclosure might be taken up by different women, but also for how it might be taken up by the same woman. The participants generated multiple meanings of disclosure. They saw disclosure as truth telling, as activist naming, as constituting the self, and as creating lesbian space.

Disclosure as Truth Telling

In the conversations with the women about disclosure to self and to others, there emerged an epistemological discourse of truth. Some women had come to believe or to act as if there were an indisputable truth to be discovered about their sexuality, the confirmation of which placed them under pressure to "tell the truth." One participant, Clara, wanted to tell her mother that she considered herself a lesbian, that she was attracted to women, even though she knew this would jeopardize both her son's and her own relationship with her mother. For Clara, "honesty is the most important thing." Jade said, "To actually put the truth out there is an incredible journey." Jade had lost her family and her job; she had moved across the country to make a new start; her mental health was precarious. Rose said, "I can't raise a daughter who is true to herself when as a mother I am not true to myself." Rose's male partner had accused her of being an unfit mother and vowed to reduce her to poverty. Rose went to jail to defend her truth. Judith spoke of having plunged her family into a crisis with her disclosure and of their disbelief over her truth; her mother had said, "I raised you and I would know if you were a lesbian — you've just had bad marriages." What is the effect of a mother's denying the identity of her daughter? Does it undermine the daughter's sense of herself, particularly in view of her discovery of having, even joyously, found a way to make a life for herself, to make sense of the life that she lives?

This incitation to confess assumes that "there is such a thing as a literal account, the final truth of the matter, stripped of connection with other matters, told without metaphor" (Gadow, 1995, p. 213). Lives as they are lived clearly illuminate "truths" as constructed in relationships, as inseparable from the social, material, and discursive realties in which those lives are lived.

In the practice literature, disclosure is positively associated with psychological and emotional health and authenticity in relationships (Deevey, 1993; Jordan & Deluty, 1998; Kahn, 1991; Morrow, 1996; Radonsky & Borders, 1995; Saddul, 1996; Scasta, 1998; Taylor, 1999). The conversations with the women in the present study, as well as McWhorter's (1999) reading of Foucault, complicate this correlation of health and disclosure. In fact, McWhorter is wary of the findings in the practice literature: "What we're always told, of course, is that knowledge is the first step towards health, happiness, and freedom, because the opposite of knowledge is repression." She suggests instead: "Knowledge is the first step toward discrimination" (p. 13). This point is made not to support the notion that discrimination will always follow on the heels of disclosure but, rather, to speak to the assumption that interpersonal relationships should be grounded in an authenticity that derives from honest interaction and the belief that living with a secret impinges on authentic interpersonal engagement (Yalom, 1985).

There is no doubt about the broad compliance to the incitation to confess the "truth" of one's sexuality, particularly to those whose understanding or acceptance the woman especially values. Paradoxically, it may be within the relationships in which a woman has the greatest emotional investment and thus the most to lose that she feels compelled to disclose the "truth" of her membership in a particular historically and socially constructed category.

To suggest that a woman is "living a lie" or that her relationships are less than authentic if she does not always and everywhere disclose her sexuality is to reify a narrow understanding of truth. Like categories of sexuality, truth itself can be considered an epistemological construction. Instead of deriving the "truth" of sexuality from an internal identity, we could understand the truth of a woman's sexuality as historically constructed in her particular social, material, and discursive world. Depending on a woman's situatedness, it may be more constitutive of her health to construct the truth as "I am living with a woman," or even as "I love a woman," than as "I am a lesbian."

Disclosure as Constituting Self

Some of the participants spoke about disclosure as a way of being in the world, as the means by which they intentionally and inadvertently presented themselves to others "under the sign of lesbian." While disclosure can be seen as a manifestation of wishing another to know (presumably, the "truth"), it can also serve to remind a woman of who she is. In the study, reminding or reconstituting of self was presented most clearly in the non-verbal lesbian disclosure. Tattooing the sign of lesbian on one's body, wearing the rainbow colours, or wearing jewellery constructed of two female symbols was meant not only to disclose to others but also to remind the woman herself of her identification with the sign of lesbian. Disclosure through wearing a lesbian symbol, acting demonstratively with another woman in public, or verbally telling are ways of practising/being lesbian. Repetition of disclosure re-enacts lesbian. Jade wore her lesbianism tattooed on her body, literally and figuratively:

> *I have incredibly short hair — it's a buzz. I dress in jeans and shirts. I don't wear the rainbow necklace for everyone to see that I'm a lesbian. I don't have the tattoo for everyone to see that I'm a lesbian. I have it for myself. It's difficult to explain. I went through a lot of crises because of my lesbianism, and I deserve to be able to say, yeah, I'm a dyke and I'm very proud of that. I've earned the right… It's about every single day; you have to fight to say I'm okay to be here. There's nothing abnormal about me. I'm just me, you know... I don't care what you think about me because I'm a great person, and it's your loss if you don't want to get to know me…but every day I still struggle with that.*

Disclosure as Active(ist) Naming

Some women practise lesbian disclosure as an obligation. The participants spoke of their responsibility to not only raise the lesbian flag but to stand under it, to claim allegiance as a way of disrupting taken-for-granted heteronormativity. There is a belief that heteronormativity would topple and discrimination against homosexuals plummet if people discovered that their mother/teacher/sister/friend/neighbour/professor/aunt/roommate/minister was a lesbian. There is a desire to counteract the image of lesbians as evil or pathological and to demonstrate to non-lesbian people that lesbians are similar to them in many respects. Judith, a university professor, described her activist role of using every available opportunity to educate others:

> *It's part of my feminist perspective. It's part of my convictions as a psychologist about our larger responsibility to society. I see it as a part of my work to educate, and my sexual orientation has become a part of my work…and what I see as my career goals or what I integrate into my role as a psychologist…educating people and encouraging more open understanding.*

Disclosure as Creating Lesbian Space

"Lesbian space" is a place or places where lesbian women experience respect, acceptance, and safety. Within such a space, heterosexual dominance recedes and, at least temporally, the power of heteronormativity is contested. Lesbian space can be manifested in diverse places and mediums: an office door in a nursing faculty or a hospital unit where a "positive space" rainbow decal promises respect for sexual diversity, literature in which lesbian realities are accurately portrayed, formal and informal gatherings during which lesbians play and dance and celebrate their lives. The participants spoke repeatedly of belonging, joining, visiting spaces where they felt fully accepted as lesbian women. They also spoke about ways in which their own disclosure had opened discursive and social lesbian spaces.

The creation of these spaces in our society is seldom happenstance; it is more likely to result from deliberate, strategic effort. And while it would be remiss to not acknowledge the contribution of non-lesbian women to the production of lesbian spaces, lesbian disclosure is one of the strategic practices through which safe and respectful spaces are created for lesbian women.

After 21 years in a heterosexual marriage, Alex left to live her life as a lesbian. She spoke of a life that no longer served her: "I could not stay in my life. I could not pretend any more. I felt really wonderful because I felt like I truly found myself and wouldn't everybody be so happy for me?" Instead, however, Alex experienced rejection by family members and friends: "I was ostracized…a lot of people I have never heard from since." Yet Alex was committed to her own disclosure and to providing a space in which she and other women could celebrate their lives:

> *I am very open in disclosing still. I felt that this was important enough to me to always continue to be open, which I have always been, in every situation… Okay, no matter how much I had felt hurt…this is my life. I have nothing to be ashamed of. I'm proud to be a lesbian. I feel like this: I've waited all my life to know who I am, and so, you know, I mean, I've done nothing wrong and I'm a good person. What do I have to hide? I have nothing to hide.*

Nursing Situatedness

In writing about difference as a feature of the world of nursing, Ceci (2003) reminds us of nurses' position of access to the lives of others: "As nurses, we encounter people in their most vulnerable moments and so have the opportunity to cause harm by unthinking adherence to the false and damaging beliefs and assumptions often contained in categories and labels" (p. 428). The unexamined beliefs of health-care providers, often imbued with erroneous voices from the past, contribute to our complicity in maintaining authoritative and inaccurate discourses. The willingness of care providers to question our own assumptions about difference instigates the disruption of taken-for-granted categories and labels.

Nurses might also view themselves as in a position to engage in strategic practices to destabilize heteronormativity and the unthinking use of categories of sexuality in the health-care environment. Nurses' knowledge of and place in the power structures of the health-care system positions them to effectively participate in destabilizing practices.

Implications for Nursing

The results of this study may be useful to nurses involved in direct patient care, in education, and in research endeavours, by disrupting the norm of heterosexuality in nursing discourse and questioning the adequacy of categories of sexuality to speak to the realities of women's lives. We are challenged to consider the possibility that any given woman may be living a life outside of the dominant norm of heterosexuality, and to engage with this reality as we encounter women as colleagues, patients, students, and research participants.

As nurses come to understand heteronormativity and the effects of categorization, our complicity in maintaining these discourses is challenged and new possibilities for practice are generated. Disruption of the assumptions of heterosexism is a means for nurses to reduce the deleterious impact of social exclusion, isolation, discrimination, and stigmatization as social determinants of health (Wilkinson & Marmot, 2003). How would health-care practices be altered if space were created to consider the differences in women's lives and experiences of health? Posters, pamphlets, and films would reflect women partnered with women, women partnered with men, men partnered with men, people not partnered, people with and without children; medical history forms would have a space for significant relationships, family practice would include all families, and the health-care system would ensure equal rights and privileges for every type of partner. Health-care providers would have conversations with all women about the alternatives available for having children, and all women would receive accurate information and intervention about their sexual health, based on their past and current sexual practices. Relationships with health-care providers would be a safe place for lesbians to talk about their relationships with lovers, friends, and family. Domestic violence in women's relationships would be addressed as seriously as other forms of violence against women. Women who name themselves lesbian would feel safe and supported in their relationships with health-care providers.

Nurses who engage in interpretive practice consider the multiple meanings that may be at play in a woman's life. We are challenged to question the assumptions that are attached to labels and categories and to become vigilant as to the ways in which received language misrepresents the lives of women. The results of the present inquiry point to an understanding of all women's lives as constructed of multiple and complex realities: realities constituted under social, material, and discursive influences. We cannot escape history. Categories of classification and scientification are our inheritance; they are alive in our world. We are not, however, destined to dutifully, unquestioningly accept our inheritances. Rather, we are invited to unpack the categories, to disrupt the taken-for-granted meanings that have been handed to us from the past and to remain open to the future as it unfolds.

References

Bergum, V. (1989). Being a phenomenological researcher. In J. Morse (Ed.), *Critical issues in qualitative research methods.* Thousand Oaks, CA: Sage.

Butler, J. (1990). Performative acts and gender constitution: An essay in phenomenology and feminist theory. In S. Case (Ed.), *Performing feminisms: Feminist critical theory and theatre* (pp. 270–282). Baltimore: Johns Hopkins University Press.

Butler, J. (1991). Imitation and gender insubordination. In D. Fuss (Ed.), *Inside/out: Lesbian theories, gay theories* (pp. 13–31). New York: Routledge.

Butler, J. (1999). *Gender trouble: Feminism and the subversion of identity.* New York: Routledge.

Ceci, C. (2000). Not innocent: Relationships between knowers and knowledge. *Canadian Journal of Nursing Research, 32*(2), 57–73.

Ceci, C. (2003). When difference matters: The politics of privilege and marginality. In M. McIntyre & E. Thomlinson (Eds.), *Realities of Canadian nursing: Professional, practice and power issues.* Philadelphia: Lippincott.

Deevey, S. (1993). Lesbian self-disclosure strategies for success. *Journal of Psychosocial Nursing, 31*(4), 21–26.

Forstein, M. (2003). Foreword. In A. Peterkin & C. Risdon, *Caring for lesbian and gay people: A clinical guide.* Toronto: University of Toronto Press.

Gadamer, H. G. (1998). *Truth and method* (2nd ed.). New York: Continuum.

Gadow, S. (1995). Narrative and exploration: Toward a poetics of knowledge in nursing. *Nursing Inquiry, 2,* 211–214.

Gramling, L., Carr, R., & McCain, N. (2000). Family responses to disclosure of self as lesbian. *Issues in Mental Health Nursing, 21,* 653–669.

Gray, P., Kramer, M., Minick, P., McGehee, L., Thomas, D., & Greiner, D. (1996). Heterosexism in nursing. *Journal of Nursing Education, 35*(5), 204–210.

Hall, J., Stevens, P., & Meleis, A. (1994). Marginalization: A guiding concept for valuing diversity in nursing knowledge development. *Advanced Nursing Science, 16*(4), 23–41.

Hitchcock, J., & Wilson, H. (1992). Personal risking: Lesbian self-disclosure of sexual orientation to professional health care providers. *Nursing Research, 41*(3), 178–183.

Jordan, K, & Deluty, R. (1998). Coming out for lesbian women: Its relation to anxiety, positive affectivity, self-esteem and social support. *Journal of Homosexuality, 35*(2), 41–63.

Kahn, M. (1991). Factors affecting the coming out process for lesbians. *Journal of Homosexuality, 21*(3), 47–70.

Mathieson, C. (1998). Lesbian and bisexual health care: Straight talk about experiences with physicians. *Canadian Family Physician, 44,* 1634–1640.

McWhorter, L. (1999). *Bodies and pleasures: Foucault and the politics of sexual normalization.* Bloomington: Indiana University Press.

Misner, T., Sowell, R., Phillips, K., & Harris, C. (1997). Sexual orientation: A cultural diversity issue for nursing. *Nursing Outlook, 45*(4), 178–181.

Morrow, D. (1996). Coming out for adult lesbians: A group intervention. *Social Work, 41*(6), 647–656.

Radonsky, V., & Borders, L. (1995). Factors influencing lesbians' direct disclosure of their sexual orientation. *Journal of Gay and Lesbian Psychotherapy, 2*(3), 17–37.

Robertson, M. (1992). Lesbians as an invisible minority in the health services arena. In P. Stern (Ed.), *Lesbian health: What are the issues?* Washington: Taylor & Francis.

Saddul, R. (1996). Coming out: An overlooked concept. *Clinical Nurse Specialist, 10*(1), 2–5.

Scasta, D. (1998). Issues in helping people come out. *Journal of Gay and Lesbian Psychotherapy, 2*(4), 87–97.

Scott, J. (1999). *Gender and the politics of history* (rev. ed.). New York: Columbia University Press.

Stevens, P. (1994a). Protective strategies of lesbian clients in heath care environments. *Research in Nursing and Health, 17,* 217–229.

Stevens, P. (1994b). Lesbians' health-related experiences of care and non-care. *Western Journal of Nursing Research, 16*(6), 639–659.

Stevens, P. (1995). Structural and interpersonal impact of heterosexual assumptions on lesbian health care clients. *Nursing Research, 44*(1), 25–30.

Stevens, P., & Hall, J. (1988). Stigma, health beliefs and experiences with health care in lesbian women. *Image: Journal of Nursing Scholarship, 20*(2), 69–73.

Stevens, P., Tatum, N., & White, J. (1996). Optimal care for lesbian patients. *Patient Care,* (March), 121–141.

Taylor, B. (1999). Coming out as a life transition: Homosexual identity formation and its implications for health care practice. *Journal of Advanced Nursing, 30*(2), 520–525.

Webster's new collegiate dictionary. (1980). Springfield, MA: Merriam-Webster.

Wilkinson, R., & Marmot, M. (Eds.). (2003). *Social determinants of health: The solid facts* (2nd ed.). Copenhagen: World Health Organization. Retrieved November 30, 2005, from html://www.who.dk/documents/e81384.pdf.

Yalom, I. (1985). *The theory and practice of group psychotherapy*. New York: Basic Books.

Acknowledgements

I would like to acknowledge financial support towards the completion of this research in the form of a Graduate Research Scholarship, Faculty of Nursing, University of Calgary; a Faculty of Graduate Studies Award, University of Calgary; and a Province of Alberta Graduate Fellowship Award. In addition, I express my appreciation for the support of the Women's Health Initiative Research Group at the Faculty of Nursing, University of Calgary.

Carol McDonald, RN, PhD, is Assistant Professor, School of Nursing, University of Victoria, British Columbia, Canada.

2009 update: *Carol McDonald's position is unchanged. She is currently working on a study funded by the Social Sciences and Humanities Research Council exploring the experiences of lesbian disclosure among older women.*

CJNR 2009, Vol. 41 N° 1, 276–290

Résumé

Une exploration des préférences des patients en matière de traitements dans le cadre d'une étude sur échantillon partiellement aléatoire et contrôlé

Joyal Miranda

L'étude sur échantillon partiellement aléatoire et contrôlé (ÉÉPAC) est une conception modifiée dont le but est de tenir compte des préférences des participants en matière de traitement. Les connaissances concernant les facteurs qui influencent ces préférences sont très limitées. Cette étude évalue le degré de consentement des participants à collaborer à un processus aléatoire ainsi que les facteurs qui influent sur leurs préférences en matière de traitement. Les données quantitatives et qualitatives cueillies dans le cadre d'une ÉÉPAC de deux interventions comportementales dans des cas d'insomnie ont été analysées. Parmi les participants, 75 % ont refusé d'être aléatoirement assignés à un groupe thérapeutique. Ce chiffre a grimpé à 90 % après l'introduction de renseignements concernant les deux interventions. L'information que détenaient les participants concernant le traitement, la pertinence de celui-ci et leur capacité d'y adhérer selon leur perception ont influencé leur préférence en matière de traitement. Quelques participants qui n'avaient pas de préférence marquée et qui nécessitaient un traitement étaient disposés à être assignés de façon aléatoire. Les résultats soulèvent des questions concernant l'impact de la préférence en matière de traitement et de la procédure d'assignation sur la validité des conclusions de l'étude.

Mots clés : préférence en matière de traitement, ÉÉPAC

CJNR 2009, Vol. 41 N° 1, 276–290

An Exploration of Participants' Treatment Preferences in a Partial RCT

Joyal Miranda

The partial RCT is a modified design meant to account for participants' treatment preferences. Little is known about the factors that influence such preferences. This study investigated the extent to which participants are willing to be randomized and the factors that affect their treatment preferences. The quantitative and qualitative data collected as part of a partial RCT evaluating 2 behavioural interventions for insomnia were analyzed. Of the participants, 75% were unwilling to be randomly allocated to a treatment group. This figure increased to 90% after information on the 2 interventions was provided. Participants' knowledge of the treatment, its suitability, and their perceived ability to adhere to it influenced their treatment preference. A few participants who had no strong preference and who required treatment were willing to be randomized. The findings raise questions about the impact of treatment preference and allocation procedures on the validity of study conclusions.

Keywords: treatment preference, random assignment, partial RCT

Introduction

Demonstrating the effectiveness of interventions is a prerequisite for their use in practice. Effectiveness is concerned with the robustness of the intervention outcome under actual conditions and with different clinical populations (Sidani & Braden, 1998; Whittemore & Grey, 2002). Studies to evaluate the effectiveness of interventions focus on the clinical applicability of the treatment under investigation and seek to duplicate the situations that clinicians will encounter in their practices (Streiner, 2002; TenHave, Coyne, Salzer, & Katz, 2003). Of the situations that clinicians encounter, selection of the most appropriate treatment for individual patients reflects an important aspect of patient-centred care. Patient-centred care (PCC) is viewed as an approach that results in high-quality care (Attree, 2001; Larrabee & Bolden, 2001). Its essence is to view each patient as a unique person, respect patients' values and beliefs, and respond flexibly to patients' individual needs and preferences (Lauver et al., 2002; McCormack, 2003). Application of PCC implies that nurses assess patients' needs, values, and preferences; inform patients of available treatment options and the risks and benefits of each; ask patients which treatment they prefer; and provide patients with the treatment of their choice (O'Connor, Mulley, & Wennberg, 2003; Tunis, Stryer, & Clancy, 2003). Interventions that are consistent with patients' preferences are posited as beneficial, as they increase patients' sense of personal control, patients' satisfaction with care, and the achievement of desired outcomes (Cahill, 1996).

Patient preference is the expression of the value of various courses of action following informed deliberation on their risks and benefits (Bowling & Ebraham, 2001). Inquiring about patients' treatment preferences is necessary to guide practice. Knowledge about which interventions have been perceived by patients as acceptable, suitable, and desirable assists the practitioner in selecting which ones to discuss with and recommend to patients. Interventions that have been found to be effective but viewed by patients as unacceptable, unsuitable, or undesirable will not be adhered to in everyday life (Morin, Gaulier, Barry, & Kowatch, 1992; Vincent & Lionberg, 2001), thereby hindering the achievement of desired outcomes (Bradley, 1993). It is therefore important that patient preferences be assessed and accounted for in the evaluation of an intervention's effectiveness.

The randomized control trial (RCT), often considered the gold standard for evaluating the effectiveness of interventions, does not take patient preferences into account. Random assignment of participants to the experimental or control group is the key feature of RCT design. This is the most critical safeguard of internal validity; however, it ignores the participants' desires and preferences regarding the treatment options included in the study. Several authors propose alternative research designs in which the participants' treatment preferences are examined (e.g., Lambert & Wood, 2000; McPherson & Chalmers, 1998) and taken into account in the allocation of participants to a treatment group (e.g., Brewin & Bradley, 1989; Coward, 2002). The partial RCT is proposed as a modified RCT design in which patients' treatment preferences are taken into consideration while the rigour of the RCT design is maintained (Torgenson & Sibbald, 1998). The partial RCT allows participants to say whether they would rather be randomly allocated to a treatment option or allocated to their preferred treatment.

Little is known about the process underlying participants' preferences regarding method of allocation and treatment options offered in effectiveness studies (Horne, 1999). The purposes of the present study were to (1) determine the extent to which participants are willing to be randomly assigned to a treatment before and after being informed about the options, and (2) explore the factors that influence participants' treatment preferences. The data for the study were obtained from a large partial RCT evaluating the effectiveness of two behavioural interventions, stimulus control instructions (SCI) and sleep restriction therapy (SRT), in managing insomnia.

Literature Review

Accounting for participants' treatment preferences, as is done in a partial RCT, has advantages and disadvantages. These are discussed at the methodological and clinical levels.

Several studies have investigated patients' treatment preferences. Overall, the results indicate that most participants (60–79%) express a preference for a particular intervention (e.g., Awad, Shapiro, Lund, & Feine, 2000; Morin et al., 1992; North-West Uro-Oncology Group, 2002; Torgerson, Klaber-Moffet, & Russell, 1996; Vincent & Lionberg, 2001; Walter, Vincent, Furer, Cox, & Kjernisted, 1999). Accounting for such preferences has several methodological advantages. It makes recruitment of participants and achievement of the required sample size easier, as compared to the traditional RCT. The results of some studies indicate that many people who are unwilling to be allocated to a treatment based on chance refuse to take part in an RCT (King, 2000). People may decline to participate in an RCT if they highly favour one treatment option, are aware that they have only a 50% chance of receiving it, and wish to avoid receiving the less desired treatment (Bradley, 1993). For instance, O'Reilly, Martin, and Collins (1999) found that only one of 20 patients agreed to be randomized to either of two treatments for prostate cancer. They report that patients who were well informed about the two treatments refused random assignment, preferring to make their own treatment choice. Thus, the rather small number of persons who agree to participate reflect a subgroup of the target population who are willing to take the risk of receiving any treatment. Informing potential participants that their treatment preferences will be taken into consideration is an effective strategy for increasing the rate of participation in a study and facilitates achievement of the required sample size. Furthermore, the resultant sample is representative of the target population and the results are generalizable to various subgroups of the population (TenHave et al., 2003).

In contrast to random assignment, accounting for participant preferences can minimize attrition and promote adherence to the treatment protocol. Random assignment may result in a mismatch between the treatment option that participants prefer and that to which they are randomly allocated. Participants who do not receive their preferred treatment may become demoralized, disappointed, uncooperative, noncompliant, and prone to drop out of the study. Attrition reduces the sample size, which decreases the statistical power to detect significant intervention effects. Offering participants the treatment of their choice improves their satisfaction with and adherence to the treatment they receive and reduces attrition (Corrigan & Salzer, 2003; TenHave et al., 2003). Retention of a large number of participants and adherence to the intervention increase the statistical power to detect significant intervention effects (Lipsey, 1990; Shadish, Cook, & Campbell, 2001).

Accounting for patient preferences in a research study may lead to results that are clinically useful and that provide a profile of participants who have strong preferences for a particular treatment and who benefited most from the intervention under evaluation. Equipped with this type of knowledge, nurses can provide care that is based on the best available evidence while responding to their patients' values and wishes (O'Connor et al., 2003). The benefit of providing care in accordance with patient preferences is illustrated in a study conducted by Ruland (1998). This study found that when nurses were given information on their patients' preferences regarding self-care goals, 74% tailored their care to those preferences, which, in turn, resulted in the achievement of self-care goals.

In contrast, accounting for participants' treatment preferences in a partial RCT has methodological disadvantages. First, it requires a large sample. A large sample is necessary to ensure adequate statistical power to compare the four groups of participants: those assigned to the experimental group and are either satisfied or disappointed with the treatment received, and those assigned to the control group and are either satisfied or disappointed with the treatment received. The four groups may vary in their response to the intervention and the achievement of the expected outcomes (Bradley, 1993; Corrigan & Salzer, 2003; McPherson & Britton, 2001; TenHave et al., 2003). Second, if participants are allowed to choose the method of assignment to a group (random or preference) and the treatment option, then there is an increased possibility of an unbalanced design resulting — that is, an unequal number of participants in the four groups (Corrigan & Salzer, 2003). Several strategies can be used to address this limitation, such as randomly selecting a subsample from the larger group size to equal the smaller group size, conducting the analysis with the unequal and the equal group sizes, and comparing the results to determine whether the between-group differences are due to unequal group size. Third, the assignment of participants to their preferred treatment option may increase their expectation that the treatment will be effective and cause them to respond accordingly, resulting in improved outcomes (Corrigan & Salzer, 2003). The evidence supporting this limitation is inconclusive. In some studies treatment preference was associated with the achievement of outcomes (e.g., Thomas, Craft, Paterson, Dziedzic, & Hay, 2004), but in other studies it had no impact on outcomes (e.g., Klaber-Moffett et al., 1999).

There are a few published studies investigating participants' treatment preferences using a partial RCT (e.g., Coward, 2002; Thomas et al., 2004). However, the reports of these studies provide limited information on the process underlying such preferences. Specifically, the factors that shape the preferences are not clear or explicit. Yet these factors would assist in the identification of the specific information that patients need during the process of forming their treatment preferences, which is a requirement of PCC. This study represents an attempt to describe this process in terms of the factors that influence participants' preferences with regard to the allocation procedure and the treatment options.

Study Design

Data for this study were obtained from a large partial RCT evaluating the effectiveness of two behavioural interventions for managing insomnia. The partial RCT design consisted of asking participants about their preferences for either of the two interventions and assigning them accordingly. A questionnaire was used to elicit their preference with regard to the allocation procedure and the intervention under investigation. The quantitative and qualitative data collected in this questionnaire were used to address the objectives of the study.

The questionnaire was administered by the researcher, in an individual interview format, after the participants consented to take part in the study and completed the pretest measures. The interview proceeded as follows. First, the participants were asked whether they were willing to be randomly allocated to a treatment group. Second, they were informed, using a script, of the nature, effectiveness, and disadvantages of each intervention. Third, they were requested to evaluate each intervention on its acceptability, suitability, and effectiveness in managing their insomnia. Finally, they were asked which intervention they preferred and how they wished to be assigned to one of the two interventions — that is, either randomly or based on their preference. Participants with a preference were allocated to their preferred/selected intervention, while those with no preference were randomly allocated to a treatment group by means of an opaque, sealed envelope. The researcher documented, verbatim, each participant's verbal responses throughout the interview. The participants' quantitative answers to the questions eliciting their qualitative verbal responses comprised the data for understanding the process underlying their preferences.

Sample

The convenience sample consisted of 67 participants. Persons were eligible for the study if they (1) lived in a non-institutional dwelling in the community, (2) were 21 years of age or older, (3) were able to read and write English, and (4) had a complaint of insomnia that met the criteria for disorder regarding initiation or maintenance of sleep — that is, sleep onset latency and/or time awake after sleep onset of 30 minutes or more per night for a minimum of 3 nights per week, of 3-month duration or longer, as corroborated by sleep diaries and self-report. Exclusion criteria included cognitive impairment as ascertained by a Mini-Mental State Exam score of over 27 and the presence of severe psychological impairment evidenced by the Brief Symptom Inventory Global Severity Index T-score of under 50. The behavioural intervention for managing insomnia requires the active participation of the client in making the behavioural changes, which may be hindered by cognitive or severe psychological impairment.

Variables and Measures

A treatment-preference questionnaire was developed by the investigators to elicit information about the participants' preferences regarding treatment allocation method (i.e., random or based on preference) and the two behavioural interventions for managing insomnia (i.e., SCI or SRT). The questionnaire consisted of four parts. The first part inquired whether the participant was, in general, willing to be randomly assigned to a treatment option in a research study. The second part described one intervention for managing insomnia in terms of its name, nature, effectiveness (based on available empirical evidence), and disadvantages. Following the description, the participants were asked to rate the intervention for suitability, acceptability, effectiveness, and their willingness to adhere to it. The third part included a description of the other intervention and the rating scales to evaluate it. In the fourth part, participants were asked how they would like to be assigned to one of the two treatment options described in the second and third parts — that is, based on chance or on preference. The responses to the questions in the first and fourth parts of the questionnaire formed the quantitative data analyzed in this study to determine the extent to which participants were willing to be randomly assigned to treatment. In the last part of the questionnaire, the participants commented verbally on their choice. The researcher recorded these comments in writing. These responses formed the qualitative data that were content analyzed to identify the factors that influenced preferences with regard to the intervention.

Procedure

The study protocol was approved by the Research Ethics Board at the University of Toronto. When obtaining participants' consent, the research assistant (RA) described the purpose of the study, the data-collection procedure, participants' rights as human subjects, the two behavioural interventions offered in the study, and the procedure for treatment allocation (i.e., the participants were told that the two interventions demonstrated efficacy and that they could choose the one they wished). After obtaining consent and pretest data, the RA administered the treatment preference questionnaire. The RA read the questions and the response options, and recorded the option selected by the participant. The RA did not provide any information not available on the questionnaire and did not discuss the participant's choice. After rating each intervention, the participants indicated how they wished to be allocated. Those who chose to be randomly assigned learned about their assignment by opening a sealed envelope. Those who were not willing to be randomly assigned were asked which of the two treatment options they preferred and were then assigned to an experimental group based on their preference. The participants' verbal responses upon learning of their group assignment were recorded at the end of this data-collection session.

Data Analysis

Descriptive statistics were used to characterize each participant's profile and responses to the treatment preference questionnaire. In reviewing participants' responses to the initial question (i.e., first part of the questionnaire) and the final question (i.e., fourth part of the questionnaire) concerning treatment allocation, the participants were classified into four groups: (1) those who consistently chose not to be randomly assigned, (2) those who consistently chose to be randomly assigned, (3) those who changed their decision from random to preference allocation, and (4) those who changed their decision from preference to random allocation. Within each group, verbal responses were content analyzed. The emerging themes reflected factors that influenced the participants' preferences regarding the method of allocation and the interventions.

Results

The results are presented in relation to the participants' profiles, the participants' responses to the treatment preference questionnaire, and the factors that influenced their preferences. The majority (69%) of the 67 participants were women, with a mean age of 45 years (*SD* = 16). Most (42%) were married, well-educated (mean years of education = 17, *SD* = 4), and employed either part-time or full-time. They rated their insomnia as severe, bothersome, and interfering with daily functioning. Their perceived severity of insomnia was supported by mean scores on sleep onset latency (*mean* = 50 minutes, *SD* = 36) and wake after sleep onset (*mean* = 54 minutes, *SD* = 39).

When initially asked about their willingness to be randomly assigned to a treatment group, 50 participants (75%) responded that they were not willing to be randomly assigned. However, after learning about the two particular treatment options offered in the study and rating each, 60 participants (90%) chose not to be randomly assigned. Thus, 12 participants (18%) changed their mind about how they wanted to be assigned once the information on the interventions was provided, and 55 (82%) did not change their mind. Of those who changed their mind, some selected random allocation first and allocation based on preference second, while others selected preference first and random allocation second. Of those who did not change their mind, some consistently selected random allocation and others consistently selected allocation based on preference. The distribution of the participants across the four groups is presented in Table 1.

Table 1 ***Distribution of Participants in Method of Treatment Allocation***

Group	***N* (%)**	**Themes**
1. Consistently chose treatment allocation based on preference	49 (73)	Suitability (*n* = 27) Acquired knowledge (*n* = 20) Familiarity (*n* = 18) Compliance (*n* = 17) Control (*n* = 16)
2. Consistently chose randomization	6 (9)	No preference (*n* = 6) Just wanted treatment (*n* = 3)
3. Changed from randomization to preference	11 (16)	Acquired knowledge (*n* = 11) Control (*n* = 6)
4. Changed from preference to randomization	1 (1)	Indiscretion (*n* = 1) No preference (*n* = 1)

The themes that emerged during content analysis of the verbal responses identified factors that influenced the choice of allocation procedure. For the first group, five themes explained the consistent choice of treatment allocation based on preference. First, these participants tended to base their choice of treatment on its perceived suitability to their particular sleep problem. One person stated: "The [first] treatment sounds better for me since it deals with a number of…strategies. The [second] treatment looks at time scheduling. I'm very consistent with my bedtimes. I don't think that's my problem." Second, they rejected random assignment because they preferred to rely on their acquired knowledge of the treatment options rather than on chance. One participant stated: "With the information I got, and knowing myself and the sleep problem I have, I would rather choose myself than leave it to a 50/50 chance; that makes no sense to me." Third, some participants based their decision against random assignment on their familiarity with one of the treatment options — that is, they did not want to risk being allocated to the treatment they were familiar with and had previously received; they wanted to receive the other, new, treatment. Fourth, these participants rejected random assignment based on their perceived ability to comply with one treatment better than the other — that is, participants who believed they were unable to adhere to a treatment protocol wanted to make sure they were not allocated to that treatment. This theme is captured in the following comment: "My life is a busy one. I'm constantly on the go. My sleep schedule often changes based on my plans for the day, so I know the [second] treatment is not for me. I wouldn't be able to follow it." Finally, some participants seized the opportunity to have control over the decision-making process and selected allocation based on preference.

For the second group — those who consistently chose to be randomly assigned — two themes emerged. One theme reflected lack of a strong preference for a treatment option. Within this group, the majority (*n* = 6) did not have a preference for either of the treatment options. After receiving information on the two interventions, they felt they had "not tried" or were "not familiar" with either and therefore did not care which one they received. The second theme related to the need for treatment. Some participants (*n* = 3) did not care about the method of allocation. They just wanted some type of treatment for their sleep problem. One participant explained: "I need a good night's sleep. I'm desperate. I'll do either one. I just want some help."

For the third group — those who changed from random to preference allocation — two themes emerged. These were similar to those identified for the first group, the participants who consistently chose not to be randomly assigned. First, the members of this group changed their mind once they received information on the two treatment options. Soon after learning about the nature, effectiveness, and disadvantages of each intervention, they developed a preference for one over the other. This preference was related to the person's familiarity with one treatment. They felt they had already learned everything there was to know about it. Also, these participants developed a preference for one treatment option based on its suitability to their particular sleep problem. One participant said: "I know what I should and should not be doing to help my sleep, but it's not working. So I'll have to go with [this intervention] and see if [it] helps." Second, the issue of control arose in this group. The participants explained that reliance on chance to place them in a treatment option did not consider what was best for them. They preferred to choose a treatment, based on their knowledge of their sleep problem and the information obtained about the treatments. One participant said: "I'd rather rely on myself to make the decision with the information I have…than [take] a 50% chance."

The last group consisted of one participant who changed the response to the method for treatment allocation from preference to random assignment. This person showed indecisiveness and lacked a strong treatment preference. After obtaining the information about the two interventions, the participant was still indecisive as to which one would be more beneficial and therefore chose to be randomly assigned. This participant felt no real connection to either of the two treatments.

Discussion

The results indicate that the majority of participants (75%) would not like to be randomly assigned to a treatment option in any research study. This finding is consistent with that reported by O'Reilly and colleagues (1999) and supports the observation that participants are not willing to be randomly assigned to treatment groups (King, 2000). The proportion of participants who refused random allocation increased to 90% after they were informed of the nature, effectiveness, and disadvantages of the two options. Knowledge of the treatment option was one factor influencing the participants' preference with regard to the options and non-random allocation to treatment. This finding replicates the observation by O'Reilly and colleagues that well-informed patients increasingly refuse randomization and choose to make their own treatment decision. The factors that influenced the participants' choice of treatment included suitability, compliance, and familiarity with the intervention. This finding is supported by the conclusion of Morin et al. (1992) and Vincent and Lionberg (2001), who suggest that patients will not choose or adhere to interventions that are unacceptable, unsuitable, or undesirable. The issue of control in selecting a treatment has been cited as a factor in a person's decision to participate in an RCT and in treatment. Those who have a clear idea about the treatment options under investigation are less willing to leave group assignment to chance (Bradley, 1993; Ellis, 2000; Jenkins & Fallowfield, 2000).

In summary, the results of this study provide preliminary evidence indicating that participants in intervention evaluation studies do not wish to be randomly allocated to a treatment group. These findings elucidate the factors that influence a participant's decision regarding the allocation procedure. Knowledge of the treatment options apparently informs participants of not only the nature of the treatment but, more importantly, its suitability to their problem and the extent to which they will be able to adhere to it. These factors appear to play a key role in determining their selection of allocation procedure.

These results are based on a rather small sample of persons seeking non-pharmacological treatment for their insomnia. In order to enhance generalizability, they should be replicated with a larger number of participants with different clinical conditions and seeking various types of interventions. Nonetheless, they provide some empirical support for the clinical observations that patients do have treatment preferences and that these preferences are shaped by the perceived suitability of each treatment to their condition and the extent to which their lifestyle permits adherence to it. Nurses can discuss the suitability of interventions and the patients' ability to adhere to treatment when eliciting their preferences, which is an important aspect of PCC. Further, the results show that participants who have no strong preference for a treatment option and participants who perceive a need for treatment are willing to be randomly assigned. It can therefore be concluded that the factors that influence the decision to be allocated based on preference differ from those that influence the decision to be allocated based on chance. The extent to which these factors directly or indirectly affect adherence to treatment, and whether any placebo effect associated with the expectation of improved outcome resulting from the chosen treatment, is not known and should be investigated in future studies.

Conclusion

When given the option of not being randomly allocated to a treatment group and presented with information on the treatments being offered, few participants in intervention studies are willing to be randomly allocated; most tend to choose a treatment based on preference. Information on the treatment and perceptions about its suitability and one's ability to adhere to it, as well as the desire to have a role in decision-making, are factors that affect participants' treatment preferences and their decision with regard to allocation. Therefore, it may be important for researchers conducting intervention studies to account for participants' treatment preferences and to determine the extent to which these preferences influence the outcome of the treatment and the patient's satisfaction with it. Examination of the extent to which patient preferences affect outcomes enhances the validity and clinical relevance of findings in effectiveness research.

References

Attree, M. (2001). Patients' and relatives' experiences and perceptions of "good" and "not so good" quality care. *Journal of Advanced Nursing, 33*(4), 456–466.

Awad, M. A., Shapiro, S. H., Lund, J. P., & Feine, J. S. (2000). Determinants of patients' treatment preferences in a clinical trial. *Community Dental Oral Epidemiology, 28*(2), 119–125.

Bowling, A., & Ebraham, S. (2001). Measuring patients' preferences for treatment and perceptions of risk. *Quality in Health Care, 10*(Suppl 1), 12–18.

Bradley, C. (1993). Designing medical and educational intervention studies. *Diabetes Care, 16,* 509–518.

Brewin, C. R., & Bradley, C. (1989). Patient preferences and randomized clinical trials. *British Medical Journal, 299,* 313–315.

Cahill, J. (1996). Patient participation: A concept analysis. *Journal of Advanced Nursing, 24,* 561–571.

Corrigan, P. W., & Salzer, M. S. (2003). The conflict between random assignment and treatment preference: Implications for internal validity. *Evaluation and Program Planning, 26,* 109–121.

Coward, D. (2002). Partial randomization design in a support group intervention study. *Western Journal of Nursing Research, 24,* 406–421.

Ellis, P. M. (2000). Attitudes toward and participation in randomized clinical trials in oncology: A review of the literature. *Annals of Oncology, 11,* 939–945.

Horne, R. (1999). Patients' beliefs about treatment: The hidden determinant of treatment outcome? *Journal of Psychosomatic Research, 47*(6), 491–495.

Jenkins, V., & Fallowfield, L. (2000). Reasons for accepting or declining to participate in randomized clinical trials for cancer therapy. *British Journal of Cancer, 82*(11), 1783–1788.

King, M. (2000). The effects of patients' and practitioners' preferences on randomized clinical trials. *Palliative Medicine, 14,* 539–542.

Klaber-Moffett, J., Torgerson, D., Bell-Syer, S., Jackson, D., Llewlyn-Phillips, H., Farrin, A., et al. (1999). Randomized controlled trial of exercise for low back pain: Clinical outcomes, costs, and preferences. *British Medical Journal, 319*(7205), 279–283.

Lambert, M. F., & Wood, J. (2000). Incorporating patient preferences into randomized trials. *Journal of Clinical Epidemiology, 53,* 163–166.

Larrabee, J. H., & Bolden, L. V. (2001). Defining patient-perceived quality of nursing care. *Journal of Nursing Care Quality, 16*(1), 34–60.

Lauver, D. R., Ward, S. E., Heidrich, S. M., Keller, M. L., Bowers, B. J., Brennan, P. F., et al. (2002). Patient-centered interventions. *Research in Nursing and Health, 25,* 246–255.

Lipsey, M. W. (1990). Design sensitivity: Statistical power for experimental research. Newbury Park, CA: Sage.

McCormack, B. (2003). Researching nursing practice: Does person-centredness matter? *Nursing Philosophy, 4,* 179–188.

McPherson, K., & Britton, A. (2001). Preferences and understanding their effects on health. *Quality in Health Care, 10*(Suppl 1), 161–166.

McPherson, K., & Chalmers, I. (1998). Incorporating patient preferences into clinical trials: Information about patients' preference must be obtained first. *British Medical Journal, 317*(7150), 78.

Morin, C. M., Gaulier, B., Barry, T., & Kowatch, R. A. (1992). Patients' acceptance of psychological and pharmacological therapies for insomnia. *Sleep, 15,* 302–305.

North-West Uro-Oncology Group. (2002). A preliminary report on a patient-preference study to compare treatment options in early prostate cancer. *BJU International, 90,* 253–256.

O'Connor, A. M., Mulley, A. G., & Wennberg, J. E. Jr. (2003). Standard consultations are not enough to ensure decision quality regarding preference-sensitive options. *Journal of the National Cancer Institute, 95*(8), 250.

O'Reilly, P. H., Martin, L., & Collins, G. (1999). Controversy in managing patients with prostate cancer. *British Medical Journal, 318,* 126.

Ruland, C. M. (1998). Improving patient outcomes by including patient preferences in nursing care. *Journal of the American Medical Informatics Association,* Suppl S, 448–454.

Shadish, W. R., Cook, T. D., & Campbell, D. T. (2001). *Experimental and quasi-experimental design for generalized causal inference.* Boston: Houghton-Mifflin.

Sidani, S., & Braden, C. J. (1998). *Evaluating nursing interventions: A theory-driven approach.* Thousand Oaks, CA: Sage.

Streiner, D. L. (2002). The 2 "Es" of research: Efficacy and effectiveness trials. *Canadian Journal of Psychiatry, 47*(6), 552–556.

TenHave, T. R., Coyne, J., Salzer, M., & Katz, I. (2003). Research to improve the quality of care for depression: Alternatives to the simple randomized clinical trial. *General Hospital Psychiatry, 25,* 115–123.

Thomas, E., Craft, P. R., Paterson, S. M., Dziedzic, K., & Hay, E. M. (2004). What influences participants' treatment preference and can it influence outcome? Results from a primary care-based ransomised trial for shoulder pain. *British Journal of General Practice, 54,* 93–96.

Torgerson, D. J., Klaber-Moffett, J., & Russell, I. T. (1996). Patient preferences in randomized trials: Threat or opportunity? *Journal of Health Services Research Policy, 1*(4), 194–197.

Torgerson, D. J., & Sibbald, B. (1998). What is a patient preference trial? *British Medical Journal, 316*(7128), 360.

Tunis, S. R., Stryer, D. B., & Clancy, C. M. (2003). Practical clinical trials increasing the value of clinical research for decision making in clinical and health policy. *Journal of the American Medical Association, 290*(12), 1624–1632.

Vincent, N., & Lionberg, C. (2001). Treatment preference and patient satisfaction in chronic insomnia. *Sleep, 24*(4), 411–417.

Walter, J., Vincent, N., Furer, P., Cox, B., & Kjernisted, K. (1999). Treatment preference in hypochondriasis. *Journal of Behavioral Therapy and Experimental Psychiatry, 30,* 251–258.

Whittemore, R., & Grey, M. (2002). The systematic development of nursing interventions. *Journal of Nursing Scholarship, 34*(2), 115–120.

Acknowledgements

This study was supported by grant #NR05075 from the National Institutes of Health/National Institute of Nursing Research. The principal investigator was Dr. Souraya Sidani.

Joyal Miranda, RN, MN, is a PhD student in the Faculty of Nursing, University of Toronto, Ontario, Canada.

2009 update: *Joyal Miranda is currently working on research examining participant-related and treatment-related factors in interventions for HIV prevention.*

CJNR 2009, Vol. 41 N° 1, 292–319

Résumé

Vers un horizon déontologique : une étude qualitative multicontextuelle des pratiques déontologiques au sein de la profession infirmière

**Paddy Rodney, Colleen Varcoe, Janet L. Storch,
Gladys McPherson, Karen Mahoney, Helen Brown,
Bernadette Pauly, Gwen Hartrick et Rosalie Starzomski**

Cet article rapporte les résultats d'une étude qualitative portant sur la prise de décision axée sur des principes déontologiques chez les infirmières. Des groupes de discussion rassemblant des infirmières travaillant dans divers contextes professionnels ont été mis sur pied pour explorer la signification du concept d'éthique et la mise en œuvre d'interventions fondées sur des principes déontologiques. Les résultats s'appuient sur la notion d'horizon déontologique (moral horizon) — l'horizon représentant « le bien », l'objectif que les infirmières ciblent dans leur pratique. Les résultats indiquent que les courants du climat moral dans lequel œuvrent les infirmières influencent de façon importante le cheminement de celles-ci vers l'horizon déontologique qu'elles visent. Bien trop souvent, les infirmières ont été forcées à naviguer contre un courant qui privilégie la biomédecine et la culture corporative. Par ailleurs, un courant favorisant le soutien entre collègues, la présence de lignes directrices et de normes professionnelles, et l'éducation déontologique les a aidées à cheminer vers cet objectif. Les implications quant à la pratique infirmière et une compréhension d'une prise de décisions fondées sur des principes déontologiques font l'objet d'une discussion.

CJNR 2009, Vol. 41 N° 1, 292–319

Navigating Towards a Moral Horizon: A Multisite Qualitative Study of Ethical Practice in Nursing

Paddy Rodney, Colleen Varcoe, Janet L. Storch, Gladys McPherson, Karen Mahoney, Helen Brown, Bernadette Pauly, Gwen Hartrick, and Rosalie Starzomski

This paper reports the results of a qualitative study of nurses' ethical decision-making. Focus groups of nurses in diverse practice contexts were used as a means to explore the meaning of ethics and the enactment of ethical practice. The findings centre on the metaphor of a moral horizon — the horizon representing "the good" towards which the nurses were navigating. The findings suggest that currents within the moral climate of nurses' work significantly influence nurses' progress towards their moral horizon. All too often the nurses found themselves navigating against a current characterized by the privileging of biomedicine and a corporate ethos. Conversely, a current of supportive colleagues as well as professional guidelines and standards and ethics education helped them to move towards their horizon. The implications for nursing practice and for our understanding of ethical decision-making are discussed.

The field of health-care ethics[1] has not attended to nurses' concerns very well over the four decades or so of its development.[2] Theory, research, and practice have tended to overlook or trivialize the kinds of ethical problems that nurses confront in their practice and the difficulties they experience in their role as moral agents (Chambliss, 1996; Jameton, 1984, 1990; Liaschenko, 1993a, 1993b; Rodney, 1997; Sherwin, 1992;

---

[1] The terms biomedical ethics, bioethics, and medical ethics are often used to refer to ethical differences between health-care providers (usually physicians) and patients. Our preferred term is health-care ethics, as it encompasses ethical concerns related to providers, patients, families, communities, health organizations, and society as well as biomedicine — all of which are relevant for nursing.

[2] Ethics is a branch of philosophy that focuses on questions of right/wrong, value or disvalue. The widespread application of ethical theory to health care is a recent phenomenon. The term bioethics first appeared about 30 years ago with the publication of a text on biological knowledge and human values (Roy, Williams, & Dickens, 1994, pp. 3–4; see also Jonsen, 1997; Pellegrino, 1997; Storch, Rodney, & Starzomski, 2002) and came to represent academic and professional efforts to address ethical issues posed by developments in the biological sciences (Roy et al., 1994, p. 4). With roots in medical ethics, philosophical ethics, and religious ethics, bioethics flourished and diversified as a result of rapid advances in medical science and technology and societal changes (Evans, 2000; Fox, 1990; Jonsen, 1997; Pellegrino, 1997; Roy et al., 1994, pp. 4–13).

Originally published in CJNR 2002, Vol. 34 N° 3, 75–102

Starzomski, 1997; Storch, 1992; Warren, 1992; Yeo, 1994). Fortunately, this is beginning to change. Health-care ethics is moving out of the dominance of the biomedical paradigm (Benner, 2000; Churchill, 1997; Coward & Ratanakul, 1999; Evans, 2000; Frank, 1998; Gadow, 1999; Hoffmaster, 2001; Kaufman, 2001; Levi, 1996; Sherwin, 1992, 1998; Winkler, 1993; Wolf, 1994) and nursing is becoming much more engaged in contemporary work on health-care ethics, as this issue of the Journal attests.

Understanding ethical decision-making[3] is an important part of understanding professionals' enactment of their moral agency.[4] That is, we ought to know how moral agents approach and deal with ethical problems in their practice. However, despite the progress made on contemporary work in health-care ethics, we still know little about how ethical decisions are actually arrived at and acted upon, and what moral agents experience when they are unable (or are able) to follow through on their decisions, what they believe the consequences are, and what they have to say about the effects of their practice environments on their decision-making (Calam, Far, & Andrew, 2000; Evans, 2000; Fox, 1990; Hoffmaster, 1990, 1999; Kaufman, 2001; Redman & Fry, 2000; Rodney, 1997; Saks, 1995; Solomon, 1995; Starzomski, 1997; Weisz, 1990).

Our purpose in this paper is to report on a recent study that sheds some light on the complexity of nurses' ethical decision-making. We will explicate our methodology and relevant findings, then use our findings to reflect on the implications for ethical decision-making, relational practice, and policy. Qualitative data such as ours have great promise for the ongoing development of theory and practice in ethics (Hoffmaster, 1990, 1991, 1993; Jameton & Fowler, 1989; Jennings, 1990; Yeo, 1994). It is therefore our hope that what we have to say will be helpful for our colleagues in nursing as well as other disciplines.

Inquiry: Background for This Study

Focus

Our study constituted the first exploratory stage in a program of research, so our focus was quite broad.[5] Our first research question concerned the

---

[3] Ethical decision-making has traditionally been thought of as a structured form of moral deliberation. Moral deliberation occurs when a moral agent confronts an ethical problem and asks the question "What ought I to do?" (Beyerstein, 1993, p. 422).

[4] Traditional perspectives on moral agency reflect a notion of individuals engaging in self-determining value-based choice (Sherwin, 1992; Taylor, 1992). Newer perspectives see moral agency as enacted through relationships in particular contexts (Mann, 1994; Rodney, 1997; Sherwin, 1992, 1998; Taylor, 1992). For discussions of moral agency in nursing, see Benner (2000), Georges and Grypdonck (2002), Jacobs (2001), Raines (1994), and Varcoe and Rodney (2002).

meaning of ethics for nurses providing direct care, for nurses in advanced-practice positions, and for nursing students. Our second research question concerned the *enactment of ethical practice* by these three groups. Finally, our third research question concerned the *integration of ethical content* in current nursing curricula. The study was therefore conducted in three interrelated parts:

Part 1: Describing community and hospital nurses' enactment of ethical practice. Qualitative data were obtained from nurses involved in direct care to gain a better understanding of the ethics of their practice. This included an exploration of the effect of the practice context on ethical decision-making and interdisciplinary team functioning.

Part 2: Understanding the role of advanced-practice nurses in fostering ethical practice in hospital and community care. Qualitative data were obtained from nurses in advanced-practice positions. The investigators explored how these nurses did (or did not) get involved in ethical practice. This included understanding how advanced-practice nurses foster ethical decision-making while providing support for nursing practice.

Part 3: Examining the integration of ethical theory in the delivery of nursing curricula. Qualitative data were obtained from students in a baccalaureate nursing program to explore their understanding of and involvement in ethical practice. This included inquiry into what students have experienced in their practice, and how this was or was not addressed through the integration of ethical content in their curriculum.

The main goal of our study was to contribute to a theoretical and practical foundation from which to promote the ethical practice of nurses. Our secondary goal was to contribute to a theoretical and practical foundation to support the ethical practice of professionals in other disciplines. While our findings were multifaceted,[6] there was a significant subset of findings related to ethical decision-making. We learned from our participants how ethical decisions were actually arrived at and acted upon, what they experienced when they were unable (or were able) to follow through on their decisions, what they saw as the consequences of their decisions, and the effects of their practice environments on their decision-making.

---

[5] "The Ethics of Practice: Context and Curricular Implications for Nursing." Principal Investigator J. Storch; Co-investigators G. Hartrick, P. Rodney, R. Starzomski, & C. Varcoe (July 1999). Funded by Associated Medical Services Inc. (Bioethics Division) and internal University of Victoria Social Sciences and Humanities Research Council grants.

[6] For other findings, see Hartrick (2002a); Storch, Rodney, Pauly, Brown, and Starzomski (2002); and Varcoe et al. (2002).

Methodology and Methods

Our study was qualitative in nature and was conducted using the constructivist (naturalistic) inquiry methodology explicated by Lincoln and Guba (1985). We used focus groups as the method of data collection. This method is particularly well suited for qualitative data collection (Morgan, 1997) and has been employed successfully in a study of ethical decision-making around resource allocation (Starzomski, 1997). Moreover, the focus group has several attractive features: researcher influence on the data is limited, participants in the group tend to exercise a good deal of control, and participants can react to and build upon the responses of other members of the group, creating a synergistic effect (Madriz, 2000; Morgan & Krueger, 1993; Wilkinson, 1998). Our study benefited from all of these features. For instance, both practising and student nurses in the focus groups generated rich reciprocal dialogue. At the same time, we were aware of some of the inherent limitations of the focus-group method, including "groupthink," uneven participant contributions, and replication of organizational power dynamics in the group (Madriz, 2000; Morgan, 1997; Morgan & Krueger, 1993; Starzomski, 1997; Wilkinson, 1998). We attempted to attenuate such limitations by having at least two researchers present — one to facilitate the group process and one to observe, take field notes, and contribute as necessary. We also attempted to make our focus groups homogeneous; members of the group were usually known to each other and were not (as much as possible) in hierarchical relationships. Further, we ensured that the designated facilitator had expertise in group process and interpersonal dynamics.

Approximately half the focus groups were conducted in a mid-sized metropolitan area with one health region and half in a large metropolitan area with several health regions. Administrative and ethics approval was obtained from the University of Victoria and from the research ethics committee of the region in the case of the mid-sized metropolitan area and each of the regions in the large metropolitan area. Data collection took place from January 2000 to January 2001 inclusive.

Guided by a process of theoretical sampling (Strauss & Corbin, 1998), we formed 19 focus groups, for a total of 87 participants. Once research ethics and administrative approval had been obtained, nurses from the identified clinical areas were invited to participate in focus groups through a variety of means. In most cases, a clinical supervisor or clinical resource nurse was approached and asked to facilitate one of the researchers attending a staff meeting to discuss the study and invite staff participation verbally and through a letter describing the study. Usually this method was effective, but sometimes repeated contact was needed to arrange a focus group. Our agency contacts always expressed interest in and support for the study, but it took time to negotiate the logistics of setting up focus groups in busy practice environments.

Three focus groups were conducted with advanced-practice nurses, 12 with other practising nurses, and four with nursing students at a local university school of nursing in the 3rd or 4th year of their baccalaureate program. Open-ended trigger questions were posed. These questions, which varied in phrasing and timing, asked the participants what they understood good (ethical) practice to be, what helped them in or constrained them from engaging in good practice, how they felt about their practice, and, finally, what their experience had been as focus-group participants. It is important to note that we introduced each focus group by setting guidelines for confidentiality and respectful participation. We also said at the outset that we were not interested in a particular theoretical approach to ethics or a "list" of particular issues. We explained that we saw ethics in terms of good practice, and wanted participants to explore that subject in whatever way was relevant for them, providing examples as needed. Our rationale for this preamble was based on our past experiences with research studies as well as with clinical and educational seminars — as soon as we began to ask about ethics, the nurses assumed we had a list of issues in mind.

The practising nurses came from a variety of settings, agencies, and units: maternity, pediatrics, medicine, surgery, critical care, emergency, operating room, oncology, psychiatry, rehabilitation, long-term care, home care, and community care. Meetings and focus groups were held on-site in a cafeteria or meeting room, or, in the case of student focus groups, a classroom. At the beginning of each focus group, the participants were asked to read/discuss the consent form regarding data collection. The participants were assured of confidentiality by the research team and were asked to respect the confidentiality of the group. Subsequently, identifiers were removed from the transcribed interviews and field notes.

All focus groups were audiotaped and transcribed and detailed field notes were taken. The investigators, joined by four graduate students in nursing (two of whom were also research assistants), met monthly to guide and facilitate the data collection and begin the analysis. Data analysis commenced with each member reading pre-assigned transcripts and conducting a thematic analysis. Then the team met and discussed the themes, modifying them as the data were reviewed within a given transcript and across transcripts. Field notes were used to supplement this process. Gradually, relationships among themes were identified and descriptions of the findings developed. An overview of the findings was prepared for a summary paper (Varcoe et al., 2002). Further analysis was conducted by smaller teams to enhance our understanding of particular aspects of the findings, which generated other papers (e.g., Hartrick, 2002a; Storch, Rodney, Pauly, Brown, & Starzomski, 2002), including the present one.

We will now present those findings that shed light on nurses' engagement in ethical decision-making. We will conclude by reflecting on some of the implications for nursing practice and for our understanding of ethical decision-making.

Findings

Given the exploratory nature of our study, it is not surprising that our findings were multifaceted. Overall, the practising and student nurses described ethics in their practice as both a *way of being* and a *process of enactment* (Varcoe et al., 2002). They described drawing on a wide range of sources of moral knowledge in a dynamic process of developing awareness of themselves as moral agents. Enacting moral agency involved working within a shifting moral context and working "in between" their own values and those of their employing organization, "in between" their own values and those of others, and "in between" competing values and interests. The moral identities of the participants emerged and evolved as they navigated their way through the contextual and systemic forces that shaped the moral situations of their practice (Hartrick, 2002a). We also learned about practice realities that created a climate for moral distress, and the ways in which nurses attempted to maintain their moral agency (Storch, Rodney, Pauly, et al., 2002).

Our findings include insights that are significant for an understanding of ethical decision-making. What was most striking about the nurses' engagement in ethical decision-making was the processual and contingent nature of their decisions and subsequent action. Their decisions and actions evolved over time and were not always in a straight line. We therefore concluded that a nautical metaphor, navigation, best reflected the nurses' ethical decision-making: they were navigating towards a moral horizon, but their course was often not smooth or certain.

The Moral Horizon

In our analysis, the horizon[7] reflected a notion of "the good"[8] towards which the nurses were navigating. The horizon was not a fixed point, but

---

[7] Our notion of moral horizon is informed by Bernstein (1991) and Taylor (1992). Bernstein speaks of a moral horizon as a moral point of view, while Taylor speaks of negotiating a value-based direction.

[8] Our understanding of this term is influenced by Patricia Benner and her colleagues, who build on Aristotle's work. We understand ethics in terms of *good practice* — practice that comes from good character and good action (Aristotle, c. 320 BC/1985; Benner et al., 1996). In other words, "one's acts are governed by concern for doing good in

a negotiated direction. Nurses' descriptions of the horizon suggested that this direction was co-created by patients, families, and teams (see Table 1) — that is, the horizon was not necessarily set as an objective, but, rather, emerged in the context of treatment and care. For example, in a focus group of nurses working in intensive care, the participants indicated that their treatment and care made sense only in relation to the patient's illness trajectory and personal background and goals, rather than in relation to just the particulars of the disease process.

The nurses' navigation was guided by different features of the horizon — each representing a moral good. The features included relief of suffering, preservation of human dignity, the fostering of choice, physical and psychological safety, the prevention and minimization of harm, and patient and family well-being. For instance, an operating room nurse said, "I've often wondered whether the patients in these situations have been adequately informed by the physician or the surgeon. I know for a fact, in a lot of cases, that they haven't been." Choice was evident in her description of the moral horizon, as were relief of suffering caused by the surgery and prevention of harm caused by unnecessary intervention. Family well-being and choice were prominent features of the horizon described by a pediatric nurse: "Part of feeling good about what we do is when the family takes control and they are empowered to be looking after this child at home."

The features of the horizon suggested by the words of these nurses were consistent across all focus groups, albeit expressed in different ways by different groups of practising and student nurses. However, it is important to note that negotiating a shared horizon was not easy. Members of the health-care team (including nurses) were often headed in different directions. Family members were also often headed in different directions, both from each other and from members of the health-care team, as recounted by a pediatric nurse:

> *Not that long ago we had a premature baby who had a huge bleed in the head. [The physicians] talked about discontinuing life support. And the [mother] couldn't do it; she could not live with herself. So we cared for the child for 2 more days and the baby died on the ventilator. For the nurses, that was really hard…because they believed it should just end.*

---

particular circumstances, where being in relationship and discerning particular human concerns are at stake and guide action" (Benner, 2000, p. 5). In nursing, we use various principles or concepts to help us to articulate ethical goods (e.g., autonomy, beneficence/nonmaleficence, justice, fidelity, care); importantly, ethics is part of our daily work, not just in life-and-death situations. "Even in clinical situations, where the ends are not in question, there is an underlying moral dimension: the fundamental disposition of the nurse toward what is good and right and action toward what the nurse recognizes or believes to be the best good in a particular situation" (Benner et al., 1996, p. 6).

Table 1 ***The Moral Horizon for the Patient, Family, and Health-Care Team***

Features of the Moral Horizon
Relief of suffering
Preservation of human dignity
Fostering of choice
Physical and psychological safety
Prevention and minimization of harm
Patient and family well-being
Choosing Alternative Routes
Waiting a while
Having others act
Shifting course away from the horizon
Reaching the Horizon
Feeling you care
Being able to cope
Coming together
Feeling respected and heard
Feeling good about the decision
Being able to let go
Being heard
Creating a sense of home
Not Reaching the Horizon
Being dehumanized
Not being valued
Suffering unnecessarily
Being punished for being ill or old
Being let down
Broken up
Feeling unsafe
Feeling powerless

The nurses saw continuing treatment as causing suffering and threatening the dignity of the newborn, while the mother may have constructed the treatment as preserving life and family. In this example the nurses' notions of the moral horizon needed to be negotiated with the mother. This case shows that the direction of those involved in a situation was not necessarily shared.

At times the nurses chose to or were forced to take an alternative route to the horizon, such as having other team members act in their stead or waiting a while. Another pediatric nurse, for example, told the story of supporting the mother of a brain-injured newborn who was to be discharged. The nurses and physicians tried to impress upon the mother the severity of the child's condition and the consequences of treatment. After waiting a while, the nurse realized that her initial course (providing the mother with as much hospital and home support as possible) was not what the mother actually needed — she needed to be able to do as much as possible independently for her child. At other times, nurses veered away from the horizon. This shift occurred if they judged someone as undeserving of their care, usually described in terms of "distancing" themselves or "not caring."[9] For instance, in a focus group with emergency nurses, a nurse spoke of distancing herself from patients who came in repeatedly with problems related to substance use.

The nurses constructed their success in terms of reaching the horizon or making the best progress possible. Success was defined as the patient "feeling you care," the family "being able to cope," the team "coming together," and nurses "feeling respected and heard," "feeling good about the decision," "learning to let go," and "being heard." Learning to let go, for instance, is evident in the above story of the pediatric nurse realizing that the mother of the newborn needed to make her own choices about coping at home. They also spoke of reaching the horizon in terms of "creating a home" for patients — a point emphasized in our focus groups with nurses working in long-term care and rehabilitation. Success in reaching the horizon was usually associated with satisfaction and fulfilment. One 4th-year nursing student said, "You just know it. You can see it in your patient's face, your client's family's face, whoever it is, and you can feel it inside you that you've done the right thing." And an emergency nurse affirmed, "I'd say I love my job, I still love my job."

On the other hand, some nurses spoke of not getting close to or arriving at the horizon in terms of the patient being "dehumanized," not being "valued," "suffering unnecessarily," or being "punished for being ill or old," the family being "let down" or "broken up," and nurses feeling "unsafe" or "powerless." A nurse working in intensive care expressed it this way:

> *Ethics was a frustrating issue in the sense that you would come on a shift and the decision [to withdraw treatment] had [not been] made…that seemed apparent to me should have been made, and we sustain them through the night until maybe the next day. And that seemed to be the primary sort of dilemma that I faced. Because I'm casual, I also found that I didn't have a lot of continuity in looking after the same patients, so these*

---

[9] For discussions of deservedness, see Rodney and Varcoe (2001), Varcoe (1997, 2001), and Varcoe and Rodney (2002).

> *issues would come up…over the course of a shift…unless the patient had been a long-term, chronic-care patient in the unit, so I never really got to address them because we had what was required (kind of reports and rounds in the early evening) and then over the course of the night some things would become sort of questions, but, you know, we never had an opportunity then to go on [to resolve the issues].*

This nurse's sense of powerlessness and her concerns about suffering and harm are evident. Such concerns about not reaching the moral horizon were echoed by nurses from widely divergent practice contexts, as shown by comments made in a focus group with community nurses:

> First community nurse: *The maternity client is a very complex client because they're in need of a lot of different programs, not just [like] someone who has abdominal surgery coming out [of hospital] and they need a dressing change and they have a family and they go through home care. [A complex maternity client] in the community — they're a breast-feeding client, they're bipolar [have a mental health condition] and they have no family support.*
>
> Second community nurse: *But nobody recognizes that. The maternity client is [supposed to be] "just a piece of cake." "Birth is normal," you know.*
>
> Third community nurse: *It happens everywhere. Breastfeeding is [assumed to be] automatic.*
>
> First community nurse: *I think the mental health [aspect] is really important to keep in mind too. And I think of our partners in the social services ministry and the difficulties sometimes that have been demonstrated around being able to have an appropriate plan. I can think of an occasion where we had a family whose children were apprehended…the family were not able to provide enough resources themselves to be able to care adequately…mother [maternity client] had become psychotic in hospital, and of course English is a second language, which made it…more difficult. So, what ended up happening, because the resources weren't available, those children ended up being apprehended…when what needed to happen was that family needed to be supported in order to be able to remain together… I think ethically we really failed this family. Not just community health but the whole health-care system, including the social services ministry, because what happens time and time again is that the social services ministry holds the resources, we're here saying people need the resources, and then the fight begins in terms of trying to seek out those very few resources to keep that family together for the period of time it takes to get better. And it doesn't happen in 2 days, 3 days, a week. It*

> *takes a longer period of time for some stability and for the crisis to ease. And to me that's very distressing.*

This segment reveals a great deal about the moral horizon of nurses' work. The features of the moral horizon included meaningful choice in childbearing, the physical and psychological safety of the woman, newborn, and family, appropriate social services intervention, and the long-term well-being of the family unit. Waiting a while (an alternative route) was not an option. This nurse did not feel that she had arrived at — or even come close to — a moral horizon for the woman, her newborn, or the family. She felt that the family's unique needs were not being valued, that they were suffering unnecessarily, and that they were being let down and broken up as a family unit. In fact, the participant who related the story later said, "It's like being punished for being ill. Bottom line. You're ill, you can't cope, that's it, end of discussion."

In summary, we have used the metaphor of moral horizon to describe nurses' understanding of the good in particular practice situations — an understanding that was shared with others and developed through a process of negotiation, and that provided direction for practice.[10] This is not to say that the nurses always negotiated effectively, or that their horizon was not overly circumscribed, or that they were accurate in identifying when (if ever) they arrived. Those are questions for further research and theoretical inquiry.

Currents Affecting Navigation

Many of the insights we gained concerned the complex and pervasive influences on nurses' ability to move towards their moral horizon. Throughout our study, nurses in every practice context identified their practice as frequently constrained or facilitated by influences beyond their immediate control. We came to understand such influences as currents affecting navigation and, thus, affecting progress towards the moral horizon (see Table 2). In what follows we will articulate those currents that nurses identified as having the most profound influence on their practice.

One current the nurses often found themselves navigating against was a privileging of biomedicine and a corporate ethos. A segment of a focus group with operating room nurses will serve to illustrate:

> First OR nurse: *I don't feel that my nursing work is complete, because I don't have the time to provide the caring emotional support that I think*

---

[10] Sally Gadow (1999) calls this type of negotiation a "relational narrative": "Ethical narratives created by patient and nurse from the homeland of their engagement are…more than individual accounts: they are relational narratives" (p. 65).

Table 2 ***Currents Affecting Navigation***

Currents Constraining Navigation
Privileging of biomedicine
Corporate ethos
Currents Facilitating Navigation
Supportive colleagues
Professional guidelines and standards
Education in ethics

> *this particular kind of patient requires. You feel like it's a race…truly, you are ruled by the clock and not by what your patients' needs are. [There is rarely] a case where you feel that you can actually do something for your patient or make a difference to them. I feel that every minute with your patient before they're put to sleep is a bonus for that patient when they wake up, everything you can do for that person. And when you have less than 2 minutes in a less than ideal, busy hallway…then it's a very unsatisfying experience, because I just know I haven't done a good job.*
>
> Second OR nurse: *Ethically, how can I say I'm the bad guy? I'm not the bad guy. The work environment is the bad guy… I can speak to having to do 10 cataract extractions every day, and feeling as though you're working with a gun at your head. Literally, that is the emotional feeling that I have, that the surgeon is holding a gun at my head and I am under constant pressure. So, I say I am extremely dissatisfied with my job when I have to work like that. I hate it.*

These OR nurses were trying to navigate to a place where they could spend time with and support their patients through the experience of surgery. However, the privileging of biomedicine meant that the focus was on surgical procedure. The corporate ethos meant that nurses' time spent caring was not counted or planned for, and as many procedures as possible were pushed through. The corporate goal of efficiency took precedence over patient well-being, interdisciplinary team cohesion, and nurse satisfaction. Time for quality nursing care became a prized and contested commodity. No member of the research team will ever forget the comment of the OR nurse who felt as if she was practising with a gun to her head. For her, the consequences of being unable to move towards a moral horizon were more than just dissatisfaction: she felt unsafe, exhausted, and demoralized; it was almost impossible for her to make any headway against the current.

While the words of the OR nurse are particularly poignant, similar concerns were expressed in every focus group with nurses involved in direct care. For instance, in the segment with community nurses cited above, the privileging of biomedicine meant that the intersection of a mental health problem with a birth experience, inability to speak English, and poverty fell outside the scope of agency policies,[11] and the corporate ethos meant that resources were squeezed and traded off between health and social services. Time for quality nursing care was also contested, even if not as urgently as in the operating room.

Comments from a focus group with nurses practising on a medical unit in the large urban hospital illustrate the effect of the constraining current on nurses' well-being:

> First medical unit nurse: *We're not getting anything back and…it depletes us. And it's the depletion, and the burnout and the quitting and the three-career kind of thing. How are we…going to help our nursing profession when we're not working with [adequate] staff?… Everyone's so distraught on the unit, and I find myself, I am like that, and I try to be a really positive, energetic person. At 27, I'm starting to dwindle away, thinking what am I going to do with my life? At 27. If I'm feeling that now, I don't want to be burnt out in 5 years.*
>
> Second medical unit nurse: *[It's difficult to find the time to] participate in things like this [focus group] and things like in-services…it's frustrating when you can't get 20 minutes to go to an in-service…because you haven't finished your charting, or because you've got your vital signs to take and because you've got a new admission coming in and you know you can't get away on the floor.*
>
> First medical unit nurse: *There's no administration support.*
>
> Second medical unit nurse: *I think that's what it is. They want you to attend them but…*
>
> First medical unit nurse: *…on your own time, energy, etc., etc. I find that there's not a lot of support. I don't think that they [administration] don't want to give it, I don't think they have the availability to give it to us.*

The workload on the acute-care medical unit where these nurses practised was increasingly demanding, and resources to support staff (such as in-services) were described as largely unavailable or inaccessible. The above statement "I don't think they have the availability to give it to us"

---

[11] Cassidy, Lord, and Mandell (1995) offer an insightful analysis of intersectionality and oppression.

suggests that the corporate ethos was controlled at a level beyond first-line management. In the province where our study was conducted, the provincial government distributed funds to regional boards, which then made allocation decisions.[12]

Fortunately, there were also situations in which the prevailing currents facilitated nurses' attempts to navigate towards a moral horizon. Supportive colleagues in nursing and other disciplines were a major influence. One nurse practising on a maternity unit put it this way:

> *For me a problem shared is a problem halved. I have shared it and [got] someone else's perspective on it, and maybe it wasn't really that huge a deal. When someone else's perspective comes to it…all of a sudden it isn't such a huge problem any more — "gee, it's not just me that felt this way, it's a more common feeling than I realized." I guess it gives me permission to have felt that way, knowing that other people have the same issues. It just cuts it down inside.*

Likewise, in a focus group with emergency nurses, the participants spoke of situations in which interdisciplinary team work generated mutual respect with their medical colleagues. In fact, when we asked participants in all of the focus groups what helped them to deal with ethical problems in their practice, the consensus was "supportive colleagues."[13]

Nurses in advanced-practice and management positions told of numerous initiatives they had taken to improve the moral climate of the workplace. These initiatives included a focus on interdisciplinary team work, the establishment of accessible practice guidelines and policies, and education in ethics, all three of which were affirmed by other practising nurses as improving the moral conditions of their work (Storch, Rodney, Pauly, et al., 2002). An advanced-practice nurse explained:

> *I think…of the patient consults that I get involved in, there's always a huge element of ethics involved, and many times the reason why I'm there is because there's some sort of breakdown in the system and there's a perception that there's a gap in service…so the whole notion of being an advocate for patients [is part of it]…promoting the team unity and collegial relationships…fostering and maintaining those relationships but at the same time recognizing what is happening with the patient, that things are not going the way they should…that can be quite stressful at times…and it really involves a lot of courage and sometimes standing up and being the voice calling out in the wilderness with not a lot of backup until you manage to convince people to go along with you.*

---

[12] See Brown (1996) for an interesting analysis of the power relationships between provinces and regional boards.

[13] See Rodney (1997) for similar findings from an ethnography conducted on two acute-care medical units.

The actions of this advanced-practice nurse no doubt helped the nurses and other team members to move towards their moral horizon. Dealing with "gaps" in service and "being an advocate for patients" would do much to counteract the privileging of biomedicine and the corporate ethos. By "fostering and maintaining those relationships," this nurse was helping colleagues to be mutually supportive, "recognizing…that things are not going the way they should" indicates that she was attentive to professional standards and guidelines, and managing to "convince people to go along with you" certainly reveals at least some informal education in ethics. While this is the story of just one advanced-practice nurse, it is reflective of what we heard from her colleagues in nursing leadership positions (Storch, Rodney, Pauly, et al., 2002).

Implications for Practice

The findings from our study shed some light on the process of ethical decision-making and nurses' experiences in terms of their ethical decisions and the role of ethics in their practice environments. We have used a nautical navigation metaphor to describe the processual and contingent nature of the nurses' experiences. The notion of a moral horizon reflects "the good" towards which the nurses were navigating. The horizon was not a fixed point but, rather, a direction negotiated by patients, families, and teams. Currents within the moral climate of nurses' work significantly influenced their progress. All too often, nurses found themselves navigating against a current characterized by the privileging of biomedicine and a corporate ethos.[14] Fortunately, supportive colleagues as well as professional standards and guidelines and ethics education constituted strong currents, helping nurses to move towards the horizon.

We emphasize, though, that the nurses in this study, as moral agents, often experienced a great deal of difficulty navigating. One nurse working in long-term care said: "Not being able to make decisions is like atrophy of a muscle. I can hardly remember being in control of nursing practice, of my ethics, of making these decisions — it's eroding." People in nursing and other health-care professions, health-care ethics, and health policy need to take such comments seriously. We have argued elsewhere that strengthening nurses' moral agency means attending to nurses' personal needs while at the same time improving the moral climate of their practice (Hartrick, 2002a; Rodney, 1997; Rodney & Varcoe, 2001; Starzomksi, 1997, 1998; Storch, 1999; Storch, Rodney,

---

[14] See Rodney and Varcoe (2001), Varcoe (2001), and Varcoe and Rodney (2002) for similar findings from ethnographies conducted in two acute-care medical units and two emergency units.

Pauly, et al., 2002; Varcoe et al., 2002; Varcoe & Rodney, 2002). While there is some research identifying and implementing positive workplace initiatives,[15] much more is needed. In the meanwhile, we will highlight some of the practice implications of the present findings.

It is not surprising to find that the currents constraining the nurses' moral agency were so pervasive. Today's practice environments pose myriad ethical challenges, including increasing complexity of patient, family, and community needs, escalating biotechnological advances, a rightward shift in sociopolitical climate, and increasingly stressed nursing workplaces (Adams & Bond, 2000; Aiken, Clarke, & Sloane, 2000; Barry-Walker, 2000; Canadian Nurses Association, 1998a; Duncan et al., 2001; Health Canada Office of Nursing Policy, 2001; Mohr, 1997; Nagle, 1999; Oberle & Tenove, 2000; Redman & Fry, 2000; Rodney & Varcoe, 2001; Varcoe, 2001; Varcoe & Rodney, 2002). While we do not claim to have identified an exhaustive list of currents, we believe that those we have identified are salient ones. Understanding how such currents affect nurses' progress towards a moral horizon provides a foundation from which to improve the moral climate of nursing practice.

One improvement we can make is to *enhance the quality of the relationships* between nurses, other health-care providers, patients, and families. The interpersonal context in which ethical decisions are made is profiled in our study. Negotiating a shared horizon was often difficult, requiring effective communication among all the various parties involved. Further, the current created by the privileging of biomedicine and the corporate ethos disrupted interdisciplinary team functioning. This is evident in the OR nurse's comment that she felt as if she was practising with a gun to her head — a gun held by the surgeon but put there by an organizational mandate to process as many patients as possible. Conversely, positive relationships with colleagues in nursing and other disciplines have tremendous potential to help nurses stay on course. While there is growing attention in the health-care and ethics literature to the role of trust in resolving end-of-life issues (Burgess, Rodney, Coward, Ratanakul, & Suwonnakote, 1999; Kuhl & Wilensky, 1999; Rodney, 1994, 1997; Solomon et al., 1993; Starzomski, 1997, 1998; Taylor, 1995; Tilden, Tolle, Nelson, Thompson, & Eggman, 1999), not enough has been written about the role of trust in day-to-day processes.[16] We need to better artic-

---

[15] See Laschinger, Finegan, Shamian, and Casier (2000) for an insightful research study on the effects of organizational trust and empowerment in restructured health-care settings on staff nurse commitment. See also Aroskar (1995), Corley and Goren (1998), Jameton (1990), McDaniel (1998), and Olson (1998) regarding strengthening nursing as a moral community.

[16] For a notable exception, see Peters and Morgan's (2001) exploration of trust in a home-care context.

ulate — and subsequently defend — the day-to-day relational processes that influence the moral climate of nursing practice and interdisciplinary team functioning (Bergum, 1993, 1994; Gadow, 1999; Hartrick, 2002b; Jameton, 1990; Liaschenko, 1993b; Liaschenko & Fisher, 1999; Sherwin, 1998).

Secondly, we can help nurses to *use the language of ethics in a way that supports their practice.* Throughout the focus groups, nurses told us that their voices were seldom heard as they confronted everyday as well as quandary ethical problems. To some extent, they were not heard because they tended not to explicitly flag a problem as ethical. While all of the nurses spoke about good practice, most did not consciously speak of it in terms of ethics. For instance, a maternity nurse referred to the embeddedness of ethical decisions in her practice:

> *You make so many decisions, it sort of comes from the heart…almost automatically… I don't think we can, it would be very difficult to just try and label…to try and figure this was an ethical decision, this was a decision that was totally governed by my profession or my obligation to the situation. I'm not sure that I can verbalize [it].*

Their failure to use ethical language is no indication that the nurses were not making ethical decisions or practising ethically. Indeed, as is indicated by our horizon metaphor, they were almost always aware of (though not necessarily following) a value-based direction in their practice. A number of participants spoke of formal education in ethics having helped them to find their voice. Thus, one of the implications of our research is the need for more formal and informal nursing education in ethics (Storch, Rodney, Pauly, et al., 2002). Such education ought to attend to the relational context of nursing practice and everyday as well as quandary ethical problems.

Thirdly, we need *to improve the moral foundations of health policy.* In our study, health policy influenced the nurses' ability to work towards a moral horizon at every level of practice — from staffing decisions to resuscitation guidelines to discharge criteria to relationships between government departments. We need nursing expertise and nursing leadership to analyze the moral foundations of health policy (Malone, 1999; Mitchell, 2001; Storch, Rodney, Pauly, et al., 2002). And we need to involve nurses at every level of practice in re-shaping health policy so that it is more supportive of the ethical practice of nurses and other health-care providers.

We realize that our recommendations for improved practice will not be easy to implement. In the words of an advanced-practice nurse cited earlier, it will also take courage on the part of individuals and groups (Storch, Rodney, Pauly, et al., 2002). However, as one intensive-care nurse said:

> *Well, we have to have some hope. And so that's how I look at it. …I am in no way thinking that there's not more work to be done. There definitely is. But I have seen successes, and so I think it is possible. But we need to engage everybody…it has to be a level playing field. So people have to have — all people, physicians, nurses…and our health-care team — …basically the same values and mission, really, about what we're trying to do.*

Nursing has tremendous capacity to make a difference, to move towards moral horizons for the benefit of patients, families, and communities.

Reflection: Ethical Theory and Ethical Decision-Making

We will close by reflecting back on theory and practice in health-care ethics. Our findings show that ethical decision-making is much more than the rational, objective application of ethical principles that traditional ethical theory implies. Traditionally, ethical problems in health care have been seen to collapse into dichotomous (yes/no) questions about what a moral agent (usually a lone physician) should do with a patient, usually in a life-or-death situation. The answers have been seen as residing in the application of foundational ethical principles — autonomy, beneficence, nonmaleficence, and justice (Beauchamp & Childress, 1989). It is assumed that an objective, rational, analytic process will furnish a concrete and correct answer, outside the familial, social, cultural, and political context of the problem (Baylis, Downie, Freedman, Hoffmaster, & Sherwin, 1995; Burgess et al., 1999; Churchill, 1997; Evans, 2000; Fox, 1990; Gadow, 1999; Hoffmaster, 1990, 1999; McDonald, 1999; Stephenson, 1999; Weisz, 1990; Yeo, 1994).[17] At the same time, much of the early nursing research on ethical decision-making was based on theories of moral reasoning, applying principles of justice and/or care to hypothetical situations (Cameron, 1991; Cassidy, 1991; Cooper, 1991; Fry, 1987; Georges & Grypdonck, 2002; Ketefian, 1989; Munhall, 1983; Omery, 1983; Penticuff, 1991; Rodney, 1997). The participants in our study, in contrast, portrayed decision-making as processual and highly contextual. Decisions were gradual and constituted a journey towards a

---

[17] Such criticisms of principle-oriented ethics sometimes have more to do with how the principles have been traditionally used in health-care ethics than with a weakness in the principles themselves (Churchill, 1997; Rodney, 1997). The principles have been somewhat unfairly caricatured (Levi, 1996; Wolf, 1994; Yeo, 1994). Beauchamp and Childress (1989) make it clear that they view principles in terms of what they call "composite theory" (p. 51). They explain that "each basic principle [has] weight without assigning a priority weighting or ranking. Which principle overrides in a case of conflict will depend on the particular context, which always has unique features" (p. 51). In other words (and contrary to what many critics imply), the principles are "binding but not absolutely binding" (p. 51). The principles can thus be viewed as useful heuristic devices (Stevenson, 1987) rather than as rigid prescriptions.

mutually constructed and pluralistic moral horizon. This finding is consistent with those of other nursing studies. When studies began to move from hypothetical situations to accounts of *practice*, ethical decision-making came to be seen as more nuanced and contextual (Benner, Tanner, & Chesla, 1996; Chambliss, 1996; Fry, 1999; Gaul, 1995; Georges & Grypdonck; Rafael, 1996; Redman & Fry, 2000; Rodney, 1997; Sherblom, Shipps, & Sherblom, 1993). Our findings thus support those of nursing studies on moral reasoning and ethical decision-making that emphasize context and action.

Nursing research on ethical decision-making that emphasizes context and action parallels current theoretical shifts in health-care ethics. These shifts entail a proliferation of alternatives to principlism, and include (but are not limited to) a revival of casuistry, the call for an inductivism based on empirical information or ethnography, interest in narrative bioethics, the articulation of care-based ethics, and relational ethics (Wolf, 1994, p. 400; see also Bergum, Boyle, Briggs, & Dossetor, 1993; Churchill, 1997; Gadow, 1999; Hoffmaster, 1999; Levi, 1996; Omery, 1983; Starzomski, 1997; Yeo, 1994).[18] Each of these alternative approaches to ethical theory can be considered a form of *contextualism*. Contextualism takes into account the reciprocity of facts and values: "moral problems must be resolved within concrete circumstances, in all their interpretive complexity, by appeal to relevant historical and cultural traditions, with reference to critical institutional and professional norms and virtues" (Winkler, 1993, p. 344). In other words, contextualism transcends the reductionist tendency of principle-based ethics by focusing on particular people and particular relationships in particular contexts.

The rise of contextual ethics has been associated with approaches to ethical decision-making that are more sensitive to context (see, for instance, Jonsen, Sieglar, & Winslade, 1986; Keatings & Smith, 2000, pp. 42–43; Kuhl & Wilensky, 1999; McDonald, 2002). Theorists and health-care providers who use a contextual approach to ethical decision-making aim for a "philosophical understanding of the fundamental concepts used in moral analysis and the tensions between them" in order to "sort out confusions, clarify disagreements, and promote creative problem-solving" (Yeo, 1996). Contextual ethical theory therefore corresponds with models

---

[18] Casuistry is an inductive approach to ethics that proceeds through case analyses (Arras, 1991; Jonsen, 1995; Jonsen & Toulmin, 1988; Levi, 1996; Toulmin, 1981). Inductivism is a more general term referring to the use of qualitative and quantitative data to inform ethical theorizing (Hoffmaster, 1991, 1993; Jameton & Fowler, 1989). Narrative bioethics has emerged as the use of story to inform ethical practice (Frank, 2001; Nisker, 2001). The primary focus in care-based ethics is relationships and care (Flanagan, 1991; Gilligan, 1982; Sherwin, 1992), while in relational ethics it is human meaning and connectedness (Bergum et al., 1993; Sherwin, 1998).

of ethical decision-making that are more attentive to the real world of clinical practice. Such models can be used to help nurses to participate with patients, families, and other providers in working towards a moral horizon. For example, McDonald's (2002) model provides guidelines for a group to move towards conflict resolution and consensus.

Further, insights from nursing research can help to shape the evolution of ethical decision-making models. Nurses, other members of the health-care team, and patients and families are engaged in multiple decisions as they work their way towards a horizon. Not all of the decisions are life-and-death (Benner, Tanner, & Chesla, 1996; Canadian Nurses Association, 1998b; Chambliss, 1996). In the account by the pediatric nurse cited earlier, for instance, the mother taking her seriously ill newborn home had made some initial decisions about life-saving treatment (a quandary problem); subsequent decisions about support at home (everyday problems) would follow, and would take time. Current models and frameworks are not sufficient. We need more research into decision-making approaches that will address the interface of everyday and quandary ethical problems and their evolution (Rodney, 1997; Storch, Rodney, & Starzomski, 2002). Nurses are in a good position to contribute to such research.

References

Adams, A., & Bond, S. (2000). Hospital nurses' job satisfaction, individual and organizational characteristics. *Journal of Advanced Nursing, 32*(3), 536–543.

Aiken, L. H., Clarke, S. P., & Sloane, D. M. (2000). Hospital restructuring: Does it adversely affect care and outcomes? *Journal of Nursing Administration, 30*(10), 457–465.

Aroskar, M. A. (1995). Envisioning nursing as a moral community. *Nursing Outlook, 43*(3), 134–138.

Arras, J. D. (1991). Getting down to cases: The revival of casuistry in bioethics. *Journal of Medicine and Philosophy, 16,* 29–51.

Barry-Walker, J. (2000). The impact of systems redesign on staff, patient, and financial outcomes. *Journal of Nursing Administration, 30*(2), 77–89.

Baylis, F., Downie, J., Freedman, B., Hoffmaster, B., & Sherwin, S. (1995). Preface. In F. Baylis, J. Downie, B. Freedman, B. Hoffmaster, & S. Sherwin (Eds.), *Health care ethics in Canada* (pp. v–vii). Toronto: Harcourt Brace.

Beauchamp, T. L., & Childress, J. F. (1989). *Principles of biomedical ethics* (3rd Ed.). New York: Oxford University Press.

Benner, P. (2000). The roles of embodiment, emotion and lifeworld for rationality and agency in nursing practice. *Nursing Philosophy, 1,* 1–14.

Benner, P. A., Tanner, C. A., & Chesla, C. A. (with contributions by H. L. Dreyfus, S. E. Dreyfus, & J. Rubin). (1996). *Expertise in nursing practice: Caring, clinical judgment, and ethics.* New York: Springer.

Bergum, V. (1993). Participatory knowledge for ethical care. *Bioethics Bulletin, 5*(2), 4–6.

Bergum, V. (1994). Knowledge for ethical care. *Nursing Ethics, 1*(2), 71–79.

Bergum, V., Boyle, R., Briggs, M., & Dossetor, J. (1993). *Principle-based and relational ethics: Both essential features of bioethics theory and analysis.* Unpublished manuscript, Bioethics Centre, University of Alberta, Edmonton, and University of Alberta Hospitals.

Bernstein, R. J. (1991). *The new constellation: The ethical-political horizons of modernity/postmodernity.* Cambridge, MA: MIT Press.

Beyerstein, D. (1993). The functions and limitations of professional codes of ethics. In E. R. Winkler & J. R. Coombs (Eds.), *Applied ethics: A reader* (pp. 416–425). Oxford: Blackwell.

Brown, M. C. (1996). Changes in Alberta's Medicare financing arrangements: Features and problems. In M. Stingl & D. Wilson (Eds.), *Efficiency vs equality: Health reform in Canada* (pp. 137–151). Halifax: Fernwood.

Burgess, M., Rodney, P., Coward, H., Ratanakul, P., & Suwonnakote, K. (1999). Pediatric care: Judgements about best interests at the outset of life. In H. Coward & P. Ratanakul (Eds.), *A cross-cultural dialogue on health care ethics* (pp. 160–175). Waterloo, ON: Wilfrid Laurier University Press.

Calam, B., Far, S., & Andrew, R. (2000). Discussions of "code status" on a family practice teaching ward: What barriers do family physicians face? *Canadian Medical Association Journal, 163*(10), 1255–1259.

Cameron, M. (1991). Justice, caring, and virtue. *Journal of Professional Nursing, 7*(4), 206.

Canadian Nurses Association. (1998a). *The quiet crisis in health care.* Paper submitted to the House of Commons Standing Committee on Finance and the Minister of Finance. Ottawa: Author.

Canadian Nurses Association. (1998b). *Everyday ethics: Putting the Code into practice.* Ottawa: Author.

Cassidy, B., Lord, R., & Mandell, N. (1995). Silenced and forgotten women: Race, poverty, and disability. In N. Mandell (Ed.), *Feminist issues: Race, class and sexuality* (pp. 32–66). Scarborough, ON: Prentice-Hall.

Cassidy, V. R. (1991). Ethical responsibilities in nursing: Research findings and issues. *Journal of Professional Nursing, 7*(2), 112–118.

Chambliss, D. F. (1996). *Beyond caring: Hospitals, nurses, and the social organization of ethics.* Chicago: University of Chicago Press.

Churchill, L. R. (1997). Bioethics in the social context. In R. A. Carson & C. R. Burns (Eds.), *Philosophy of medicine and bioethics* (pp. 137–151). Amsterdam: Kluwer Academic.

Cooper, M. C. (1991). Principle-oriented ethics and the ethic of care: A creative tension. *Advances in Nursing Science, 14*(2), 22–31.

Corley, M. C., & Goren, S. (1998). The dark side of nursing: Impact of stigmatizing responses on patients. *Scholarly Inquiry in Nursing Practice, 12*(2), 99–118.

Coward, H., & Ratanakul, P. (Eds.). (1999). *A cross-cultural dialogue on health care ethics.* Waterloo, ON: Wilfrid Laurier University Press.

Duncan, S. M., Hyndman, K., Estabrooks, C. A., Hesketh, K., Humphrey, C. K., Wong, J. S., et al. (2001). Nurses' experience of violence in Alberta and British Columbia hospitals. *Canadian Journal of Nursing Research, 32*(4), 57–78.

Evans, J. H. (2000). A sociological account of the growth of principlism. *Hastings Center Report, 30*(95), 31–38.

Flanagan, O. (1991). *Varieties of moral personality: Ethics and psychological realism.* Cambridge, MA: Harvard University Press.

Fox, R. C. (1990). The evolution of American bioethics: A sociological perspective. In G. Weisz (Ed.), *Social science perspectives on medical ethics* (pp. 201–217). Philadelphia: University of Pennsylvania Press.

Frank, A. W. (1998). First-person microethics: Deriving principles from below. *Hastings Center Report* (July/Aug.), 37–42.

Frank, A. W. (2001, February 23). *The politics of authenticity.* Paper presented at the Advances in Qualitative Methods Conference, Edmonton, Alberta.

Fry, S. T. (1987). Research on ethics in nursing: The state of the art. *Nursing Outlook, 35*(5), 246.

Fry, S. T. (1999). The philosophy of nursing. *Scholarly Inquiry for Nursing Practice, 13*(1), 5–15.

Gadow, S. (1999). Relational narrative: The postmodern turn in nursing ethics. *Scholarly Inquiry for Nursing Practice, 13*(1), 57–69.

Gaul, A. L. (1995). Casuistry, care, compassion, and ethics data analysis. *Advances in Nursing Science, 17*(3), 47–57.

Georges, J. J., & Grypdonck, M. (2002). Moral problems experienced by nurses when caring for terminally ill people: A literature review. *Nursing Ethics, 9*(2), 155–178.

Gilligan, C. (1982). *In a different voice: Psychological theory and women's development.* Cambridge, MA: Harvard University Press.

Hartrick, G. (2002a). Am I still ethical? The socially-mediated process of nurses' moral identity. *Nursing Ethics, 9*(6), 623–635.

Hartrick, G. (2002b). Beyond interpersonal communication: The significance of relationship in health promoting practice. In L. E. Young & V. Hayes (Eds.), *Transforming health promotion practice: Concepts, issues, and applications* (pp. 49–58). Philadelphia: F. A. Davis.

Health Canada Office of Nursing Policy. (2001). *Healthy nurses, healthy workplaces.* Ottawa: Author.

Hoffmaster, B. (1990). Morality and the social sciences. In G. Weisz (Ed.), *Social science perspectives on medical ethics* (pp. 241–260). Philadelphia: University of Pennsylvania Press.

Hoffmaster, B. (1991). The theory and practice of applied ethics. *Dialogue, 30,* 213–234.

Hoffmaster, B. (1993). Can ethnography save the life of medical ethics? In E. R. Winkler & J. R. Coombs (Eds.), *Applied ethics: A reader* (pp. 366–389). Oxford: Blackwell.

Hoffmaster, B. (1999). Secular health care ethics. In H. Coward & P. Ratanakul (Eds.), *A cross-cultural dialogue on health care ethics* (pp. 139–145). Waterloo, ON: Wilfrid Laurier University Press.

Hoffmaster, B. (2001). Introduction. In B. Hoffmaster (Ed.), *Bioethics in social context* (pp. 1–11). Philadelphia:Temple University Press.

Jacobs, B. B. (2001). Respect for human dignity:A central phenomenon to philosophically unite nursing theory and practice through consilience of knowledge. *Advances in Nursing Science, 24*(1), 17–35.

Jameton, A. (1984). *Nursing practice: The ethical issues.* Englewood Cliffs, NJ: Prentice-Hall.

Jameton, A. (1990). Culture, morality, and ethics: Twirling the spindle. *Critical Care Nursing Clinics of North America, 2*(3), 443–451.

Jameton, A., & Fowler, M. D. M. (1989). Ethical inquiry and the concept of research. *Advances in Nursing Science, 11*(3), 11–24.

Jennings, B. (1990). Ethics and ethnography in neonatal intensive care. In G. Weisz (Ed.), *Social science perspectives on medical ethics* (pp. 261–272). Philadelphia: University of Pennsylvania Press.

Jonsen, A. R. (1995). Casuistry: An alternative or complement to principles? *Kennedy Institute of Ethics Journal, 5*(3), 237–251.

Jonsen, A. R. (1997). The birth of bioethics: The origins and evolution of a demi-discipline. *Medical Humanitarian Review, 11*(1), 9–21.

Jonsen, A. R., Sieglar, M., & Winslade, W. J. (1986). *Clinical ethics: A practical approach to ethical decisions in clinical medicine* (2nd ed.). New York: Macmillan.

Jonsen, A. R., & Toulmin, S. (1988). *The abuse of casuistry: A history of moral reasoning.* Berkeley: University of California Press.

Kaufman, S. R. (2001). Clinical narratives and ethical dilemmas in geriatrics. In B. Hoffmaster (Ed.), *Bioethics in social context* (pp. 12–38). Philadelphia: Temple University Press.

Keatings, M., & Smith, O. B. (2000). *Ethical and legal issues in Canadian nursing* (2nd Ed.). Toronto: W. B. Saunders.

Ketefian, S. (1989). Moral reasoning and ethical practice in nursing: Measurement issues. *Nursing Clinics of North America, 24*(2), 509–521.

Kuhl, D. R., & Wilensky, P. (1999). Decision making at the end of life: A model using an ethical grid and principles of group process. *Journal of Palliative Medicine, 2*(1), 75–86.

Laschinger, H. K. S., Finegan, J., Shamian, J., & Casier, S. (2000). Organizational trust and empowerment in restructured healthcare settings: Effects on staff nurse commitment. *Journal of Nursing Administration, 30*(9), 413–425.

Levi, B. H. (1996). Four approaches to doing ethics. *Journal of Medicine and Philosophy, 21,* 7–39.

Liaschenko, J. (1993a). *Faithful to the good: Morality and philosophy in nursing practice.* Unpublished doctoral dissertation, University of California, San Francisco.

Liaschenko, J. (1993b). Feminist ethics and cultural ethos: Revisiting a nursing debate. *Advances in Nursing Science, 15*(4), 71–81.

Liaschenko, J., & Fisher, A. (1999). Theorizing the knowledge that nurses use in the conduct of their work. *Scholarly Inquiry for Nursing Practice, 13*(1), 29–41.

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry.* Newbury Park, CA: Sage.

Madriz, E. (2000). Focus groups in feminist research. In N. K. Denzin and Y. S. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed.) (pp. 835–850). Thousand Oaks, CA: Sage.

Malone, R. E. (1999). Policy as product: Morality and metaphor in health policy discourse. *Hastings Centre Report* (May/June), 16–22.

Mann, P. S. (1994). *Micro-politics: Agency in a postfeminist era.* Minneapolis: University of Minnesota Press.

McDaniel, C. (1998). Ethical environment: Reports of practicing nurses. *Nursing Clinics of North America, 33*(2), 363–372.

McDonald, M. (1999). Health, health care, and culture: Diverse meanings, shared agendas. In H. Coward & P. Ratanakul (Eds.), *A cross-cultural dialogue on health care ethics* (pp. 92–112). Waterloo, ON: Wilfrid Laurier University Press.

McDonald, M. (2002). *An ethical decision making framework.* Unpublished paper, University of British Columbia Centre for Applied Ethics (http://www.ethics.ubc.ca).

Mitchell, G. J. (2001). Policy, procedure and routine: Matters of moral influence. *Nursing Science Quarterly, 14*(2), 109–114.

Mohr, W. K. (1997). Outcomes of corporate greed. *Image: Journal of Nursing Scholarship, 29*(10), 39–45.

Morgan, D. L. (1997). *Focus groups as qualitative research* (2nd Ed.). Newbury Park, CA: Sage.

Morgan, D. L., & Krueger, R. A. (1993). When to use focus groups and why. In D. L. Morgan (Ed.), *Successful focus groups: Advancing the state of the art* (pp. 3–19). Newbury Park, CA: Sage.

Munhall, P. L. (1983). Methodologic fallacies: A critical self-appraisal. *Advances in Nursing Science* (July), 41–49.

Nagle, L. M. (1999). A matter of extinction or distinction. *Western Journal of Nursing Research, 21*(1), 71–82.

Nisker, J. A. (2001). Chalcedonies. *Canadian Medical Association Journal, 164*(1), 74–75.

Oberle, K., & Tenove, S. (2000). Ethical issues in public health nursing. *Nursing Ethics* (5), 425–438.

Olson, L. L. (1998). Hospital nurses' perceptions of the ethical climate of their work settings. *Image: Journal of Nursing Scholarship, 30*(4), 345–349.

Omery, A. (1983). Moral development: A differential evaluation of dominant models. *Advances in Nursing Science, 6,* 1–17.

Pellegrino, E. D. (1997). *Helping and healing: Religious commitment in health care.* Washington: Georgetown University Press.

Penticuff, J. H. (1991). Conceptual issues in nursing ethics research. *Journal of Medicine and Philosophy, 16*(3), 235–258.

Peters, E., & Morgan, K. (2001). Explorations of a trust approach for nursing ethics. *Nursing Inquiry, 8,* 3–10.

Rafael, A. R. F. (1996). Power and caring: A dialectic in nursing. *Advances in Nursing Science, 19*(1), 3–17.

Raines, D. A. (1994). Moral agency in nursing. *Nursing Forum, 29*(1), 5–11.

Redman, B. K., & & Fry, S. T. (2000). Nurses' ethical conflicts: What is really known about them? *Nursing Ethics,* 7(4), 360–366.

Rodney, P. (1994). A nursing perspective on life-prolonging treatment. *Journal of Palliative Care, 10*(2), 40–44.

Rodney, P. A. (1997). *Towards connectedness and trust: Nurses' enactment of their moral agency within an organizational context.* Unpublished doctoral dissertation, University of British Columbia, Vancouver.

Rodney, P., & Varcoe, C. (2001). Towards ethical inquiry in the economic evaluation of nursing practice. *Canadian Journal of Nursing Research, 33*(1), 35–57.

Roy, D. J., Williams, J. R., & Dickens, B. M. (1994). *Bioethics in Canada.* Scarborough, ON: Prentice-Hall.

Saks, M. (1995). *Professions and the public interest: Medical power, altruism and alternative medicine.* London and New York: Routledge.

Sherblom, S., Shipps, T. B., & Sherblom, J. C. (1993). Justice, care, and integrated concerns in the ethical decision making of nurses. *Qualitative Health Research, 3*(4), 442–464.

Sherwin, S. (1992). *No longer patient: Feminist ethics and health care.* Philadelphia: Temple University Press.

Sherwin, S. (1998). A relational approach to autonomy in health care. In S. Sherwin & Feminist Healthcare Network (Eds.), *The politics of women's health* (pp. 19–47). Philadelphia: Temple University Press.

Solomon, M. Z. (1995). The enormity of the task: SUPPORT and changing practice. *Hastings Center Report, 25*(6), S28–S32.

Solomon, M. Z., O'Donnell, L., Jennings, B., Guilfoy, V., Wolf, S. M., Nolan, K., et al. (1993). Decisions near the end of life: Professional views on life-sustaining treatments. *American Journal of Public Health, 83*(1), 14–23.

Starzomski, R. (1997). *Resource allocation for solid organ transplantation: Toward public and health care provider dialogue.* Unpublished doctoral dissertation, University of British Columbia.

Starzomski, R. (1998). Ethics in nephrology nursing. In J. Parker (Ed.), *Nephrology nursing: A comprehensive textbook* (pp. 83–109). Pitman, NJ: American Nephrology Nurses Association.

Stephenson, P. (1999). Expanding notions of culture for cross-cultural ethics in health and medicine. In H. Coward & P. Ratanakul (Eds.), *A cross-cultural dialogue on health care ethics.* Waterloo, ON: Wilfrid Laurier University Press.

Stevenson, J. T. (1987). *Engineering ethics: Practices and principles.* Toronto: Canadian Scholar's Press.

Storch, J. L. (1992). Ethical issues. In A. J. Baumgart & J. Larsen (Eds.), *Canadian nursing faces the future* (2nd Ed.) (pp. 259–270). St. Louis, MO: Mosby Year Book.

Storch, J. L. (1999). Ethical dimensions of leadership. In J. M. Hibberd & D. L. Smith (Eds.), *Nursing management in Canada* (2nd ed.) (pp. 351–367). Toronto: W. B. Saunders.

Storch, J., Rodney, P., Pauly, B., Brown, H., & Starzomski, R. (2002). Listening to nurses' moral voices: Building a quality health care environment. *Canadian Journal of Nursing Leadership, 15*(4), 7–16.

Storch, J., Rodney, P., & Starzomski, S. (2002). Ethics in health care in Canada. In B. S. Bolaria & H. Dickinson (Eds.), *Health, illness, and health care in Canada* (3rd ed.) (pp. 409–444). Toronto: Harcourt Brace.

Strauss, A. L., & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (2nd ed.). Thousand Oaks, CA: Sage.

Taylor, C. (with A. Gutmann, S. C. Rockefeller, M. Walzer, & S. Wolf). (1992). *Multiculturalism and "the politics of recognition."* Princeton, NJ: Princeton University Press.

Taylor, C. (1995). Medical futility and nursing. *Image, 27*(4), 301–306.

Tilden, V. P., Tolle, S. W., Nelson, C. A., Thompson, M., & Eggman, S. C. (1999). Family decision making in foregoing life-extending treatments. *Journal of Family Nursing, 5*(4), 426–442.

Toulmin, S. (1981). The tyranny of principles. *Hastings Center Report, 11,* 31–39.

Varcoe, C. (1997). *Untying our hands: The social context of nursing in relation to violence against women.* Unpublished doctoral dissertation, University of British Columbia, Vancouver.

Varcoe, C. (2001). Abuse obscured: An ethnographic account of emergency unit nursing in relation to violence against women. *Canadian Journal of Nursing Research, 32*(4), 95–115.

Varcoe, C., & Rodney, P. (2002). Constrained agency: The social structure of nurses' work. In B. S. Bolaria & H. Dickinson (Eds.), *Health, illness, and health care in Canada* (3rd ed.) (pp. 102–128). Toronto: Harcourt Brace.

Varcoe, C., Storch, J., Hartick, G., Pauly, B., Rodney, P., Starzomski, R., et al. (2002). *Ethical practice in nursing: Working the in-betweens.* Unpublished manuscript, University of Victoria School of Nursing, Victoria, BC.

Warren, V. L. (1992). Feminist directions in medical ethics. *H E C Forum, 4*(1), 19–35.

Weisz, G. (1990). Introduction. In G. Weisz, *Social science perspectives on medical ethics* (pp. 3–15). Philadelphia: University of Pennsylvania Press.

Wilkinson, S. (1998). Focus groups in feminist research? Power, interactions and the co-construction of meaning. *Women's Studies International Forum, 21*(1), 111–125.

Winkler, E. R. (1993). From Kantianism to contextualism: The rise and fall of the paradigm theory in bioethics. In E. R. Winkler & J. R. Coombs (Eds.), *Applied ethics: A reader* (pp. 343–365). Oxford: Blackwell.

Wolf, S. M. (1994). Shifting paradigms in bioethics and health law: The rise of a new pragmatism. *American Journal of Law and Medicine, 20*(4), 395–415.

Yeo, M. (1994). Interpretive bioethics. *Health and Canadian Society, 2*(1), 85–108.

Yeo, M. (1996). Introduction. In M. Yeo & A. Moorhouse (Eds.), *Concepts and cases in nursing ethics* (2nd ed.) (pp. 1–26). Peterborough, ON: Broadview.

Acknowledgements

We would like to thank all the nurses and student nurses who participated in this study. We would also like to thank Dana Kemes, RN, MSN, and Lian McKenzie, RN, BSN, who contributed as research assistants. We are grateful for grant monies received from Associated Medical Services, Inc. (the Bioethics Program) and from the University of Victoria internal Social Sciences and Humanities Research Council program. Finally, we wish to thank two anonymous reviewers and the Journal's editors for their constructive feedback on this paper.

Paddy Rodney, RN, MSN, PhD, is Associate Professor, School of Nursing, University of Victoria, British Columbia, and Faculty Associate, Centre for Applied Ethics, University of British Columbia, Vancouver, Canada. Colleen Varcoe, RN, MEd, MSN, PhD, is Associate Professor, School of Nursing, University of Victoria, and Research Associate, BC Centre for Excellence in Women's Health. Janet L. Storch, RN, PhD, is Professor, School of Nursing, University of Victoria, and Faculty Associate, Centre for Applied Ethics, University of British Columbia. Gladys McPherson, RN, MScN, is a doctoral student, School of Nursing, University of British Columbia. Karen Mahoney, RN, BSN, is a master's student, School of Nursing, University of British Columbia. Helen Brown, RN, MSN, and Bernadette Pauly, RN, MN, are doctoral students, School of Nursing, University of Victoria. Gwen Hartrick, RN, MA, PhD, is Associate Professor, School of Nursing, University of Victoria. Rosalie Starzomski, RN, MN, PhD, is Associate Professor, School of Nursing, University of Victoria, and Faculty Associate, Centre for Applied Ethics, University of British Columbia.

2009 update: *Paddy Rodney is Associate Professor and Undergraduate Program Coordinator, School of Nursing, University of British Columbia, Vancouver; her other positions/affiliations are unchanged. Colleen Varcoe is Associate Professor and Associate Director, Research, School of Nursing, University of British Columbia. Janet L. Storch is Professor Emeritus, School of Nursing, University of Victoria; her other positions/affiliations are unchanged. Gladys McPherson (PhD) is Assistant Professor, School of Nursing, University of British Columbia. Karen Mahoney (MSN) is Clinical Nurse Specialist, Renal Program, Fraser Health Authority. Helen Brown (PhD) is Assistant Professor, School of Nursing, University of British Columbia. Bernadette Pauly (PhD) is Assistant Professor, School of Nursing, University of Victoria. Gwen Hartrick Doane is Professor, School of Nursing, and Associate Dean, Faculty of Graduate Studies, University of Victoria. Rosalie Starzomski is Professor, School of Nursing, University of Victoria, and Clinical Ethicist, Vancouver Coastal Health Authority.*

CJNR 2009, Vol. 41 N° 1, 320–339

Résumé

L'influence du personnel infirmier sur les patients en regard de leur guérison : Évolution d'une étude internationale

Julie Sochalski, Carole A. Estabrooks et Charles K. Humphrey

Des réformes effectuées aux États-Unis, au Canada et en Europe influant sur toute l'industrie du secteur de la santé ont donné lieu à une occasion unique, celle d'examiner les effets de la restructuration des hôpitaux sur les soins infirmiers auprès des malades hospitalisés et des résultats en regard de leur guérison, et ce dans un éventail de situations. Sept équipes de recherche interdisciplinaires, en provenance d'Alberta, de Colombie-Britannique, d'Angleterre, d'Allemagne, d'Ontario, d'Écosse et des États-Unis, ont formé un consortium international dont le but est d'étudier les effets d'une telle restructuration. Chaque équipe a recruté un grand nombre d'hôpitaux et d'infirmières pour cerner le rôle que joue l'organisation des soins infirmiers, ciblés par les mesures de restructuration hospitalière, en regard de la guérison des patients. L'étude vise à favoriser la compréhension de l'influence qu'exerce le personnel infirmier autant que l'environnement de la pratique professionnelle à l'égard d'une telle guérison. Une discussion sur la fondation théorique, la conception de l'étude et le processus de développement des méthodes et des instruments de mesure utilisés dans le cadre de l'étude illustre le déroulement du processus jusqu'à maintenant, en plus de la faisabilité d'un tel projet international et des occasions générées.

CJNR 2009, Vol. 41 N° 1, 320–339

Nurse Staffing and Patient Outcomes: Evolution of an International Study

Julie Sochalski, Carole A. Estabrooks, and Charles K. Humphrey

Industry-wide health sector reforms in the United States, Canada, and Europe have provided a unique opportunity to examine the effects of hospital restructuring on inpatient nursing care and patient outcomes across an array of settings. Seven interdisciplinary research teams — 1 each in Alberta, British Columbia, England, Germany, Ontario, Scotland, and the United States — have formed an international consortium whose aim is to study the effects of such restructuring. Each site has enrolled large numbers of hospitals and nurses to explicate the role that organization of nursing care, a target of hospital restructuring, plays in differential patient outcomes. The study seeks to understand more fully the influence of both nurse staffing and the nursing practice environment on patient outcomes. Discussion of the theoretical foundation, study design, and process of developing the study instruments and measures illustrates the process to date, as well as the feasibility of and opportunities inherent in such an international endeavour.

International Study Consortium
(in alphabetical order by site and within sites):

Alberta: Carole Estabrooks, RN, PhD, Konrad Fassbender, PhD, Phyllis Giovannetti, RN, PhD, and Phil Jacobs, PhD (University of Alberta).

British Columbia: Sonia Acorn, RN, PhD (University of British Columbia); Heather Clarke, RN, PhD (Registered Nurses Association of British Columbia); Arminée Kazanjian, Dr.Soc, and Robert Reid, PhD (University of British Columbia).

England: Jane Ball (Employment Research, Inc.); James Coles, MSc, FSS (CASPE Research, Inc.); Martin McKee, MD, and Anne Marie Rafferty, PhD, RGN (London School of Hygiene and Tropical Medicine).

Germany: Reinhard Busse, MD, MPH, and Thorsten Koerner, PhD (Hannover University Medical School); Gabriele Müller-Mundt, MA, RGN (University of Bielerfeld).

Ontario: Geoffrey M. Anderson, MD, PhD (Institute for Clinical Evaluative Sciences and University of Toronto); Judith Shamian, RN, PhD, and Donna Thomson, RN, MBA (WHO Collaborating Centre,

Originally published in CJNR 1999, Vol. 31 N° 3, 69–88

Mount Sinai Hospital, Toronto); Jack V. Tu, MD, PhD (Institute for Clinical Evaluative Sciences and University of Toronto).

***Scotland**:* F. Andrew Boddy, MD (University of Glasgow); James Buchan, PhD (Queen Margaret College, Edinburgh); Suzanne Hagen, MSc, and Jennifer Hunt, M.Phil, RGN (Nursing Research Initiative for Scotland, Glasgow); Alastair H. Leyland, PhD (University of Glasgow).

***United States**:* Linda H. Aiken, RN, PhD, Eileen T. Lake, RN, PhD, Jeffrey H. Silber, MD, PhD, Douglas M. Sloane, PhD, and Julie Sochalski, RN, PhD (University of Pennsylvania).

Widespread hospital reforms, undertaken during the 1990s in response to both marketplace and public policy initiatives to increase efficiency, have succeeded in transforming hospitals in the United States, Canada, and Europe (Anderson, 1997; Chan & Lynn, 1998; Office of Technology Assessment, US Congress, 1995; Saltman & Figueras, 1998; Sochalski, Aiken, & Fagin, 1997). These reforms have left behind hospitals whose workforce and work-flows have been substantially reorganized (Decter, 1997; Harrison, 1997; Walston, Burns, & Kimberly, 2000; Walston & Kimberly, 1997). In particular, many hospitals have altered their nursing skill mix — employing fewer RNs to supervise growing numbers of lesser-trained assistive personnel — and have redefined the roles of nurses and other staff in the delivery of patient care (Bernreuter & Cardona, 1997; Brannon, 1996; Shamian & Lightstone, 1997; Shindul-Rothschild & Duffy, 1996; Siehoff, 1998; Vincent, 1997; Willmot, 1998).

In its recent report to the US Congress on nurse staffing in hospitals, the Institute of Medicine (IOM) issued a call for empirical studies to determine if the quality of care in hospitals was being adversely affected by the reorganization of the nursing workforce (Wunderlich, Sloan, & Davis, 1996). Spurred by this call for research from the IOM, as well as by the international escalation of hospital reorganization and the growing number of reports from hospital nurses of deteriorating working conditions (Driedger, 1997; Gordon, 1997; Shindul-Rothschild, Berry, & Long-Middleton, 1996), researchers from the University of Pennsylvania convened a state-of-the-science conference on hospital workforce restructuring. With funding from the Rockefeller Foundation, the Penn team, led by Drs. Linda Aiken and Claire Fagin, invited experts from the hospital sector, public policy, health workforce, nursing and medicine, and health outcomes research in the United States, Canada, the United Kingdom and Germany to the Rockefeller Conference Center in Bellagio, Italy, in November 1996 to participate in this conference (Sochalski, Boulis, Shamian, Buchan, & Müller-Mundt, 1997). The purpose of the conference was to determine the extent and nature of hospital workforce restructuring across countries with differently organized and financed health-care systems, and to assess the feasibility of an international study on the outcomes of hospital restructuring. Within 1 year, participants in the Bellagio conference had organized interdisciplinary research teams in seven sites — Alberta, British Columbia, England, Germany, Ontario, Scotland, and the United States (Pennsylvania) — each of which procured funding from broad-based government and private foundation sources to support their participation in a large international study to assess the impact of hospital reorganization on patient outcomes (Sochalski & Aiken, 1999).

The study asks whether changes in the numbers of nurses and the practice environment in hospitals resulting from workforce restructuring have affected patient outcomes (McKee, Aiken, Rafferty, & Sochalski, 1998; White, 1997). Each site is treated as an "independent replication" of a common study design, with the goal of determining the strength and consistency with which the organization of nursing care explains differences in patient outcomes across sites. A multinational study affords the opportunity to capture a greater degree of variation in levels of nurse staffing, characteristics of the nursing practice environment, and patient outcomes than one would get from studying any one country, thus providing a stronger test of the relationship among these factors.

In this paper we present an overview of the study and its theoretical framework, focusing on the efforts undertaken to create robust measures of the organization of nursing care in each site by adapting instruments and methods developed in the United States. We illustrate the steps taken to incorporate important site-specific features of nursing practice and the health-care system, and we describe the activities involved in the preparation of the study data for data-sharing and cross-site analysis. Finally, we discuss the implications of this international research initiative for the future of health services and nursing research.

Study Aims and Design

This multi-site study poses the question: *Does the organization of nursing care in hospitals contribute substantively to differences in patient outcomes independent of other organizational features that have been shown empirically to be associated with outcomes?* Specifically, we are endeavouring to explicate the *direct* and *indirect* effects of both nurse staffing *and* the nursing practice environment on outcomes, while controlling for other contributing organizational characteristics of hospitals (Aiken, Sochalski, & Lake, 1997). The impetus for this line of inquiry comes from a US study that found lower mortality rates in "magnet" hospitals — hospitals identified through a reputational study as having superior professional nursing practice environments (Gleason-Scott, Sochalski, & Aiken, 1999; Kramer &

Schmalenberg, 1988a, 1988b) — than in a comparison group of non-magnet hospitals matched on organizational characteristics associated with patient outcomes, such as size, teaching status, qualifications of physicians, and technology (Aiken, Smith, & Lake, 1994). These lower mortality rates persisted even after controlling for differences in nurse staffing. The Aiken et al. (1994) study established an important link between magnet hospitals and better patient outcomes, but left unanswered the question as to whether it was the professional nursing practice environment in these hospitals that was substantively responsible for these outcomes or some other unspecified feature of the hospital. This research initiative takes up that question by employing, in a single study, data on the characteristics of the nursing practice environment and nurse staffing for a large number of institutions that vary on key organizational features.

The theoretical framework guiding this investigation is drawn from the fields of nursing, sociology, and organizational theory and articulates the role that the organization of nursing care plays in effecting patient outcomes. The study model defines the organization of nursing care as comprising two elements: nurse staffing levels and attributes of the nursing practice environment. Nurse staffing levels have been linked with patient outcomes in studies conducted in the United States and the United Kingdom (Aiken, Sloane, Lake, Sochalski, & Weber, 1999; Blegen, Goode, & Reed, 1998; Czaplinski & Diers, 1998; al-Haider & Wan, 1991; Hartz et al., 1989; Hunt, 1997; Kovner & Gergen, 1998; Shortell & Hughes, 1988), as have a number of other hospital organizational characteristics, such as teaching status and the availability of state-of-the art technology. There is little theory explaining *how* these characteristics influence patient outcomes, a noted shortcoming of most organizational research in health care (Flood, 1994). This study seeks to address that shortcoming, proposing that organizational attributes that characterize the hospital's nursing practice environment, in addition to nurse staffing and other hospital characteristics, not only play an important role in differential patient outcomes but may in fact serve to explain in part why these features have been associated with outcomes in previous studies. Indeed, Rosenthal, Harper, Quinn, and Cooper (1997), who found better patient outcomes in major teaching hospitals in the United States as compared with teaching-affiliated and non-teaching hospitals, speculated that the "teaching effect" may actually be a proxy for such features as the organization of nursing care, and emphasized the need for outcomes studies that examine more fully the organizational features of hospitals.

To that end, this study links both primary data from hospital staff nurse surveys and administrative data on patient outcomes and organizational characteristics of hospitals in a nested study design — that is, the responses of nurses are "nested" within hospitals and hierarchical regression models are used to assess the effects of both hospital-level characteristics and nurse-level characteristics within hospitals on patient outcomes. The hospitals included in the sampling frame were determined by the availability of patient outcomes data. In the United States, the state of Pennsylvania has a particularly rich public-use hospital discharge data set that is available annually for the full census of acute-care hospitals and admissions. Furthermore, these hospitals are representative of hospitals throughout the United States on a number of organizational features (e.g., size, urban/rural location, teaching status). Consequently, the full census of acute-care hospitals in Pennsylvania make up the US component of the study. For all three participating provinces in Canada and for Scotland, comparable hospital discharge data exist for the full census of acute hospitals within their borders, thus allowing for their inclusion in the study sample. In England and Germany, the sample includes a subset of hospitals for which data on patient outcomes and hospital characteristics are available through a private firm contracted to manage their information systems (see Table 1).

Registered nurses working in each of the study sample hospitals were the sampling frame for a staff nurse survey that would provide information on the nursing practice environment and other features of the workplace at each of these institutions. Staff nurses work across all patient-care departments within hospitals, and consequently they are well positioned to assess critical features of an institution affecting patient care and its outcomes. Uniform criteria for drawing the staff nurse sample were developed and applied in each site. In Canada and the United States, the nurse registry lists served as the data source for the sampling frame; sampled nurses were asked on the survey to identify the hospital where they worked, which would allow their responses to be assigned to the appropriate hospital. In England, Scotland, and Germany, lists of eligible staff nurses were obtained directly from the hospitals enrolled in the study, making up their sampling frame. As seen in Table 1, the final

Table 1 ***Hospital and Staff Nurse Study Samples***

Number of:	Alberta	British Columbia	England	Germany*	Ontario	Scotland	United States
Hospitals	109	97	32	30	209	27	210
Nurses	6,558	2,838	5,006	4,000	8,778	5,238	14,145

* The number of nurses in the study sample for Germany is an estimate; in the fall of 1999 the study was to commence.

sample included thousands of nurses in each site, whose responses are nested within large numbers of hospitals. The scale of this survey effort, while ambitious, was dictated by the nested study design, which requires that a representative sample of nurses be obtained for each hospital.

Outcome Measures

The study design rests on patient outcome measures that (a) are sensitive and reliable indicators of quality of care and nursing practice (Strickland, 1997), and (b) could be derived from secondary data sources in each country. To that end, two key measures have been selected: hospital mortality rates, which as noted earlier have a well-documented empirical record of association with nursing, and a new and empirically promising outcome measure developed in the United States and using data from secondary or administrative sources — the failure-to-rescue rate (Silber, Rosenbaum, & Ross, 1995; Silber, Rosenbaum, Schwartz, Ross, & Williams, 1995; Silber, Rosenbaum, Williams, Ross, & Schwartz, 1997). The failure-to-rescue rate is defined as the rate of death among patients experiencing complications, and can be thought of as the probability that a hospital fails to rescue patients who experience complications. The ability to rescue patients from complications is a function of nursing vigilance, of which surveillance is a large component. Nurse staffing levels determine the amount and quality of the interaction between nurses and patients and thus the effectiveness of the surveillance system in detecting early signs of complications. Furthermore, the nursing practice environment enhances or impedes nurses' timely interventions once complications are detected. Early detection of complications and a rapid response are related to survival, hence the conceptual link between nurse staffing, the practice environment, and patient outcomes.

Measures of the Organization of Nursing Care

In each study site, administrative or secondary data sources are available that contain at least rudimentary information from which commonly used aggregate measures of nurse staffing and nursing workload can be readily calculated, such as nurse-to-patient ratios and nursing skill mix. Procuring information on the nursing practice environment of hospitals, however, required the collection of primary data from the staff registered nurses in the study hospitals. A staff nurse survey used in a previous study in the United States (Aiken, Lake, Sochalski, & Sloane, 1997) served as the basis for development of the international nurse survey that would be used to obtain measures of the nursing practice environment and other features that characterized the work setting and nurses' work. The survey contained both study instruments and groups of items capturing features of the workplace: (1) the Revised Nursing Work Index (NWI-R), a 49-item inventory of work-environment features that nurses report as being important to delivering high-quality patient care (see Table 2), which had been adapted from Kramer and Hafner's (1989) original 65-item Nursing Work Index from their work with magnet hospitals; (2) the Maslach Burnout Inventory (Maslach & Jackson, 1982; Maslach, Jackson, & Leitner, 1997), a well-established instrument measuring domains of job stress and burnout; (3) reported incidence of needle-stick injury, risk factors, and prevention measures available (Aiken, Sloane, & Klocinski, 1997) that had been used to assess workplace safety; (4) a series of questions describing the nursing workload on a typical shift; and (5) questions about their work experience and level of expertise, characteristics of their current position (e.g., full-time, shifts worked), their job satisfaction, and demographic information.

Previous studies in the United States using the NWI-R have linked attributes of the nursing practice environment derived from its items with patient outcomes. In one study, nurses working in a sample of magnet hospitals were much more likely to report having access to sufficient patient-care resources than nurses working in a comparative group of non-magnet hospitals (Sochalski, Boulis, et al., 1997). These findings suggest that nursing practice environment attributes derived from the NWI-R may be able to distinguish hospitals with better patient outcomes, in this case magnet hospitals, offering support for an empirical link between the practice environment and patient outcomes. This link is underscored by the findings of a study by members of the Penn team evaluating the outcomes of organizational innovations in inpatient AIDS care in the United States (Aiken et al., 1999). Higher levels of patient satisfaction were found on units where nurses reported better access to patient-care resources, after controlling for patient and hospital characteristics as well as nurse staffing levels. These findings suggest that the nursing practice environment can play a significant and independent role, beyond that of nurse staffing, in effecting patient outcomes.

Preparation of a Multinational Nurse Survey

To assess the face validity and applicability of the US survey instrument across each of the international sites, two approaches were employed: focus groups (Krueger, 1994; Morgan, 1998; O'Brien, 1993) and pilot/feasibility studies. The focus group procedure entailed distributing the survey to small groups comprising staff nurses, nurse researchers, and nurse administrators. Each member of a focus group was asked to review the instrument for its face validity, completeness, appropriateness, applicability, and language.

Table 2 ***Revised Nursing Work Index (NWI-R)***

For each item, the respondent indicates on a 4-point scale (strongly agree, somewhat agree, somewhat disagree, strongly disagree) the extent to which the item is present in their current job.

1. Adequate support services allow me to spend time with my patients.
2. Physicians and nurses have good working relationships.
3. A good orientation program for newly employed nurses.
4. A supervisory staff that is supportive of nurses.
5. A satisfactory salary.
6. Nursing controls its own practice.
7. Active staff development or continuing education programs for nurses.
8. Career development/clinical ladder opportunity.
9. Opportunity for staff nurses to participate in policy decisions.
10. Support for new and innovative ideas about patient care.
11. Enough time and opportunity to discuss patient care problems with other nurses.
12. Enough registered nurses on staff to provide quality patient care.
13. A nurse manager who is a good manager and leader.
14. A chief nursing officer who is highly visible and accessible to staff.
15. Flexible or modified work schedules are available.
16. Enough staff to get the work done.
17. Freedom to make important patient care and work decisions.
18. Praise and recognition for a job well done.
19. The opportunity for staff nurses to consult with clinical nurse specialists or expert nurse clinicians.
20. Good working relationships with other hospital departments.
21. Not being placed in a position of having to do things that are against my nursing judgment.
22. High standards of nursing care are expected by the administration.
23. A chief nursing officer equal in power and authority to other top level hospital executives.
24. A lot of team work between nurses and physicians.

25. Physicians give high quality medical care.
26. Opportunities for advancement.
27. Nursing staff are supported in pursuing degrees in nursing.
28. A clear philosophy of nursing that pervades the patient care environment.
29. Nurses actively participate in efforts to control costs.
30. Working with nurses who are clinically competent.
31. The nursing staff participate in selecting new equipment.
32. A nurse manager who backs up the nursing staff in decision making, even if the conflict is with a physician.
33. Administration that listens and responds to employee concerns.
34. An active quality assurance program.
35. Staff nurses are involved in the internal governance of the hospital (e.g., practice and policy committees).
36. Collaboration between nurses and physicians.
37. A preceptor program for newly hired RNs.
38. Nursing care is based on a nursing rather than a medical model.
39. Staff nurses have the opportunity to serve on hospital and nursing committees.
40. The contributions that nurses make to patient care are publicly acknowledged.
41. Nurse managers consult with staff on daily problems and procedures.
42. A work environment that is pleasant, attractive, and comfortable.
43. Opportunity to work on a highly specialized patient care unit.
44. Written, up-to-date nursing care plans for all patients.
45. Patient care assignments that foster continuity of care, i.e., the same nurse cares for the patient from one day to the next.
46. Staff nurses do not have to float from their designated unit.
47. Staff nurses actively participate in developing their own work schedules (i.e., what days they work; days off; etc.).
48. Each patient care unit determines its own policies and procedures.
49. Working with experienced nurses who “know” the hospital system.

An integral task of the focus group was to determine if the NWI-R offered a meaningful and appropriate way to capture key features of nursing practice environment. The groups were then convened and collectively they reviewed the instrument, item by item, on the above criteria. A total of 10 focus groups were held in the six non-US study sites. Each focus group comprised from five to 10 members, and the mix of nurses, while dominated by staff nurses, varied across the groups. In each site, the consensus from the focus group was that the NWI-R possessed considerable face validity for the purposes of the study. Minor language changes were required in a minimal number of items to accommodate site-specific terms and expressions. The Maslach Burnout Inventory was also viewed as having sufficient face validity and required no changes, and it had been used in other nursing studies in Canada, the United Kingdom, and Germany (Hatcher & Laschinger, 1996; Hayter, 1999). Modifications were required of some items assessing the nurses' work experience and characteristics of their current job and setting in order to reflect accurately the realities of the practice settings. For example, shift lengths, lines of reporting, and safety devices to prevent needle-stick injury varied widely among the study sites. Items assessing these features were individually tailored across sites in ways that would preserve the *intent* of the item while reflecting the actual practice in the setting.

In three of the six sites, two hospitals were selected in which to pilot test the survey. The goal of the pilot test was to assess the applicability of the instrument in these settings and to determine if similar nursing practice environment attributes could be found in these non-US sites. The survey was distributed to a random sample of inpatient staff nurses in two hospitals in Ontario, England, and Germany, and at least half of the nurses in each hospital completed and returned the survey. A statistically significant difference was found between hospitals in Ontario and England on the nurses' access to patient-care resources, and the difference approached statistical significance in Germany (see Table 3). In each country, the hospital with the higher mean score was a large teaching hospital with national reputation for excellence in patient care and nursing practice. The scores obtained for nurse access to patient-care resources for a magnet (Hospital A) and non-magnet (Hospital B) in the United States show the same pattern as the international sites. Both the range of scores and their pattern suggest that the NWI-R can be used in international settings to capture attributes of the nursing practice environment that may help to explain differences in patient outcomes.

The results of the focus groups and the feasibility studies were part of the agenda for a 3-day investigators' meeting held in Washington, DC, in June 1998. Team members from each of the seven sites were convened to

Table 3 ***Differences in Mean Scores on Nurse Access to Patient-Care Resources for Hospitals in England, Germany, Ontario, and the United States***

Site	Hospital A	Hospital B	t-stat	*p*
England	10.9 (3.2) (n = 260)	9.6 (3.0) (n = 336)	4.90	< 0.001
Germany	9.2 (2.7) (n = 235)	8.6 (2.6) (n = 99)	1.60	0.110
Ontario	9.1 (3.2) (n = 56)	6.9 (3.1) (n = 40)	3.30	0.001
United States	10.5 (2.9) (n = 177)	8.0 (2.9) (n = 138)	7.53	< 0.0001

review the status of the study in each site and to prepare for fielding the staff nurse survey in the fall of 1998. An important goal of the meeting was the construction of a common nurse survey instrument for use in each site. To that end, each site presented the results of their focus groups and pilot/feasibility studies. The seven teams then collectively reviewed the instrument item by item. Consensus was reached that the international survey would comprise a revised common or "core" survey and a site-specific section at the end containing a limited number of items assessing issues of salience in that country or province. The core survey included the major elements of the pilot survey — the NWI-R, the Maslach Burnout Inventory, a streamlined set of questions on needle-stick injury and workplace safety, nursing care workload on the last shift worked, and characteristics of their position, their work experience, and job satisfaction. A number of items were added to the core survey to extend the domains assessed and to facilitate cross-site comparisons. These items included questions on the quality of nursing care, frequency of adverse events (e.g., patient falls, nosocomial infections), patient readiness for discharge, use of student nurses to support nursing personnel, prevalence of overtime, and nursing interventions left undone for lack of time. The items added at the end of the survey varied by site: Alberta and British Columbia added questions on abuse in the workplace to explore the scope and degree of this problem, which has been increasingly reported by nurses; Ontario included a scale measuring effort-reward imbalances in the workplace (Peter & Siegrist, 1997); and England and Scotland added items on the incidence of and reasons for time away from work and perceptions of involvement in decision-making at the hospital.

Data Preparation and Documentation

With consensus on the survey items in place, preparation of a database that can be shared across sites has become the next task. While not commonly addressed in the health-research literature, data sharing and the attendant preparation required is increasingly common in the social sciences (Estabrooks & Romyn, 1995). Here the task is twofold: assuring uniformity in coding and data entry; and developing a suitable data file that can be shared and used across sites. Typically, the temptation in many studies is to expedite the data-entry phase so that tabulations can be generated, while the data files themselves may end up, unfortunately, being treated as by-products or research "refuse." However, when data sharing is a planned objective, the data products take on a much higher profile and must be viewed as separate and significant contributions of the overall research project. The data products include raw data files, machine-readable data documentation, command files for statistical software, and internal or system files from statistical systems such as SAS or SPSS.

To share data — or to prepare data so that sharing is a possibility — attention must be given to several issues. First, since the data may be available to researchers other than the investigators who collected the data, details about the data must be clearly documented. Several data sources comprise this study — the staff nurse survey, the administrative data files containing information on hospital characteristics, and hospital discharge data files from which patient outcomes data are derived — each of which is a separate data file. Documenting each data source and its resulting data products is a critical step, including the original instrument for each and the rules for converting items to variables in the data file. Furthermore, since the study design requires linking these three data sources, each data file must include a common identifier, in this case a hospital identifier, so that they can be subsequently merged.

Second, if comparisons are to be conducted across sites, the common variables need to be organized similarly in each data file. Mapping the record layout so common items have comparable formats and can be readily located across the multiple surveys is essential at an early stage in planning the content of these files. Coding schemes must be harmonized to ensure that the values of variables across the surveys are identical. Furthermore, administrative variables that identify the component parts of the overall project need to be incorporated in both the documentation and the data. For example, a separate variable to identify the country within which the survey was conducted may be the first variable in the data file.

Third, data sharing raises further concerns about protecting the identity of subjects and taking steps to guard against disclosure. While confidentiality is an issue, options do exist for anonymizing data to minimize the risk of disclosure. There are various ways of preparing data so that they can be shared with others outside the original research team. For example, all personal information that might lead to the easy identification of subjects may be kept in a file that will not be shared but that has a key variable permitting access to the data file by the original investigators. Another strategy employed by national statistical agencies is to prepare public-use files of confidential surveys: A master file is produced containing all of the information in its fullest detail; from this file, a public-use file is created and shared with other researchers.

The study team in Alberta took the lead in developing the template for data coding, entry, and documentation for the study. Careful mapping of the record layout was undertaken so common items could be readily located, and coding schemes were harmonized so that the values assigned to all the variables would be comparable. Furthermore, administrative variables (e.g., country/site) were incorporated in both the documentation and the data. Steps are now underway to establish the final protocol to protect the identity of subjects and to guard against disclosure. The product of these efforts in data preparation, we believe, will be data products that will not only support sophisticated analysis to meet the research aims of the international study, but will also be useful in the pursuit of a broader agenda in outcomes research.

Implications and Future Directions

Primary data collection with the nurse survey is complete in six of the seven study sites and we anticipate completion of the nurse survey by the end of 1999. Survey response rates have ranged from 45% to nearly 60% across the six sites, and a review of the data across sites has revealed minimal missing data across the entire survey. A second meeting of the investigators was held in June 1999 in conjunction with the International Council of Nurses Centennial meetings in London. At this meeting, preliminary analyses of the survey data were presented and reviewed and plans for intra- and inter-site analyses were developed (these are currently underway). Acquiring the survey data has been a labour-intensive and resource-intensive process, made more so by our goal of maximizing the utility and comparability of the data sets and our commitment to sharing the survey data across sites and more broadly on completion of the study. The result, we believe, is an unprecedented and valuable collection of nurse and organizational data that can be linked to patient outcomes —

data from thousands of hospital staff nurses in five countries that can be used to characterize the organizational environment of hospitals. To date, much of the research undertaken to characterize hospitals and the effects of organizational change uses information obtained from surveys and interviews of small numbers of executive and administrative staff. In this endeavour, it is the staff nurses in the hospital who are providing an assessment of the organization and an evaluation of the presence of features important to the delivery of quality patient care.

As with the survey data, work is underway to develop and refine the patient outcomes measures, particularly the failure-to-rescue measure. Calculation of the failure rate requires the identification of patients experiencing complications during their hospital stay, a challenge in many sites where administrative or secondary data sources lack the depth and detail in diagnosis and procedure coding necessary to accurately and reliably identify complications among hospitalized patients (Iezzoni, Daley, Heeren, Foley, Fisher, et al., 1994; Iezzoni, Daley, Heeren, Foley, Hughes, et al., 1994; McKee, & James, 1997). An alternative method for calculating the failure rate that does not rely on these data to identify patients with complications — one that substitutes a prolonged hospital length of stay (LOS) for a documented complication event — is currently being tested. Preliminary work with hospital discharge data in the United States and Canada shows strong correlations between failure rates calculated using complications data and rates using prolonged LOS for complications (Silber, Even-Shoshan, Sutaria, Tu, & Anderson, 1998). Extension of this work is currently underway among the other study sites to determine whether sensitive failure rates can be calculated from existing secondary data sources.

This study will also advance the agenda of nursing outcomes research by employing multi-level models to examine the influence of organizational characteristics of nursing on patient outcomes. The study design calls for estimating hospital-level scores on organizational attributes of the practice environment by nesting responses from nurses within the hospital at which they are employed (Aiken, Sochalski, & Lake, 1997). An attribute is deemed to be reliably measured when the variability in responses within hospitals is small relative to the variability among hospitals. However, responses may be influenced by certain nurse characteristics, independent of the setting where they practise, and as such could confound interpretation of the findings. For example, nurses with a baccalaureate degree, regardless of where they work, may be more likely to agree that certain attributes are present at their hospital. Recent methodological advances provide the researcher with robust methods for combining individual and aggregate-level data in the same analysis, while controlling for such potentially confounding effects, when using aggregate measures to predict patient outcomes (Aiken, Sloane, & Sochalski, 1998; Goldstein & Spiegelhalter, 1996).

Finally, this study is serving as a springboard for other research initiatives and collaborations, extending the life of the data generated in this effort well beyond the international study described here. Not only are these data a rich source of analysis in themselves, but they hold considerable potential for linkage with other relevant databases. Indeed, the Ontario team has sought and received funding for two additional studies using the nurse survey data, one of which links the practice environment attributes and burnout scores with other databases in the province containing information on workplace injuries among nurses in hospitals. The Penn team, meanwhile, is linking their study data with those from a study that has catalogued hospital reorganization activities over a 5-year period in a subset of Pennsylvania hospitals. Cross-site collaborations are also being forged, leading to secondary studies and joint publications on wide-ranging topics. For example, the research teams across the three Canadian provinces are examining nurse burnout, its causes, and its relationship to patient outcomes, and the teams at Penn, Canada, and the United Kingdom are exploring the relationship between quality of care assessments and patient outcomes.

This international study and its resulting collaborations have stimulated a systematic study of the influence of nursing on patient outcomes, in large part because of the availability of such a rich data source with which to do so. There is every indication that new opportunities to extend this outcomes research agenda will continue to arise. We envision that work on this study will lead to additional international partnerships, and will leave behind a legacy of interdisciplinary research that serves nursing and patients well.

References

Aiken, L.H., Lake, E.T., Sochalski, J., & Sloane, D.M. (1997). Design of an outcomes study of the organization of hospital AIDS care. *Research in the Sociology of Health Care, 14,* 3–26.

Aiken, L.H., Sloane, D.M., & Klocinski, J.L. (1997). Hospital nurses' occupational exposure to blood: Prospective, retrospective, and institutional reports. *American Journal of Public Health, 87*(1), 103-107.

Aiken, L.H., Sloane, D.M., Lake, E.T., Sochalski, J., & Weber, A.L. (1999). Organization and outcomes of inpatient AIDS care. *Medical Care, 37*(8), 760–772.

Aiken, L.H., Sloane, D.M., & Sochalski, J. (1998). Hospital organisation and outcomes. *Quality in Health Care,* 7(4), 222–226.

Aiken, L.H., Smith, H.L., & Lake, E.T. (1994). Lower Medicare mortality among a set of hospitals known for good nursing care. *Medical Care, 32*(8), 771–787.

Aiken, L.H., Sochalski, J., & Lake, E.T. (1997). Studying outcomes of organizational change in health services. *Medical Care, 35*(11 Suppl), NS6–18.

Anderson, G.F. (1997). In search of value: An international comparison of cost, access and outcomes. *Health Affairs, 16*(6), 163–171.

Bernreuter, M.E., & Cardona, M.S. (1997). Survey and critique of studies related to unlicenced assistive personnel from 1975 to 1997, pt. 1. *Journal of Nursing Administration, 27*(6), 24–29.

Blegen, M.A., Goode, C.J., & Reed L. (1998). Nurse staffing and patient outcomes. *Nursing Research, 47*(1), 43-50.

Brannon, R.L. (1996). Restructuring hospital nursing: Reversing the trend toward a professional workforce. *International Journal of Health Services, 26,* 643–654.

Chan, Y.L., & Lynn, B.E. (1998). Operating in turbulent times: How Ontario's hospitals are meeting the current funding crisis. *Health Care Management Review, 23*(3), 7–18.

Czaplinski, C., & Diers, D. (1998). The effect of staff nursing on length of stay and mortality. *Medical Care, 36*(12), 1626–1638.

Decter, M.B. (1997). Canadian hospitals in transformation. *Medical Care, 35*(10 Suppl), OS70–75.

Driedger, S.D. (1997, April 28). The nurses: The front-line caregivers are burned out. Is it any wonder? *Maclean's, 110*(17), 24–27.

Estabrooks, C.A., & Romyn, D.M. (1995). Data sharing in nursing research: Advantages and challenges. *Canadian Journal of Nursing Research, 27*(1), 77–88.

Flood, A.B. (1994). The impact of organizational and managerial factors on the quality of care in health care organizations. *Medical Care Review, 51*(4), 381–428.

Gleason-Scott, J., Sochalski, J., & Aiken, L.H. (1999). Review of magnet hospital research: Findings and implications for professional nursing practice. *Journal of Nursing Administration, 29*(1), 9–19.

Goldstein, H., & Spiegelhalter, D. (1996). League tables and their limitations: Statistical issues in comparisons of institutional performance. *Journal of the Royal Statistical Society, 159,* 385–443.

Gordon, S. (1997). What nurses stand for. *Atlantic Monthly, 279*(2), 81–88.

al-Haider, A.S., & Wan, T.T. (1991). Modeling organizational determinants of hospital mortality. *Health Services Research, 26*(3), 303–323.

Harrison, A.J. (1997). Hospitals in England: Impact of the 1990 National Health Service reforms. *Medical Care, 35*(10 Suppl), OS50–61.

Hartz, A.J., Krakauer, H., Kuhn, E.M., Young, M., Jacobsen, S.J., Gay, G., et al. (1989). Hospital characteristics and mortality rates. *New England Journal of Medicine, 321*(25), 1720–1725.

Hatcher, S., & Laschinger, H.K.S. (1996). Staff nurses' perceptions of job empowerment and level of burnout: A test of Kanter's theory of structural power in organizations. *Canadian Journal of Nursing Administration, 9*(2), 74–94.

Hayter, M. (1999). Burnout and AIDS care-related factors in HIV community clinical nurse specialists in the North of England. *Journal of Advanced Nursing, 29*(4), 984–993.

Hunt, J. (1997). *Nurse to patient ratio project.* Glasgow: Nursing Research Initiative of Scotland.

Iezzoni, L., Daley, J., Heeren, T., Foley, S., Fisher, E., Duncan, D., et al. (1994). Identifying complications of care using administrative data. *Medical Care, 32*(7), 700–715.

Iezzoni, L.I., Daley, J., Heeren, T., Foley, S.M., Hughes, J.S., Fisher, R.S., et al. (1994). Using administrative data to screen hospitals for high complication rates. *Inquiry, 31,* 40–55.

Kovner, C.T., & Gergen, P.J. (1998). Nurse staffing levels and adverse events following surgery in U.S. hospitals. *Image, 30*(4), 315–321.

Kramer, M., & Hafner, L. (1989). Shared values: Impact on staff nurse job satisfaction and perceived productivity. *Nursing Research, 38*(3), 172–177.

Kramer, M., & Schmalenberg, C. (1988a). Magnet hospitals. Part 1: Institutions of excellence. *Journal of Nursing Administration, 18*(1), 13–24.

Kramer, M., & Schmalenberg, C. (1988b). Magnet hospitals. Part 2: Institutions of excellence. *Journal of Nursing Administration, 18*(2), 11–19.

Krueger, R.A. (1994). *Focus groups: A practical guide for applied research.* Thousand Oaks, CA: Sage.

Maslach, C., & Jackson, S.E. (1982). Burnout in health professions: A social psychological analysis. In G.S. Sanders & J. Suls (Eds.), *Social psychology of health and illness* (pp. 227–251). Hillsdale, NJ: Erlbaum.

Maslach, C., Jackson, S.E., & Leiter, M.P. (1997). Maslach Burnout Inventory: Third edition. In C.P. Zalaquett & R.J. Wood (Eds.), *Evaluating stress: A book of resources* (pp. 191–218). Lanham, MD: Scarecrow Press.

McKee, M., Aiken, L.H., Rafferty, A.M., & Sochalski, J. (1998). Organisational change and quality of health care: An evolving international agenda. *Quality of Health Care,* 7(1), 37–41.

McKee, M., &. James, P. (1997). Using routine data to evaluate quality of care in British hospitals. *Medical Care, 35*(10 Suppl), OS102–111.

Morgan, D. (1998). *The focus group guidebook: Focus group kit 1.* Thousand Oaks, CA: Sage.

O'Brien, K. (1993). Using focus groups to develop health surveys: An example from research on social relationships and AIDS-preventative behavior. *Health Education Quarterly, 20*(3), 361–372.

Office of Technology Assessment, US Congress. (1995). *Hospital financing in seven countries (OTA-BP-H-148).* Washington: US Government Printing Office.

Peter, R., & Siegrist, J. (1997). Chronic work stress, sickness absence, and hypertension in middle managers: General or specific sociological explanations? *Social Science and Medicine, 45*(7), 1111–1120.

Rosenthal, G.E., Harper, D.L., Quinn, L.M., & Cooper, G.S. (1997). Severity-adjusted mortality and length of stay in teaching and nonteaching hospitals: Results of a regional study. *Journal of the American Medical Association, 278*(6), 485–490.

Saltman, R.B., & Figueras, J. (1998). Analyzing the evidence on European health care reforms. *Health Affairs, 17*(2), 85–108.

Shamian, J., & Lightstone, E.Y. (1997). Hospital restructuring initiatives in Canada. *Medical Care, 35*(10 Suppl), OS62–69.

Shindul-Rothschild, J., Berry, D., & Long-Middleton, E. (1996). Where have all the nurses gone? Final results of our patient care survey. *American Journal of Nursing, 96*(11), 24–39.

Shindul-Rothschild, J., & Duffy, M. (1996). The impact of restructuring and work design on nursing practice and patient care. *Best Practices and Benchmarking in Health Care, 1*(6), 271–282.

Shortell, S.M., & Hughes, E.F. (1988). The effects of regulation, competition, and ownership on mortality rates among hospital inpatients. *New England Journal of Medicine, 318*(17), 1100–1107.

Siehoff, A.M. (1998). Impact of unlicenced assistive personnel on patient satisfaction: An integrative review of the literature. *Journal of Nursing Care Quality, 13*(2), 1–10.

Silber, J.H., Even-Shoshan, O., Sutaria, N., Tu, J., & Anderson, G. (1998, June). *Modifying the failure-to-rescue rate when detailed complication data is not available: A U.S.-Canadian cross-national study.* Paper presented at the 15th annual meeting of the Association for Health Services Research, Washington, DC.

Silber, J.H., Rosenbaum, P.R., & Ross, R.N. (1995). Comparing the contributions of groups of predictors: Which outcomes vary with hospital rather than patient characteristics? *Journal of the American Statistical Association, 90*(429), 7–18.

Silber, J.H., Rosenbaum, P.R., Schwartz, J.S., Ross, R.N., & Williams, S.V. (1995). Evaluation of the complication rate as a measure of the quality of care in coronary artery bypass graft surgery. *Journal of the American Medical Association, 274*(4), 317–323.

Silber, J.H., Rosenbaum, P.R., Williams, S.V., Ross, R.N., & Schwartz, J.S. (1997). The relationship between choice of outcome measure and hospital rank in general surgical procedures: Implications for quality assessment. *International Journal for Quality in Health Care, 9*(3), 193–200.

Sochalski, J., & Aiken, L.H. (1999). Accounting for variation in hospital outcomes: A cross-national study. *Health Affairs, 18*(2), 256–259.

Sochalski, J., Aiken, L.H., & Fagin, C.M. (1997). Hospital restructuring in the United States, Canada, and Western Europe: An outcomes research agenda. *Medical Care, 35*(10 Suppl), OS13–25.

Sochalski, J., Boulis, A., Shamian, J., Buchan, J., & Müller-Mundt, G. (1997, June). *Lessons for restructuring the nursing workforce in North American and European hospitals.* Paper presented at the 14th annual meeting of the Association for Health Services Research, Chicago.

Strickland, O.L. (1997). Challenges in measuring patient outcomes. *Nursing Clinics of North America, 32*(3), 495–512.

Vincent, L. (1997). Work redesign and re-engineering: A challenge for professional and nursing practice. *Canadian Oncology Nursing Journal,* 7(4), 198–201.

Walston, S.L., Burns, L.R., & Kimberly, J.R. (2000). Does reengineering really work? An examination of the context and outcomes of hospital reengineering initiatives. *Health Services Research, 34*(6), 1363–1388.

Walston, S.L., & Kimberly, J.R. (1997). Reengineering hospitals: Experience and analysis from the field. *Hospital and Health Services Administration, 42*(2), 143–163.

White, K.L. (1997). Hospital restructuring in North America and Europe. *Medical Care, 35*(10 Suppl), OS7–12.

Willmot, M. (1998). The new ward manager: An evaluation of the changing role of the charge nurse. *Journal of Advanced Nursing, 28*(2), 419–427.

Wunderlich, G.S., Sloan, F.A., & Davis, C.K. (Eds.). (1996). *Nursing staff in hospitals and nursing homes: Is it adequate?* Washington: National Academy Press.

Acknowledgements

This research is supported by: Alberta Heritage Foundation for Medical Research; British Columbia Health Research Foundation; Ministry of Education, Science, Research, and Technology (Germany); Nuffield Provincial Hospital Trust (United Kingdom); National Institute for Nursing Research at the National Institutes of Health, Agency for Health Care Policy and Research, Commonwealth Fund of New York, and Baxter Foundation (United States).

Julie Sochalski, RN, PhD, FAAN, is Assistant Professor of Health Services Research and Nursing and Associate Director, Center for Health Outcomes and Policy Research, University of Pennsylvania, Philadelphia, United States. Carole A. Estabrooks, RN, PhD, is Assistant Professor, Faculty of Nursing, University of Alberta, Edmonton, Canada, and Postdoctoral Fellow, Institute for Clinical Evaluative Sciences (ICES), Toronto, Ontario, Canada. Charles K. Humphrey, MA, is Data Library Coordinator, Humanities and Social Science Library, University of Alberta.

2009 update: *Julie Sochalski is Associate Professor of Nursing, University of Pennsylvania. Carole A. Estabrooks is Professor and Canada Research Chair in Knowledge Translation, Faculty of Nursing, University of Alberta. Charles K. Humphrey is Academic Director, Alberta Research Data Centre.*

Résumé

Les notions d'économisme, d'efficacité et d'écologie morale dans le cadre de pratiques infirmières saines

Sara M. Weiss, Ruth E. Malone, Joseph R. Merighi et Patricia Benner

La rhétorique du marché concurrentiel qui domine les discussions en matière de politiques de santé aujourd'hui identifie les produits et les services médicaux comme des commodités destinées à être consommées par le public, qui les achète ou ne les achète pas, selon le prix. Les systèmes de soins sont révisés et les hôpitaux restructurés sous l'angle de l'accroissement de l'efficacité et de la productivité. À partir des expériences des infirmières cliniciennes œuvrant aux États-Unis, cet article démontre comment l'application de la notion d'économisme à la profession peut gravement porter atteinte à l'écologie d'une pratique infirmière saine et rend difficile le maintien de normes de soins minimales. De plus, elle limite sérieusement les gestes de compassion qui doivent être posés lorsque les gens vivent la maladie, la perte et la mort. Des préoccupations portant sur la responsabilité morale et les oppositions entre objectifs institutionnels et objectifs infirmiers sont émises. La présence d'une méfiance de plus en plus grande face aux systèmes de santé de la part des praticiens, des patients et des familles suggère que le temps est venu de se pencher attentivement sur la question de l'écologie morale dans le domaine des soins infirmiers.

CJNR 2009, Vol. 41 N° 1, 340–364

Economism, Efficiency, and the Moral Ecology of Good Nursing Practice

Sara M. Weiss, Ruth E. Malone, Joseph R. Merighi, and Patricia Benner

The free-market rhetoric dominating health-policy discussions today frames health-care goods and services as commodities that consumers will or will not buy at a given price. Health-care systems are being redesigned and hospitals restructured with a view to increased efficiency and productivity. Drawing on the experiences of clinical nurses in the United States, this paper shows how the application of economism to nursing may severely disrupt the ecology of good practice, leading to difficulties in meeting minimal standards of nursing care and severely constraining the acts of compassion called for by the human experiences of illness, loss, and death. Concerns about moral responsibility and conflicts between institutional and nursing goals are described. Increasing mistrust of health-care systems on the part of practitioners, patients, and families suggests that it is time to attend closely to the moral ecology of caring practices.

> *A lot of issues that are simply monetary for a lot of people around us, above us, below us, are completely ethical and moral for us. I find that particular situation is the most difficult situation for me as a professional, and it's getting worse and worse.*
>
> – Registered nurse practising in the United States

Over the past two decades, proponents of free-market competitive models of health care have argued with unwarranted optimism that such models are the answer to accelerating health-care costs in the United States (Ellwood & Enthoven, 1995; Enthoven, 1981, 1988). These models have been the subject of considerable criticism based on the conflicts of interest they can cause for physicians, the way in which they have changed the locus of clinical decision-making, and the economic threat that market-based institutions pose to safety-net services for the uninsured (Kassirer, 1995, 1996; Malone, 1999; McKenzie & Bilofsky, 1994; Mechanic, 1996; Relman, 1992; Smith & Lipsky, 1992; Socolar, Sager, & Hiam, 1992). Even in countries with excellent public health-care systems, such as Canada, ideological pressures for privatization and competition raise similar concerns. The discussion of competitive, market-based models has focused on the relationship between physicians

Originally published in CJNR 2002, Vol. 34 N° 2, 95–119

and patients or between physicians and payers, as though these were the only actors. Yet clinical nurses occupy a unique place in the health-care system. As has been noted elsewhere (Andre, 1998), they hold a central and morally difficult position insofar as they act as interpreters between patient, family, physician, and system; bear a largely unacknowledged responsibility for critical, moment-to-moment decision-making; and spend more time than other health-care providers in direct contact with patients — yet have little structural power to alter the institutional conditions under which they practise.

Nursing as a practice carries both practical and symbolic meanings, embedded in an ethic of caring for vulnerable, commonly ill or injured, others (Benner, 1994a, 1994d, 1997; Benner, Tanner, & Chesla, 1996; Benner & Wrubel, 1989). To become educated and socialized into any practice is to develop the skills, knowledge, and character traits suitable for that practice. However, caring professions such as nursing, medicine, and social work are socially organized: institutional structures and spaces support them and facilitate their passage to successive generations of practitioners (Malone, 2003). A practice embodies more than technology and science, more than individual knowledge and technique. Practitioners adopt styles and patterns of relating and attending to those they serve. Social institutions play an important part in the quality of caring practices, in that good public institutions and good citizenship are mutually supportive:

> The relationship between compassion and social institutions is and should be a two-way street: compassionate individuals construct institutions that embody what they imagine; and institutions, in turn, influence the development of compassion in individuals. As both Rousseau and Tocqueville show, empathy and the judgment of similar possibilities are profoundly influenced by the ways in which institutions situate people in relation to one another… Similarly, institutions teach citizens definite conceptions of basic goods, responsibility, and appropriate concern, which will inform any compassion that they learn. Finally, institutions can either promote or discourage, and can shape in various ways, the emotions that impede appropriate compassion: shame, envy, and disgust. (Nussbaum, 2001, p. 405)

Here, Nussbaum outlines the shape of a moral ecology, calling attention to the way in which institutions structure moral action. Moral activity, in turn, shapes institutions. Caring practices develop not in a vacuum but within specific institutional settings. Nursing takes place almost entirely within institutions: hospitals, home-care agencies, public health departments, and schools. How these institutions are structured, and the organizational values they embrace as primary, directly affect the practice of nursing.

The Ecology of Practice

Aristotle (1985) made a distinction between production and practice. The making of things can be reduced to narrow, rational technique, whereas practice is relational and entails a responsibility to do right by others. A practice has goods that are internal to it; these notions of good are socially embedded in the teaching and expectations of practitioners (Dunne, 1997; MacIntyre, 1981). In this view, individual practitioners are members rather than competitors seeking independent goals; they must be open to experiential learning and ongoing education and research. Experiential learning involves the recognition of failures and errors as well as insight and innovation. In forming habits, thoughts, and actions, the practitioner envisions and adopts the standards of good practice.

Experiential learning in a complex and rapidly changing practice is necessarily risky and expensive. It is irresponsible for practitioners to keep innovations or errors a secret from colleagues because, as members of a socially organized group, they hold joint responsibility for continually improving the practice (Rosner, Berker, Kark, Potash, & Bennett, 2000). The practitioner develops traits and skills that are characteristic of excellent practice in order to achieve the ends of the practice. Just as an athletic team trains in order to achieve mental and physical mastery of the sport and a coordinated response, so the practitioner develops the character and skills to be a good practitioner. To be a good practitioner is to embrace the structures and processes that embody the principles of good practice and that organize a community of practitioners around common goals. We suggest that the interaction between a practice and the institutions upon which it depends constitutes a moral ecology, and that critical examination of the ecology of nursing practice is essential to its survival. In this paper, we analyze data from qualitative research findings to show dimensions of the ecology of hospital nursing practice in the United States under conditions of increasing cost-containment.

By moral ecology, we mean the institutional influences that shape the social and moral working environment. Ecology, as a concept derived broadly from the environmental movement, asserts that an endangered plant or animal cannot be considered in isolation; it must be considered in terms of the ecosystem of which it is a part. Thus the concept of an ecology of nursing practice implies temporal and moral dimensions, in addition to the physical, institutional dimensions that are essential to good practice.

In an ecological approach, particular attention is paid to aspects of caring work that resist abstraction and commodification (Donnelly, 1995). Such an approach also considers the goal of *sustainability*, although how that is to be defined is a matter of ongoing ideological and theoretical debate (Norton, 1995). It seems reasonable to assume that as a society we have a basic interest in healing those who are sick or injured and in maintaining health, and thus should consider how to sustain the kinds of practices that support these aims. In a sustainable moral ecology of good nursing practice, or of any health-care practice, the etiquette and social norms of the institutions will be congruent with the ethics and ethical comportment of its members (Benner, 1994b; Day, 2001; Day & Benner, 2002).

Methods

This paper reports findings from the second phase of an interpretive phenomenological study of skill acquisition and clinical and ethical reasoning among nurses caring for critically ill patients in the United States (see Table 1). The first phase, Expertise in Nursing Practice, articulated the knowledge embedded in critical-care nursing practice, the exercise of clinical judgement, and the acquisition of skills (Benner et al., 1996). The second phase, Teaching Critical Thinking and Clinical and Ethical Reasoning, extended the first phase and coincided with dramatic changes taking place in the US health-care system and in critical-care nursing under the expansion of managed care and the market model during the mid-1990s (Benner, Hooper-Kyriakidis, & Stannard, 1999). The second phase updated the earlier findings and also included areas of critical care not covered in the first phase: burn intensive care, neurologic intensive care, emergency care, flight nursing, operating-room nursing, post-anesthesia care, and home care. In the second phase we interviewed 75 nurses from 20 hospitals and one home-care agency and observed a subsample of 31 nurses in their practice, documenting critical-care nursing at a time of extreme destabilization of health-care delivery.

Audiotaped interviews were conducted with nurses individually and in small groups. The participants were asked to share episodes in their practice in which they felt they had made a difference or learned from the experience. The observations of the subsample of nurses in their everyday practice were conducted by trained nurse ethnographers. Transcriptions of both the interviews and the nurse ethnographers' notes were analyzed with a view to exploring the context in which the episodes described in the interviews took place. The study was approved by the University of California at San Francisco Committee on Human Research and all nurse participants provided written consent prior to being interviewed or observed. To protect confidentiality, names and

Table 1 *Phase One and Phase Two*

	Dates	Hospitals	Home-Care Agency	Nurses Interviewed	Nurses Observed*
Phase One Expertise in Nursing Practice	1988–92	8		130	48
Phase Two Teaching Critical Thinking and Clinical and Ethical Reasoning	1996–97	20	1	75	31

* Subsample of nurses interviewed.

identifying information are omitted from this report. In both phases of the study, data collection and analysis were guided by the following aims:

1. To delineate the practical knowledge embedded in expert practice
2. To describe the nature of skill acquisition in critical-care nursing practice
3. To identify institutional impediments and resources for the development of expertise in nursing practice
4. To begin to identify educational strategies that encourage the development of expertise (Benner et al., 1996)
5. To articulate the nature of knowledge and interventions in critical care.

(Benner et al., 1999, p. 6)

As well as confirming many of the findings of the first phase, the second phase revealed new means of acquiring and sustaining moral agency in the face of economic restructuring. The interview and observational data on skill acquisition and clinical and ethical reasoning included large segments on the disruptive effect of economic pressures and downsizing. By analyzing these segments using interpretive approaches described elsewhere (see Benner, 1994c; Benner et al., 1996), we identified new themes capturing the effect of institutional changes on nursing. This paper presents an interpretive analysis of thematic data on disrupted nursing practice in the face of new economic pressures.

Findings

In the hospitals studied, system reorganization had been undertaken in response to perceived market pressures to be more competitive and minimize staffing costs. This had resulted in hiring freezes, staff cuts, and altered work expectations. The altered working conditions disrupted the continuity of specific nursing units. An Adult Critical Care Clinical Nurse Specialist (CNS) drew attention to the additional labour needed to compensate for the disruption:

> Interviewer: *What is the size of your staff?*
>
> CNS: *We have a lot of [vacancies]. We couldn't hire for so long…so we have per diems [nurses hired by the day], floats [nurses not regularly assigned to any one unit], new people. And they're great nurses! But we don't have that…core group of people that…all knew the standards, and so we're doing some standards revisions on the [leadership] committee right now… We're working on that, but it's also saying, "What's realistic today…in practice? Do you mount strips [the practice of incorporating EKG recordings into the patient chart at regular intervals]? How frequently?" I had the staff nurses calling other institutions in [the area] to find out… And saying, "Is this really possible to do any more?" Because it doubles [nurses caring for twice the number of patients they are customarily assigned] like crazy in here, and it's not regular staff. So we have to really look at what we're doing. When I started in critical care we checked capillary refill [examining how quickly and adequately capillaries refill after pressure is applied to the fingernail, a sign of the patient's perfusion] every 2 hours and wrote it down once a shift and PRN [as needed]. Do we really need to do that for every patient, and when does judgement, nursing judgement, come in? We have to give them a base to start from: "This is the minimum." But then, from there…nursing judgement has to come in.*

The core group to which the CNS refers is a community of caregivers who have shared understandings, standards, and visions of good practice. Such a community forms a socially embedded ethos and style of vigilance. The group recognizes blind spots and weaknesses as well as strengths, and cross-monitoring serves to strengthen, augment, and correct (Risser, Simon, Rice, & Salisbury, 1999). When the group is composed of per diem workers and floats, and when turnover is high, the community of vigilance and internal control is disrupted. Nurses working on the same unit are unfamiliar with one another's practice style, pace, and special abilities; thus, shared understandings must be replaced with written standards. The word *standards* as used here suggests a minimum level of safety. When standards are lowered to fit the reality of minimal staff resources, rather than being established on the basis of safety requirements and excellent practice, their meaning and social function are reversed.

There is a conflict here in that written standards are brought in to make up for the gaps in knowledge and continuity caused by the loss of the core group. When expectations are lowered to a minimum, nurses must rely on their "judgement" to decide whether additional measures are needed. This requirement for judgement comes just when there are fewer nurses and fewer institutional supports to ensure the kind of stable staffing and continuity that foster good judgement. The ecology of good nursing practice thus appears to be disrupted, as "flexible" staffing serves to minimize familiar and relational knowledge exchanges.

The institutional value systems under which nursing is practised must sustain some congruence with both cultural and practice values. This *moral* ecology of practice warrants close attention, because it is critical to the socialization of new practitioners. As unit stability diminishes, so too does the ability of practitioners to maintain reasonable standards:

> Nurse: *I've brought my standards down, too, a level. But there's a minimum, you know, a bottom that I won't go past. And it's very frustrating to witness.*
>
> Interviewer: *When you say "standards," what exactly are you talking about?*
>
> Nurse: *About the level of nursing care that's provided in terms of assessment, interventions, and even documentation… If a patient has a dressing on, then I expect the nurse to know or find out what's under that dressing… What happens now is [a nurse may say], "The docs didn't write an order to change anything," so they just leave it. And that can't be an excuse… In the past, nurses were always either saying [to physicians or to each other], "Well, that's the wrong dose," or "Hey, you haven't addressed [the fact] that this person is a diabetic and we haven't checked any sugars yet." [Now there are] oversights, many oversights.*

This nurse calls attention to the fact that cross-monitoring requires time, staff, and/or familiarity among practitioners. Contrary to constricted views of nursing practice as merely carrying out the orders of physicians, nurses do recall, check, question, and verify the treatment decisions of physicians and other nurses. However, staff instability and the need for increased efficiency make this kind of monitoring difficult to sustain, and nurses noted that there seemed to be little institutional recognition of its importance to their clinical roles.

In one small-group interview, the nurses said that the focus of nursing leadership meetings had shifted to organizational and system changes, to the extent that there was little discussion of clinical issues:

> First nurse: *Our focus is on team-building, incorporating PCAs [patient care assistants] and care assistants, and whatever else, but not about clinical care for years, a couple of years probably…*
>
> Second nurse: *…it was the first time we talked about anything clinical in…I don't know, a year and a half.*
>
> First nurse: *We've spent a lot of time learning about the health-care systems out there…about all services, all the different levels of care, all the different insurances, all the new review processes… Most of it we need to know, but it was all going to that, and how you can use your computer now that you've finally got one so that you can enter that you've given a review to the insurance company. I mean, all this time on that stuff and not at the bedside, and clinical care has suffered.*

System redesign often displaces direct clinical care and increases nurses' responsibility for supervising the non-licensed personnel who have stepped into bedside roles. However, it also creates new clinical education needs, as illustrated in the following discussion by an intensive-care unit (ICU) nurse about the move to place more critical patients on regular units:

> *With the whole managed care, they are asking [us] to make changes without any support. An example is on our acute floors. Now they take [patients with] dobutamine infusions, dopamine infusions [both are intravenous vasopressors to maintain blood pressure and cardiac output], and Pronestyl infusions [an anti-arrhythmic medication]. And it just happened, and they didn't change the staffing ratio, yet the patients have to be monitored more frequently. They [nurses on floor units] didn't get education. There's no educator. I mean, they didn't get a formal education [planned inservice]. It was all kind of thrown out there. And the patients are put on mechanical ventilation, a bi-pap format [a type of ventilation in which endotracheal intubation is not required] on the floor [regular unit]. They call me, "Can you come see this patient?" There's no planning, it's just "gotta push them out," and we're pushing patients out of the ICU because we need the bed, and then they are still critically ill.*

Not only is the core group of practitioners disrupted, but patient allocations are changed, so that nurses are responsible for more acutely ill patients and are expected to administer therapies for which they have received little or no training.

Compressed Time for Contact and Connection

Weber (1964) forecasted the problem of the relational and the moral being overlooked in the drive towards ever more efficient systems. The human functions of vigilance, engagement with others, and commitment to excellence may also be overlooked as means are separated from ends and efficiency is disassociated from efficacy. In the systems engineering approach, differences in temperament and skills are minimized and human beings are treated as standard units of labour rather than as unique resources for the teaching and advancement of good practice. Demoralization of the work group can occur when informal leadership patterns are disrupted, significant aspects of the work are overlooked in the redesign, and tasks considered essential for safety and relational work are omitted.

In a group interview, several operating room (OR) nurses discussed the impact of their hospital's efforts to reduce the "turnover time" between patients' entry into the OR suite from the pre-operative room and their departure for the recovery room:

> First nurse: *Turnover time isn't inherently bad. It's how that time gets used… They can't say that the turnover's over when the nursing hasn't been done. So turnover isn't an inherent evil. It's when they are saying, "Get rid of the nurses"…*
>
> Interviewer: *We can eliminate nursing?*
>
> Second nurse: *There's a movement underfoot…*
>
> First nurse: *…to eliminate that time.*
>
> Third nurse: *Nursing assessment time?*
>
> First nurse: *Nurses going to the pre-op room and pre-opping the patients and taking patients to the recovery room…there's a movement to get rid of them.*
>
> Third nurse: *And replace it with what? We just wait in our rooms and they just bring us a patient?*
>
> First nurse: *That's right.*
>
> Fourth nurse: *And we say goodbye to our patients at the OR door? We don't deliver them to the hands of another nurse to whom we give report?*
>
> First nurse: *That's right. The first time we see them is when they hit the OR door… That's why I say very strongly that they're trying to compress this nursing time.*
>
> Second nurse: *Because they don't see value in it.*

> First nurse: *That's right. This [administrative] person said right out to me, he said, "Well, I don't see any value in what you do. You need to be in the operating room itself, getting things ready." He feels that our patient contact is totally unnecessary and he's not happy with it.*

In the OR environment, where the processing of larger numbers of surgical cases per day was identified as the goal, the time during which the nurse meets, assesses, and transfers a patient from the pre-op room to the OR, and similarly to the post-anesthesia recovery unit (PACU) following surgery ("patient turnover time"), was being scrutinized for possible elimination. Yet this time, viewed as superfluous to the "real" work entailed in the actual surgical procedure, was regarded by nurses as essential to preserving the patient's humanity and security in a highly threatening, highly technological atmosphere. This move to speed up patient processing is at odds with the fact that the OR is at particular risk for errors in patient care (Risser et al., 1999, p. 237).

It is worth noting that nurses do not view this process in terms of industrial production — with the patient moving along a sort of surgical conveyor belt as the nurses stand ready to administer therapies to one patient after another. Rather, the patient is delivered "into the hands" of the next nurse, an image suggesting an awareness of the trust placed in nurses by patients and families and the nurses' responsibility to ensure the safe passage of the patient. This process of receiving and transferring the patient includes double-checking of location of surgery, any allergies, and other particulars, and reassuring patients and families that they are in capable and trustworthy hands. This kind of vigilance is impossible if the nurse sees the patients for the first time as they "hit the OR door." In complex organizations made up of strangers, attention to detail and double-checking are essential. Operating room nurses also speak of connecting with families, because it is difficult for family members to say goodbye and turn their vulnerable relative over to strangers. Likewise, in returning the patient from surgery, the nurse obtains crucial information about what has transpired during the procedure.

Nurses also consider the time with the alert patient and family members as vital for ensuring that the planned surgical procedure is the correct one as well as other details. Such last-minute double-checking is essential in a complex system, and the nurses were able to cite many examples where it was crucial to the patient's safety:

> First nurse: *It's a frequent occurrence that they want to just rush somebody in — the surgeon or the anesthesiologist. But I tell them, "Just because we're in a hurry, we don't skip nursing." And I make that point, that it is nursing we have to do… So, "I don't care if we are short on time. I don't care if you have to get out of here by 3 o'clock. We don't*

> *skip nursing… [There are] some things that I have to check, and it's important."*
>
> Second nurse: *It's a little different when you know the people and you can talk to them one on one. But when you get the message from above [from hospital administration] that you are of little value, it's very demoralizing. I mean, I value the people I work with and I love what I do, but it's so demoralizing to realize that you are still not really valued much at all.*

Time, in this view, is not merely the minutes it takes to perform a particular task multiplied by the number of times it must be performed. Rather, time provides a space for meaningful human interaction to occur. Two pediatric nurses drew attention to this fact when speaking about the importance of developing trust with parents of hospitalized children:

> First nurse: *Most of the time families want you to stay, whether you talk or not… If you're just standing there, they're very happy, if you're just there, watching and being with them…you don't even have to talk…you don't have to do anything.*
>
> Second nurse: *Because if you're hyper and uptight, that's a terrible thing to do to them; that gives them a bad message.*
>
> First nurse: *Sometimes you can sense if they want you to take care of the child and they don't want to…if they're so frustrated, overwhelmed, worried [that] they cannot deal with that child. You don't know that unless you stay there and spend some time in a relaxed atmosphere and get the feeling of what's happening in the family.*

Later in the same interview the second nurse added: "I like to quit moving when I get in there [the child's room]… I like to find a chair and sit down and just quit moving… I think it just changes the whole tone…the whole atmosphere, you know, of everybody."

Attending to the "tone" or "atmosphere," intentionally altering it from one of rushed tasks to one that is restful and conducive to healing, is at the heart of nursing's most cherished traditions (Nightingale, 1969). For pediatric nurses, whose practice epitomizes nursing's focus on the whole patient as part of a family and community, such time is especially critical, because they must tailor their practice to the patient's developmental needs and the family's coping resources. Pediatric nurses are concerned not only with the patient's medical problem, but also with preserving and supporting the family through the child's illness. They see therapeutic value in "just being there," bearing witness, offering solace, and attending to a situation in which families are at their most distressed and vulnerable.

People are rarely more vulnerable than during recovery from anesthesia following surgery. At this time patients need both expert management of their physiological needs, such as ensuring that they have sufficient oxygenation, and close attention to their emotional needs, as post-operative patients frequently wake up feeling helpless and confused. When staffing in this setting is reduced to minimum levels, the nursing functions that have to do with physiological management have such priority that care of the patient's vulnerability and personhood, a central precept of nursing practice, may be neglected. Nurses in a PACU commented:

> First nurse: *Oftentimes I find it very frustrating. We get so busy that sometimes it's the tasks we have to do to get the patient out of there. Sometimes they just want to hold my hand — that's all they want to do. "I want to hold your hand." I say, "You can have it for 5 minutes and then I have to run off to the next bed." That's what I find very frustrating, that a lot of the care that we can give [is] much more the physical aspect. We don't really have the time to give the spiritual and psychological and emotional care that they really want. Sometimes they just want a closeness to somebody.*
>
> Second nurse: *Right.*
>
> First nurse: *And the way health care is going to be restructured, if the powers that be have their way there will never be an opportunity for that, if they restructure the PACU in a way where other people that are untrained are taking care of our patients and we are supervising eight patients at a time. The patients will never benefit from our expert care. What will happen to us when we're old? Who's going to take care of us? Not people like us.*

"People like us" suggests an ethos of direct-care expertise that this nurse regards as threatened by cost-cutting efforts that move nurses away from the bedside and into roles as the supervisors of less-trained personnel. The distinction between practice and production is evident here. Technicians can be well trained to perform discrete technical tasks, but such narrow training and supervisory delegation of tasks does not take into account good clinical judgement guided by patient needs and vulnerabilities and changes in the patient's condition over time.

Efficiency is the driving force behind much of the health-care restructuring that has taken place. In this context, efficiency is defined in terms of producing more in less time and with fewer resources such as personnel and equipment. In effect, producing more actually means moving consumers (commodities) along a planned trajectory as rapidly and inexpensively as possible. Efficiency may be a worthy goal, but it is jeopardized when the pace of work is such that practitioners have no time to assess their patients in a meaningful way, weigh priorities, and share their knowledge with patients, families, and one another.

Being responsible for eight patients precludes the ability to follow changes in any one patient over time. Continuous monitoring of a patient's trajectory is replaced by snapshot judgements at particular points in time. To be effective, such a managerial approach to patient care has to include time for assessing patients, talking to patients, and conveying clinical assessments to other nurses.

If nursing care is the provision and monitoring of various technological fixes, and if efficient care is the provision and monitoring of more such technological fixes, whether pharmaceutical, mechanical, or other, for more "consumers" in less time, then what these nurses describe doing (or yearning to do) is not only inefficient but irrelevant. If, in contrast, nursing practice is embedded in human relationships of healing and caring, then what these nurses describe is essential to good practice. Single-minded pursuit of outcomes, without consideration of what nurses and patients are forced to become in the process, undermines the essential good in nursing and medicine (Taylor, 1997). Optimal conditions for healing and care within the family system are possible only when nurses, patients, and family members are treated as persons, not as commodities to be managed as rapidly and inexpensively as possible. The moral ecology of nursing is sustained by institutional structures that allow adequate time for nurses' relational work with patients, families, and colleagues in order to skilfully assess the patient's safety, physiological, and emotional needs and to intervene with appropriate timing and care.

Paradoxically, the industrial production model may lead to reduced efficiency, as nurses lack the time to evaluate and monitor their practice in a cohesive way. Two advanced-practice nurses expressed their frustration with an administrative leadership session they had attended:

> First nurse: *We are led by hospital administrators who have to be very concerned about the financial problems, so that's what's constantly being told to us over and over and over again about the constraints and the budget cuts and the this and the that, and it's hard. …what we still want to be able to do is maintain quality care… I'm not saying there's no leadership, I'm not saying people don't care, but that's not really what we're hearing, is it?*
>
> Second nurse: *I've heard it from the administrator of our hospital, "Quality patient care is what we want," but it's just…that's said over there, but in terms of our nursing department…we didn't even talk about [patient care] goals… I mean, we didn't even have time to say, "What is our goal today and what are the priorities?"*

These nurses are describing an "Emperor's New Clothes" situation in which the administration's stated goals are at odds with the reality of the practice environment. When nurses are regarded as line workers, care becomes reduced to a piecemeal series of tasks, and the aims of care may be obscured or ill-defined, increasing the potential for misunderstandings, errors, and ethical conflicts between families, patients, payers, and staff.

Erosion of Trust Between Nurses and Patients

In situations where patients and families do not feel cared for, nurses must do additional work in order to overcome suspicion, resistance, and mistrust (Mechanic, 1996). Trust is jeopardized when temporal or structural constraints preclude relational work. A nurse whose husband had been hospitalized shared insight into some of the basic nursing requirements of patients and families:

> First nurse: *The attending [physician] came in and I said to him, "I'm not leaving. I'm not leaving till I know he's okay, then I'm going to go." He goes, "It's fine. It's fine." But really, you know, that's what patients want and family members want. They want to know that you care. If you don't care, they can't trust you. And that's it, you know.*
>
> Second nurse: *Well, you have to care about the patient but you also have to care about the members of the family. Because essentially they are an extension of the patient. They need the information, they need the reassurance, and they need the guidance. They need…to know that you care, that you are a caring person. That trust has to be built…*
>
> First nurse: *…and just let them know that we're watching and caring, yeah, because the minute you act like you don't care…*
>
> Third nurse: *…well, the thing is, you lose the trust.*

A healing atmosphere is one in which patients, families, and caregivers trust one another and recognize and commit to a common good. When caregivers are unable to establish trust, their work may become for them a matter of enforcing controls rather than nurturing and healing, resulting in a loss of their identity as healers. Central to the practice of nursing is the poorly articulated and poorly understood social function of meeting the other and bearing witness to his or her plight and concerns. It is in this relational arena that trust and safety thrive and patients are assured of not being reduced to a number.

When clinicians feel rushed and harried, their ability to engage with patients and families is impaired, resulting in a disruption of their self-identity as healers. They express moral outrage on behalf of their patients and themselves. This reflects not merely a concern with niceties but an assault on nurses' identity as caring practitioners. An OR nurse described the atmosphere that results from staff cutbacks:

> *The [operating] room's still bloody and dirty. And so, if nobody's there to clean up, then we're [nurses are] expected to grab a mop and mop the floor, and wash the walls and wash the bed. This is what happened to us last week. There was a patient who was very ill and it was a big messy room and…I had to grab a mop and start sweeping and mopping away. Our next patient was a young man who needed a double valve [replacement] and he was absolutely terrified. I met him in the pre-op area. His whole family was terrified. They were all just very emotionally uptight. And the anesthesiologist rolled this guy back to the room that's still covered with blood and parks him next to the two big trash cans with the big containers of blood and guts and trash and says, "Are you ready? Can we bring him in?" And he's right there in the door of the operating room and I'm swinging a mop. And, you know, to me it was the worst thing that I've seen happen to somebody in a long time, and I just — it's like the patient is not significant to them, I'm not significant to them, and all they want to do is roll as many bodies in and out of that room as they can. And that's terrible! That's terrible what that man went through. He was scared to death… I think that our profession is being eroded away by incidents like this and attitudes like this, and cutting way back on the staffing and trying to cut corners at all costs. You know, that to me is very upsetting because I feel my professional practice is being eroded as well.*

The ideal of patient as consumer that is foundational to free-market ideologies in health care breaks down under such circumstances (Malone, 1998). This patient, partially anesthetized for surgery to correct a life-threatening problem, is utterly vulnerable; he is not a consumer who can pick and choose among options. Likewise, the ideal of nurse as manager of a "service line" breaks down as her efforts to ensure a safe and humane atmosphere are disregarded. This example also illustrates the limitations of construing "medical errors" as discrete sentinel events or critical incidents. A breakdown in civility and lack of concern for the patient's integrity constitute bad practice that could have harmful effects on the patient's well-being. An ethos of civility and concern that *discloses* the patient's basic humanity creates social practices of "etiquette" that determine the proper ethical comportment in a particular situation (Day & Benner, 2002). In this case, etiquette, ethical comportment, and an ethics of civility and concern broke down, causing the nurse to become angry and disgusted (see Nussbaum, 2001). Such incidents are likely to be detected or disclosed only by practitioners whose intention is to do no harm and to show compassion, thus fulfilling their fiduciary responsibility to the patient (Sharpe & Faden, 1998).

Such a health-care environment devalues the humanity of both patient and nurse in favour of a system in which actual service is supplanted by the rapidity with which it can be delivered. Nurses are put in the awkward position of having to coach family members to be vigilant and to become involved in the care of their hospitalized loved ones because of staff shortages:

> *Because we are number one witnesses to just how the retrenchment has affected my institution, I am acutely aware that patients need someone with them to help them while they're in the hospital, whereas before I did not feel that way; I did not see the shortage of…nurses.*

This participant and others related instances of members of their own immediate family being hospitalized or too hastily discharged and needing their nursing skills and vigilance. A nurse described the advice she now gave to patients' family members:

> *I try and educate my families about how they need to stay with their family member to protect them. I don't quite say that, but I will say to the wife that's coming to visit the husband, "Are you staying the night tonight?" And she'll say, "Well, I'm not sure." I'll say, "I think you should stay. I would stay if I were you." …I would not think of leaving my own family member, even my husband.*

The moral ecology of nursing requires a trusting relationship so that patient and family vulnerabilities are identified and protected. Trust and the relationships necessary to build and maintain trustworthiness in health care are central to curing, healing, and palliative treatment. Caring practices such as bearing witness, developing trust, getting to know a patient, and being present point to the relational work that is central to the art of healing (Benner et al., 1999; Benner & Wrubel, 1989). Yet this is the very work that is most vulnerable to cost-cutting strategies; it does not fare well in proving its worth in instrumental ways. In the long run, however, it may be more economical to preserve those professional practices that sustain trust than to try to restore trust and good will once they have been supplanted by suspicion and doubt.

Loss of Identity: Patients and Nurses as Commodities

The managerial practice of making physicians and nurses accountable for patient populations rather than individual patients represents a major shift in the moral landscape (Shultz, 1999). For example, while nurses cite the positive effects of managed care for getting premature infants weaned from technological supports and sent home more quickly, earlier discharge for well babies is based upon an acceptance of the risk that some babies will end up being readmitted. The current emphasis on acceptable levels of complications within a patient population — versus a fiduciary concern for the individual and the family, whose losses may be considerable and irreversible — is a major shift in the ethos of practice. One group of nurses spoke about the early discharge of well babies:

> First nurse: *[There are problems with] sending babies home too fast.*
>
> Second nurse:Y*ou know, they…go home at 12 hours or 24 hours, and they haven't — the milk isn't in, they haven't latched on, they don't know how to breastfeed, they come back in and the poor baby…*
>
> First nurse: *…they become dehydrated with hyperbilirubin…*
>
> Second nurse: *…hyperbilirubinemic and dehydrated…*
>
> Third nurse: *…and the mother feels completely inadequate.*
>
> First nurse: *It's devastating for the mother.*
>
> Third nurse: *She'll stop breastfeeding. It's a horrible experience. They feel failures as parents… You know, they have no one — they don't have extended families [to] teach them to breastfeed. By the time they get back [to the hospital] the baby is so dehydrated and so listless, because its bilirubin is so high, that breastfeeding is just not going to happen… And then the mother's milk supply dwindles, and it's — it's…oh, it's terrible, it's awful!*
>
> First nurse: *When you look at the overall number of well babies who go home…it's a small percentage that gets readmitted and so they're saying it's not economically feasible to hang on to everybody for 24 hours or 48 hours or whatever. And, I mean, that's true, it is a small number, but it's still the ones that slip through the cracks.*

Nurses acknowledge the fact that some patients and families benefit from streamlined care and early discharge. However, streamlining entails a shifting of costs to parents and family members, who may not be prepared to provide the level of care that is required. The moral boundaries of care and responsibility have been redrawn. The policy of standardized discharge practices is drawn up with "acceptable risks" for patient populations in mind. However, nurses do not see their work with individual babies in terms of "acceptable risks"; when babies are readmitted, nurses feel the moral burden of their failure to avert harm. Additionally, parental responsibility for medical monitoring is considerably greater and more daunting than the usual parental responsibility to protect and nurture. It is little wonder that many parents feel ill-prepared.

The moral ecology of responsible nursing practice is radically altered when insurance criteria for discharge take precedence over professional judgement and must be overridden or negotiated by professional arguments in favour of additional hospital services. Interestingly, the nurses identified the "well babies" and their parents as at greater risk from the ever shorter hospital stays than the babies in neonatal intensive care, whom the system recognizes as at risk. In the well-baby group, there is little or no indication of which well mothers and infants will have difficulty with breastfeeding, so there is no clinical basis for altering the insurance guidelines for early discharge. Sending infants and mothers home before the mother's milk comes in precludes the breastfeeding instruction formerly provided by nurses.

It will be years before the liability costs and the relative costs of re-admission are weighed against the new early-discharge practices. But the costs must also be weighed against the question of whether any infant and mother should be discharged before safe feeding patterns have been established. The potential for harm caused by failed early feeding for a certain percentage of babies may be an acceptable economic risk but an unacceptable human risk.

The shift to a population-based model is accompanied by a shift towards institutional accountability to insurers and purchasers of insurance. This latter shift was evident in the pressure not to admit day-surgery patients to the ICU because increased complications, and thus costs, would mar the hospital's and the physician's record with payers. For example, one nurse was observed negotiating for an ICU bed for a pediatric patient who was in respiratory distress and would likely need continued ventilatory support. The decision was postponed as long as possible, the nurse explained, in order to avoid an "unnecessary" admission and elevated complication rates for the hospital and the physician. Ultimately, the patient was admitted to the ICU, but against the gradient serving to protect the performance statistics of the hospital and the physician group. The addition of this institutional and group focus to the existing family and patient focus creates a new layer of accountability and indicates a need to consider new models of accountability (Malone & Luft, 2002).

The ethos of saving money to increase profits in a for-profit system is very different from that of cutting costs to improve distributive justice. The Kantian ethic of treating people as ends in themselves, rather than as means to some other end, is violated when cost savings do not support improved services for more people but, rather, support increased profits for stockholders (Weisskopf, 1977). This ethos sacrifices clinicians' fiduciary trust with patients for "acceptable" levels of complications and risks within patient populations. At the individual level, complications add to suffering and even death; the risk is unacceptable (Shultz, 1999). In hospital environments that have been redesigned for the "efficient" provision of various "service lines," based on an industrial production model, the patient is viewed not as a consumer but as a commodity to be produced and traded. In this model, the least expensive patients are the most valued patients. Contrary to this ethic of processing patients (commodities) in order to maximize shareholders' profits, the moral ecology of nursing is contingent upon institutional values that situate the patient's and nurse's humanity at the centre.

Health Care in the Marketplace

Health-care restructuring is often justified on the grounds that it limits the overuse of expensive services. The claim is that health care, as a business, can be run more efficiently by trimming staff, reducing waste, and using other measures designed to minimize per-patient costs. Protection of patients from unscrupulous acts in a climate of cost-cutting relies heavily upon the patients themselves, as consumers who will shop elsewhere if services are unsatisfactory, and upon professional ethics and the ability of clinicians to uphold them. These means, however, are constrained by the interests of payers, insurers, and groups of physicians who share risks and profits. In such an environment it is difficult for patients and individual nurses and physicians to exert control over the style and quality of practice:

> First nurse: *[I] need to touch base with the fact that I'm a human being…it's not just hemostats and scalpels.*
>
> Second nurse: *As we get caught up in the busy day-to-day, short length of stay, people moving in and out, it's almost Greyhound. It's a Greyhound depot…the basics get lost.*

The rhetoric of this system redesign — that the changes promote better care at lower cost — is revealed as a fraud by the nurses' expression of frustration at their inability to provide what they regard as basic nursing care. In fact, such system redesign creates temporal and other barriers to the provision of safe care. The aim becomes not care but the rapid processing of people, compelling clinicians to struggle on a daily basis to convince themselves that they are doing good. Such circumstances undermine the basic moral ecology of good nursing practice. In situations of cost-driven urgency, nurses' concern for patients on a human level can actually become a problem insofar as it requires time and resources that are not forthcoming. Confronted with this situation, clinicians may resort to subverting the system in order to preserve fragments of their identity as healers, as suggested by a critical-care nurse:

> *I guess more or less for myself as a nurse, I basically have expectations… I make sure that patients are always kept cleaned up. I make sure they're*

> *okay. It's kind of hard [in ICU] because most of my patients are intubated so we don't have that rapport, but we do have the rapport with families… I was a patient myself for two and a half weeks, and it wasn't that bad but it changes everything, you know. Like sometimes you have patients call you every 5 minutes and you're, like, what does she have to call me every 5 minutes for? [embarrassed laugh] And then I realize that, being on bed rest for two and a half weeks, you have no concept of time, 24 hours just keep going for days and days and days… For me, I have to always straighten up my patients' sheets, or change them, make sure the patient's comfortable, because I was lying in bed for two and a half weeks and that bed can be really uncomfortable, where you get body aches and you're not even doing anything. And that's a big thing for me. I get upset when they're telling us to cut back on linen and [not to] change the sheets unless they're soiled. I mean, that bothers me a lot, but I still manage to do it. If I have to sneak them into [the] room I still do it.*

Care becomes something to be surreptitiously snatched, a covert activity. Human caring for those who are suffering becomes something for which clinicians no longer have time:

> First nurse: I *mean, [second nurse] and I help support each other that it's okay to stay in that role, you know, and that's good. "This is what this is all about," and "Yes, what I am identifying is important." What I have been doing is important even though nobody else — we feel like nobody else really is doing that or sees it [direct patient care and comfort measures] as important.*
>
> Second nurse: *How to keep the patient care as the priority through all of this other extraneous bombardment — things that just weren't there [before].*
>
> Third nurse: *I try to look at the very big picture, and I just remind myself from time to time that managed care is not only inadequate, it's probably a deliberate fraud in that it's an attempt to further privatize care under the guise of reform, and in that it specifically and deliberately ignores the uninsured. What I say to myself is…managed care is to national health what the Depression was to social security.*

Conclusion: A Moral Ecology of Care

In this study, critical-care nurses told stories about their practice that revealed strains in sustaining an ethic of good nursing in the face of the economic restructuring of health care in the United States. For example, despite increased patient acuity, downsizing has resulted in greater utilization of less-trained per diem and float nurses, requiring written standards to establish minimum safety requirements for a pool of inconsistent staff, in place of a team of nurses whose cohesiveness promoted nursing excellence. The press for efficiency has resulted in system restructuring that allows less time for nursing care and assumes an indifferent if not dismissive stance towards the relational practices in which nurses engage to ensure the security, well-being, and humanity of their patients. An institutional environment in which the trust of patients and families is compromised puts nurses in the awkward position of having to coach families to be vigilant. Redesigned systems that view nursing care through the lens of an industrial production model, wherein patients are treated as consumers at best and as commodities at worst, have compelled nurses to act surreptitiously to sustain caring practices that ensure patients and families a safe and humane passage.

As members of an institutionally based profession, nurses rely on institutional structures to support the caring functions that constitute good nursing practice. Besides the physical dimensions, the temporal and moral dimensions of institutions can increase or decrease the likelihood that a community of practitioners, organized around common goals, will adopt the standards and visions of good practice and pass them on to new generations of practitioners. This moral ecology, or the interaction between nurses and the institutional environments on which they rely, directly affects nursing practice and the well-being of patients and families. Discussions of organizational ethics should be broadened to address the issue of whether institutional resources and structures enhance or constrain patient care as they impact on nursing and medical practice.

Medicine and nursing are founded on a vision of healing and responsiveness to suffering. Aristotle was the first to see a distinction between the production of things and the practice of an art or science, which requires character, skill, responsiveness, and relationship. Survival of an institutionally based practice like nursing requires an ecology wherein caring and compassion are the raison d'être of the practice. In such an ecology, practitioners and patients have the time to integrate experience; pass on experiential learning to novice practitioners; develop creative ways of effecting change; sustain a sense of trust and connection on a human level; and grow and move forward in innovative, responsive ways (Benner et al., 1996, 1999). Alasdair MacIntyre has written on the value of institutionalizing practices so that their visions can be fulfilled:

> Lack of justice, lack of truthfulness, lack of courage, lack of relevant intellectual virtues — these corrupt traditions, just as they do those institutions and practices which derive their life from the traditions of which they are the contemporary embodiments. To recognize this is of course also to recognize the existence of an additional virtue, one whose impor-

> tance is perhaps most obvious when it is least present, the virtue of having an adequate sense of the traditions to which one belongs or which confront one. This virtue is not to be confused with any form of conservative antiquarianism; I am not praising those who choose the conventional conservative role of *laudator temporis acti.* It is rather the case that an adequate sense of tradition manifests itself in a grasp of those future possibilities which the past has made available to the present. Living traditions, just because they continue a not-yet-completed narrative, confront a future whose determinate and determinable character, so far as it possesses any, derives from the past. (MacIntyre, 1981, p. 207)

What kinds of caring traditions do we as a society want to sustain for ourselves and our families? The experiences of these nurses warn us that the moral ecology of caring practice is in jeopardy. Both nursing and medicine, as living traditions and as professions, must shoulder part of the responsibility for curtailing the escalation in health-care costs. However, in order to do so while providing morally grounded care, they must act within systems and institutions that instantiate and support a healthy ecology of practice, not merely an assembly line of tasks.

References

Andre, J. (1998). Learning from nursing. *Medical Humanities Report, 19*(2), 1–7.

Aristotle. (1985). *Nicomachean ethics* (T. Irwin, Trans.). Indianapolis, IN: Hackett.

Benner, P. (1994a). Caring as a way of knowing and not knowing. In S. S. Phillips & P. Benner (Eds.), *The crisis of care: Affirming and restoring caring practices in the helping professions* (pp. 42–62). Washington: Georgetown University Press.

Benner, P. (1994b). Discovering challenges ethical theory in experience-based narratives of nurses' everyday ethical comportment. In J. F. Monagle & D. C. Thomasma (Eds.), *Health care ethics: Critical issues* (pp. 401–411). Gaithersburg, MD: Aspen.

Benner, P. (Ed.). (1994c). *Interpretive phenomenology: Embodiment, caring, and ethics in health and illness.* Thousand Oaks, CA: Sage.

Benner, P. (1994d). The role of articulation in understanding practice and experience as sources of knowledge in clinical nursing. In J. Tully (Ed.), *Philosophy in an age of pluralism: The philosophy of Charles Taylor in question* (pp. 136–155). New York: Cambridge University Press.

Benner, P. (1997). A dialogue between virtue ethics and care ethics. *Theoretical Medicine, 18*(1/2), 47–61.

Benner, P., Hooper-Kyriakidis, P., & Stannard, D. (1999). *Clinical wisdom and interventions in critical care: A thinking-in-action approach.* Philadelphia: W. B. Saunders.

Benner, P., Tanner, C., & Chesla, C. (1996). *Expertise in nursing practice: Caring, clinical judgment, and ethics.* New York: Springer.

Benner, P., & Wrubel, J. (1989). *The primacy of caring: Stress and coping in health and illness.* Menlo Park, CA: Addison-Wesley.

Day, L. (2001). Timing the offer of organ donation: An articulation of ethics and etiquette in nursing. *American Journal of Critical Care, 10*(5), 306–312.

Day, L., & Benner, P. (2002). Ethics, ethical comportment, and etiquette. *American Journal of Critical Care, 11*(1), 76–79.

Donnelly, S. (1995). The art of moral ecology. *Ecosystem Health, 1*(3), 170–176.

Dunne, J. (1997). *Back to the rough ground: Practical judgment and the lure of technique.* Notre Dame, IN: University of Notre Dame Press.

Ellwood, P. M., & Enthoven, A. C. (1995). "Responsible choices": The Jackson Hole group plan for health reform. *Health Affairs, 14*(2), 24–39.

Enthoven, A. (1981). The competition strategy: Status and prospects. *New England Journal of Medicine, 304*(2), 109–112.

Enthoven, A. (1988). Managed competition: An agenda for action. *Health Affairs,* 7(3), 25–47.

Kassirer, J. P. (1995). Managed care and the morality of the marketplace. *New England Journal of Medicine, 333*(1), 50–52.

Kassirer, J. P. (1996). The new health care game. *New England Journal of Medicine, 335*(6), 433.

MacIntyre, A. (1981). *After virtue.* Notre Dame, IN: University of Notre Dame Press.

Malone, R. E. (1998). Against "consumers." *Administrative Radiology Journal, 17*(6), 27–28.

Malone, R. E. (1999). Policy as product: Morality and metaphor in health policy discourse. *Hastings Center Report, 29*(3), 16–22.

Malone, R.E. (2003). Distal nursing. *Social Science and Medicine, 56*(11), 2317–2326.

Malone, R. E., & Luft, H. S. (2002). Perspectives on accountability: Past, present, and future. In M. Danis, C. Clancy, & L. R. Churchill (Eds.), *Ethical dimensions of health policy* (pp. 263–280). New York: Oxford University Press.

McKenzie, N. F., & Bilofsky, E. (1994). Shredding the safety net: The dismantling of public programs. In N. F. McKenzie (Ed.), *Beyond crisis: Confronting health care in the United States* (pp. 140–153). New York: Meridian.

Mechanic, D. (1996). Changing medical organization and the erosion of trust. *Milbank Quarterly, 74*(2), 171–189.

Nightingale, F. (1969). *Notes on nursing: What it is and what it is not.* New York: Dover.

Norton, B. G. (1995). Evaluating ecosystem states: Two competing paradigms. *Ecological Economics, 14,* 113–127.

Nussbaum, M. C. (2001). *Upheavals of thought: The intelligence of emotions.* New York: Cambridge University Press.

Relman, A. S. (1992, March). What market values are doing to medicine. *Atlantic Monthly, 269*(3), 99–106.

Risser, D. T., Simon, R., Rice, M. M., & Salisbury, M. L. (1999). A structured teamwork system to reduce clinical errors. In P. L. Spath (Ed.), *Error reduction in health care: A systems approach to improving patient safety* (pp. 235–278). San Francisco: Jossey-Bass.

Rosner, F., Berker, J., Kark, P., Potash, J., & Bennett, A. J. (2000). Disclosure and prevention of medical errors. *Archives of Internal Medicine, 160*(14), 2089–2092.

Sharpe, V. A., & Faden, A. L. (1998). *Medical harm: Historical, conceptual, and ethical dimensions of iatrogenic illness.* New York: Cambridge University Press.

Shultz, M. M. (1999). *Essay: Can medical ethics survive managed care?* Unpublished manuscript, University of California, Berkeley.

Smith, S. R., & Lipsky, M. (1992). Privatization in health and human services: A critique. *Journal of Health Politics, Policy and Law, 17*(2), 233–253.

Socolar, D., Sager, A., & Hiam, P. (1992). Competing to death: California's high-risk system. *Journal of American Health Policy, 2*(2), 45–50.

Taylor, C. (1997). Leading a life. In R. Chang (Ed.), *Incommensurability, incomparability, and practical reasoning* (pp. 170–195). Cambridge, MA: Harvard University Press.

Weber, M. (1964). *Max Weber: The theory of social and economic organization* (A. M. Henderson & T. Parsons, Trans.). New York: Free Press.

Weisskopf, W. A. (1977). The moral predicament of the market economy. In G. Dworkin, G. Bermant, & P. G. Brown (Eds.), *Markets and morals* (pp. 33–41). New York: Wiley.

Acknowledgements

This research was funded by the Helene Fuld Health Trust.

Sara M. Weiss, RN, PhD, is Research Scientist, Institute on Aging, San Francisco, and Assistant Clinical Professor, Department of Physiological Nursing, University of California, San Francisco, United States. Ruth E. Malone, RN, PhD, is Acting Associate Professor, Department of Social and Behavioral Sciences, School of Nursing, and Institute for Health Policy Studies, University of California, San Francisco. Joseph R. Merighi, MSW, PhD, is Assistant Professor, College of Social Work, San José State University, San José, California. Patricia Benner, RN, PhD, FAAN, is Professor, Department of Social and Behavioral Sciences, School of Nursing, University of California, San Francisco.

2009 update: *Sara M. Weiss is a staff nurse in Behavioral Health, Marin General Hospital, Greenbrae, California. Ruth E. Malone is Professor, Department of Social and Behavioral Sciences, School of Nursing, and Institute for Health Policy Studies, University of California, San Francisco. Joseph R. Merighi is Associate Professor, College of Social Work, San José State University. Patricia Benner is Professor Emerita, Department of Social and Behavioral Sciences, School of Nursing, University of California, San Francisco.*

CJNR 2009, Vol. 41 Nº 1, 366–384

Résumé

Apprendre à vivre avec la démence aux stades précoces

Leona Werezak et Norma Stewart

Les études sur la démence précoce se concentrent en grande partie sur la perspective des prestataires de soins, si bien que l'on sait peu de choses sur l'expérience des personnes atteintes aux stades débutants. La présente étude a été conçue dans le but de découvrir comment elles apprenaient à vivre avec cette maladie durant cette période. On a mené des entrevues auprès de 6 participants (3 hommes et 3 femmes) âgés de 61 à 79 ans. On a élaboré un modèle théorique sur la base d'une approche qualitative et d'une théorie à base empirique. On a ensuite établi un cadre théorique préliminaire à partir des données obtenues : les sujets s'apprivoisent à la démence selon un processus en cinq étapes, commençant avec les antécédents et se poursuivant avec les stades de l'anticipation, de l'apparition, de l'assimilation et de l'acceptation. Cette démarche évolue à mesure que la perception des sujets sur eux-mêmes et le monde extérieur se transforme. En définitive, les implications découlant de cette recherche sont nombreuses pour les cliniciens et les chercheurs qui interviennent auprès des personnes atteintes de démence aux stades précoces.

CJNR 2009, Vol. 41 N° 1, 366–384

Learning to Live With Early Dementia

Leona Werezak and Norma Stewart

Much of the literature on early dementia is focused on caregiver perspectives, while little is known about the perspective of persons with early-stage dementia such as what it is like to live with this syndrome. This study was conducted to explore the process of learning to live with early-stage dementia. Interviews were conducted with 6 early-stage participants (3 men and 3 women) ranging in age from 61 to 79 years. Theory construction was facilitated using a qualitative approach and grounded theory. A preliminary theoretical framework was developed from the data which outlines a 5-stage process of learning to live with dementia that begins with various antecedents and proceeds through the stages of anticipation, appearance, assimilation, and acceptance. This process evolved as participants' awareness of themselves and their outer world changed. Ultimately, the findings of this study have several implications for clinicians and researchers working with persons in early-stage dementia.

Context of the Study

The term *dementia* refers to a clinical syndrome comprising a wide range of neurological diseases that typically occur with increasing age and are distinguished by progressive memory loss, impaired judgement, and a decreased capacity for abstract reasoning (Langston Lind, 1995). The most common cause of dementia is Alzheimer's disease, with an overall prevalence rate of 5.1% in Canada for people over the age of 65 (Canadian Study of Health and Aging Working Group, 1994). In order to provide effective care and services for people with dementia, health-care providers have to understand the needs and issues facing this client group. Unfortunately, though, the views of people with dementia have been conspicuously absent from the literature until recently. At present, most of the information about the needs and concerns of dementia clients has been obtained from family members (McWalter et al., 1998) or formal caregivers (Gordon, Carter, & Scott, 1997). The few existing studies from the perspective of persons with dementia suggest that their views may differ from those of their caregivers (Cotrell & Schulz, 1993). Consequently, there is growing recognition in the literature that the perspective of persons with dementia must be sought out, particularly in the early stages of the disease process when language skills are relatively intact (Cotrell & Schulz, 1993).

Originally published in CJNR 2002, Vol. 34 N° 1, 67–85

To address this gap in the literature, we designed a study to explore and conceptualize the process of learning to live with memory loss in older adults with early-stage dementia. Through the use of grounded theory methodology, participants' experiences were examined and a broad theoretical framework evolved that outlined how persons with dementia gradually learned to live with early memory loss (Werezak, 2001).

Persons With Dementia as Research Participants

An extensive literature review revealed little research that included self-reports by persons with dementia as research participants. As one might expect, the paucity of information in this area is due to methodological problems of self-report reliability as cognitive decline occurs (Ballard et al., 1991; Burgener & Dickerson-Putman, 1999). Therefore, most of the literature is focused on caregiver needs (Luscombe, Brodaty, & Freeth, 1998; Nankervis, Schofield, Herrman, & Bloch, 1997) and level of caregiver burden (Freyne, Kidd, Coen, & Lawlor, 1999; Schneider, Murray, Banerjee, & Mann, 1999) rather than on the perspective of persons with dementia.

The studies that have included persons with early-stage dementia as participants have addressed the issue of reliability and staging of the disease in various ways. In the study by Burgener and Dickerson-Putman (1999), participants were "mostly in the early disease stages" (p. 35), as assessed by a diagnosis of Alzheimer's disease or related disorder within the previous 12 months and a Mini-Mental State Examination (MMSE) score between 12 and 26 ($M = 20.5$) — with a maximum score of 30 representing no cognitive impairment. Although no specific reliability testing was conducted, consistency was found in participants' responses from baseline interview to 6-month follow-up. Other researchers have also begun to demonstrate that information provided by persons with early-stage dementia is reliable (McAuslane & Sperlinger, 1994) and "insightful" (Keady & Nolan, 1995, p. 1338); hence, the importance and feasibility of continued research in this area with persons in early-stage dementia have received increasing support.

The Experience of Living With Dementia

In order to better understand the issues related to living with dementia, researchers have outlined two preliminary models that conceptualize the experience of persons with dementia on a continuum with identifiable stages or phases (Cohen, Kennedy, & Eisdorfer, 1984; Keady & Nolan, 1994). Cohen et al. (1984). delineate six psychological phases in the cognitively impaired individual based on several hundred clinical interviews with dementia sufferers. These phases are: prediagnosis — recognition and concern; during diagnosis — denial; post-diagnosis — anger, guilt, and sadness; coping; maturation; and separation from self. Similarly, Keady and Nolan (1994) propose a preliminary nine-stage model defining the experience of dementia from the perspective of persons with the disease. The nine stages are: slipping, suspecting, covering up, revealing, confirming, surviving, disorganization, decline, and death. Both of these frameworks suggest that persons with dementia undergo a process beginning with initial memory impairment and ending with terminal disability. However, what has yet to be determined is how individuals progress through the early stages of the disease, and it is during these stages that they may be most involved in their own care and planning for the future. Although the above-noted authors propose two different models that explicate the entire process of dementia from diagnosis to death (based on research in the United States and the United Kingdom), the model proposed in this paper is unique in that it describes the early stage of dementia exclusively while offering a Canadian perspective on this devastating syndrome.

Methods

Design and Sampling

A qualitative grounded theory approach was used to explore the subjective experience of persons with early-stage dementia (Strauss & Corbin, 1998). Theoretical sampling was carried out to obtain six participants (three men and three women) with early-stage dementia (five with Alzheimer's disease and one with vascular dementia). Participants ranged in age from 61 to 79 years. All participants were in Global Deterioration Scale (GDS) (Youngjohn & Crook, 1996) stage 3 out of seven possible stages, with Modified Mini-Mental State examination (3MS) scores (Teng & Chui, 1987) ranging from 79 to 91 out of a possible 100. All participants were living in their home communities with their spouses. Four participants stated that they had participated in a support group for persons with early-stage dementia. Each participant was assigned a pseudonym. To ensure anonymity, the pseudonyms were assigned alphabetically in the order in which the participants were interviewed (e.g., participant #1: Mr. A. = Mr. Arnold). Inclusion criteria were: (1) diagnosis of Alzheimer's disease or related disorder, (2) early stage of dementia, and (3) all ages of onset of dementia (< 65 and > 65 years). In addition to meeting the above criteria, participants were selected on the basis of their ability to provide data relevant to the development of emerging conceptual categories.

Ethical Considerations

When recruiting people with dementia as research participants, the investigator should consider three issues: competence, ability to provide informed consent, and use of proxy consent. Resau (1995) notes that "a diagnosis of dementia is not necessarily synonymous with incompetency," since a person with mild or early-stage dementia may still be able to perform relatively simple routine tasks such as handling small sums of money (p. 57). The current consensus in the literature is that many individuals with dementia, particularly those in the earliest stages of the disease, are still capable of making numerous decisions competently, including the decision whether or not to participate in research (American Geriatrics Society Ethics Committee, 1998; Resau, 1995).

With regard to proxy consent, there is recent evidence that proxy decisions in favour of research participation do not always match dementia persons' decisions to participate in research (Sachs et al., 1994). As a result, the current best practice is to obtain informed consent from both the potential dementia participant and that person's proxy (Sachs et al., 1994). The present study was approved by a university-based ethics committee and received consent from all dementia participants and their proxies.

Recruitment and Screening

In order to recruit participants from various agencies, the researchers supplied the agency contact persons with a one-page letter describing the study. Agency personnel distributed the letter to potential participants and then provided contact information for the study. The first author then phoned potential participants to arrange a meeting in their homes to further inform them about the study. Participants who provided signed consent (with their proxies) were interviewed during this first visit.

The first level of screening was the clinical assessment of early-stage dementia by the agency contact person. Interviews were conducted based on this initial screening. After the first interview, two screening instruments were used to confirm the participant's degree of cognitive decline (3MS; Teng & Chui, 1987) and stage of dementia (GDS; Youngjohn & Crook, 1996). Two potential participants were excluded from the study because their 3MS scores fell below the cut-off of 78 (McDowell, Kristjansson, Hill, & Hebert, 1997). Finally, participants' family physicians or specialists were contacted by mail in order to confirm the diagnosis of dementia. The authors did not ask participants the length of time since diagnosis, since their possible inability to remember due to dementia could cause undue stress and anxiety during interviewing. Neither was this information sought from physicians, since frequently a definitive diagnosis is not made on a specific date, but rather the diagnosis is made over time as the symptoms worsen and various tests rule out other possible diagnoses.

Data Collection

Data were initially collected from participants using a semi-structured interview format based on previous research (Keady & Nolan, 1995). Each participant was interviewed twice. Proxies were allowed to be present during the interview process but were informed that the purpose of the interview was to elicit the perspective of the person with dementia. Once transcripts from the first interviews were coded and analyzed, a preliminary theory comprising six categories was identified. A second interview was conducted with each participant for the purpose of verifying and clarifying the emerging theory. During this second interview (1 to 3 months later), the interview process evolved and became more unstructured and open-ended as clarification was sought on issues that emerged in the previous interview.

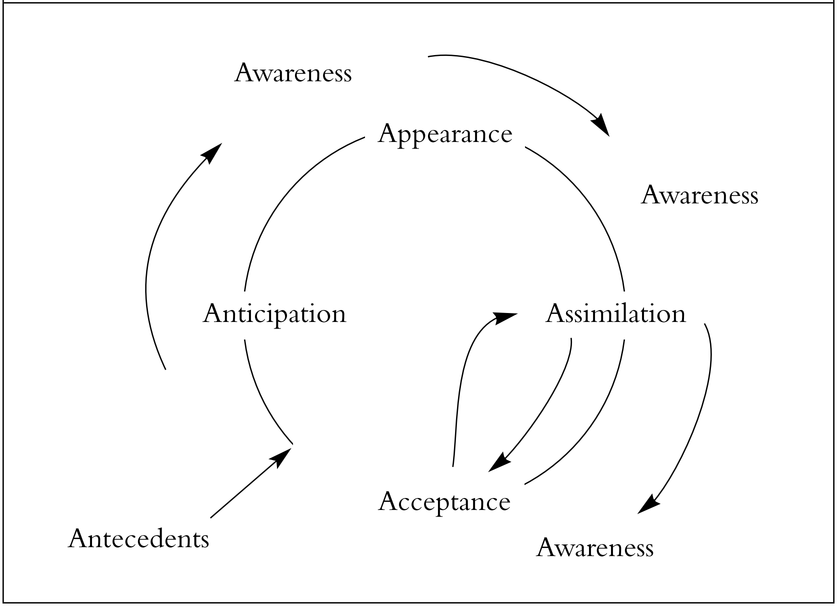
Data Analysis

Data were analyzed using constant comparison analysis to identify core concepts that described the experience of living with dementia from the perspective of the person with early memory loss (Strauss & Corbin, 1998). Negative case analyses were also carried out by including participants who had different types of dementia (i.e., Alzheimer's disease and vascular dementia). Data analysis was conducted using three types of coding: open coding, axial coding, and selective coding (Strauss & Corbin, 1998). Coding was facilitated by the use of NVivo qualitative analysis software. During the process of coding the first interviews, five preliminary categories emerged from the data, which the first author "validated" and expanded on based on the second interviews (Strauss & Corbin, 1998, p. 159).

Findings

The theory that emerged from the interviews can best be described as a *continuous process of adjusting to early-stage dementia.* The process consists of five core categories or stages that evolve over time, namely *antecedents, anticipation, appearance, assimilation,* and *acceptance* (see Figure 1). The participants described a process of adjusting to early-stage dementia beginning with various *antecedents* and progressing through the next four stages of the model with differing levels of *awareness* connecting each stage to the next. The findings that follow explicate the sub-processes of these stages

Figure 1 ***The Continuous Process of Adjusting to Early-Stage Dementia***



in greater detail based on the information obtained from the participants. Negative case analyses did not reveal any differences among participants.

Antecedents

There were several sub-processes that preceded participants' being diagnosed with dementia. These made it difficult for participants to obtain a diagnosis of dementia.

Recognizing that a problem exists. At the beginning of the interview process, participants were asked what they first noticed when they began experiencing difficulties with their memory. Not surprisingly, five of the six participants responded that they were not aware that they even had a problem with their memory when the dementia began. The following statement illustrates this point:

> *Actually, I don't think I really realized at the beginning that I had memory loss. I'd say, "I can't think of it right now," if somebody asked me something, and I didn't realize I had memory loss.*

This initial reaction appeared to be due to the insidious onset of symptoms that the participants with Alzheimer's disease referred to, which some attributed to benign forgetfulness or stress at work. Unlike the other participants, who described an insidious onset of symptoms, one participant described experiencing an acute onset of what she said her physician called "vascular dementia." She described the beginning of her memory loss as follows:

> *I was crocheting this one day and all of a sudden it was just like if somebody had taken something sharp and just jabbed it into here [pointing to her forehead] and it cracked, and I just yelled, "Ouch!"*

The other five participants cited various reasons for deciding to seek medical assessment, most commonly due to the progression of their memory loss.

Recalling previous memory quality. When participants discussed the onset of their memory loss, many inevitably spoke about what their memory was like before the dementia began. During the first interview, one participant suggested that his memory was not good even before he was diagnosed with Alzheimer's disease:

> *Remembering at any time in my life, I mean, playing bridge was never a big thing, and any card game for that matter, you had to remember…memorize your numbers…. It wasn't my bag.*

In sharp contrast, one participant remarked that her memory was excellent before the onset of dementia. Because the change in her memory was so drastic, both she and her husband were initially quite upset about her memory loss:

> *I feel I'm very forgetful, and I think that bothered [my husband] so much…because I've never been like that. I've always had an excellent memory. But that was a very hard, hard thing for me, to not be able to remember things, because I just never had that experience before.*

Identifying family members with and without dementia. Another issue participants raised in relation to being unaware, initially, of their memory loss was whether any family member had ever been diagnosed with dementia or Alzheimer's disease. Participants who had a family history of other diseases such as cancer or heart disease often said they expected to develop one of these diseases rather than dementia:

> *I was thinking I'd maybe [get] cancer or heart disease or some damn thing, because that's what was in my family. My dad died of…angina, and my mother had cancer…. I expected one of them anyway [laughs] …not this one.*

Confounding health problems. Finally, some participants described facing other complex health problems prior to being diagnosed with dementia, which made it difficult for them to identify which disease process was causing the memory loss, decreased attention span, and fatigue. For example, one participant explained that he had suffered from attention deficit since childhood and initially attributed his memory problems to his attention deficit disorder rather than dementia. Another participant, who was receiving radiation treatment for prostate cancer, voiced the following concern:

> *I'm overly tired, but I don't know whether that has anything to do with Alzheimer's or whether it's something else.*

In summary, the sub-processes of the *antecedents* stage were precursors to participants seeking medical attention and subsequently obtaining a diagnosis of dementia.

Anticipation

Once participants recognized that they were experiencing difficulties with their memory and sought medical help for this problem, they described moving to the next step, *anticipation.* They discussed *anticipating* the diagnosis, their reactions to learning that they had dementia, and speculating about possible causes. Many participants recalled *anticipating* what losses they might face in the future, how they would become dependent on others for their basic needs, and how others would react when they learned that the participant had memory loss.

Obtaining a diagnosis. Although they used different words and phrases to describe their feeling when they learned they had early dementia, the participants' common reaction could be described as shock, horror, and disbelief. The following excerpt vividly describes one participant's response to the news:

> *That was quite an experience…because he did all these tests. He sat down and he said, "Well, I think you've got Alzheimer's." Like, there was no…nothing else but… No, he didn't say, "I think"; he said, "You have Alzheimer's." Well, I was just devastated.*

Some participants also tried to determine what might have caused their dementia. One participant wondered whether having his eardrum punctured accidentally by a physician and needing to have it surgically repaired could have caused his memory loss. Another participant described consistently waking up with severely reddened eyes, which she thought might be related to her memory loss.

Considering future losses. After the initial reaction to their diagnosis, the participants soon wondered what restrictions the dementia would impose on their lives. The issue of "becoming a burden" to their spouses became central as they anticipated slowly losing the ability to care for themselves. One participant described her reaction to being diagnosed with Alzheimer's disease as follows:

> *I think maybe I could probably handle somebody telling me I had whatever, but when it's your mind it's just really devastating, because you think, oh, how long is it going to be until I'm going to be a burden? That's one of the first things you think of…like, how long is it going to be before I'm a…I'm not able to look after myself and I have to have [my husband] doing everything for me.*

Other participants expressed concern about losing the intellectual and social abilities and skills necessary to function as productive members of society: "I'm staying in contact with everybody, just so I don't just become a blob."

Some participants remarked that they expected to need help as their disease progressed. Indeed, some pointed out that they were already relying on the assistance of others, especially their spouses, to serve as a memory aid. Most participants were observed doing this during the interviews. For example, when asked if he was still working, one participant replied, "Oh, I retired," and, after pausing for a few seconds, turned to his wife, who was sitting in the adjoining room, and asked, "What year did I retire?"

Telling others. Finally, in the anticipation stage, participants unanimously recalled feeling anxious about how others would respond if and when they discovered that the participant had memory loss. Two primary factors they considered when contemplating whether to disclose their memory loss were how people might react if they knew about the dementia and how people had reacted when they discovered the participant had memory loss. One participant explained why she had not disclosed her memory loss:

> *I haven't really told anyone else, because I figure if they know they're always watching for you to do things that are not what you should be doing. [chuckles]*

Appearance

Telling others was closely linked to the next stage of the process, *appearance*, in which participants began to consider that others were *noticing* their memory impairment, how others viewed them in light of their memory impairment, and how they saw themselves as persons with memory loss.

Noticing the sufferer's memory loss. Two different components of this category became evident in the data. Looking back at the onset of their dementia, the participants recalled slowly becoming aware that family members, friends, or co-workers were "noticing" their memory loss although they themselves were not aware or were only beginning to become aware of their memory deficits. Similarly, as participants became increasingly aware of their memory impairments, they became greatly concerned that others were also noticing these deficits.

Most of the participants recounted hurtful situations in which others were insensitive or indifferent to what the dementia sufferer was experiencing as a result of the disease process. Perhaps most unsettling was the fact that often these painful situations occurred at the hand of a family member, friend, or co-worker. For example, when the first author asked one participant how she knew that members of her women's group were "gossiping" about her memory loss, she replied, "Well, because they'll go and talk to themselves…and then look at me." As a result of this experience, the participant and her husband decided not to tell anyone about her memory loss when they moved to a large city. She said, "I just cover it up and no one knows."

Seeing self as the "same person." Finally, the participants also addressed how they viewed themselves since being diagnosed with dementia. All the participants described feeling that they were "still the same person" despite the memory impairments they faced. When asked what she thought other people should know about living with memory loss, one woman eloquently summarized what other participants expressed in different words:

> *Maybe it's important that, although you have a memory loss, you haven't lost your mind completely, you know…. You've lost your memory but you haven't lost your mind. And you're still the same person, and you do make mistakes when you're…when you repeat yourself, but you're still knowledgeable, you're still the same person, and I think it's important that people realize that you don't change. I mean, things…your life changes, of course, but you're still the same person inside…at least I think I am. [laughs]*

Assimilation

The fourth stage in the process of adjusting to early dementia was a subprocess called *assimilation. Assimilation* refers to the process of "fitting the dementia" into one's life, similar to the way one might learn to adapt to a physical disability such as adult-onset blindness. First of all, the participants described assimilating the disease into their *inner world*, which included their personal feelings and thoughts about the disease, the need to educate themselves about memory loss, and some of the physiological changes that occurred as a result of the disease. When asked if he had any concerns at the time of diagnosis about things he eventually might not be able to do, one participant replied:

> *When we walked out from [the physician's office] we were handed a brown envelope about it…. And that's what you got from [the physician], and he is a specialist… I didn't feel that they really gave us anything to guide us. I mean, he said, did we know ourselves. Well, we didn't know. I mean, we were looking for answers. So we finally said, hey, something's got to happen here. I mean, we hear about things in brochures, we hear about things on the radio and stuff like that, and we are not getting any smarter here, which is when we sort of decided to drop in to [the Alzheimer's Society].*

Secondly, participants described assimilating the disease into their *outer world*, which included incorporating lifestyle changes related to their memory loss, interacting with supportive and unsupportive significant others, and relating to other persons with dementia. Referring to the support group she attended, one participant explained:

> *…there's people that are about in the same stages as I am, and I think that's important…. And we talk back and forth about things we do and things we do wrong and stuff, and I think that helps a lot. It doesn't make you feel so isolated.*

Discussions with participants revealed that, like the larger process of adjusting to early memory loss, this sub-process of *assimilation* was cyclical and continuous, the end result being increased *acceptance* of the disease. The transition from the *inner world* to the *outer world* was facilitated by *positive mediating experiences* such as feeling supported and accepted by significant others, retaining certain skills and abilities that gave life meaning and purpose, and being able to relate to others who were experiencing memory loss or other conditions. *Negative mediating experiences* such as progression of the disease, feeling unsupported or unaccepted by others, feeling unable to function in social or work situations, or simply having an unexplained setback and wanting to "give up" or "quit" resulted in participants "retreating" or "withdrawing" into their *inner world*. Retreating into their *inner world* served as a coping mechanism whereby participants were able to deal with the negative experience internally and decide how they wanted to proceed with their life from that point on.

Acceptance

The last step in the process of adjusting to early dementia was *acceptance*. Throughout the interviews, participants discussed various aspects of *acceptance* in relation to having dementia. Clearly, the most salient step in the process of adjusting to dementia was learning to *accept* the disease as an integral, albeit unwelcome, component of one's life. One woman summarized her acceptance of her memory loss as follows:

> *I think I am very fortunate. I have really managed to accept it and to say that I'm a lot luckier than a lot of other people. I could be a lot worse. I still can do my [lay ministry work], I still can see my kids, I can still do things that I like doing, and I think you have to sometimes just be grateful for what you have.*

Participants recounted a number of factors in their acceptance of memory loss, notably others' acceptance of the disease, using humour to cope, maintaining hope, and, finally, wanting to help others. Alluding to his sense of hope, one participant confessed during the second interview:

> *In my mind I still feel like I'm going to beat this, but then after reading about it I know there's no cure.*

Later in the interview, the first author tried to determine whether he believed this was his way of maintaining some hope about his illness, to which he replied:

> *Yeah, yeah. And it helps me in a way, because I think I am accepting the fact but I still have a bit of hope that it may not be actually Alzheimer's.*

Having adopted a variety of these coping methods, the participants unanimously described having achieved a degree of acceptance of their disease, which permitted them to focus on enjoying the remainder of their lives rather than dwelling on their illness.

Awareness

Awareness was a common link connecting each stage of the adjustment process to the next. It became readily apparent after all the first interviews had been completed that the participants' *awareness* had gradually developed and changed. Reflecting back on her reaction to the news that she had Alzheimer's disease, one participant described her thoughts as follows:

> *One of the things I thought of right away was, oh, I hope I live to see my grandchildren graduate. But I think that was quite normal because I just…of course, being a grandmother, you always do adore your grandchildren, and I always thought it would be so wonderful to see them graduate and get married and…all of a sudden I thought I might not ever be able to do that. And that would really bother me.*

As the participants discussed moving through the various stages in the process of adjusting to their memory loss, they demonstrated considerable insight and awareness about themselves, their disease, and, finally, those around them. An example of this insightfulness is one participant's description of his family as treating him "like a leper" upon learning he had Alzheimer's disease. When the first author asked how he currently felt about his family's attitude towards him and his dementia, he replied:

> *It doesn't bother me any more, but it did at first… I had the concept that, well, "he's not all there," and [I was] very seldom asked for an opinion or anything of that nature.*

As participants became more comfortable living with their memory loss, their awareness began to change from highly introspective to more outwardly focused, particularly in their interactions with others.

Discussion

Theoretical and Clinical Implications

Support for the various components of the proposed model are found interspersed throughout the literature on early dementia, chronic illness, mental illness, and stigma. One of the concerns Phinney (1998) identified through interviews with dementia sufferers was that the unpredictability of changes in symptoms left them "with a feeling of uncertainty" (p. 11). In other words, escalating anxiety and uncertainty during the *anticipation* stage may be the result of participants perceiving their memory loss as a threat to their sense of order and personal control (Bahro, Silber, & Sunderland, 1995; Gwyther, 1997; Nygard & Borell, 1998). Nurse clinicians and researchers should be cognizant of the emotional strain endured by dementia sufferers and seek to minimize any further emotional distress that may result from the interview process during a nursing assessment or research study. One means of minimizing distress may be to conduct assessments or interviews in the dementia sufferer's home, as was done in this study and recommended by Cotrell and Schulz (1993).

Although denial has been identified as a common coping method among individuals with early memory loss (Bahro et al., 1995; Cohen et al., 1984), evidence of denial did not surface in this study. On the contrary, participants demonstrated a striking openness and willingness to talk about their memory impairment and its effects on their lives. However, some participants did describe employing avoidance and conscious detachment in response to negative events (e.g., gossip), as opposed to unconscious defence. Intellectualizing the disease (e.g., by educating oneself about it) was another conscious means used by participants to assimilate it into their lives.

One of the factors participants saw as instrumental in the assimilation process was connecting with and learning from other dementia sufferers in support groups. The literature cites numerous ways in which self-help and support groups help people to adapt to chronic illness. In a phenomenological study with chronically ill adults, Michael (1996) found that "seeking support helped people feel connected/less isolated and helped them understand what others had done to deal with their illness" (p. 261). Similarly, Collins, Hooton, and Thirkettle (1999) found that participants who were members of a support group appreciated the opportunity to talk with other dementia sufferers about their life situations, feelings, and experiences. The participants in the current study who attended a support group identified all of these benefits. These findings clearly indicate that more support groups should be established for persons with early-stage dementia. Research into the design, function, and efficacy of such groups, once established, could serve to ensure maximum benefit for participants and to secure funding to staff them with educated personnel such as nurses.

Many of the participants in the current study indicated that lack of support from family and friends hindered them from accepting their dementia. Collins et al. (1999) report similar findings. These researchers also found that family members treated the person with dementia "very differently," which contributed to the sufferer's stigmatization and negative self-perception (p. 98). In the current study, supportive family and friends played a key role in enabling participants to come to terms with their memory loss. Based on this finding, nurses can play a role in educating family members and others in the importance of learning to understand and support persons in the early stages of the disease.

Another implication concerns the clinical approach of health-care professionals who work with people with early-stage dementia. For example, one participant explained that the insensitivity of her physician in blurting out to her the news that she had Alzheimer's disease had discouraged her from asking the physician questions about the diagnosis. Michael (1996) found that the insensitivity of health-care professionals contributed to feelings of loss among chronic disease sufferers: "In seeking health care, patients had hoped to be seen as more than their illness and to find help in living with their illnesses. Instead participants felt insignificant and misunderstood" (p. 263). Participants in the current study shared similar feelings about their experiences with health-care professionals. These findings suggest that nurse clinicians and researchers must become aware of the impact of their verbal and non-verbal communication on early-stage sufferers. Clinicians and researchers should adopt an individualized, unhurried approach in working with early-stage sufferers, and should demonstrate their recognition of and respect for the unique difficulties and concerns of these persons.

Research Implications

Some of the participants commented that they received insufficient information from their physician at the time of diagnosis. Research into this area could look at the kinds of information that newly diagnosed sufferers want, who they would expect to dispense such information, and the form that such information should take. Based on the participants' comments as well, an equally important area of dementia research concerns the issues of stigmatization and its effect on self-esteem, adaptation, and acceptance of the disease. As persons are being diagnosed earlier in the disease process, it is becoming increasingly important to identify the coping methods that early-stage sufferers employ and whether they facilitate or hinder adaptation to early dementia.

Limitations of the Study

Several factors may influence the transferability of these findings. First, it should be noted that saturation was reached relatively quickly in the study, with a sample size of only six due to the homogeneity of the sample. For example, these participants represented a relatively well-educated group (all had completed Grade 10 and several had some post-secondary education), which would account for their ability to articulate and describe their experiences in living with the disease. In addition, all of the participants were married, financially secure, and retired from work outside the home. Second, the participants volunteered to take part in the research, which suggests that they had achieved a measure of acceptance of their disease before enrolling in the study. As a result, the findings of this study should not be generalized to all early-stage sufferers but rather be used as preliminary findings that may shed some light on the issues to consider when sampling early-stage sufferers for dementia research.

Another factor to consider is that four of the six participants had attended or were attending a support group for persons with early dementia. The support of and contact with other sufferers was instrumental in their adjustment to early dementia. Dementia sufferers who do not have contact with other sufferers may in fact experience greater difficulty in adjusting to their memory loss. Because support-group participation significantly influenced the findings of this study, it would not be appropriate to generalize the results to early-stage sufferers who have not been part of an early-stage support group.

A final possible limitation concerns the technique of negative case analysis as used in this study. Many factors, such as the stigmatization of the disease and the fact that the disease is often not diagnosed until it has progressed, made it difficult to obtain a sample of early-stage sufferers. Because of this difficulty in obtaining a sample, true negative case analyses could not be conducted by selectively sampling participants to expand on emerging categories. Nevertheless, some negative case analyses were performed indirectly by sampling participants based on characteristics such as age, gender, type of dementia, and age of onset.

Conclusion

Although the current study began as a general exploration of the process of learning to live with early dementia, the depth and breadth of insight revealed in the interviews permitted the development of a preliminary theoretical framework of how persons with early-stage dementia learn to live with their memory loss. Theory development from the voice of the person with dementia makes this study unique. Previous studies have been almost exclusively descriptive in design (Bahro et al., 1995; Phinney, 1998) and have focused on caregiver perspectives (Freyne et al., 1999; Luscombe et al., 1998; Nankervis et al., 1997). From a nursing perspective, the proposed framework offers a base of valuable information to nurses working with persons who have early-stage dementia, while the core concepts provide a foundation for future research to test the applicability of the model in the larger population of persons with this devastating syndrome.

References

American Geriatrics Society Ethics Committee. (1998). Informed consent for research on human subjects with dementia. *Journal of the American Geriatrics Society, 46,* 1308–1310.

Bahro, M., Silber, E., & Sunderland, T. (1995). How do patients with Alzheimer's disease cope with their illness? A clinical experience report. *Journal of the American Geriatrics Society, 43*(1), 41–46.

Ballard, C. G., Chithiramohan, R. N., Handy, S., Bannister, C., Davis, R., & Todd, N. B. (1991). Information reliability in dementia sufferers. *International Journal of Geriatric Psychiatry, 6*(5), 313–316.

Burgener, S. C., & Dickerson-Putman, J. (1999). Assessing patients in the early stages of irreversible dementia: The relevance of patient perspectives. *Journal of Gerontological Nursing, 25*(2), 33–41.

Canadian Study of Health and Aging Working Group. (1994). Canadian Study of Health and Aging: Study methods and prevalence of dementia. *Canadian Medical Association Journal, 150*(6), 899–913.

Cohen, D., Kennedy, G., & Eisdorfer, C. (1984). Phases of change in the patient with Alzheimer's disease: A conceptual dimension for defining health care management. *Journal of the American Geriatrics Society, 32*(1), 11–15.

Collins, C., Hooton, S., & Thirkettle, B. (1999). Shared experience. *Mental Health Care and Learning Disabilities, 3*(3), 96–99.

Cotrell, V., & Schulz, R. (1993). The perspective of the patient with Alzheimer's disease: A neglected dimension of dementia research. *Gerontologist, 33*(2), 205–211.

Freyne, A., Kidd, N., Coen, R., & Lawlor, B. (1999). Burden in carers of dementia patients: Higher levels in carers of younger sufferers. *International Journal of Geriatric Psychiatry, 14*(9), 784–788.

Gordon, D., Carter, H., & Scott, S. (1997). Profiling the care needs of the population with dementia: A survey in central Scotland. *International Journal of Geriatric Psychiatry, 12*(7), 753–759.

Gwyther, L. P. (1997). The perspective of the person with Alzheimer's disease: Which outcomes matter in early to middle stages of dementia? *Alzheimer Disease and Associated Disorders, 11*(6), 18–24.

Keady, J., & Nolan, M. (1994). Younger onset dementia: Developing a longitudinal model as the basis for a research agenda and as a guide to interventions with sufferers and carers. *Journal of Advanced Nursing, 19*(4), 659–669.

Keady, J., & Nolan, M. (1995). FADE: A strategy for action in the mild stage of dementia. *British Journal of Nursing, 4*(22), 1335–1339.

Langston Lind, A. (1995). Delirium, dementia, and other cognitive disorders. In M. O. Hogstel (Ed.), *Geropsychiatric nursing* (2nd ed., pp. 171–207). St. Louis, MO: Mosby.

Luscombe, G., Brodaty, H., & Freeth, S. (1998). Younger people with dementia: Diagnostic issues, effects on carers and use of services. *International Journal of Geriatric Psychiatry, 13*(5), 323–330.

McAuslane, L., & Sperlinger, D. (1994). The effects of relocation on elderly people with dementia and their nursing staff. *International Journal of Geriatric Psychiatry, 9,* 981–984.

McDowell, I., Kristjansson, B., Hill, G. B., & Hebert, R. (1997). Community screening for dementia: The Mini-Mental State Exam (MMSE) and Modified Mini-Mental State Exam (3MS) compared. *Journal of Clinical Epidemiology, 50*(4), 377–383.

McWalter, G., Toner, H., McWalter, A., Eastwood, J., Marshall, M., & Turvey, T. (1998). A community needs assessment: The care needs assessment pack for dementia (CarenapD) – its development, reliability and validity. *International Journal of Geriatric Psychiatry, 13*(1), 16–22.

Michael, S. R. (1996). Integrating chronic illness into one's life: A phenomenological inquiry. *Journal of Holistic Nursing, 14*(3), 251–267.

Nankervis, J., Schofield, H., Herrman, H., & Bloch, S. (1997). Home-based assessment for family carers: A preventative strategy to identify and meet service needs. *International Journal of Geriatric Psychiatry, 12*(2), 193–201.

Nygard, L., & Borell, L. (1998). A life-world of altering meaning: Expressions of the illness experience of dementia in everyday life over 3 years. *Occupational Therapy Journal of Research, 18*(2), 109–136.

Phinney, A. (1998). Living with dementia from the patient's perspective. *Journal of Gerontological Nursing, 24*(6), 8–15.

Resau, L. S. (1995). Obtaining informed consent in Alzheimer's research. *Journal of Neuroscience Nursing, 27*(1), 57–60.

Sachs, G. A., Stocking, C. B., Stern, R., Cox, D. M., Hougham, G., & Sachs, R. S. (1994). Ethical aspects of dementia research: Informed consent and proxy consent. *Clinical Research, 42*(3), 403–412.

Schneider, J., Murray, J., Banerjee, S., & Mann, A. (1999). Eurocare: A cross-national study of co-resident spouse carers for people with Alzheimer's disease: I – Factors associated with carer burden. *International Journal of Geriatric Psychiatry, 14*(8), 651–661.

Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (2nd ed.). Thousand Oaks, CA: Sage.

Teng, E. L., & Chui, H. C. (1987). The Modified Mini-Mental State (3MS) examination. *Journal of Clinical Psychiatry, 48,* 314–318.

Werezak, L. J. (2001). *Learning to live with early stage dementia.* Unpublished master's thesis, University of Saskatchewan, Saskatoon.

Youngjohn, J. R., & Crook, T. H. III. (1996). Dementia. In L. L. Carstensen, B. A. Edelstein, & L. Dornbrand (Eds.), *The practical handbook of clinical gerontology* (pp. 244–246). Thousand Oaks, CA: Sage.

Acknowledgements

The research for this paper was completed as part of the first author's master's thesis at the University of Saskatchewan.

Leona Werezak, RN, MN, is a nursing instructor at the Saskatchewan Institute of Applied Science and Technology, Kelsey Campus, Saskatoon, Saskatchewan, Canada. Norma Stewart, RN, PhD, is a Medical Research Council Scientist and Associate Professor, College of Nursing, University of Saskatchewan, Saskatoon.

2009 update: *Leona Werezak is a full-time faculty member, Nursing Education Program of Saskatchewan, SIAST Kelsey Campus, Saskatoon. Norma Stewart is Professor, College of Nursing, University of Saskatchewan, Saskatoon.*