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EDITORIAL

## **A Tribute to the Calgary Family Nursing Unit: Lessons That Go Beyond Family Nursing**

When I received an e-mail from the Calgary Family Nursing Unit announcing its 25th anniversary, my immediate thought was: It can't be. It can't be that the Calgary Family Nursing Unit has been in existence for such a long time! It can't be that this unit has been able to accomplish all that it has in just 25 years! Two opposing reactions yet both true. I immediately dashed off a congratulatory note, but in the back of my mind I knew this would not suffice. The occasion warranted much greater recognition than a mere congratulatory e-mail from me. The Calgary Family Nursing Unit, under the visionary leadership of Lorraine Wright, Janice Bell, and Wendy Watson, deserved much more. These women deserved to be recognized, celebrated, and feted for their work in family nursing both in Canada and worldwide.

In the 15 years that I have been Editor of *CJNR*, I have devoted only one editorial to individual nursing leaders (Gottlieb, 1995). I have shied away from editorializing on specific nursing leaders because I find it difficult to choose from among the riches of talented, committed nurses who have guided Canadian nursing through the second half of the 20th century and into the 21st. On the other hand, the energy, activities, creativity, and experimentation taking place across the country, under the able leadership of so many nursing leaders, cannot be ignored. Over a decade ago we at *CJNR* introduced the feature section *Happenings* to keep readers abreast of innovations taking place across Canada, particularly those related to nursing research. In describing these exciting projects and programs, we have in effect been showcasing the people whose brainchildren they are — our nursing leaders. All this to say that we already had a place to showcase the Calgary Family Nursing Unit. But no, the *Happenings* section would not do.

I leave the historical analysis of the Calgary Family Nursing Unit to the historians. I am writing this editorial to hail the work of Wright, Bell, Watson, and the many others responsible for founding and running the Unit and to celebrate its impact on a whole generation of nurses who now practise from a family nursing perspective. The Unit stands as an

example of what can be achieved when the right people with the right knowledge and skill set come together at the right time. Wright amassed a team of nurses who shared her vision, her passion, and her commitment to families. These nurses believed in families. They knew that families are the heart of and are *at* the heart of what determines our health and well-being, that families experience suffering and are transformed by illness. I write these lines out of deep respect and admiration, having witnessed where we were in family nursing three decades ago and seeing where the Calgary group has taken us.

Cast your mind back to the late 1970s. Very few nurses were trained in family nursing, or nursing the family. Those who believed that families were important were maternal-child nurses, along with some pediatric and public health nurses. Yes, many appreciated families, but few *knew about* families, and even fewer knew how to work effectively with them. Theories that guided nursing research on families were borrowed from family theory, rooted in sociology, family therapy, and the emerging discipline of family studies. Theory and practice skills for assessing and working with families relied heavily on practice guidelines developed in family therapy by psychiatrists and, to a lesser extent, social workers. The few nursing programs that did value families and a family-centred approach to care had little nursing knowledge to impart about family experiences in everyday practice. Those educators who taught nursing with families had few clinical tools and strategies for doing so. Nurses had to obtain additional training by working with families outside nursing and then adapting their knowledge and training to clinical nursing situations.

The Calgary approach to family nursing was begun in such a fashion. Lorraine Wright and Maureen Leahey recognized the inadequacy of taking an approach developed in one discipline and transplanting it to another. They set out to develop family nursing by drawing heavily on the ideas and principles of family therapy and applying them to nursing. If they had waited until they had developed a “unique” family nursing theory and nursing approaches, we might still be waiting today. Wright and Leahey were visionaries, but they were also pragmatists. They began with their own experience and went from there. They taught us an invaluable lesson: Just start.

In 1982 the Calgary Family Nursing Unit was established, and two years later Wright and Leahey published what has become a primer on family nursing: *Nurses and Families: A Guide to Family Assessment and Intervention* (Wright & Leahey, 1984). This book made complex ideas accessible to nurses in everyday practice and gave nurses the foundational knowledge and tools they needed to assess and work with families.

Wright and Leahey followed up this success with three books, published simultaneously, on how to nurse families facing specific health challenges: life-threatening illness, psychosocial problems, and chronic illness. In addressing these issues separately, they showed that family nursing was relevant across nursing situations and throughout the lifespan. In effect, they broke down the barrier that relegated family nursing to nurses working with families of infants and sick children. Lesson two: Demonstrate the relevance and application of fundamental ideas to a wide and diverse range of nursing situations, and nurses will identify the situations that are applicable to them.

Having made a significant contribution to the development of nursing, Wright and Leahey could have rested on their laurels. But no, they were far from done. Their vision was to bring family nursing to all nurses. They transcended the borders of Calgary, Alberta, and Canada long before the word “global” was part of our lexicon. Janice Bell and, later, Wendy Watson joined the team, and together they built a movement — whether by chance or by design — by targeting education, research, and practice and inextricably linking the three missions together. Every belief and conviction was translated into action. Case in point: The team brought together clinicians, educators, and researchers from around the world to learn from each other. And they did so with grace and generosity, blurring any differences that may have existed among the groups. They showed that each group had a significant contribution to make to the mission of promoting and developing family nursing. Lesson three: Be inclusive, value diversity, and build a strong, integrated “family” of clinicians, educators, and researchers.

Wright and colleagues systematically monitored and studied their work with families. They videotaped their own work with families. Video became their signature way of teaching other nurses how to work with families. They reflected on and analyzed their own work and shared their reflections with other nurses. Nurses converged on the Calgary Family Nursing Unit from across Canada and from Europe, Asia, and South America to be trained in family nursing. The team also began to develop a theoretical model for working with families (Wright, Watson, & Bell, 1996).

Today, family nursing is entrenched around the world. The Eighth International Family Nursing Conference was held this past summer in Thailand. The *Journal of Family Nursing* (whose first and only editor is Janice Bell) is in its 13th year of publication. The Calgary team’s Beliefs model is an important theory, taught in many family nursing courses, and is a framework for research and practice. Something else to be learned from this group of nurses is that knowledge can be put to work to

change the profession; practice, research, and education exist not as separate entities in family nursing but as parts of an integrated whole.

I salute Wright, Bell, and their colleagues at the Calgary Family Nursing Unit for their enormous contributions to nursing. They have transformed the health-care landscape by putting families first. Families around the world owe them a debt of gratitude for sensitizing, educating, and training nurses to care for them with knowledge and compassion. Nurses around the world owe them a debt of gratitude because they now have the knowledge, “moves,” and experience to alleviate family suffering when families are at their most vulnerable; nurses no longer feel impotent and helpless around families.

I conclude this editorial with a poem I read at the opening of the Third International Family Nursing Conference in Chile in 1996. This was the first time the conference had been held outside North America, and the event captured the spirit of the new and expanding family nursing movement. The pebble of an idea was that of Lorraine Wright, Janice Bell, and all those who played a role in setting up and supporting the Calgary Family Nursing Unit. In 25 short years they have created avenues of unity for nurses worldwide.

A pebble of an idea  
honed  
on the whetstone  
of women's experience  
went skipping  
across once-perceived barriers  
creating a rippling out,  
ever widening,  
circles meeting,  
becoming one:  
and that which once seemed insuperable  
through sharing  
became  
avenues of unity

– Gracie, a friend from Fiji;  
poem published in *Women at Work*  
(Women's World Banking, 1990)

**Laurie N. Gottlieb**  
**Editor-in-Chief**



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*Guest Editorial and Discourse*

## **The Importance of Geography and Health in Nursing Research**

**Shirley M. Solberg and Christine Way**

Where we live has critical implications for our health and well-being as well as for the type of health services that are provided and our ability to access them (Christofides, Schauer, & Zlotkin, 2005; Filate, Johansen, Kennedy, & Tu, 2003; Gillis, 2005; Williams, 2006). Geographical reporting or mapping of various cancers (Canadian Cancer Society/National Cancer Institute of Canada, 2007), cardiovascular disease (Heart and Stroke Foundation, 2003), and obesity (Canadian Population Health Initiative, 2006) provides visual representations of areas of high and low incidence and reminders about regional variations. Mapping of aging patterns in Canada suggests that some parts of the country may require particular health services to help meet the demands of an aging population (Government of Canada, 2002). Illustrative maps of this sort nicely profile the health differences and disparities within a country.

The relationship between health disparities and place of residence illustrates the influence of place in the health of human populations (Boyle, Curtis, Graham, & Moore, 2004). Equally important are the social, cultural, and political factors that interact with place, as well as the lived experiences of people who reside in a place and the meanings attached to particular experiences. Newer theoretical approaches to geography and health enable us to consider variant factors and experiences in our research (Gesler & Kearns, 2001).

Where we live is so critical that it is considered a determinant of health (Stafford & McCarthy, 2006). 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.

The idea for this particular issue of *CJNR* was germinated when the Editor-in-Chief, Laurie Gottlieb, visited us at Memorial University of Newfoundland. At that time we talked about some of the research we were doing and how we were relating our findings to particular geo-

graphical parts of the province of Newfoundland and Labrador. As researchers, we have come to appreciate the impact of geography on health as we pursue our research into the patterns of social inequalities of health associated with environmental and natural resource changes in the province's rural communities (Ommer & Coasts Under Stress Research Project Team, 2007; Parrish, Turner, & Solberg, 2007), as well as the disparate health/illness states and health-care needs of individuals living in families with genetic-based diseases. In the first instance, research findings point to the importance of considering geographical location when developing health and social policy to enhance the health of the population, the community, and the environment (Ommer, 2006). In the second instance, the challenges related to geography are a critical factor. Continuity of care is a key concern following predictive genetic testing for disease risk, as individuals and families struggle to adhere to and gain timely access to screening protocols and prophylactic interventions and as they adjust to the psychosocial and emotional burden of an uncertain health state. Regardless of the critical event (impact of genetic-based diseases or resource change), there is a pressing need for us to better understand the context of people's lives, how they experience health or illness within that context, and the personal resources — namely resiliency and reflective capability — that help them to face multiple stressors of varying magnitude.

Our research is not unique in demonstrating the importance of geography to health. There is a growing discourse on health and geography, and nursing geography in particular (Andrews, 2003; Andrews & Moon, 2005; Carolan, Andrews, & Hodnett, 2006). Consideration of geography in nursing research could contribute greatly to the evidence needed for decision-making in nursing practice and health policy — evidence that is grounded in “place.” Place may become more important as nurse researchers increase their work in emerging priority research areas such as health and climate change, where geographical location provides an important context (Clarke, 2005). As Walker (2005) suggests, with climate change there will be “increased exposures, existing sensitivities, and low adaptive capacities” (p. 22), according to where the population is located in terms of physical and social environment.

In addition to the conceptual tools defining place and space that it brings to our research, geography has a number of research tools to offer. The Geographical Positioning System (GPS) and Geographical Information Systems (GIS) are just two of these (Nuckois, Ward, & Jarup, 2004). Mapping is another tool that has not been used extensively in nursing research. We are not suggesting that nurse researchers need to enrol in GIS courses or to include these methods in their research proposals. However, we do recommend GIS use for certain types of

research, in order to enhance our understanding of health risks and disease entities and to enhance the targeting of health resources and services. An example of nursing research using GIS/GPS is a study by Donna Murnaghan and her colleagues at the University of Prince Edward Island (Murnaghan, Perry, LaRosa, & McGrath-Gaudet, 2007). The technology has enabled these researchers to locate cigarette acquisition and smoking behaviours among urban youths. As a consequence, they are able to map out these activities and create a visual image of where youths buy and smoke cigarettes, and therefore to develop more effective school health programs and policies around smoking prevention and cessation.

When we embarked on the journey of co-editing this issue on Geography and Health, we were in close geographical proximity at Memorial University of Newfoundland. Soon, however, we had the added challenge of working with others across the country. We were able to transcend different time zones and timetables with the aid of technology, and to overcome some of the challenges inherent in collaborating at a distance. We did, of course, have the support of Laurie Gottlieb, as well as Joanna Toti, Managing Editor, and other *CJNR* staff members, who answered our many questions, notified us of the latest correspondence regarding submissions, and kept the system up to date regarding submissions and reviews. They certainly made our work much easier and more enjoyable, helping us to surmount our geographical challenges, and they deserve our appreciation and gratitude. We also gained a greater appreciation for the work, care, and attention that goes into publishing each issue of the Journal.

Throughout the process it has been a rewarding experience to locate reviewers, discuss comments, and select manuscripts for publication. We received a good response to our call for papers and were pleased to find that nurse researchers are seriously considering the role of both place and space in nursing theorizing and research. Nurse scholars are not only considering this role but investigating it as well. The willingness of the nursing academic community in Canada to review submissions for the Journal has been a wonderful reaffirmation of not only the esteem in which these people hold *CJNR* but also the principle of peer review. The very rare refusal tended to be tempered with “but I can suggest another colleague for that review.”

Selecting contributions for this Geography and Health issue was not easy, as we attempted to identify those submissions that best exemplified research in the genre. The article by Amy Bender, Laurie Clune, and Sepali Guruge on nursing geography and community health nursing provides an excellent review of the literature on geography and health in general and nursing in particular. The authors give convincing reasons

why place, as both geographical location and lived experience, ought to matter to community health nurses. They note that the multi-layered and complex patterns of nurse-client relating are shaped by a careful balancing of openness and distancing as nurses care for clients in their homes and communities.

The article by Valorie Crooks, Allison Williams, Kelli Stajduhar, Diane Allan, and Robin Cohen extends our understanding of geography and health to how policy changes can have quite divergent impacts on intended and unintended target groups. These authors explore caregivers' ability to access and use relevant information in order to formulate meaningful knowledge about how to obtain the Compassionate Care Benefit, which can ease the financial burden of providing palliative care to a family member. The concept of "geographies of informational transfer and knowledge acquisition" is highlighted as integral to evaluating the response of health and social policies and programs to the needs of individuals and their families. Because information gaps and inaccuracies pose strong barriers to knowledge acquisition, the authors recommend the use of a central person (e.g., nurse) or repository.

Josephine Etowa, Juliana Wiens, Wanda Thomas Bernard, and Barbara Clow, in their article on participatory action research with Black women in Nova Scotia, bring us back to the importance of both lived experience and geographical location in health research. By examining factors affecting the health status of women and their families in a particular location, they illustrate the central role of place in women's lives. The women's lived experience of race and racism, coupled with poverty and unemployment, demonstrates some of the inequalities confronted. The limited access to health services that is a feature of many rural and remote areas, extenuated with a conspicuous absence of culturally sensitive care, further compromises the health of these women.

The research by Marilyn Hodgins and Judith Wuest primarily examines the role of geographical location in health-seeking behaviours. The authors address a critical question concerning how place influences the use of emergency departments for less urgent health problems. Their findings highlight the difficulty of not only identifying relevant factors but also determining their singular and interactive impact on emergency department use in diverse and similar urban and rural areas. The authors' work serves to illustrate the complexity entailed in considering the interplay between environmental and population factors.

William Rutakumwa and Naomi Krogman's exploration of the health problems, coping strategies, and health-care needs of women living in rural Uganda also points out the importance of geographical location for health status. This study illustrates how anthropogenic activity — that is, conflict and war and spread of HIV/AIDS — can interact with the

physical environment to cause further deterioration in health services and increase health problems. The authors show how a complex array of environmental, health-care, and health factors interact to shape women's lived experience of health.

The last article, by Denise Tarlier, Annette Browne, and Joy Johnson, demonstrates how nursing practice, continuity of care, and health outcomes are significantly influenced by the interaction of divergent place and spatial orientations in a remote First Nations community in Canada. The emphasis on the biomedical, to the exclusion of other, equally important, aspects of primary health care, illustrates the importance of space issues, even within a defined physical place, in shaping not only the nature and quality of nursing practice but also overall continuity of care.

All of the articles in this issue of *CJNR* provide a unique perspective on the intersection of geography and health. Nurse researchers are at a critical juncture. We are increasingly being asked to engage in knowledge-translation activities that will provide evidence for informed decision-making in nursing and other health professions. What we do at this juncture has implications for not only what we study but also how we conceptualize and implement our research.

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Résumé

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## **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



# 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.

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 sub-discipline 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.). 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). 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 stig-

matized 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). 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), 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). 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; 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). 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. 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 bound-



aries 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), nurses’ perceptions of their work (Reutter & Ford, 1996), and client competence and empowerment (Courtney, Ballard, Fauver, Gariota, & Holland, 1996; Reutter & Ford). 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 rela-

tionships 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.

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## **Géographies du transfert de l'information et de l'acquisition des connaissances chez les personnes soignantes : une analyse du programme de prestations de soignant en vigueur au Canada**

**Valorie A. Crooks, Allison Williams, Kelli I. Stajduhar,  
Diane E. Allan et S. Robin Cohen**

Les auteures explorent ici une branche encore peu développée de la géographie de la santé en proposant une étude sur le transfert d'information et l'acquisition de connaissances qui s'opèrent dans le cadre d'un programme social lié à la santé. Plus précisément, elles ont analysé les conclusions d'une évaluation à petite échelle du programme des prestations de soignant en vigueur au Canada. Ce programme permet aux travailleurs admissibles à l'assurance-emploi de prendre congé dans le but s'occuper d'un proche à la fin de sa vie. Sur la base de 25 entrevues auprès de personnes soignantes, les auteures dressent des géographies du transfert de l'information et de l'acquisition des connaissances. Elles présentent d'abord le groupe de répondantes et brossent un portrait de leurs vies sociospatiales comme personnes soignantes. Elles examinent ensuite trois des thèmes qu'elles ont relevés : la connaissance du CCB; l'accès à l'information; les démarches relatives à la demande. Les auteures analysent les implications de leur recherche en ce qui a trait au fardeau des personnes soignantes, à leurs besoins en matière d'information et à la prestation des soins au Canada. Elles proposent également des avenues de recherche concernant le programme de prestations de soignant.

Mots clés : programme de prestations de soignant du Canada, transfert d'information, acquisition des connaissances, géographie de la santé, personnes soignantes



# **The Information Transfer and Knowledge Acquisition Geographies of Family Caregivers: An Analysis of Canada’s Compassionate Care Benefit**

**Valorie A. Crooks, Allison Williams, Kelli I. Stajduhar,  
Diane E. Allan, and S. Robin Cohen**

The authors explore an underdeveloped area of health geography by examining information transfer and knowledge acquisition for a health-related social program. Specifically, they discuss the findings of a small-scale utilization-focused evaluation of Canada’s Compassionate Care Benefit (CCB). The CCB allows workers who are eligible for employment insurance to leave work to care for family members at end-of-life. Using the findings of 25 interviews with family caregivers, the authors explore their geographies of information transfer and knowledge acquisition. First, however, they introduce their respondent group and provide an overview of their socio-spatial lives as family caregivers. They then examine 3 specific thematic findings: awareness of the CCB, access to information related to the CCB, and the application process. The authors discuss the implications of the findings for the information needs and burdens of family caregivers and for Canadian nursing practice. They also consider directions for future CCB research.

**Keywords:** Caregiver geographies, utilization-focused evaluation, Canada’s Compassionate Care Benefit, information transfer, knowledge acquisition, health geography, palliative, family caregiving

## **Introduction**

Health geography is a dynamic sub-discipline of human geography. Although originally founded on inquiry related to disease mapping and spatial epidemiology (Curtis, 2004), over the past decade research undertaken by health geographers has become increasingly diverse due to the infusion of new methodologies and theoretical approaches; such changes are inspired by what is referred to as the “cultural turn” (see Gesler & Kearns, 2002). For example, research related to caregiving, in both the voluntary and informal sectors, is gaining attention in the sub-discipline (e.g., Milligan & Conradson, 2006; Williams, 2002). State restructuring, social policy creation in the neoliberal state, and changing philosophies

of care are resulting in the delivery of increased amounts of care in the community (e.g., in the home, in community-based care facilities) and a simultaneous shift of the burden of care onto paid and unpaid caregivers in community settings (Milligan & Conradson; Skinner & Rosenberg, 2005; Williams, 2006). Health geographers are interested in understanding the social and spatial outcomes of such shifts and the impacts on certain groups, including unpaid family caregivers.

Information transfer and knowledge acquisition have received little attention by health geographers relative to other, more established, areas of inquiry. These processes are, however, inherently spatial, as they create relational connections between disparate places (Crooks, 2006), involve the development of information networks (Cravey, Washburn, Gesler, Arcury, & Skelly, 2001), and have outcomes that can literally and figuratively place people in more or less privileged positions (Gesler, 1999). Certainly, informal caregivers at the palliative/end-of-life (P/EoL) stage need to gain access to information in order to provide the best possible care. Ashpole's (2004) review of the information needs of Canadian family caregivers reveals that such individuals constantly need to refine their knowledge about topics such as disease progression and treatment, administration of medications, availability of home care and other social services, and coping strategies. Also, Ashpole contends that there is a distinct temporality to the information needs of family caregivers, in that these needs will be different at the various stages between the diagnosis and the death of the care recipient.

In this article we focus on the information needs of family caregivers at the P/EoL stage. However, we draw our attention away from the more standard types of information needs that Ashpole reviews and focus instead on those related to applying for and receiving assistance from a federal social caregiving program: the Compassionate Care Benefit (CCB). The goal of Canada's CCB legislation is to enable people who are employed and eligible for employment insurance (EI) to take a temporary leave in order to care for a terminally ill family member. Family caregivers who take a leave from a paid job in order to provide P/EoL care and take advantage of the CCB must not only gain information related to the care recipient's illness in a specific time frame, but also develop a familiarity with the program. This has the potential to add an informational burden onto this specific group of family caregivers.

We draw on 25 interviews conducted with family caregivers from eight Canadian provinces in a pilot evaluation of the CCB, in order to explore their experiences of negotiating the application process, accessing information, and developing a knowledge base about the program. Our purpose in undertaking this research was to examine the usefulness of the CCB for family caregivers in different types of P/EoL caregiving situa-

tions and to inform the development of a full-scale evaluation of the program.

### **CCB Overview and Context**

While it is common for family members to neglect their physical and mental health in order to provide P/EoL care (Kissane, Bloch, Burns, McKenzie, & Posterino, 1994; Stajduhar & Davies, 2005), financial and workplace obligations are more difficult to disregard. For example, in addition to having to meet existing personal financial responsibilities during the caregiving period, often by continuing to work, family members providing P/EoL care contribute, on average, \$6,000 in unpaid caregiving during the final 4 weeks of life (Greaves et al., 2002). Grunfeld et al. (2004) report that not only do family members caring for terminally ill patients experience depression and anxiety, but their caregiving has adverse impacts on work, such as missed shifts, and typically brings a financial burden, such as the cost of prescription drugs, due in part to lost income. Thus, access to financial support is a particular need of families providing P/EoL care (Scott, Whyler, & Grant, 2004). Further, in the absence of job-protection legislation, Canadian family caregivers have traditionally been dependent on the good will of their employers, even if they wish to take unpaid leave, forcing many to continue working at a time when they need to be at the bedside of their loved one. The burden of having to remain in the workforce while providing P/EoL care is significant, and it typically negatively affects the physical, emotional, and mental health of family caregivers (Grunfeld et al.). In order to alleviate such burdens on family caregivers and to support the delivery of P/EoL care outside of institutionalized settings, the Canadian government established the CCB (Williams, Crooks, Stajduhar, Allan, & Cohen, 2006).

As noted above, the goal of Canada's CCB legislation is to enable employed and EI-eligible individuals to take a temporary leave in order to care for a terminally ill family member. The benefit came into effect in January 2004 through changes to the EI Act and the Canadian Labour Code and is administered as an EI special benefit. Its establishment was based on recommendations in the Kirby (2002) and Romanow (2002) reports, the 2002 Speech from the Throne, and years of lobbying by members of the palliative care and caregiving communities.

Successful CCB applicants can receive up to 55% of their average insured earnings, to a maximum of \$413/week, over a 6-week period to care for a family member at risk of death within 6 months. The 6 weeks of income assistance can be taken at once, broken down into 1-week periods spread over 6 months, and/or be shared among family members. Successful applicants are required to undergo a 2-week unpaid waiting

period before receiving payments and to determine when payments will start (within 28 days of making the claim). In order to qualify, applicants must have worked a minimum of 600 EI-insurable hours over the preceding 52 weeks. They must also meet the designation of “family member” and provide a medical certificate from the doctor of the gravely ill family member indicating that death is imminent (i.e., within 6 months). Eligible family members are (in relation to the care recipient): child; child of spouse or common-law partner; wife/husband/common-law partner; father/mother; or father’s wife/mother’s husband or common-law partner (Osborne & Margo, 2005).<sup>1</sup>

Critics of the CCB program have focused on issues such as the 2-week waiting period (Picard, 2005), the narrow definition of “family member” (Osborne & Margo, 2005), and the labour-market participation requirements, which cannot be met by those who have been providing long-term P/EoL care (Canadian Caregiver Coalition, 2004). Further, the Canadian Women’s Health Network has pointed out the gender-based disadvantage inherent in the program, in that women are more likely to be stay-at-home parents and part-time workers who do not meet the CCB’s eligibility criteria (Armstrong & O’Grady, 2004). While significant attention has been paid to barriers to accessing the program, there has been less consideration of the actual experiences of applicants. The present study therefore makes a unique contribution, particularly with regard to its focus on information transfer and knowledge acquisition.

The CCB program and the legislative changes that shape its administration have come about in an era of neoliberally informed social policy. An ideology underpinning the creation of social policies in such a political/economic climate is that families and voluntary agencies, rather than local states, should bear the responsibility for assisting persons in need (see Chouinard & Crooks, 2005, for an explicit discussion of this in relation to another Canadian social program). Another element of policy-making in response to the current neoliberal climate has been a focus on providing care in the community as opposed to in institutional settings (James, 1999), an outcome of which has been increased reliance on the voluntary sector and unpaid labour to meet care needs (Skinner & Rosenberg, 2005). It is these types of changes to the role of the state in Canadian society that have informed the development and implementation of the CCB — a program that facilitates the provision of care by

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<sup>1</sup> The eligibility criteria and figures discussed here are those that were in effect at the time of the study. Since then, there have been two significant changes to the CCB. The maximum payment allowed per week is now slightly higher, and the definition of family member has been revised to include siblings, cousins, aunts/uncles, grandparents, and others.

family members in community settings. Complex application processes and increasingly strict eligibility requirements for social programs are also hallmarks of social policy in a neoliberal climate (Chouinard & Crooks; Roulstone, 2000). The present study provides a unique glimpse into how such characteristics of Canadian state restructuring and policy-making inform the administration of the CCB.

## **Methods**

The purposes of this pilot study were to examine the usefulness of the CCB for family members in different types of P/EoL caregiving situations and to inform the development of a full-scale evaluation of the CCB. Thus, the study was exploratory in nature and was driven by these purposes and not a solitary research question.

### ***Evaluative Approach***

Patton's (1997) method of utilization-focused evaluation was used. The objective of utilization-focused evaluation is to inform program and policy improvement using research findings. As Patton notes, "*Utilization-Focused Evaluation* begins with the premise that evaluations should be judged by their utility and actual use... Use concerns how real people in the real world apply evaluation findings and experience the evaluation process. Therefore, the *focus* in utilization-focused evaluation is on *intended use by intended users*" (p. 20; emphasis in original). Thus, this evaluative approach necessitates a focus on intended use (i.e., the usefulness of the CCB for family members in different types of P/EoL caregiving situations) and gathering the input of intended users (i.e., Canadian family P/EoL caregivers).

The method is shaped by 12 broad tasks: (1) determine readiness for assessment, (2) assess the readiness of the evaluators, (3) recruit an evaluation taskforce (ETF), (4) consider the evaluation context, (5) identify the intended users, (6) determine the evaluation focus, (7) design evaluation techniques, (8) test data-collection techniques, (9) collect data, (10) analyze data, (11) facilitate the use of the findings, and (12) assess the evaluation process. The pilot study was designed to fully complete tasks 1 through 8 while also collecting some data for task 9.

### ***Recruitment***

The sample comprised three categories of respondents from across Canada: (1) successful CCB applicants, (2) unsuccessful CCB applicants, and (3) those who had never applied for the CCB. The non-applicant group was made up of people who did not meet the prerequisites for the CCB, such as being outside the criteria of "family member" or the

minimum qualifications with respect to insurable employment (e.g., retired, self-employed, unemployed). These three groups were deliberately sampled as they were all *intended* users of the CCB, in that they had provided P/EoL care for a family member, and thus it was believed they would have useful input to offer in the pilot evaluation. Participants were recruited primarily through newspaper advertisements, newsletters of caregiver organizations, offices of Members of Parliament, and e-mail advertisements. Those interested in participating were invited to call a toll-free number where a bilingual telephone message requested that they leave contact information. They were then called to confirm eligibility and book an interview time. Eligibility criteria were minimal: participants had to be at least 18 years of age and had to have provided/be providing P/EoL care for a family member.

A total of 43 potential respondents phoned the toll-free number, of whom 25 eventually participated. Of the 18 individuals who did not eventually participate, the majority did not meet the inclusion criteria because they were long-term caregivers and were not/had not provided P/EoL care, while a few others had called to simply learn more about the CCB. Two people who had booked interviews did not follow through but did not give an explanation for this decision.

### ***Data Collection***

Prior to data collection, approval was obtained from the McMaster University Research Ethics Board. Participants were interviewed by phone as this method is cost effective and is known to yield reliable data (Sturges & Hanrahan, 2004). Prior to the interview, respondents were mailed a package containing information on their rights as participants and a letter confirming the interview time and date. Once informed consent was obtained verbally, at the start of the interview, participants were asked a series of open-ended questions using a semi-structured format, followed by a limited number of demographic questions.

A semi-structured interview format was selected for data collection as it allows for a set of common questions for all participants while offering the flexibility for the probing of new topics raised during the interview (but not included in the interview guide) (Holstein & Gubrium, 1995). The questions concerned how respondents learned about the CCB, their experiences of its administration (e.g., application process), employee/employer interactions with regard to the negotiation of leave, and their experiences as P/EoL caregivers. The interviews lasted approximately 30 minutes (ranging from 20 to 50 minutes) and were audiotaped and transcribed verbatim. Data were collected over a 3-month period spanning the summer of 2005.

### ***Analytic Approach***

Data were thematically analyzed by respondent group; coding was facilitated through the use of NVivo<sup>®</sup> qualitative data-management software. Coding schemes were created for each of the three respondent groups and the constant comparative technique (Boeije, 2002) was employed in order to identify commonalities and differences within and between the groups. The coding scheme was reviewed and refined by two investigators prior to the first stage of coding, and all members of the research team read and commented on summaries of the analysis in order to strengthen the interpretation. Including such steps in the analytic process and the use of investigator triangulation in this manner served to enhance the credibility and integrity of the findings. Regular consultations with the ETF (in the form of teleconferences) and among the research team throughout the pilot study lent authenticity to the interpretation. Specifically, divergent and common issues emerging from the data set and during data collection were discussed openly and feedback was sought from individuals with different stakes in the study; these ranged from ETF policy-makers to the research assistant who had conducted the interviews. Therefore, the process was openly reflexive and thus inclusive of criticality<sup>2</sup> in data interpretation and analysis.

During the first stage of coding, the data set was organized according to the scheme that had been created. Themes emerging from the data set were discussed among the team members and with the ETF. Feedback on the themes and the comparative review of findings emerging from the different respondent groups informed the second stage of coding, which consisted mostly of eliminating redundant codes. A number of thematic codes were common to all three respondent groups: family caregiving background; caregiving logistics; employment experience before, during, and after the caregiving experience; CCB knowledge; and suggestions for improvement. For the successful and unsuccessful applicant groups, extensive codes about the process of applying for, receiving, appealing, and/or being denied the benefit were generated. Explanatory links were sought between the codes within and across respondent groups (which is part of the constant comparative process); this resulted in the emergence of the themes presented in this article as important and centrally linked to processes of information transfer and knowledge acquisition.

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<sup>2</sup>Our references to credibility, authenticity, criticality, and integrity in the analytic process are based on the assessment questions developed by Whittemore, Chase, and Mandel (2001, p. 534).

## **Respondent Overview**

The sample consisted of 25 caregivers who collectively cared for 27 P/EoL family members. Respondents resided across Canada, with the largest number residing in Ontario ( $n = 8$ ). With respect to gender, 20 were female and five male. The familial relationship of the respondent to the gravely ill person varied: seven caregivers were siblings, 16 were children, one was a grandchild, and one was a partner/spouse. The mean age was 46 for respondents (median: 51) and 71 for care recipients (median: 79). The mean length of the overall caregiving period was just under 6 years (median: 4 years). Care recipients were diagnosed with cancer ( $n = 12$ ), Alzheimer's disease ( $n = 8$ ), Parkinson's disease ( $n = 2$ ), stroke ( $n = 2$ ), and some other non-malignant advanced chronic illness ( $n = 3$ ).

Of the 25 participants, 16 were non-applicants for the CCB, four were successful applicants, and five were unsuccessful applicants. All successful applicants had provided care for less than 9 months and used the benefit primarily for arranging and providing hands-on and emotional care specifically at the terminal phase. Conversely, four of the five unsuccessful applicants had provided care for more than 1 year. The non-applicants had provided care for the longest period (an average of just under 8 years), most often prior to the palliative stage.

Many of the respondents provided irregular care (i.e., primarily during acute phases or periodically over an extended period) or temporally limited intensive care (i.e., daily care at the end-stage). Therefore, unique caregiving geographies were reported. For example, nine participants relocated out of town, province, or country in order to provide irregular or temporally limited care; 11 respondents changed residences (typically retaining their own homes), moving in with the care recipient in order to provide more intensive, hands-on care, typically for a temporally limited period; and in five instances the care recipient moved permanently in order to be closer to the caregiver.

## **Findings**

The analytic process revealed three somewhat interrelated themes regarding information transfer, knowledge acquisition, and the CCB. The first relates to how all respondents had initially learned of the CCB's existence. The other two relate specifically to experiences shared by the nine participants who had applied for the benefit. The three themes are discussed separately below.

### ***Awareness of the CCB***

Respondents were generally aware of the existence of the CCB prior to taking part in the study but struggled to learn the details, specifically in



relation to the application process. Those who had the least knowledge about the benefit were the non-applicant group; indeed, these individuals were likely to ask questions about the logistics of the benefit during the interview and to reveal an incomplete understanding of the CCB program in general.

Of the 25 respondents, 20 were aware of the benefit prior to participating in the study. These caregivers had first heard of the CCB from a variety of sources: community/support groups ( $n = 2$ ), newspapers ( $n = 7$ ), radio ( $n = 2$ ), television newscasts ( $n = 3$ ), their employment (in that their jobs required familiarity with the benefit) ( $n = 4$ ), and health professionals ( $n = 2$ ).

Several respondents commented that there was too little advertising of the CCB, leading some to speculate that this could lead to misinformation. For example, a successful applicant stated:

*I think there needs to be more [advertising]. I think it was very gung-ho there [when the CCB was first announced] and I haven't seen any of it since. And, actually, I had heard that they had cancelled [it]... Somebody just mentioned it. Maybe it was just hearsay.*

This respondent went on to suggest that better marketing or advertising of the CCB could serve to reach more potential applicants or those who may need to provide care in the future.

### ***Access to Information about the CCB***

Participants' comments indicated that being aware of the benefit's existence and having a working knowledge of its administration are two separate issues. Respondents who had applied for the benefit ( $n = 9$ ), whether successful or not, repeatedly cited difficulty accessing reliable and accurate information from a variety of sources, including the Internet and government offices. For example, one CCB recipient who had applied in order to provide care for a parent recounted her difficulty getting accurate information about the application process:

*I understood that I had to leave my job, and after leaving my job serve a 2-week waiting period and then apply for it, so that's what I did... [That I could apply before going on leave] was unclear. And it's kind of crazy, because I work in the system so it should have been clear to me but it wasn't somehow.*

When another successful applicant who had provided care to a parent was asked about her experience of receiving CCB income support, she stated:

*[The EI employees] said [that] once you wait the 2-week period and then you're plugged into the system then you...can get paid [in] up to 28 days. Like, you get your first payment within 28 days... But nobody really tells you when that is.*

Other successful applicants had also experienced difficulty finding out when their payments would start or stop, stating that the information about the benefit was lacking such details or was inaccessible in easily understandable formats.

Respondents found that even EI staff members were not always able to provide them with the information they needed. One successful applicant stated:

*They weren't really that clear about things themselves. That certainly made it that much more difficult for us.*

An unsuccessful applicant noted that government employees “weren’t organized” when describing the application process and discussing his eligibility for the benefit.

### ***The Application Process***

A total of nine respondents had completed the CCB application process. Their comments reveal it to be a difficult process to negotiate, for several reasons. Many applicants found communicating with EI staff to be a challenge. A successful applicant said:

*I got three letters in the span of 4 days telling me three different things, so that part was really confusing.*

Although not all CCB applicants had experienced this specific situation, they all related similar experiences of confusion and/or misinformation.

A successful applicant described the application process as “quite complicated” and said that it was important to be able to get assistance from government staff. The need for assistance during the application process was echoed by others:

*[The online application form] took an hour at the EI office... It's a good thing there was this lady standing behind me...helping me to do almost every step of it, because it was...not user-friendly.*

*I was very fortunate. I went into the [EI] office and they said, “Well, you can do it online on the computer.” And I said, “No, I'd rather speak with an individual.” And I think that's where to go, because you're already emotionally stressed. I'm not that great with computers, so they were very helpful.*

These comments point to the fact that many respondents needed help completing the application forms. The online forms were described as difficult to navigate and several applicants cited a preference for one-on-one assistance. One unsuccessful applicant, despite receiving assistance from EI staff, reported experiencing a “scramble with the paperwork.”

Another difficulty associated with the application process was the time required to gather the supporting documentation (e.g., medical certificate). Respondents reported having to take time off work, during an already busy period in their lives, to deal with the necessary paperwork. One unsuccessful applicant described the process as “time-consuming.” A final difficult aspect of the application process touched on by several participants was the fact that the process itself is undertaken during a period when one’s time, energy, and other resources are particularly taxed:

*I was really coping with a lot of stuff at the time and, really, to be very honest, whether I got [the CCB] or not was not my priority right at that moment. But I kind of filed it [the idea of applying] away and later looked into it... So I didn't [think about the CCB] for a little while. But then, amazingly, within a couple of weeks my sister...started improving a bit...she didn't die! So, you know, as the weeks went by I thought, "I better look into this a bit further," so that's when I did.*

This respondent’s comment is reflective of the fact that participants had to organize their time carefully during the caregiving period, as taking time to access information and apply for the CCB reduced the number of hours they could devote to the care recipient.

## **Discussion and Recommendations**

Ashpole (2004) contends that “informal caregivers are faced with taking on a new job with no previous experience, no job description to guide them or employee incentive program to encourage them, and where their own health and well-being may be at risk” (p. 32). Family caregivers need access to information so they can develop a body of knowledge regarding care provision. The data collected in the present study suggest that this group has two sets of simultaneously pressing information needs: those pertaining to the dynamics of caregiving, and those pertaining to applying for and receiving the CCB. With regard to the second set of needs, there were three temporally distinct periods during which the respondents’ information transfer and knowledge acquisition geographies were most active: when they first learned about the CCB, when they applied for it, and when they received it.

Our brief discussion of the complex nature of the caregivers' geographies reveals that several of the respondents underwent significant transitions in their daily lifeworlds in order to provide care for a relative at end-of-life. The demands of providing care, relocating and/or travelling, acquiring knowledge about managing the recipient's illness, and fulfilling other familial roles (e.g., parent, spouse) were taxing on respondents' time; having to seek out CCB information only added to the heavy burden for this specific group of family caregivers. Several applicants identified such information-seeking as problematic. They had found inaccurate or incomplete CCB information on Web sites and when visiting EI offices and speaking with administrative personnel. Having to verify information in order to enhance their knowledge about the benefit was yet another time-consuming task.

The experiential evidence described above reveals the complicated nature of applying for the CCB, including a challenging computer application process. Complex rules and regulations added to the importance of developing a personal knowledge base about the program. Respondents spoke of using numerous strategies to gain access to information about the CCB. These included searching the Internet and speaking with EI staff. Such information was then relationally connected to numerous other spaces in the caregivers' lives (including the workplace) as they applied for the benefit, the doctor's office as they sought to secure the medical certificate, the home or EI office as they completed the application process, and ultimately (for successful applicants) the caregiving space, since it was by receiving the CCB that they could have greater presence within the caregiving space. As Crooks (2006) suggests, "relational connections are drawn between these disparate spaces, which are linked by the information carried between one another" (p. 63). Thus, the respondents' geographies of information transfer and knowledge acquisition involved their developing connections between information-rich sites (e.g., EI offices) and information-use sites (e.g., doctors' offices), all of which were linked by the knowledge about the CCB they had gained over time.

Sites that were initially identified by respondents as information-rich, namely EI offices and the Internet, were later found by several respondents to be sites of misinformation or non-information. This general lack of familiarity with the application process on the part of EI staff may have been due to the newness of the program. Interruptions to respondents' spatio-temporal routines and caregiving tasks for the purpose of information-seeking were often of no avail. The risks of misinformation were high for the applicants and the care recipients. More specifically, lack of knowledge about specific details of the CCB program (e.g., when the first payment would be issued, whether one must apply for the

benefit before taking leave) can cause frustration, uncertainty, and even financial hardship.

This pilot evaluation has revealed much about both the nature of P/EoL family caregiving and the respondents' geographies of information transfer and knowledge acquisition. Our ultimate purpose in evaluating the CCB from the perspective of family caregivers was to offer recommendations for improving the administration of the program. We therefore propose that:

- advertising about the CCB be intensified in order to ensure that all those who are eligible to receive it are aware of its availability
- Web sites be kept up-to-date and old sites be made inactive
- each EI office have available at least a few staff members who are fully acquainted with and knowledgeable about the CCB
- all information about the CCB be made as clear and accessible as possible
- the computer application process be streamlined

Following through on these and other recommendations with respect to the CCB program (see Williams et al., 2006) also requires that policy-makers have a greater recognition of the burdens placed on P/EoL family caregivers during this "emotionally stressed" period.

### **Implications for Nursing Practice**

Restructuring of the Canadian health-care system has resulted in more health care being provided in the home (McKeever, 2001). One of the key components of effective home-based P/EoL care is the availability of a family caregiver (Stajduhar & Davies, 1998; Wilson, 2000). Family caregivers assume the majority of responsibility for the coordination and/or delivery of care for those dying at home (Luker, Austin, Caress, & Hallett, 2000; McCorkle, Robinson, Nuamah, Lev, & Benoliel, 1998). This puts their own health at risk. Therefore they are viewed by palliative care practitioners as patients in need of care and support in their own right (Ferris et al., 2002).

Health-care providers, including nurses, are acutely aware of the financial and health repercussions of acting as a caregiver while continuing to hold down a job (Stajduhar, 2003). Although combining paid work and caregiving has been shown to have mental health benefits (Martire, Stephens, & Atienza, 1997; Scharlach, 1994), the dual role is also associated with increased caregiver strain (Mutschler, 1993) as well as emotional and physical stress, including depression and fatigue (Lee, Walker, & Shoup, 2001; Scharlach). The CCB is a social program with the potential to ameliorate the burdens associated with the dual role, by

giving employed family caregivers the option of taking time off work in order to provide P/EoL care.

Information about the CCB would likely be welcomed by many family caregivers who might be eligible for the program. Nurses, especially those working in home care and outpatient clinics, are in a key position to inform family caregivers about the CCB, given their extensive involvement with P/EoL patients and family caregivers. These nurses could be an important conduit for such information exchange and for ensuring that family caregivers are given accurate information. Nurses are already responsible for providing information to palliative patients and family caregivers about pain and symptom management and available community supports. Information about the CCB in the form of fact sheets or pamphlets could become part of the standard package of information they offer to patients and families facing life-threatening illness. In addition, organizations such as the Canadian Nurses Association or specialty groups such as the nurses interest group of the Canadian Hospice Palliative Care Association could provide guidance on how to incorporate social policies, including the CCB, into nursing practice; this would serve to enhance the uptake of policy into the practice arena, with the aim of preventing financial hardship and negative health outcomes for families affected by terminal illness.

### **Limitations**

This study had a number of limitations, partly due to the pilot nature of the research. In addition to having an over-representation of family caregivers residing in the province of Ontario, the sample was small in size due to the untested nature of the sampling strategies. The sample comprised 25 family caregivers, of whom only nine were CCB applicants — four successful and five unsuccessful. Given the large proportion of non-applicants, the results may not be sufficiently representative of the experiences of successful and unsuccessful applicants. Also, the sample included only one partner/spouse caregiver; this group warrants further investigation, particularly since many partner/spouse caregivers are retired and thus would not meet the CCB's eligibility requirements.

### **Continuing Research**

This pilot study served as the foundation for a successful grant application (to the Canadian Institutes of Health Research) to conduct a full national evaluation of the CCB from the perspective of family caregivers. In addition to accessing a larger sample of each of the three family caregiver groups (successful and unsuccessful applicants and non-applicants), we plan to collect data from a number of key informant groups,

including employers, human resources personnel, and front-line palliative care practitioners. This work is underway and will be completed by 2009.

## Conclusion

Analysis of the P/EoL family caregiver data set reveals three informational themes: awareness of the CCB, access to information, and the application process. Despite their calls for more advertising in order to increase awareness of the CCB and ensure its continuance, a large majority of the respondents were aware of the program before taking part in the study. According to those respondents who had applied for the benefit, access to reliable, accurate, up-to-date information and to knowledgeable personnel was a key component of familiarity with the CCB program. The respondents reported a number of challenges specific to the CCB application process. These included (1) a lack of knowledge about specific details of the benefit, (2) the complicated nature of the application form, (3) the time required to gather supporting documentation, and (4) the need to undergo this process during a particularly difficult and emotionally draining period in their lives. Nurses are well situated to alleviate some of the informational burdens associated with the CCB program.

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Résumé

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## Déterminants de la santé des femmes noires dans les communautés rurales et éloignées

Josephine Etowa, Juliana Wiens,  
Wanda Thomas Bernard et Barbara Clow

Les instigatrices du projet *On the Margins* se sont attachées à étudier l'état de santé, la prestation des soins et la fréquentation des services de santé au sein de la population des femmes afro-canadiennes vivant dans les régions rurales et éloignées de la Nouvelle-Écosse. On a fait appel à un modèle de recherche-action participative et procédé à la triangulation des méthodes de collecte de données — entrevues, groupes de discussion et questionnaires. Le codage et l'analyse des données ont été effectués au moyen du logiciel de gestion *Atlas ti*. Six thèmes s'en dégagent : les rôles multiples des femmes noires; les perceptions en matière de santé; les expériences relatives au système de santé; les facteurs qui influent sur la santé; les stratégies de gestion de la santé; et les solutions envisagées. Les auteures se concentrent sur l'un de ces thèmes, soit les facteurs qui influent sur la santé, et proposent une analyse de trois sous-thèmes connexes : race et racisme; pauvreté et chômage; et accès aux soins de santé.

Mots clés : femmes noires, déterminants de la santé, racisme, communautés rurales

# Determinants of Black Women's Health in Rural and Remote Communities

Josephine Etowa, Juliana Wiens,  
Wanda Thomas Bernard, and Barbara Clow

The On the Margins project investigated health status, health-care delivery, and use of health services among African-Canadian women residing in rural and remote regions of the province of Nova Scotia. A participatory action research approach provided a framework for the study. Triangulation of data-collection methods — interviews, focus groups, and questionnaires — formed the basis of data generation. A total of 237 in-depth one-on-one interviews were conducted and coded verbatim. *Atlas-ti* data-management software was used to facilitate coding and analysis. Six themes emerged from the data: Black women's multiple roles, perceptions of health, experiences with the health-care system, factors affecting health, strategies for managing health, and envisioning solutions. The authors focus on 1 of these themes, factors affecting Black women's health, and discuss 3 subthemes: race and racism, poverty and unemployment, and access to health care.

Keywords: Black women, health determinants, racism, rural communities

## Background

Discrepancies in health are intimately associated with differences in social, economic, cultural, and political circumstances (Aday, 1993; Backlund, Sorlie, & Johnson, 1996; Bloom, 2001; Brown, 1995; Chen & Fou, 2002; Rogers, 1997). Economic inequities, in particular, have been implicated in poor health. Individuals of lower socio-economic status are at a much greater risk of illness and are much less likely to have timely access to health and social services than individuals of higher socio-economic status (Hay, 1994; Lynch, 1996; Lynch, Kaplan, & Shema, 1997; Pappas, Queen, Hadden, & Fisher, 1993; Poland, Coburn, Robertson, & Eakin, 1998). Yet while researchers have amply demonstrated the effects of such determinants on the health of people in Black communities, the vast majority of health research on Black women, men, and children originates in the United States, and only a small number of needs assessments and student theses focus on the health of African Canadians living in the province of Nova Scotia (Atwell & Atwell Human Resource Consultants, 2002; Enang, 1999; Enang, Edmonds, Amaratunga, & Atwell,

2001; Lawrence, 2000; Sharif, Dar, & Amaratunga, 2000; Thomas Bernard, 2001).

Current evidence suggests that the barriers to appropriate care and the health deficits faced by Black women in Canada are similar to those faced by African-American women, yet more definitive evidence on the circumstances and experiences of African Canadians is required (Enang, 2002). In addition, American and Canadian research on people of African descent tends to focus on urban conditions and experiences (Calvert, 1997; Dana, 2002; Enang, 1999; Enang et al., 2001; Geronimus, 1992; Graham, Raines, Andrews, & Mensah, 2001; Schulz et al., 2000). The challenges of accessing appropriate health services may be greater or simply different in rural and remote communities, and solutions recommended for African Americans living in the inner city may have limited value for African Canadians living along the south and west shores of Nova Scotia (Atwell & Atwell Human Resource Consultants, 2002).

Another shortcoming of health research with respect to marginalized populations is the fact that many studies are conducted *on* rather than *with* communities (Acker, Barry, & Esseveld, 1991; Maguire, 1987; Mays & Pope, 2000; Nielsen, 1990). In the absence of genuine partnerships between communities and academic researchers, the questions posed by investigators, the instruments designed to answer those questions, and the conclusions reached may not be meaningful for the people being studied (Dickson & Green, 2001; Douglas, 1998; Richard & Jagielski, 1999; Sullivan, Kone, Senturia, & Chrisman, 2001). These factors not only serve to devalue the experiences and expertise of African Canadians but can lead to misunderstanding or misidentification of the problems facing Black people and to inappropriate solutions. Local Black researchers point out that health-care providers often do not understand the needs of Black women, while academic researchers tend to impose biomedical definitions of health and care, ignoring the ways in which Black women view and manage their own health and that of their families (Crawley, 1998; Edmonds, 2001; Fraser & Reddick, 1997). African Canadians constitute one of the largest visible minorities in the country and have lived throughout Nova Scotia for centuries. Yet they remain socially, economically, and politically disadvantaged and are underrepresented in health-care delivery, in health research, and in the design and implementation of health policy. As a result, there is a critical gap in research-based knowledge with respect to the health issues of Black Nova Scotians.

### **Objectives and Procedure**

The On the Margins project was designed to investigate health status, health-care delivery, and health-services utilization among African

Canadians residing in rural and remote regions of Nova Scotia from the perspectives of both community members and academic researchers. Its specific research objectives were to raise awareness of the issues that affect the health status of African Canadians living in southwest Nova Scotia, to establish collaborative research partnerships with Black communities, and to build the community capacity needed to eliminate barriers to health and appropriate health care.

The project combined qualitative and quantitative research methods, as well as a participatory action research (PAR) approach, to explore the intersecting inequities that compromise the health and health care of African women in Nova Scotia, their families, and their communities. Because each methodology has specific strengths, produces specific kinds of information, and creates specific relationships among investigators, use of a mixed methodology not only produced much needed insight into the health of African-Canadian women and their families but also allowed for triangulation of research methodologies and research perspectives, which enhanced the rigour of the research process and the significance and validity of the findings (Kirk & Miller, 1986; Mays & Pope, 2000).

The PAR approach combined community action and capacity-building. Three Community Facilitators were hired for the duration of the study. Each possessed a high degree of motivation and had close ties with the community, and each was trained in the PAR paradigm, Black people's health issues, focus group facilitation, and interview techniques, ready to gather information about the needs and experiences of Black women, families, and communities. The Community Facilitators were also trained in information technology skills and furnished with computer equipment and Internet access so that they could gather and disseminate health information to members of the Black community.

A prototype semi-structured interview was developed by the research team, but the Community Facilitators were instrumental in refining this guide and other research instruments. The prototype interview contained a qualitative portion as well as a quantitative questionnaire to be completed by the participant at the time of the interview. Ethical approval to conduct live research was obtained from the Social Sciences and Humanities Human Research Ethics Board at Dalhousie University prior to the start of the project, with continuation of approval granted following subsequent yearly reviews.

The Community Facilitators conducted 12 focus groups with women in various Black communities for the purpose of refining the research instruments. They then carried out 237 in-depth one-on-one interviews with Black women throughout the southwestern region of the province. Snowball sampling was used to recruit participants as the

Community Facilitators built on their contacts with members of their communities. Purposive sampling was used to ensure that a multiplicity of perspectives and experiences was captured in the interviews and group consultations, while snowball sampling served to identify exceptional or atypical perspectives (Kidd & Parshall, 2000; Mays & Pope, 2000; Patton, 1999). The interviews were audiotaped; they varied in length from 35 minutes to more than 2 hours.

Data analysis involved the development of codes and the use of thematic analysis to categorize codes into themes. *Atlas-ti* data-management software was used to facilitate this process. The entire research team met regularly to analyze the data. In keeping with the principles of the PAR approach, which involves the creation of genuine partnerships with community members in order to generate research *with* rather than *about* communities, the team ensured that the Community Facilitators were actively engaged in every aspect of the research process, including data coding and analysis.

Rigour in the research process was ensured in a number of ways. Firstly, multiple sources of data (triangulation) were used, including interviews and focus groups, to obtain a comprehensive account of the women's experiences. Secondly, the participation of the Community Facilitators in the data-analysis meetings served as a means for them to review the researchers' interpretations of the stories, confirmed their analyses, and extended the data analysis. In addition, eight focus groups were held with community members who participated in the individual interviews in order to validate our interpretation of their experiences and to extend the data analysis. Guba and Lincoln (1989) describe such member "checks" as the best technique for establishing credibility. Thirdly, we admitted that, as researchers, we represented the instrument of data generation and that our research skills and experience could affect the credibility of the study (Patton, 2002). In response, we addressed credibility from this perspective through "peer debriefing." Peer debriefing was evident during the data-analysis meetings at which various researchers analyzed codes and themes and provided feedback to the research associate who led the data analysis. This process ensured consistency in the collective interpretation of the data. In addition, credibility and reliability of the study were ensured through an audit trail, which documented the details of the research process and the techniques and processes of data generation and analysis.

## Findings

The participants identified numerous issues affecting the health of their families and communities. The researchers identified several themes in

the data, including the multiple roles of Black women, perceptions of health, experiences with the health-care system, factors affecting Black women's health, strategies for managing health, and envisioning solutions. One of these themes — factors affecting Black women's health — is the main focus of this article. In exploring this theme, we are able to fulfil one of the main objectives of the study, namely to become more aware of issues that affect the health status of Black Nova Scotian women and their families. Key factors in or determinants of Black women's health that emerged during data analysis were racism, poverty, unemployment, access to health services, and caregiving roles. It is important to note that these factors are not mutually exclusive. Determinants such as access to employment and access to health services affect many rural populations, yet for these women racism was a key factor, intertwined with all of the other issues. For the purpose of this discussion, racism serves as the lens through which we examine all other determinants. None of these determinants exist separately in the lived experience, and we separate them only for the purpose of ensuring clarity for the reader. These key determinants of Black women's health are presented below under the headings of Race and Racism, Poverty and Unemployment, and Access to Health Care.

### ***Race and Racism***

In order to proceed with the main focus of this article, it is imperative that we attempt to clarify the concepts of race and racism and their link with health, given that race is the main factor distinguishing Black women from their white counterparts and racism is the factor that makes race salient. Race was originally viewed as a biological construct defined by one's physical characteristics such as skin colour, hair texture, and facial features (Thompson & Neville, 1999). In the recent past, natural scientists acknowledged the limitations of such a notion, while social scientists have moved towards defining race as a social construct (Thompson & Neville). Although the concept of race applies to phenotypical distinctiveness of human beings and one cannot deny the variations in physical characteristics of people around the world, the use of these human biological characteristics for racial significance is a social and historical process. Williams (1999) states:

There is no more genetic variation within our existing racial groups than between them. Moreover, genetics is not static but changes over time as human populations interact with their natural and social environment... Our racial groups importantly capture differences in power, status, and resources. (p. 175)



Winant (2000) defines race as “a concept that signifies and symbolizes sociopolitical conflicts and interests in reference to different types of human bodies” (p. 172). Historically, racial categorization has its roots in racism, and the construct of racism may enhance our understanding of racial differences in health. Williams defines racism as “an ideology of inferiority that is used to justify unequal treatment (discrimination) of members of groups defined as inferior, by both individuals and societal institutions” (p. 176). He asserts that this ideology of inferiority can lead to negative attitudes towards and beliefs about racial minorities (prejudice), but he argues that racism lies primarily within organized institutional structures and not in individual attitudes or behaviours.

How does racism affect health? Racism and other forms of social inequality can affect health in many ways, by impacting on economic, environmental, psychosocial, and iatrogenic conditions (Krieger, 2003). For example, racism can limit the socio-economic progress of minority groups. Racial inequalities are created and reinforced via limited access by minority groups to educational and employment opportunities through processes such as segregation (Collins & Williams, 1999). Racial difference in socio-economic status is well documented in the literature, and health researchers examining the association between race and health routinely adjust for this variable (Williams, 1999). Thus, socio-economic status is considered not only a cofounder of racial differences in health but “part of the causal pathways by which race affects health” (Williams, 1999, p. 177).

Participants in this study spoke about their experiences of racism as well as the extent to which they perceived racism as a health issue affecting their families and communities. Most of the women indicated that racism was a significant problem for Black communities and went on to describe their experiences of everyday racism — the racist comments and attitudes they had endured throughout their lives, as children in school, as adults in the workplace, within their families, and in their dealings with health and social services and community organizations. It was clear to the researchers that the participants found it painful to share their stories.

Many of the women made it clear that racism caused significant stress, which in turn contributed to other issues and conditions such as low self-esteem:

*Anybody will tell you that they battle with their self-esteem every day. But I think, particularly as a Black woman, when you get ready for the day and you step outside the door, you never know what you're going to face. And as you walk the streets with your head high, people have certain*

*preconceived ideas about who you are. And some of them are good and some of them aren't. And I guess I struggle with that every day.*

The women also made a connection between racism and physical and emotional health:

*Women and children, they're the ones [who are] shafted, I find. Women are up against a lot of obstacles...and all these obstacles that they are up against have to do with their mental and physical aspects. And as far as Black people go, I find that it is very stressful if you want to become or do something in this lifetime. ...this stress, it can cause heart problems, it can cause high blood pressure, it can cause a lot of things. And migraine headaches.*

Participants explored the connection between racism and health in the context of their experiences with health-care providers. Some women felt that they were treated differently by health professionals because they were Black: in outpatient clinics they had to wait longer than white women, who sometimes were seen right away; their doctors did not believe them, stereotyped them, did not present information in an understandable way, did not spend an adequate amount of time with them, and would not touch them:

*When a woman walks into an office and she is complaining about pain, a doctor tends not to take her seriously, or to assume that she is hysterical or there is something mentally wrong, rather than saying this is a physical problem. That is, women in general and Black women especially.*

A number of women shared specific personal experiences of discrimination and mistreatment. In a particularly poignant moment, one woman recalled giving birth to her first child at the age of 19:

*I was having [child's name] at the hospital... My regular doctor couldn't come so they sent another doctor. I wasn't really worried because the nurse had everything down pat. Anyway, the cord was tied around [the baby's] neck. ...So in pops the doctor, who I never seen before. I just had the baby and he decides he's going to dig inside of me. Now, that is as blunt as I can put it. The nurse looked at me and she said, "If that was me I wouldn't let him do that." He was looking for what they call, I guess, a bleeder or something. I didn't know, but I got from the nurse that that wasn't the procedure. And then he asked me what I named the baby. I said, "I haven't figured it out yet. It may be [name]." He said, "Well, as long as you don't blame it on me." And I tried to figure it out. I think he figured that I was a single mom and didn't know whose child this was.*

When the women believed that they had not received or would not receive proper medical care because of their race, they became reluctant to seek advice from health professionals, arguing that there was little point in doing so:

*Why go to the hospital if I'm just going to be discriminated against? There's really no sense. ... If you're stressed out because you have something, why go to the hospital and be more stressed because people are going to be judging you? You might as well just stay home.*

### **Poverty and Unemployment**

Race as described in the above section is an antecedent and a determinant of socio-economic status, and racial differences in socio-economic status are to some degree a reflection of discriminatory policies and practices premised on the inferiority of certain racial groups (Williams, 1999). In support of this notion, Krieger (2003) asserts that "health is harmed not only by heinous crimes against humanity, such as slavery, lynching and genocide, but also by the grinding economic and social realities of what Essed (1991) has aptly termed, 'everyday racism'" (p. 195). Furthermore, Krieger (1987) argues that the poorer health of the Black population is the result of white privilege established through many forms of racial discrimination, rather than innate inferiority. These many forms of racial discrimination include unemployment and under-employment.

In the present study, 62% of the sample ( $n = 237$ ) indicated that their average annual personal income was under \$15,000 and 28% indicated that their average annual *household* income was under \$15,000. In addition, 75% of the sample reported having financial problems. We began our data collection with some suspicion that poverty was a major concern within Black communities, but the incorporation of qualitative methodology allowed us to examine firsthand accounts of how lack of access to economic resources affects the health and the lives of African-Canadian women living in rural areas.

When asked whether there were aspects of their lives that made it more difficult for them to be healthy, many women spoke about poverty. While some women were reluctant to discuss their actual income, others spoke at length about how their financial concerns affected their overall well-being:

*My biggest concern is not being able to...afford to eat healthy. ...last payday, when I paid my rent and paid \$50 on my phone bill, \$50 on my light bill, I had \$20 left. So I don't eat healthy. So I'll get french fries or hotdogs or something. And if I do treat myself...once in a while just to get*

*out to stop looking at the four walls, I can't really do it. I pay for it for weeks and weeks. I can't even have a social life.*

Poverty had a striking impact on the health of these Black women. Worrying constantly about how to pay their bills and provide for themselves and their families caused significant amounts of stress, which, aside from being a concern in itself, can lead to numerous health problems, including heart attack and chronic headache (Frey, 1999). As indicated in the examples below, poverty also affects the health of Black women in very specific ways. In discussing their financial concerns, many women explained that it was difficult or even impossible for them to afford healthy foods such as fruits and vegetables, especially in the wintertime when these foods are more expensive:

*To eat healthy, to do things that are good for your body, to keep you healthy, it takes money. And if I followed the Canada Food Guide and ate the way that I'm supposed to eat, I'd better go get a couple more jobs, because this one ain't cutting it. I just look at fruit on TV, because that's just ridiculous. And this winter it's going to be worse. I can't afford to buy those extras. If I've got meat and potato on my plate, I can't be looking at dessert and appetizers and all the rest that go along with it, and this and that. No, I can't.*

Although many of the participants were knowledgeable about healthy behaviours, they simply did not have the means to incorporate such behaviours into their daily lives.

Poverty also acts as a determinant of health by restricting access to health services and treatment. More than half of the 237 participants, 57%, reported that they did not have enough money for medication. Several of the women related instances of failing to seek medical attention for a health concern only because they could not afford to travel to the nearest health centre. One woman with vision problems said that she wore \$1 eyeglasses purchased from the drugstore because she could not pay for prescription glasses. Many women indicated that they could not afford dental care:

Interviewer: *Do you go to the dentist?*

Participant: *You can't afford that, woman! [giggle] I can't afford no dentist!*

Interviewer: *So you don't go?*

Participant: *No, unless it's absolutely necessary.*

...

Interviewer: *If you had the money to go, you would go?*

Participant: *Well, you know you'd go. You could be like everybody else and have your teeth cleaned.*

Very few of the women had access to medical insurance, and many of those who did have coverage were not reimbursed for all of their medical expenses.

While for some women poor housing was a sensitive aspect of poverty, others openly identified poor housing as a major concern in rural Black communities. Some participants spoke of being unable to afford the repairs necessary to keep their homes up to standard. Others faced limited housing choices because of financial constraints:

*Housing is an issue. Many people are living in...rundown apartments, homes that have been amalgamated into 20 apartments. They should be condemned...and they're still rented and the Black people take it because they can afford it. You know, the doors are thin...holes in the walls are terrible, the floor hasn't been changed. It's [a] health concern. It's unsanitary. But it's cheap — they can afford it.*

Unemployment is another indicator of health status. Due to the remote location of some of the communities concerned, and the lack of access to resources, very little employment is available. While some community members have regular full-time or part-time jobs, many others are employed only seasonally in fish plants or on lobster boats. Unemployment rates are high, and the stress of trying to find work weighed heavily on some of the women:

*I know that I'm never going to get ahead and I'm never going to find a job in this town no matter how hard I try. Because what's the point to go work at [a fast-food restaurant], you know what I mean? I'll only be making what I'm making right now, and that's nothing. And then on top of that, I'm going to have to pay for my own babysitter because welfare doesn't want to help me pay for a sitter.*

In talking with some of these women about their lack of employment, the intersection of race and poverty became apparent. Some women shared their experiences of being unable to find work because of their skin colour:

*I went to try at some of the motels there, because I had cooking experience and they advertised for a cook, but I was told not to bother going because they wouldn't hire me because I was Black. When I went in to see the lady, just the look on her face told me I wasn't going to be hired.*

For other women, the threat of racism made it very difficult to seek employment:

*Sometimes not having a job, that stresses me out, because I feel like I'm able to work and I'm smart and I should be — I don't want to be on welfare, but it's not easy to get a job around here. Being a Black person and, like, I'm not saying every place is racist, but in this town and if you're Black and, like, if there's a Black person and a white person they'll give the job to the white person and it doesn't matter how many qualities or skills that you could offer, it doesn't matter.*

Women drew upon different explanations to account for their difficulty in finding employment, citing access and racism as significant issues.

### ***Access to Health Care***

Issues relating to access to appropriate health services are prominent in the On the Margins data. Black women living in rural and remote areas face a number of barriers to health-care access, all of which affect their health status. Some of these barriers concern the accessibility of the services themselves, and are common to most rural communities. For example, a number of participants spoke about physician shortages and long line-ups in outpatient clinics. Many women reported that they did not have a family doctor they could see on a regular basis. In one community a general practitioner who had served the area for years had passed away approximately 1 year prior to data collection. As a result, many families were left without a doctor and still had not found a new family physician at the time of the interviews. When health issues did arise, the women were forced to go to the outpatient clinic of a rural hospital and wait for hours to be seen. These barriers prevented many rural Black women from having routine checkups. Some women even resigned themselves to going without medical care when they required it:

*My doctor died, so I don't have any doctor. The only doctors that are around here are the ones that aren't taking any on, [or they're] out in the country. I don't have any transportation so I'm not getting there. So we don't go to outpatients, of course, because there's, like, a 6-hour wait, sitting in there. I'm sick right now and I can't go see a doctor or anything...my ears have been plugged for 2 weeks and I can't get to see a doctor.*

As this example demonstrates, lack of transportation was also a barrier to health-care access. Many of the communities do not have public transportation, and women who did not own a vehicle and could not afford taxis had great difficulty getting to and from appointments. Participants also spoke about the inadequacy of rural hospitals. These hospitals offer only limited services, forcing community members to travel several hours to the city for specialized testing and even for childbirth.

Lack of information is another barrier to health-care access. When the Community Facilitators spoke with women about services available in their areas, many women were not aware of these resources. For women without access to the Internet, information on available services and on specific health conditions is difficult to access. In addition, there is a general dearth of information on health issues that affect Black people specifically:

*I don't think the white doctors know enough about the Black women's anatomy to be in judgement of us, of what our bodies are about. ...I've always felt that way. I've always felt that the doctors out there — and they've all been white in my books — and I've never seen any of them give me the knowledge of a Black woman's anatomy, or how a Black woman's body functions. We have diseases in our system, in our Black history, that white people don't have. So that obviously gives us a different chemistry level right there. ...that's one thing I don't think anybody has enough information on.*

Some women believed that they would not receive culturally relevant information even if they did have access to health services.

A related barrier for Black women living in rural and remote communities is the lack of culturally sensitive and appropriate services. While the racist attitudes of health-care providers present an obvious barrier, the lack of diversity among health-care personnel also makes it difficult for some women to access suitable health-care providers:

*I would love to see Black doctors. I would love to see Black nurses. ...when I was in the hospital in [city] and I was going through my cancer treatment, there was one Black nurse and there were three white nurses, and they were all on [the doctor's] team. And the only one that I could really relate to, or actually have anything in common with, was the Black nurse.*

Some women reported a fear or mistrust of health professionals in general. Others spoke of feeling much more comfortable around Black professionals. They believed that Black doctors would be able to identify issues specific to Black people that white doctors might not know about, would be better able to understand how Black women feel, would know how to approach issues with Black people, and would be able to identify issues in the Black community.

## Discussion

The findings reveal that numerous factors affect the health status of Black women living in rural and remote Nova Scotian communities. These

factors include racism, unemployment and poverty, and lack of access to health care. The many faces of racism have a significant impact on women's health. They include the lack of information specific to the health needs of Black people, the lack of culturally sensitive health-care providers in rural and remote communities in the region, and the lack of culturally relevant outreach programs. Inappropriate and insensitive care may also arise from subtler assumptions embedded in the health-care system, particularly the tendency to embrace the white, middle-class, male experience as normative.

Racism causes additional stress in the lives of Black women, and years of accumulated stress due to racism heightens women's feelings of fatigue. When their dedication goes unrewarded with job promotion and recognition, it takes a toll on their health, as Black women must continually struggle for validation, recognition, and commendation. Working in an environment rife with overt and covert racism, and without support, Black women have little in terms of motivation. Several researchers have argued that the subjective experience of racial discrimination can have adverse effects on the health of Black people (Evans et al., 2005; Karlsen & Nazroo, 2002; Williams, 1999). Williams points to several American studies that have linked internalized racism to depression, distress, and chronic physical conditions. Socio-economic status is a powerful indicator of health, affecting overall wellness, access to health services, access to information, and even life expectancy (Hay, 1994; Lynch, 1996; Lynch et al., 1997; Pappas et al., 1993; Poland et al., 1998; Williams). Ethnocultural identity, along with socio-economic status, profoundly influences the quality of care available to Canadians (Courtney, 2000). Cultural stereotypes sometimes translate into overt discrimination. For instance, sex-trade workers, typically women, often find it difficult to access services or receive appropriate care when providers assume that immoral behaviour is at the root of their ill health (Jackson, 2002). Black people are similarly subjected to insensitive or inappropriate care, especially when their illnesses are interpreted as the consequence of a predisposition to violence or sexual promiscuity (Blake & Darling, 2000; Bolaria & Bolaria, 1994; Murrell, Smith, Gill, & Oxley, 1996; Robb, 1998; Thomas Bernard, 2001; Utsey, Ponterotto, Reynolds, & Cancelli, 2002; Van Ryn & Burke, 2000; Williams & Williams-Morris, 2000).

The impact of race, racism, and poverty has attracted increasing attention. As with class and gender, race and poverty have been strongly correlated with poor health (Barbee & Bauer, 1988; Blake & Darling, 2000; Bolaria & Bolaria, 1994; Brancati, Kao, Folsom, Watson, & Szklo, 2000; Dana, 2002; Doswell, 2000; Fisher, Cooper, Weber, & Liao, 1996; Graham et al., 2001; LeClere, Rogers, & Peters, 1997; Schulz et al., 2000; Utsey et al., 2000). For example, African Americans experience hyper-



tension at younger ages than white Americans, and are much more prone to dangerous complications such as end-stage renal disease (American Heart Association, 2001). Black people living in the United States are also twice as likely as white Americans to develop adult-onset diabetes and to face serious sequelae of the disease, including amputation and blindness (Brancati et al., 2000; National Institutes of Health [NIH], 1992). Although fewer Black than white women are diagnosed with breast cancer, Black women are more likely to be diagnosed at an advanced stage and to die from the disease (Miller et al., 1996). In the case of HIV, African-American women are approximately three times more likely to become infected than African-American men, and eight times more likely than white Americans (NIH).

Unemployment and poverty cause stress, not only because of personal economic deprivation but also because of their impact on one's identity (Beiser, Johnson, & Turner, 1993). Unemployment increases the risk of depression because work has the function of providing not only an income but also a purpose to life, defining status and identity and enabling individuals to develop and maintain meaningful social relationships (Aycan & Berry, 1996; Pernice & Brooks, 1996; Pernice, Trlin, Henderson, & North, 2000). A number of studies have explored the link between unemployment and mental health and have found unemployment to be a predictor of mental disorders (Abbott, Wong, Williams, Au, & Young, 1999, 2000; Pernice & Brooks). There is also evidence of an inverse relationship between social class and premature death; people in lower socio-economic classes die earlier than people in higher socio-economic classes (Adler, Boyce, Chesney, Folkman, & Syme, 1993; Guralnik, Land, Blazer, Fillenbaum, & Branch, 1993; Isaacs & Schroeder, 2004).

Black women in the region of Nova Scotia chosen for the study face many of the same health and access challenges that confront anyone living in a rural or remote location, including lack of hospital services, lack of transportation, and a shortage of doctors and services. However, the ability of Black women to achieve and maintain health — their own and that of their loved ones — is further compromised by discrimination and a lack of culturally competent care. In addition, the combination of racism and poverty limits women's choices in housing, employment, and education — factors that in turn affect their health status. Most vulnerable of all are people who experience overlapping disadvantages, including poverty and ethnocultural discrimination. Women from visible minorities routinely experience this double jeopardy and its pernicious effect on their health (Thomas Bernard, 2001).

## **Conclusion**

Although Black people have lived in these rural and remote Nova Scotian communities for centuries, they remain socially, economically, and politically marginalized: many are unemployed or underemployed and live in poverty; most have limited access to appropriate social, economic, and health services; and they are under-represented in health-care delivery, in health research, and in the design and implementation of health policies. Like their urban counterparts, African Nova Scotians living in rural and remote regions encounter strong barriers to appropriate health care, but their situation is compounded by their geographic location. Even when they have the financial and social resources to access health services, they are confronted with the challenge of finding culturally competent providers, programs, and facilities a reasonable distance from their homes.

While people living in rural areas, irrespective of cultural background, have been identified as lacking access to appropriate health care, Black women face additional barriers, such as racism and lack of culturally competent care. Most of the participants in this study faced higher risk of marginalization because of their triple-jeopardy situation: being Black, being poor, and living in a rural community. Although a few studies have attempted to explicate the determinants of Black women's health status in Canada in general and Nova Scotia in particular, this is the first to examine the issue in the context of rural and remote communities, thus adding a unique perspective to the growing body of literature in this area.

Health disparities along racial lines have multiple root causes, including racism, poverty, and differential health-care access, which are interwoven in complex ways. The present findings illuminate some aspects of these complex issues, including the ways in which racism impacts on Black women's health. An understanding of these issues is vital to efforts aimed at addressing diversity and social inclusion in today's culturally diverse society. Although studies in other jurisdictions have identified the health impact of racism, poverty, and access to health care, the On the Margins project has uncovered the extent to which these complex issues are interwoven to create health problems in the Nova Scotia context. The project has explicated some of the intersecting inequities that affect and compromise the health and health care of Black women, families, and communities in the region. It is important that researchers maintain the goal of forming research partnerships with African-Canadian communities in order to fully explicate their health

issues and improve the health of this population. It is also important that any future research in this area be undertaken with the recognition that race interacts with numerous other variables and experiences to determine the health of Canadian Black women and their families.

The analysis presented above also explicates the potential areas of future research, including specific conditions (i.e., hypertension, diabetes, heart disease), in order to further identify differences and similarities in the health of African Americans and African Canadians.

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**Mettre au jour les facteurs expliquant  
le recours aux services d'urgence  
pour des problèmes de santé peu urgents  
dans les régions urbaines et rurales**

**Marilyn J. Hodgins et Judith Wuest**

On dit des personnes qui se rendent à l'urgence pour des problèmes de santé peu urgents qu'elles font un usage inopportun du système de santé. Or on sait peu de choses des facteurs qui les incitent à y recourir et sur les éléments qui distinguent cette utilisation selon les endroits. Dans le cadre de cette étude descriptive et corrélationnelle fondée sur le modèle d'utilisation des services de santé Andersen, on a interrogé 1612 personnes qui se sont présentées à un service d'urgence avec un problème de santé peu urgent. L'analyse révèle qu'il existe des différences entre les régions rurales et urbaines en ce qui a trait aux caractéristiques des patients, la nature de leurs problèmes, les mesures adoptées et les facteurs qui les ont poussés à se présenter à l'urgence. Le pouvoir de prédiction du modèle Andersen s'est avéré limité, malgré la popularité de ce dernier, quand il s'est agi d'expliquer le recours aux soins auto-administrés ou la propension à attendre avant de recevoir des soins. On constate que le rôle des services d'urgence varie en fonction de leur emplacement. Ces conclusions offrent des éléments de réflexion propices à la mise en place de services s'adressant aux personnes ayant des problèmes de santé peu urgents, qui tiendraient compte de l'emplacement géographique.

Mots clés : utilisation des services de santé, services d'urgence, problèmes de santé peu urgents, emplacement géographique



# **Uncovering Factors Affecting Use of the Emergency Department for Less Urgent Health Problems in Urban and Rural Areas**

**Marilyn J. Hodgins and Judith Wuest**

People who access the emergency department for less urgent health problems have been described as inappropriate users of the health-care system. Yet little is known about the factors precipitating such use and how these differ based on location of the emergency department. In this descriptive-correlational study guided by Andersen's Model of Health Services Use, 1,612 people who presented to an emergency department with a less urgent health problem were interviewed. Analysis revealed rural/urban differences in the characteristics of patients, nature of the problems, actions taken, and factors precipitating the visit. Despite its popularity, the predictive capabilities of Andersen's model were limited in explaining use of self-treatment or willingness to wait for treatment. The findings show that an emergency department's roles and functions vary according to its location. Such insights provide direction for developing services that respond to the needs of people with less urgent health problems that are cognizant of geographic location.

**Keywords:** Health-care behaviours, health-resource utilization, rural, urban, emergency department, less urgent health problems, geographic location

More than half (57%) of patients treated in emergency departments in Canada present with less urgent or non-urgent conditions (Canadian Institute for Health Information, 2005). Use of the emergency department for such problems has been labelled as inappropriate or even as abusive of the health-care system, largely due to concerns about the impact of increasing patient volumes and overcrowding on the quality of care provided to emergency patients, especially those with life-threatening conditions (Dunne & Martin, 1997; Lee et al., 1999; Martin et al., 2002). An alternative perspective is that such use is precipitated by a health-care system that is ill-equipped to respond to these health problems (Schull, 2005). A better understanding of the factors influencing people's health-care behaviours for less urgent problems in urban and rural locations will inform debate on the appropriateness of these actions. An appreciation of the differences in the health-care behaviours of urban and rural Canadians is also needed, to allow for the planning of appropriate and accessible care for less urgent health problems. Such know-

ledge will also assist in the planning and implementation of strategies to help people more efficiently navigate the health-care system and thereby achieve better health outcomes. Guided by Andersen's (1995) Model of Health Services Use, we surveyed 1,612 people who accessed an emergency department in the province of New Brunswick for treatment of a less urgent health problem. In this article, we describe differences between people who visited urban and rural emergency departments for less urgent care as well as factors influencing their health-care behaviours.

## **Background**

Most people periodically experience the discomfort and distress caused by less urgent health problems. The term "less urgent" is used to describe non-life-threatening health problems or injuries caused by minor accidents. Other terms used to describe such conditions include "non-urgent health problems" and "minor health problems." People's response to such problems include (a) doing nothing and simply waiting to see what happens, (b) self-treating the symptoms and monitoring changes, (c) seeking advice from family or friends, and (d) accessing professional health-care services directly or by telephone. Little is known about the factors that influence when and how people respond to less urgent health problems, including the decision to access professional health-care resources such as the emergency department. Terms used for the range of activities that people engage in to promote or restore health or to treat symptoms include "health-care-seeking behaviours," "help-seeking behaviours," "care-seeking behaviours," and "health-care behaviours" (Andersen, 1995; Lauer, 1992; Weinert & Burman, 1994).

### ***Self-Evaluation and Self-Treatment***

Self-evaluation and self-treatment of health problems have been described as the basic forms of primary health care (Sorofman, Tripp-Reimer, Lauer, & Martin, 1990). Self-treatments are intentional behaviours that individuals initiate on their own behalf or on behalf of a family member to promote health or to treat an illness or injury (Dean, 1989; Fleming, Giachello, Andersen, & Andrade, 1984). They are undertaken without professional assistance, although people may have acquired knowledge and skills during previous interactions with health-care professionals and/or knowledgeable laypersons (Levin & Idler, 1983). Few studies have examined the relationship between self-treatment and the use of formal health-care services. In a secondary analysis of data from a 1976 national survey, Fleming and colleagues attempted to ascertain whether Americans self-treat as a substitute, supplement, or stimulus for professional health-care services. In addition to noting a

greater tendency towards self-treatment by those caring for young children, by women, and by those without a regular source of health care, they concluded that self-treatment is frequently used as a substitute for formal services.

### ***Effect of Place on Health-Care Behaviours***

There is increasing recognition that “place matters” to health, disease, and health-care access (Andrews, 2006; Carolan, Andrews, & Hodnett, 2006; Kearns, 1993; Kearns & Moon, 2002). Yet the role of place (also referred to as environment, location, context, or system) in shaping health-care behaviours, including the use of health-care services, is not clearly understood. Based on an examination of data from the National Center for Health Statistics, Wolinsky (1978) found that sociocultural characteristics were relatively unimportant factors in explaining Americans’ use of health-care services and suggests that characteristics of the delivery system may be more important. Although this observation was made almost three decades ago, most research continues to focus on characteristics of the people who use a service rather than the communities in which services are sought. More recently, Litaker, Koroukian, and Love (2005) noted that although there is accumulating evidence suggesting that contextual attributes affect a variety of health outcomes, the effect of these factors on people’s ability to access health-care services is less clear. Such information is required for effective health-care planning.

Within health research, *place* has frequently been operationalized as urban or rural. This operationalization stems from an appreciation of the potential impact of more than a decade of health-care reforms, including the amalgamation of health-care services in larger communities and the closure or conversion of services in smaller communities. Evaluating the effect of these reforms on health-care behaviours is complicated by the multiplicity of ways in which “rural” has been defined. Attempts to establish a common definition have been opposed by those who assert that a single, all-purpose definition of rural is neither feasible nor desirable and that the definition should be tailored to the task at hand (Halfaree, 1993; Racher, Vollman, & Annis, 2004; Vanderboom & Madigan, 2007); for example, Racher and colleagues propose that in nursing research rural should be defined in terms of the people who live in a particular area.

Several differences have been hypothesized regarding the health-care behaviours of people living in rural versus urban areas. Long (1993) proposes that, by necessity, rural dwellers learn to distinguish between health problems that if left untreated will impede functioning and those that can be tolerated for a period of time. It has also been suggested that people living in rural areas generally rely more than urban-dwellers on

informal networks of family members and friends for both the diagnosis and treatment of health problems (Long & Weinert, 1992; Weinert & Long, 1993). Distance to needed health-care services has also been identified as a critical variable for studying the health-care utilization patterns of people living in rural communities (Arcury et al., 2005; James, 1999; Weinert & Burman, 1994; Yantzi, Rosenberg, Burke, & Harrison, 2001). However, Nemet and Bailey (2000) suggest that the actual distance may contribute less to access patterns than the frequency with which people travel to a place. They label this characteristic “activity space.”

Finally, Beland, Lemay, and Boucher (1998) suggest that the roles and functions of health-care facilities are shaped in part by the community in which they are located. In their examination of two emergency departments in a large metropolitan area in Quebec, Beland and colleagues observe that the functions of these departments varied according to the availability of resources in the community (e.g., after-hours clinics) as well as the affiliated hospital. They also note that it is in this context that individuals choose whether or not to access the emergency department.

### ***Andersen’s Model of Health Services Use***

In their Model of Health Services Use, Andersen and colleagues hypothesize that people’s health behaviours and health outcomes are determined by factors (determinants) specific to the individual as well as the context (environment) in which health care is sought (Aday & Andersen, 1974; Andersen, 1968, 1995). Individual determinants, which Andersen (1995) posits as having the most immediate influence on health-care utilization, pertain to factors specific to the individual seeking health care and are grouped into three categories: need, predisposing, and enabling. Need determinants reflect the impetus for health-care use as measured by the perceived (self-rated) or evaluated (rated by a health-care professional) need for care. Predisposing factors indicate the propensity or inclination of individuals to use health-care services and include demographic characteristics (such as age and gender), attributes of social structure that may affect ability to cope and to demand resources (e.g., level of education, ethnicity), and knowledge and attitudes about health and health-care services. Enabling factors refer to resources specific to the individual that facilitate or impede the use of services, such as income, regular source of health care, and means of transportation. Meanwhile, contextual determinants encompass the social, economic, structural, and public-policy environment in which access to health-care services occurs and which is generally operationalized in terms of geographic location (Davidson, Andersen, Wyn, & Brown, 2004). In their more recent publications, Andersen and colleagues suggest that contextual determinants play a

larger role in explaining use of health-care services than originally conceptualized (Andersen & Davidson, 2001). Although Andersen's Model of Health Services Use has been utilized by a number of researchers as a theoretical framework to explain emergency department use (Halfon, Newacheck, Wood, & St. Peter, 1996; O'Brien et al., 1997), it has not been employed to examine people's health-care behaviours prior to presenting at an emergency department.

### **The Study**

A descriptive-correlational study was conducted to test the ability of Andersen's theoretical model to explain health-care behaviours for less urgent health problems. In this article, we present a partial analysis of our findings by examining factors affecting people's response to such problems. Two research questions were addressed: 1. *To what extent can people's response to less urgent health problems be predicted based on characteristics reflecting Andersen's predisposing, enabling, and need determinants?* 2. *Does the role played by these characteristics differ based on the place (geographic location) in which health care is sought?*

### **Questionnaire and Study Variables**

Based on Andersen's Model of Health Services Use and the authors' unpublished review of the research literature on emergency department use, a structured interview guide was developed. Information collected during the interview included the type of health problem experienced, actions taken prior to presenting at the emergency department, factors influencing the decision to seek professional care, and demographic characteristics. For this analysis, two dichotomous indicators of health-care behaviours were selected as outcome variables: attempted self-treatment, and willingness to wait 2 days for an appointment with a medical doctor or nurse practitioner (Table 1). Self-treatment was defined as self-reported use of over-the-counter products or home remedies. Willingness to wait 2 days for treatment was selected as an indicator differentiating participants who perceived the need for immediate care from those who might be managed by services offered on a more conventional Monday-to-Friday, 9-to-5 basis.

Five variables were selected to elicit information about the need for care. Two of these examined the nature of the current health problem (an injury; disturbing symptoms, including pain) and the remaining three addressed participants' subjective ratings of the health problem (self-reports of how bad, how worried, and how afraid). Predisposing characteristics were measured in terms of three demographic characteristics

**Table 1 Variables Used to Measure Dimensions of Andersen's Model of Health Services Use**

<b>Variables</b>	<b>Description and Coding</b>
<b>Outcome Variables</b>	
Attempted self-treatment	Prior to arrival at ED, did you try any over-the-counter product or home remedy? <i>Dichotomous variable</i>
Willingness to wait	If you could have gotten an appointment with a doctor or nurse practitioner within 2 days, would you have waited? <i>Dichotomous variable</i>
<b>Predictor Variables</b>	
<b>Need characteristics</b>	
How bad	On scale of 1 to 10 with 1 being 'not bad at all' and 10 being 'as bad as could be', how bad was problem when you decided to come to ED? <i>Recorded: 0 = 1 to 4; 1 = 5 to 7; 2 = 8 to 10</i>
How worried	How worried were you about health problem when you decided to come to ED? (5-point scale: 1 = not worried at all; 5 = very worried) <i>Recorded: 0 = not at all to somewhat worried; 1 = worried or very worried</i>
An injury	Description of presenting problem from emergency record. <i>Dichotomous variable</i>
Disturbing symptom	Based on description of presenting problem recorded on emergency record. Indication of disturbing symptom such as pain, shortness of breath, laceration, bleeding or drainage. <i>Dichotomous variable</i>

<b>Predisposing characteristics</b>	<b>Description and Coding</b>
Participant's age	Age in years grouped <i>Coded: 0 = less than 25 years; 1 = 25 to 39 years; 2 = 40 to 64 years; 3 = 65+ years</i>
Problem for self	Is this ED visit for a problem experienced by yourself (as opposed to a dependent child or adult)? <i>Dichotomous variable</i>
Participant, male	Sex of study participant <i>Dichotomous variable</i>
Has partner	Married or in common-law relationship <i>Dichotomous variable</i>
Children in household	Children less than 18 years of age in household <i>Dichotomous variable</i>
Education	Highest level of education attained by participant <i>Coded: 0 = less than high school diploma; 1 = high school diploma; 2 = some postsecondary education</i>
Health belief, internal control	Agreement with statement, "there is a lot that you can do to control this health problem" 5-point scale: 1 = strongly disagree; 5 = strongly agree <i>Recoded: 0 = strongly disagree to neutral; 1 = agree to strongly agree</i>
Health belief, external control	Agreement with statement, "care received in ED will help problem" 5-point scale: 1 = strongly disagree; 5 = strongly agree <i>Recoded: 0 = strongly disagree to neutral; 1 = agree to strongly agree</i>
<i>Continued on next page</i>	

<b>Table 1</b> ( <i>cont'd</i> )	
<b>Enabling characteristics</b>	<b>Description and Coding</b>
Household income	What was your total family income last year? <i>Coded: 0 = \$30,000 or less; 1 = \$30,001 to \$60,000; 2 = more than \$60,000</i>
Size, community of residence	How many people live in the community that you live in? <i>Coded: 0 = 1,000 or more residents; 1 = less than 1,000 residents</i>
Years lived in community	How many years have you been in the community that you live in? <i>Coded: 0 = 10 years or less; 1 = more than 10 years</i>
Distance from home to ED	How far do you live from this ED? <i>Coded: 0 = less than 20 kilometres; 1 = 20 kilometres or more</i>
Activity space	How often do you visit community in which this ED is located? <i>Coded: 0 = live in or daily visit; 1 = less frequent visits</i>
Have a family doctor	Do you have a family doctor? <i>Dichotomous variable</i>
<i>Note: All dichotomous variables are coded as 0 = no and 1 = yes.</i>	

(age, sex, problem for self), three measures of social structure (marital status, family composition, level of education), and two indicators of health beliefs (ability to control problem oneself and belief that care received in emergency department would help). Six variables were treated as enablers of health-care utilization (income, size of community, years of residence in community, distance to emergency department, activity space, and have a family doctor).

Location of the emergency department (urban vs. rural) was used as a grouping variable to investigate the effect of place. The two emergency departments defined as urban were located in regional tertiary-care facilities offering specialized consultative services in cities with more than 50,000 people. The two emergency departments defined as rural were located in community health centres situated in communities with fewer than 5,000 people.



### **Method**

Prior to commencement of the study, approval was obtained from the research ethics boards of the university and two regional hospital corporations. In the interests of data quality and security, the Entryware® palm-pocket data-entry program was used. Data collectors were registered nurses who lived in the participating communities. Prior to the start of data collection, training sessions were held to familiarize the research assistants with the research process and the interview guide. Also, team meetings were held every 3 months to monitor the consistency and quality of the data-collection process. Issues or concerns that arose between these meetings were addressed via e-mail communication.

Participant recruitment took place by convenience during periods when a research assistant was present in the emergency department. Although research assistants were able to self-select their hours of data collection, they were instructed to vary their schedules to cover all the days of the week and the hours between 7 a.m. and midnight. Data collectors were not in the emergency department between midnight and 7 a.m., but they did recruit people who presented during these hours and were still waiting for treatment. Of the participants, 64% presented to the emergency department during regular working hours (i.e., Monday to Friday between 9 a.m. and 5 p.m.). Research assistants approached people who were triaged to the waiting area, as this was deemed to be an indicator of a less urgent health problem based on the evaluation of a health-care professional (i.e., evaluated need). Of the people approached by the research assistants, 90% agreed to participate in the study.

Between December 2003 and December 2004, data were collected from a convenience sample of 1,612 New Brunswickers who accessed one of the emergency departments for a less urgent health problem experienced by themselves or a dependant. Participants answered questions while waiting for treatment. On average, this interview took 14 minutes to complete ( $SD = 5.2$ ). Information pertaining to the initial triage code, times of arrival and discharge, and final diagnosis and disposition was obtained from the emergency patient record.

### **Characteristics of Sample**

The typical participant was a middle-aged ( $mean = 43$  years;  $range = 16$  to 93) woman (61%) who accessed the emergency department for a problem experienced by self (84%). Over half of the participants had resided in the same community for over 10 years (60%) and reported no postsecondary education (53%). As evidenced in Table 2, participants

recruited in the rural emergency departments tended to be older, to report lower levels of education and income, and to be less likely to have a family physician. Interestingly, although urban residents are generally considered to be more transient, no significant difference was observed in the percentage of people who had resided in the community for 10 or more years by location of the emergency department.

**Table 2 Sample Characteristics by Emergency Department Location**

	<b>Total (N = 1,612) (%)</b>	<b>Urban (N = 731) (%)</b>	<b>Rural (N = 881) (%)</b>
Age less than 40 years*	793 (49.3)	460 (63.1)	333 (37.9)
Male	631 (39.1)	283 (38.7)	348 (39.5)
Has partner (married/common-law)*	924 (57.4)	268 (50.3)	556 (63.3)
Children in household (< 18 yrs)	712 (44.3)	341 (46.6)	371 (42.3)
No postsecondary education*	854 (53.0)	315 (43.1)	539 (61.3)
Household income ≤ \$30,000*	989 (61.4)	395 (54.0)	594 (67.4)
Resided in community 10+ years	942 (59.7)	416 (57.0)	546 (62.0)
Travel 20+ kilometres to ED*	551 (34.3)	216 (29.6)	335 (38.3)
Frequent visit to location of ED*	1,045 (64.9)	621 (85.0)	424 (48.2)
Have a family doctor*	1,384 (85.9)	664 (90.8)	720 (81.7)
Presented with problem for self	1,358 (84.2)	621 (85.0)	737 (83.7)
* Statistically significant difference by location of emergency department using chi-square analyses ( $p < .05$ ).			

### **Data Analysis**

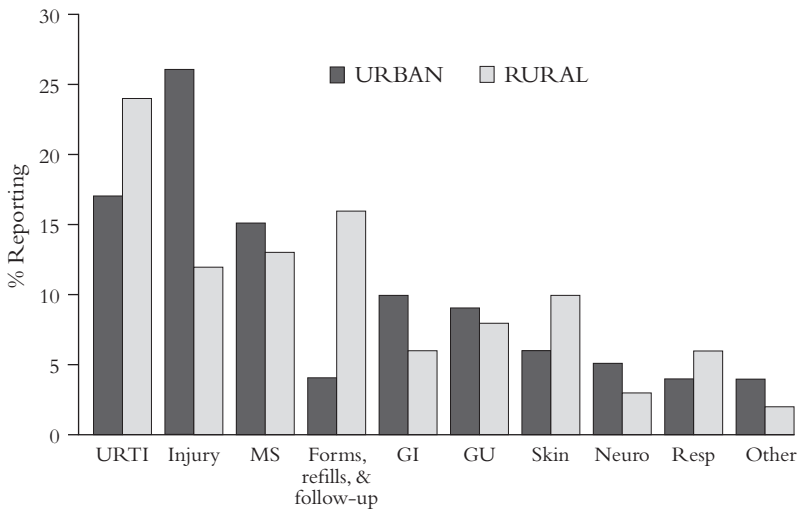
Data analysis was conducted using SPSS® version 14. Preliminary descriptive statistics were examined to evaluate data accuracy, identify potential outliers, and assess for violations in assumptions underlying regression analysis. Descriptive statistics were also generated to provide a general description of the sample. Two separate logistic regression analyses with block entry of variables were conducted to explain participants' health-care behaviours. The same sequence was used for each analysis. In the first block, the variables pertaining to need for care were entered. These variables were entered first, as Andersen views need as the most immediate determinant of health-care use. The eight predisposing variables were entered in the second block after partialling out the effects of the need characteristics. Finally, the six enabling characteristics were entered into the analysis to determine whether they affected health-care behaviours beyond that attributable to need and predisposing characteristics. Separate analyses were conducted by location of the emergency department (urban vs. rural). Level of significance for the analyses was set at less than .05.

### **Results**

Although participants accessed an emergency department for a variety of health problems, the main groupings were problems involving the upper respiratory tract (21%), injuries (18%), and non-injury-related musculoskeletal complaints (12%). Differences were observed in the percentage of participants presenting at urban and rural emergency departments by type of health problem (Figure 1). For example, injuries were a more common presenting problem for those accessing an urban emergency department, while forms, prescription refills, and follow-ups were more common among those presenting at rural emergency departments.

During the interview, participants were asked to rate the importance of 16 predetermined items in their decision to access the emergency department. These items were ranked based on the mean scores computed for the total sample and by location of the emergency department. No difference was observed in the ranking of the top seven items by location. The two items with the highest mean scores reflected participants' perceptions of need ("severity of symptoms" and "concern problem will get worse"), while the next two items dealt with characteristics of the context within which health care was sought ("no other option" and "availability of family physician"). The next three highest rankings were, respectively, "convenience of service," "needed service only available at emergency department," and "advice from family or friends."

**Figure 1 Nature of Health Problem by Emergency Department Location (N = 1,612)**



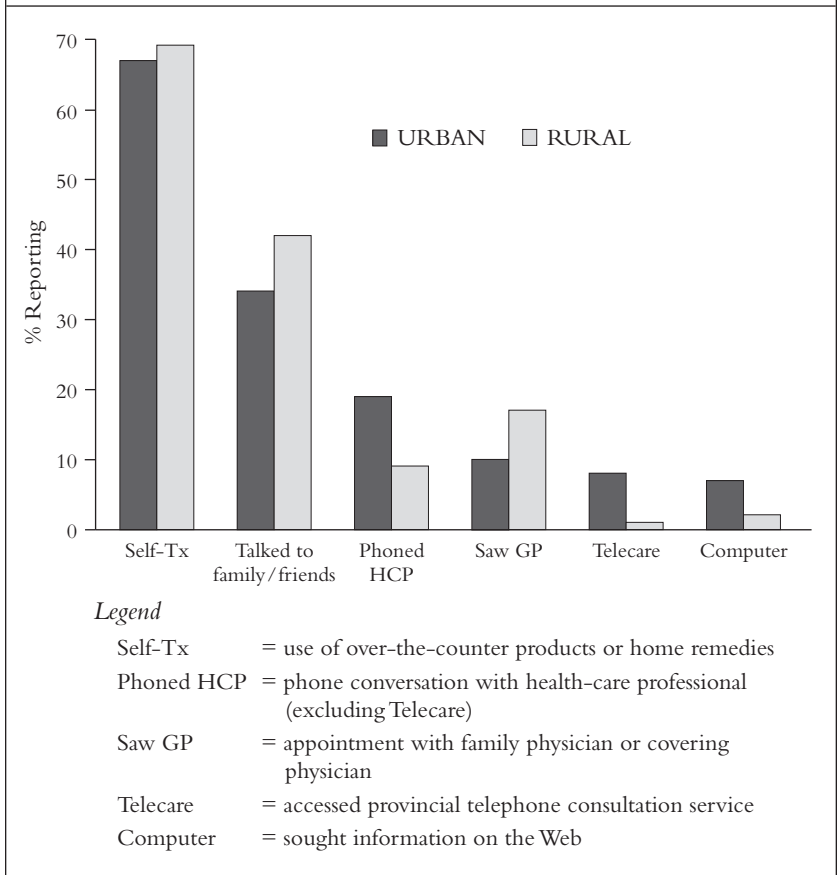
*Legend*

- URTI = problem involving upper respiratory tract (ears, nose, throat)
- Injury = problem resulting from a traumatic injury
- MS = non-traumatic musculoskeletal problems
- GI = gastrointestinal complaints
- GU = gynecological and urinary complaints
- Neuro = neurological complaints (e.g., headaches, dizziness, weakness)
- Resp = problems involving lower respiratory tract
- Other = miscellaneous: dental problems, emotional distress, etc.

**Self-Care Measures**

Figure 2 summarizes the actions initiated by participants prior to their presentation at the emergency department. Of the sample, 68% reported use of over-the-counter or home remedies (i.e., self-treatment), with no significant difference in the percentages by location. In general, participants were more likely to seek advice from a family member or friend than from a health-care professional. Overall, use of the provincial telephone consultation service (Telecare) was low, especially among those presenting at a rural emergency department. In addition, few participants reported accessing information on how to deal with their health problem from a Web site.

**Figure 2** *Actions Taken in Response to Health Problem by Emergency Department Location (N = 1,612)*



***Attempted Self-Treatment***

Results of the logistic regression for reported use of self-treatment are presented in Table 3. For both urban and rural groups, only two of the five indicators of need, entered in the first block, made statistically significant contributions to predicting use of self-treatment: ratings of “how bad” and “how afraid.” Participants who rated the health problem as worse were almost twice as likely to report the use of self-treatment. Those who indicated that they were “afraid” were less likely to self-treat. After partialling out the effect of the need characteristics, the eight predisposing variables were entered. Differences based on the location of the emergency department were evident in the variables that made statisti-

**Table 3** *Logistic Regression Model: Attempt to Self-Treat by Emergency Department Location*

Characteristic	Urban (n = 723) Odds Ratio (95% CI)	Rural (n = 844) Odds Ratio (95% CI)
<b>Block 1: Need factors</b>		
“How bad”		
1–4	1.00 (R)	1.00 (R)
5–7	2.51* (1.56–4.04)	2.34* (1.57–3.50)
8+	2.15* (1.33–3.47)	3.10* (2.01–4.78)
Worried/very worried	1.21 (0.84–1.75)	0.89 (0.63–1.25)
An injury	0.90 (0.62–1.32)	0.75 (0.48–1.18)
A disturbing symptom	0.87 (0.51–1.47)	0.94 (0.63–1.40)
Afraid about problem	0.69* (0.48–0.98)	0.60* (0.43–0.86)
<i>Step summary</i>	Chi-square 18.76, <i>df</i> 6, <i>p</i> = .005 (~R <sup>2</sup> = 3.6%)	Chi-square 36.35, <i>df</i> 6, <i>p</i> < .001 (~R <sup>2</sup> = 6.0%)
<b>Block 2: Predisposing factors</b>		
Age (years)		
Less than 25	1.00 (R)	1.00 (R)
25–39	0.92 (0.58–1.45)	0.87 (0.48–1.61)
40–64	0.99 (0.60–1.63)	0.75 (0.42–1.34)
65+	0.48 (0.21–1.14)	0.58 (0.30–1.12)
Problem for self	1.13 (0.67–1.91)	0.72 (0.43–1.20)
Male	0.44* (0.30–0.62)	1.07 (0.77–1.49)
Has partner	1.16 (0.78–1.71)	1.26 (0.90–1.76)
Children in household	0.93 (0.63–1.36)	1.14 (0.76–1.70)
Education		
Less than high school	1.00 (R)	1.00 (R)
High school diploma	1.30 (0.78–2.18)	0.90 (0.59–1.36)
Postsecondary	1.29 (0.81–2.05)	1.16 (0.78–1.72)
Believe can control	1.43 (0.99–2.09)	1.43* (1.01–2.04)
Believe ED will help	2.01* (1.26–3.19)	1.38 (0.86–2.22)
<i>Step summary</i>	Chi-square 37.67, <i>df</i> 11, <i>p</i> < .001 (~R <sup>2</sup> = 6.9%)	Chi-square 20.59, <i>df</i> 11, <i>p</i> = .04 (~R <sup>2</sup> = 3.3%)

<b>Block 3: Enabling factors</b>		
Household income		
\$30,000 or less	1.00 (R)	1.00 (R)
\$30,001–\$60,000	0.93 (0.62–1.41)	1.06 (0.70–1.60)
\$60,001 or more	1.03 (0.63–1.69)	1.11 (0.63–1.96)
Community size < 1,000	1.17 (0.75–1.82)	0.88 (0.60–1.30)
In residence > 10 yrs	1.04 (0.72–1.50)	1.34 (0.95–1.87)
Distance to ED 20+ km	0.78 (0.51–1.20)	1.40 (0.96–2.04)
ED community daily	1.29 (0.74–2.25)	1.06 (0.73–1.55)
Have a family doctor	1.54 (0.87–2.71)	1.50 (0.99–2.26)
<i>Step summary</i>	Chi-square 4.38, <i>df</i> 7, <i>p</i> = .74 (~R <sup>2</sup> = 0.7%)	Chi-square 10.87, <i>df</i> 7, <i>p</i> = .14 (~R <sup>2</sup> = 1.7%)
<i>Summary, total model</i>	Chi-square 60.81, <i>df</i> 24, <i>p</i> < .001 (~R <sup>2</sup> = 11.2%) H&L: Chi-square 17.05; <i>p</i> = .03	Chi-square 67.82, <i>df</i> 24, <i>p</i> < .001 (~R <sup>2</sup> = 11.0%) H&L: Chi-square 6.05; <i>p</i> = .64
<i>Overall predictive value</i>	65.2%	65.4%
<p>* ~R<sup>2</sup> = Nagelkerke R-square.  H&amp;L = Hosmer and Lemeshow Goodness of Fit Test (desired <i>p</i> &gt; .05).  * Statistically significant at <i>p</i> &lt; .05.  (R) = Reference category.</p>		

cally significant contributions. In the urban emergency departments, men were less likely than women to report use of self-treatment, while no such sex difference was evident for the rural group. Although health beliefs made a significant contribution in both groups, the actual variable making the contribution differed. In the rural emergency departments, those who believed they could control the health problem were more likely to report self-treatment, while those in the urban emergency department were more likely to report self-treatment if they believed the emergency treatment would help. After partialling out the effects of the need and predisposing variables, entry of the six enabling characteristics did not improve the predictive capabilities in either group. Overall, the predictive capabilities of the models were limited, as evidenced by the pseudo R<sup>2</sup> of 11% and an overall predictive value (correctly classified cases) of 65% for both groups.

**Table 4** *Logistic Regression Model:Willingness to Wait by Emergency Department Location*

Characteristic	Urban (n = 722) Odds Ratio (95% CI)	Rural (n = 841) Odds Ratio (95% CI)
<b>Block 1: Need factors</b>		
“How bad”		
1–4	1.00 (R)	1.00 (R)
5–7	0.49* (0.30–0.81)	0.64* (0.43–0.94)
8+	0.33* (0.20–0.57)	0.50* (0.33–0.75)
Worried/very worried	0.89 (0.58–1.35)	0.78 (0.57–1.08)
An injury	0.58* (0.37–0.93)	0.38* (0.23–0.61)
A disturbing symptom	1.26 (0.69–2.32)	0.66* (0.46–0.95)
Afraid about problem	0.97 (0.64–1.46)	0.94 (0.67–1.31)
<i>Step summary</i>	Chi-square 21.44, <i>df</i> 6, <i>p</i> = .002 (~R <sup>2</sup> = 4.5%)	Chi-square 48.46, <i>df</i> 6, <i>p</i> < .001 (~R <sup>2</sup> = 7.5%)
<b>Block 2: Predisposing factors</b>		
Age (years)		
Less than 25	1.00 (R)	1.00 (R)
25–39	0.76 (0.45–1.28)	1.10 (0.62–1.94)
40–64	0.72 (0.41–1.26)	1.31 (0.76–2.26)
65+	0.90 (0.35–2.29)	1.54 (0.83–2.85)
Problem for self	6.64* (2.30–19.19)	1.55 (0.97–2.48)
Male	0.79 (0.53–1.19)	0.91 (0.67–1.23)
Has partner	1.42 (0.89–2.25)	0.92 (0.67–1.27)
Children in household	0.65 (0.42–1.01)	0.67* (0.46–0.98)
Education		
Less than high school	1.00 (R)	1.00 (R)
High school diploma	0.79 (0.45–1.39)	1.09 (0.73–1.61)
Postsecondary	0.51* (0.30–0.87)	1.02 (0.70–1.48)
Believe can control	1.33 (0.88–2.02)	1.08 (0.78–1.49)
Believe ED will help	0.82 (0.48–1.38)	0.56* (0.35–0.88)
<i>Step summary</i>	Chi-square 45.17, <i>df</i> 11, <i>p</i> < .001 (~R <sup>2</sup> = 9.2%)	Chi-square 33.07, <i>df</i> 11, <i>p</i> < .001 (~R <sup>2</sup> = 4.9%)



<b>Block 3: Enabling factors</b>		
Household income		
\$30,000 or less	1.00 (R)	1.00 (R)
\$30,001–\$60,000	1.18 (0.73–1.91)	0.88 (0.59–1.30)
\$60,001 or more	1.16 (0.66–2.05)	1.40 (0.83–2.36)
Community size < 1,000	0.96 (0.56–1.64)	1.20 (0.82–1.75)
In residence > 10 yrs	0.96 (0.63–1.47)	1.22 (0.88–1.69)
Distance to ED 20+ km	0.95 (0.56–1.59)	1.04 (0.73–1.48)
ED community daily	1.00 (0.52–1.93)	0.94 (0.65–1.34)
Have a family doctor	0.46* (0.25–0.82)	0.23* (0.15–0.36)
<i>Step summary</i>	Chi-square 7.51, <i>df</i> 7, <i>p</i> = .38 (~R <sup>2</sup> = 1.4%)	Chi-square 50.76, <i>df</i> 7, <i>p</i> < .001 (~R <sup>2</sup> = 7.1%)
<i>Summary, total model</i>	Chi-square 74.13, <i>df</i> 24, <i>p</i> < .001 (~R <sup>2</sup> = 15.1%); H&L: Chi-square 3.78; <i>p</i> = .88	Chi-square 132.30, <i>df</i> 24, <i>p</i> < .001 (~R <sup>2</sup> = 19.5%); H&L: Chi-square 10.37; <i>p</i> = .24
<i>Overall predictive value</i>	63.6%	67.1%
<p>* ~R<sup>2</sup> = Nagelkerke R-square.                      H&amp;L = Hosmer and Lemeshow Goodness of Fit Test (desired <i>p</i> &gt; .05).                      * Statistically significant at <i>p</i> &lt; .05.                      R = Reference category (1.00).</p>		

### Willingness to Wait

Approximately one third of the participants (34%) indicated a willingness to wait 2 days for an appointment with a medical doctor or nurse practitioner; however, this percentage was significantly higher for participants who accessed a rural emergency department (44% vs. 21%; chi-square = 92.94; *df* = 1; *p* < .001). Similarities were evident in the two groups in terms of the need characteristics that made significant contributions to the first block of the logistic regression (Table 4). Participants who rated the severity of the health problem as worse and presented with an injury were less willing to wait for treatment. In addition, those who went to a rural emergency department were less willing to wait if the health problem was associated with a disturbing symptom, such as pain. Once again, differences were evident in the role of the predisposing characteristics by place. In the urban emergency departments, those who presented with a problem for self were more willing to wait for treatment. A second predictor for the urban group was level of education, as those with post-

secondary education tended to be less willing to wait. For the rural group, conversely, willingness to wait was affected by the presence of children in the household and the belief that the emergency care would help. Participants who did not have children and those who did not believe the emergency treatment would help were more willing to wait. After partialling out the effect of need and predisposing characteristics, the effect of the enabling factors was examined. One enabling characteristic — have a family doctor — was significant for both groups. Because the odds ratio was less than 1, this suggests that participants who did not have a family doctor were more willing to wait for treatment. However, the actual value of the odds ratio suggests that the effect of this variable was much stronger in the rural group. This is also evidenced by the fact that the predictive capability of the model for the urban group was not improved by entry of the enabling variables (i.e., chi-square for this step was not statistically significant). Once again, the regression models for both groups had limited predictive capability, as evidenced by the pseudo  $R^2$  (15% urban; 20% rural) and the percentage of correctly classified cases (64% urban; 67% rural).

### **Discussion**

The findings offer some evidence to support the assertion by Beland and colleagues (1998) that the roles and functions of an emergency department are shaped in part by its location. Differences were noted not only in the demographic characteristics of the people who presented to urban and rural emergency departments but also in their presenting problems. Rural emergency departments dealt with a potentially more vulnerable clientele in that they tended to be older and to have lower levels of education and income. They also dealt with a higher percentage of cases requiring routine or primary care (i.e., forms, prescription refills, and follow-up). Interestingly, the factors contributing to this usage differed for the two rural sites. In one of the rural emergency departments, a large proportion of physician coverage was provided by family physicians. Consequently, a number of participants saw the emergency department as an extension of their physician's office; they reported that they presented at the emergency department because they knew their physician was working there. However, in the second rural emergency department, which was staffed primarily by emergency physicians, almost 30% of participants did not have a family physician. Thus, many people viewed the emergency department as their only venue for obtaining routine care, such as prescription refills or required follow-up. Although Williams (1993) argues that this usage of rural emergency departments not only may be cost-effective but may increase the satisfaction of health-

care professionals working in these areas, it does raise questions as to continuity of care.

The findings reveal some differences in the health-care behaviours of people accessing emergency departments in urban and rural communities. Differences were not observed in the percentage of participants who self-treated with over-the-counter products or home remedies. However, those who accessed a rural emergency department were more likely to seek advice from a family member or friend and less likely to use the provincial Telecare service, which is noteworthy given the substantial investment that has been made in this resource. Although telephone consultation is a relatively new treatment option, it is frequently promoted as a means of equalizing the service availability in rural and urban areas and in reducing the burden on general practitioners and emergency departments (Hogenbirk, Pong, & Lemieux, 2005; Noorani, Fisher, Robinson, Joyce, & Pong, 2003). Limited information is available on the effectiveness of telephone consultation services in reducing access inequalities and the demand for other health-care services (Bunn, Byrne, & Kendall, 2006; Munro, Nicoll, O’Cathain, & Knowles, 2000). Because this was a study with people who had accessed the emergency department, we cannot speculate on the number of these visits that might have been prevented had Telecare been used.

Differences were also observed in the factors affecting participants’ health-care behaviours (i.e., use of self-treatment and willingness to wait) based on the location of the emergency department. Interestingly, these differences were more evident in terms of predisposing and enabling characteristics than in terms of the perception of need for care. In fact, the enabling factors made a statistically significant contribution to the predictive capabilities of the regression model only for those who accessed a rural emergency department. According to Andersen’s model, this finding may reflect inequities in the availability of health-care services for Canadians residing in rural communities. Andersen hypothesizes that access to services is equitable when the primary determinants of health-care utilization are need and predisposing characteristics and not enabling characteristics (Aday & Awe, 1997).

Given the extensive use of Andersen’s model, we were surprised by its limited ability to predict health-care behaviours. This finding may be due to the inclusion of irrelevant variables in the analysis; however, variable selection was based on a review of previous investigations of emergency department use that were guided by Andersen’s model. A second possible explanation is that Andersen’s theory, which was conceptualized to explain use of the American health-care system, may not be generalizable to the Canadian context. It is also possible that the findings indicate that use of the emergency department for less urgent health

problems is due more to contextual factors relating to the structure and delivery of current health-care services in urban and rural areas than to determinants specific to the individuals seeking care. In a recent publication (Brown et al., 2004), Andersen and colleagues note that individual characteristics tend to account for only 20 to 25% of the variance in access and propose that a significant proportion of the unexplained variance is attributable to geographic variation in access to health-care services. Establishing the validity of this statement will require more sophisticated methods of operationalizing geographic location than the conventional rural/urban dichotomy.

A possible limitation of this study is the fact that the findings are based on a convenience sample of English-speaking Canadians living in a predominantly rural eastern province with little ethnic diversity. Replication is needed to determine whether the findings hold over time and place. Future investigations would also be enriched by more comprehensive operationalization of the context in which health-care services are sought.

### ***Implications for Nurses Working in Rural and Urban Emergency Departments***

People with less urgent health problems constitute a significant proportion of those treated in Canadian emergency departments. Therefore, it is important that strategies for responding effectively to the needs of this group be identified. The primary factor in the participants' decision to access the emergency department, regardless of its location, was a perceived need for immediate care precipitated by concerns about the severity of the health problem or its potential to worsen. Although these problems were triaged as less urgent, one must appreciate the fact that the ability to assess health problems and identify those that warrant immediate intervention is a skill acquired by health-care professionals over many years. Thus, the ongoing debate on the appropriateness of using emergency departments for less urgent health problems serves little purpose. It would be more effective to restructure and staff emergency departments to reflect the actual patient population being treated (Chinnis & White, 1999; Schull, 2005; Shapiro & O'Brien, 2000).

Traditionally, excellence in emergency nursing has been measured in terms of acquiring the knowledge and skills needed to manage patients with life-threatening conditions (e.g., advanced cardiac and trauma care). Although the importance of these skills is indisputable, emergency nurses require a broader knowledge and skill base if they are to respond to the health needs of all their patients. If emergency nurses are to deal effectively with patients who present with less urgent health problems, they must be given opportunities to develop comparable proficiency in

primary care and health promotion. Many of the strategies that have been implemented to deal with patients who present with less urgent problems have reduced the involvement of registered nurses in their care (e.g., fast-track programs). Although such strategies may address problems stemming from high patient volumes, they circumvent an opportunity to augment people's ability to self-manage their health problems through teaching and the reinforcement of positive self-care practices.

Nurses, through their interaction with people seeking help for their health problems, are ideally situated to identify how changes to the structure and delivery of care are affecting patterns of health-care use in their communities. As change agents and advocates, nurses have an opportunity and a responsibility to promote the development of health-care services that match the needs of their particular geographic location.

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## **La santé des femmes vivant en région rurale en Ouganda : problèmes, mécanismes d'adaptation et recommandations**

**William Rutakumwa et Naomi Krogman**

Basée sur 63 entrevues semi-structurées, cette étude fait état des problèmes de santé et des mécanismes d'adaptation des femmes vivant en région rurale dans le centre de l'Ouganda et présente des recommandations concernant les services de santé. Les infections transmissibles sexuellement, en particulier la syphilis, les douleurs abdominales, les lésions génitales et la tension mentale comptent parmi les problèmes les plus souvent cités. Les répondantes ont relevé plusieurs obstacles à l'accès aux soins de santé, dont l'inaccessibilité des services de santé, le manque de temps et d'argent et l'obligation d'obtenir la permission des hommes pour sortir de la maison. Face à ces problèmes, elles font appel à différentes stratégies d'adaptation : ignorer le problème; se soigner elles-mêmes; faire appel aux herbes médicinales et à la médecine traditionnelle; recourir en cachette aux services de planification familiale. Parmi les besoins relevés par les répondantes, soulignons la présence de laboratoires médicaux de services de planification familiale, de services prénatals, de protection de la maternité et gynécologiques et de services de consultation en matière de santé. Les auteurs formulent des recommandations concernant l'éducation sur la santé s'adressant aux deux sexes, en particulier aux hommes en ce qui concerne la planification familiale.

Mots clés : santé des femmes vivant en région rurale, mécanismes d'adaptation, médecine traditionnelle, accès aux soins de santé, Ouganda

# **Women's Health in Rural Uganda: Problems, Coping Strategies, and Recommendations for Change**

**William Rutakumwa and Naomi Krogman**

This study draws upon 63 semi-structured interviews with rural women in central Uganda to elicit women's health problems, coping mechanisms, and recommendations for improved health services. The health problems most commonly reported by the women were sexually transmitted diseases, especially syphilis, abdominal pain, genital sores, and mental stress. Women indicated several barriers to obtaining health care, such as inaccessibility to health-care facilities, lack of time and money, and dependence on men for permission to leave the home. In response, they had devised several coping strategies for addressing their health problems, including ignoring the problem, self-care/medication, use of herbal/traditional medicine, and secret use of family planning services. The women indicated a need for medical laboratory services; family planning services; antenatal, maternity, and gynaecological services; and health counselling. They recommended health education for both genders, particularly for men regarding family planning.

**Keywords:** Health of rural African women, coping strategies, traditional medicine, access to health care, Uganda, developing country, gender

## **Introduction**

While the study of gender and health and community-based health care have been receiving attention since the 1970s, few studies have critically addressed women's health-care needs, coping strategies, and recommendations for change in rural Uganda (Uganda Bureau of Statistics [UBS] & ORC Macro, 2001). Limited access to health care in rural areas (UBS & ORC Macro) and a 3.3% natural population growth rate in Uganda (UBS, 2005) make it all the more important that the limited health services that are provided be suited to and effective for the rural population. Numerous studies report that rural women in Africa are underserved by health services (Okojie, 1994) and use other strategies to attend to their health-care needs (Whyte, 2001). This article provides (a) a general overview of the reported health problems and need for health services among women at two study sites in a rural district of central Uganda, (b) women's coping strategies at these sites in the absence of accessible and affordable health care, and (c) strategies to improve service delivery and women's health in rural Uganda.

The first author (WR), a Ugandan, had worked with rural women in Uganda for 4 years prior to undertaking this study. The inspiration for the study was his experience working with rural Ugandan women on income-generation projects and woodlot programs while employed by the Environment Conservation and Community Development Organisation and hearing women express their health-care needs in casual conversation. He also had contact with people working with the study population; this enabled the investigators to gain easy access to and acceptance by the study population.

### **Literature Review**

In the early 1970s “Uganda enjoyed a level of health services far superior to many other developing countries” (Scheyer & Dunlop, 1985, pp. 28–29). Free health services were provided by the government in hospitals, health centres, dispensaries, sub-dispensaries, maternity centres, and first-aid posts. Complementary services were provided by Catholic and Protestant medical bureaus as well as by private practitioners. However, a history of political instability in Uganda served to reverse this situation. The health-care infrastructure was destroyed (Dodge & Wiebe, 1985; Neema, 1999) and the government’s health-care expenditures dwindled due to increased military spending. The mid-1980s saw a deterioration of services in developing countries (Golladay, 1984; Neema), and Uganda was no exception.

Because of the unequal access to services, Ugandan rural women were hit hard by the situation. Common health issues among these women include early childbearing and close birth spacing (Okojie, 1994) and high fertility (United Nations Development Programme [UNDP], 1997; World Health Organization [WHO], 1999). Yet in the period 1990 to 1996 only 38% of births in Uganda were attended by trained health personnel and the maternal mortality rate in 1990 was 1,200 per 100,000 live births (UNDP, 1997), which is high by international standards (Okojie). Family planning services were poorly designed (Dixon-Mueller, 1994) and inadequate (Okojie), which likely contributed to the average annual population growth rate of 3.3% between 1991 and 2002 (UBS, 2005). A number of researchers have reported a high rate of sexually transmitted diseases (STDs), including AIDS (MacMillan & Ndegwa, 1996; Okojie; Turshen, 1991), while cervical and breast cancers have been at the top of all cancers that affect women in developing countries (Okojie). Women have also reportedly experienced nutritional morbidity (Okojie; Poostchi, 1986; Raikes, 1989) and physical stress (Raikes; Smyke, 1991; Turshen). Violence against women has also resulted in poor health (Gerbert et al., 1996; Smyke). In a study published in 1991, 46% of

women interviewed in Uganda's capital city, Kampala, reported having been abused by their spouses (Heise, Alanagh, Watts, & Zwi, 1994). In general, rural health services have not addressed the key health problems that women are likely to face (Muecke, 1996). The ministry of health has attempted to improve family planning and maternity services by training rural health-care providers to use its *Procedure Manual for Family Planning and Maternal Health Service Delivery* (Ministry of Health & Program for International Training in Health, 1995), but the availability and use of this manual have not been monitored.

Research on women's health has tended to concentrate on women's reproductive functions to the detriment of their productive functions (AbouZahr, Vlassoff, & Kumar, 1996; Eide & Steady, 1980). Moreover, women's health research rarely focuses on aspects other than family planning (AbouZahr et al.). With regard to service provision, the norm worldwide is to provide health care without taking gender into account, yet health care is experienced differently by women and men (Muecke, 1996). When those who design women's health services are insensitive to gender issues in rural health, those services either are not sought by or are inaccessible to women (Muecke).

We define rural areas as those where agricultural activities are the main source of income and where residents are at least 30 kilometres from a major urban centre. The health-care experiences of rural women are very different from those of urban women (Magadi & Curtis, 2003; McCray, 2004). Good health-care facilities are difficult to access as they are usually distant and involve travel costs (Sengooba, 2004). Travel time and costs are a particular hindrance for rural African women, whose workload has increased in the wake of the HIV/AIDS pandemic because they have taken on the responsibility of caring for sick and dying relatives (Collins & Rau, 2000). Additionally, the women's caregiving time detracts from their time for income generation, making it harder for them to afford travel costs.

In order to provide services that are relevant to women's health-care needs, one must first ask the question: What are women's health problems and needs? Since this question has traditionally been addressed to providers rather than recipients of health care, a study of recipients' perceptions is timely. A holistic approach can result in a better understanding of women's health and in the development of health-care policies that are more effective in addressing women's health-care needs. This study sought to narrow the research gaps by redirecting research attention from health-care providers to recipients, in this case rural women.

The study elicited the women's perspectives on their own health problems and how they addressed them, as well as their recommendations

for improving services to suit their health needs. Recent health research has focused on the social determinants of health or on contextual factors, such as the physical environment, social support, social and economic class, education, employment opportunities, and control over one's life choices, as key influences in individuals' health outcomes (Dixon & Welch, 2000; House, 2001; Marmot & Wilkinson, 1999; Ross, 2002; Wilken & Furlong, 2002; Wilkinson, 2000, 2005). Many of these factors can be studied using conventional statistics. For variables such as income, education, and income disparity, however, sociocultural factors are better understood using qualitative approaches with individuals who can describe their personal context as it relates to their overall health. The need for this research is all the more dire in rural Africa, where health outcomes are poorer than in most other parts of the world and life chances are heavily mediated through one's gender (Holmes, 2002; UNFPA, 2000) and cultural belief systems (Annan-Yao, undated; Holmes; Izugbara & Ukwai, 2004).

## **The Study**

### ***Setting***

Uganda is located in the eastern part of Africa. It shares borders with Sudan in the north, Tanzania in the south, the Democratic Republic of Congo in the west, and Kenya in the east. Its population in 2002, according to the census, was 24.7 million, of whom 12.6 million were female and 12.1 million male. The majority of the population, 88%, lived in rural areas (UBS, 2004). Of the 5.1 million households in the country, 3.5 million depended mainly on subsistence farming and 1.18 million were headed by females (UBS, 2005). The same census report reveals female and male literacy rates of 61% and 76%, respectively (UBS, 2005). The per capita GDP for 2001 was US\$1,490 (UNDP, 2003).

At the time of data collection (1999), our two study sites, Kasokwe and Kasana, were in the same district, Mukono District in central Uganda, with an area of 14,242 square kilometres.<sup>1</sup> The two communities are similar in size and in composition of livelihoods, but Kasokwe is more ethnically diverse. Kasokwe comprises the Baganda, Banyankore, and Rwandese tribes, whereas Kasana comprises mostly the Baganda tribe. Also, Kasokwe includes fishing as part of its economic activities, along with the crop and livestock production that is prevalent in both communities. Luganda is the major dialect of the Bantu language at the

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<sup>1</sup> At the time of the study, in 1999, before a new district was carved out of it, Mukono District had six counties: Bbale, Buikwe, Buvuma Island, Nakifuma, Ntenjeru, and Mukono (Rwabwogo, 1998). In the year 2000, one of the data-collection sites, Kasokwe, became part of the new district of Kayunga (UBS, 2002).

Kasokwe study site, as evidenced by the fact that it was preferred by all of the interviewees.

Mukono District lies between 1,158 and 1,219 metres above sea level. It usually experiences high temperatures and heavy rains in April/May and October/November. The participants in the study reported abnormally dry conditions in the late 1990s, with a negative impact on agricultural production. About 9% of the total area of Mukono District, 123,820 hectares, is covered by forest.

Agriculture is the main economic activity. Food crops include cassava, sweet potatoes, beans, maize, finger millet, ground nuts, soy beans, bananas, sorghum, simsim, cowpeas, pigeon peas, and yams. Cash crops include cotton, coffee, sugar-cane, and tea. Fruits and vegetables grown include tomatoes, onions, pineapples, vanilla, passion fruit, and cabbage. Dairy farming is also carried out, with an estimated 81,294 head of cattle in the district. According to WR's personal observations, the majority of women are involved in agricultural activities.

In addition to agricultural pursuits, the people of Kasokwe engage in fishing on Lake Victoria. There is also some industrial activity in the district, such as the processing of coffee, sugar, and tea. Manufacturing companies include Nyanza Textile Industries, Lugazi Sugar Works, and Nile Breweries. Other industrial activities include grain milling, furniture making, metal works, and animal feed manufacturing. We were unable to access information on gender distribution in formal and informal labour.

At the time of data collection, Mukono District had four hospitals, located in Kawolo, Nagalama, Nkokonjeru, and Kayunga. The Kayunga hospital was the largest. According to the study participants, the Nagalama and Kayunga hospitals were relatively accessible to the population at the two sites. Other health facilities included health centres, dispensaries, clinics, and first-aid posts. Much of the district's road network consists of unpaved roads and rural communities are not adequately served by public transportation. This situation contributes to the lack of access to health-care facilities. Mukona District is typical of rural Uganda in that agriculture is the main economic activity and access to health care is minimal.

### ***Design***

We used a qualitative research design to identify rural women's health problems, coping strategies, and recommendations for change. Given that the literature in this area is weak and it would be premature to develop categories of health problems, coping strategies, and recommendations for close-ended survey questions, our goal was to interview a random sample of rural women at two sites until we reached saturation of the response categories.

The study comprised 63 semi-structured interviews conducted at two central Ugandan study sites in January–April 1999. We used mostly open-ended questions, to elicit broader reflection on the context in which women experience health-care needs (Murphy & Dingwall, 2003; Ulin, Robinson, & Toley, 2005) (see Figure 1). This article summarizes the responses to key open-ended questions about health-care needs and the unexpected findings with regard to the women’s coping strategies in the face of inadequate health services.

**Figure 1** *Interview Guiding Questions*

1. What are the general issues/problems, if any, that trouble you in your daily life?
2. What are the health problems you usually experience in your daily life?
3. Have you always sought health care when you have a health problem? If not, what are those health problems for which you have sought prompt health care?
4. What are those health problems for which you usually do not seek (prompt) health care? Why do you not (promptly) seek health care in these cases?
5. How far are the nearest health services from your home? Are you able to obtain health care during the hours the health-care facility is open? How long do you generally wait to visit a health-care provider? What might prevent you from using the health services in your area when you feel you really should seek medical attention?
6. Were you satisfied with your last visit to a health-care clinic? Did the health-care provider request that you return for follow-up on the health problem for which the visit was made? Were you satisfied with the treatment and advice of the health-care provider? If medication was recommended, were you able to obtain the medication?
7. In general, do you have a preference for female or male health-care providers? Are there specific health problems for which you prefer specifically a female or male health-care provider?
8. Do you practise family planning? If no, why? If yes, what type of services do you get from the FP clinic (including counselling)?  
Were you asked by the provider:
  - (a) if you have had a recent delivery or abortion?
  - (b) if you have had over four pregnancies?
  - (c) if you are 35 years of age?
  - (d) if you are under 20 years of age (regardless of marital status)?

- (e) if you have any medical conditions likely to endanger the mother's life during pregnancy, childbirth, and immediately after — e.g., diabetes or heart disease?
  - (f) if you have HIV and/or AIDS?
  - (g) if you have had children within a birth interval of less than two years?
  - (h) if you have had a bad obstetric history that is likely to recur with future pregnancies, such as postpartum hemorrhage or preeclampsia?
9. Have you ever suffered from an STD? If yes, which was that? Were you tested/diagnosed? If you had treatment, did you go for post-test? If you did not go for a check-up, how did you establish the type of STD?
  10. Have you heard about cancers of the breast and cervix? If yes, have you ever taken tests for any of the above cancers? If yes, where? If no, why?
  11. Have you ever been physically assaulted by your spouse? If yes, how often?
  12. Do you have Community Health Workers in this area? If yes, what do they do? Are you satisfied with what they are doing? What would you like them to do?
  13. Reflecting on your past experiences with the health services in your village/area, what are your recommendations for improving the services that are available to you? What changes would you like to see?

### ***Sampling***

By working with the local council, WR was able to obtain a list of all the women in each village. We are confident that the lists were complete given that local councils normally maintain lists of all residents in their area of jurisdiction. By law, local councils must include a member who represents the interests of the women in the community. Because of her frequent contact with the local women, this representative is aware of the demographic distribution of the women in her village. WR selected the participants randomly from a basket of numbers corresponding to the names on the council's list. The selected women were subsequently asked by the local council representative and WR to participate in a semi-structured interview. To be included in the sample, the women had to be at least 15 years of age and to have accessed local health services for themselves or a family member. In rural areas, young women of 15 are considered mature enough to assume adult responsibilities, including responsibility for their own health. Most 15-year-old females are married or are



single mothers. Young women still living under parental control (unmarried and living at home) were excluded from the study. We suspect that some women in the community did not have access to health services due to physical inaccessibility. The interviews revealed that over 80% of women at the study sites either had no formal education or were primary school (Grades 1 to 7) dropouts. Of the sample, 92% reported being in a spousal relationship, but several of these women said that their spouses were usually away in search of jobs in urban areas. Only a few participants reported being single or widowed. Given 100% agreement to participate in the study, our sample was without replacement. Out of a total of 63 women, 32 were from Kasana and 31 from Kasokwe.

### ***Data Collection***

Permission to contact the women was obtained from the local council, which delegated the women's representative on the council to help WR contact those women who had been randomly selected. The pair paid a brief visit to each woman at her home to give her the project information sheet. Most women chose to have the information sheet read to them, which was followed by WR's asking the woman to take part in the study. If the woman indicated interest, WR set up a time for one of the female research assistants to visit for an interview. The researcher explained that his university required him to obtain consent for the interview and that the woman would be asked to sign a consent form. In two cases the woman indicated that she was willing to be interviewed but did not want to sign the consent form. The university human ethics board approved verbal consent in the absence of written consent.

The interviews were conducted by Ugandan female research assistants, fluent in Luganda, college educated, and experienced in social science research. WR held a 2-hour training session with the assistants before the start of data collection. The training entailed a review of ethical issues, with an emphasis on the need for participants' informed consent and their right to withdraw from the study at any time. The training also addressed the assistants' interviewing skills, stressing the importance of tag-and-probe questions. This was reinforced in the field by WR's regular checks on the audiotapes to assess the interviewers' skills in active listening and in posing appropriate tag-and-probe questions. WR's fluency in Luganda enabled him to fully understand the audio-taped dialogue between interviewer and participant, thereby minimizing data loss. At the end of each interview, the participant was paid a small amount of money as compensation for taking time away from her usual chores.

Another source of data was field notes. These included thick description of observations in the community regarding the conditions of health-care delivery, such as the health services available, their quality, and the adequacy and quality of staffing. Field notes also included observations of communication among community residents and reminders to WR to follow up with research assistants on particular matters. While in the field, WR also wrote memos regarding the observations and responses he was noting in the interviews. Memoing also entailed posing tentative reflective questions in a journal format and addressing them in subsequent observations and interviews.

Given the cultural constraints imposed on rural women, the participants were asked to choose the location for the interview. This enabled them to share their experiences with minimum inhibition. All of the interviews were audiotaped and most lasted approximately 45 minutes. Interviewing continued until WR found repeated themes throughout the interviews, suggesting saturation of responses.

### ***Data Analysis***

We used the constant comparative method of analysis described by Lincoln and Guba (1995) to develop descriptive categories. The central categories arising from this analysis were: (1) context, conditions, and strategies related to the women's lives; (2) the women's health experiences; (3) the women's experiences with health services; and (4) the women's recommendations for change. Coding was an iterative process during which data from the field were constantly compared to emerging categories. For instance, a statement such as "I need family planning services but do not have the money to visit<sup>2</sup> the clinic regularly as required by the service providers" was coded in "use of family planning services" as a category. Within each category, or unit of information composed of events, happenings, or instances (Strauss & Corbin, 1990), we identified several "properties" — attributes or characteristics pertaining to a category (Creswell, 1998). Thus, after examining the above statement, we identified three properties: need for family planning services, lack of money, and physical inaccessibility.

The data were closely examined and compared for similarities and differences. The emerging themes determined the information to be sought in the subsequent interviews. After the initial coding process, we carried out axial coding, whereby emerging themes were coded under central categories such as the women's (a) health experiences, (b) expe-

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<sup>2</sup> Several respondents referred to not having the money "to visit" a clinic; they meant not having the money to travel to the clinic, inferring physical distance or, in our coding scheme, physical inaccessibility to the clinic.

riences with health services, and (c) recommendations for changes to the health-care delivery system. Thus, a category such as “use of family planning services” identified during the open coding stage was subsumed as one of the various categories under the new category “experiences with health services.”

### ***Trustworthiness***

Sandelowski’s (1986) categorization of trustworthiness includes truth value (credibility), applicability (fittingness), consistency (auditability), and neutrality (confirmability). These categories were considered useful for this study. Credibility was enhanced by the trust that local council members demonstrated to WR in the field, WR’s ability to speak the local language, and WR’s quality checks on the audiotaped interviews, as described above. Fittingness was ensured through the selection of participants who were in an appropriate social location to assess and describe the health services available to Ugandan rural women. Auditability was ensured through comparison of the audiotapes with the written notes of the field assistants to assess the consistency with which they reported participant responses. Confirmability was enhanced through use of the constant comparative method to follow up on unexpected emerging themes (such as the women’s reporting stress as a health issue), and also through a concerted effort by the two principal investigators to share their findings with other experts in the field of international women’s health and to conduct “member checks” with local health-care providers to assess the persuasiveness of our findings. For example, during data collection, after preliminary analysis of the first set of interviews WR presented our preliminary findings to local health-care providers at a government-sponsored workshop on women’s health in rural Uganda. As a result of attending the workshop, WR became more sensitized to the complexities of women’s health, in particular issues around workload and stress, prompting us to explore and probe this topic a bit more in the interviews. Our sharing of findings with decision-makers in the Ugandan ministry of health served to assure us that the conditions in Mukono District were similar to those in other rural regions and permitted discussion of the services that were locally available to the women in a broader, national context.

### ***Limitations***

A few select limitations of the study warrant mention. The method of employing research assistants to conduct the interviews could have jeopardized the quality of data collected. In spite of the rigorous training of the assistants, it is possible that the interviews would have been more exhaustive had they been conducted by the principal investigators.

However, this weakness was mitigated by WR's regular perusal of the interview notes and comparison of these with the corresponding recordings. This enabled timely discovery of any issues requiring further probing and discussion with the assistants on how to improve their interviewing skills.

With regard to generalizability, Uganda has more than 50 districts and it is possible that women in the different districts have unique health problems and health-care experiences. However, Mukono District's poor socio-economic and health conditions, as well as its inadequate distribution of health services, are common across all rural districts in the country. Thus, we suspect that the findings can be generalized to some extent to all districts in Uganda.

## **Results**

### ***Perceived Health Problems***

The participants reported a range of health problems. In this article we summarize those that they considered important. Syphilis was the most frequently reported problem. Almost one in every two participants reported that they were suffering from this disease or had suffered from it and were not sure whether they had completely recovered given their lack of access to laboratory testing. Second on the list was abdominal pain, which was reported by approximately one in every four participants. This was followed by genital itching or sores, which was reported by approximately one in every five. Thus, the top three health problems were all related to reproductive health.

Other frequently reported ailments were malaria/fever, headache, respiratory problems, recurrent body weakness, heart problems, and gonorrhoea. In addition, participants reported cervical pain and breast lumps, often symptomatic of cervical or breast cancer. At the bottom of the list were ear conditions, asthma, and kidney problems. Besides those health problems reported directly by the participants, we were able to infer others based on their accounts. One such problem was mental stress. The prevalence of this problem appeared to be significant, as indicated by the frequency with which women alluded to it:

*My husband does not care for me at all. I take care of all the children's [needs]... I'm so disgusted with childbearing... That is why I decided to go for family planning. Besides, I have to walk a long distance to collect water, there is no money to buy food...I have no peace with my husband and myself.*

Our understanding of this woman's comment with respect to "no peace with my husband" was that she was resentful of her disproportionate

workload and her husband's lack of responsibility regarding household labour and use of birth control.

Services that were reported as most needed by the women included medical laboratory services; family planning; antenatal, maternity, and gynaecological services; and health counselling. The women also wanted to have health education for both genders, particularly for men with regard to family planning. Such services have traditionally focused on women and have been disproportionately concentrated in urban parts of Africa where there is relatively easy access to radio, television, and other media.

### ***Coping Strategies***

Given the inaccessibility of health services, rural women have developed coping strategies to address their health problems. Our data suggest that these coping strategies are inadequate, as the participants reported a wide range of ailments. Their coping strategies included ignoring the sickness, self-medication, use of herbal/traditional medicine, and secret use of family planning services.

The women tended to ignore their sickness because they lacked both the support of their husbands and the time needed to address the problem. Many women reported that they felt they were expected to seek permission from their husbands to obtain health care, which is consistent with the cultural expectation that husbands know the whereabouts of their family. Some women also reported that their husbands resented the cost of health care for chronic problems such as abdominal pain. Participants additionally reported that they ignored illness because of a lack of money and the distance of health services from their homes. Many said that they often ignored their ailments in the hope that they would go away on their own. The women added that usually they were forced to seek health care when the condition became serious:

*Most times when we are sick we leave the disease to heal by itself through natural ways. Because of the money limitation, I never seek health care until I become extremely sick.*

*I do not go promptly for health care, because sometimes I think the sickness will go away on its own.*

*When I develop a health problem, I take about a year before reporting it to a health-care centre, as I have to look for money.*

Self-care/medication was another common strategy. The women reported that they frequently self-diagnosed their ailments, sometimes with the help of their spouse, and purchased a drug that they deemed appropriate given their budget. Self-medication was carried out even in

cases where the women suspected STDs or had a complicated problem such as a kidney ailment. They also reported taking Panadol, a painkiller, for a host of health conditions associated with pain:

*I suffered from persistent joint pains until my husband bought me medicine for syphilis. Now I'm better.*

*I usually do self-medication. For example, I have a kidney problem and whenever I feel the pain I buy my own drugs from a drugstore.*

Given that some of the symptoms the women experienced were common to a number of health problems, there appears to be a high probability of wrong diagnosis, and thus ineffective treatment when women self-medicate.

The participants indicated that they generally preferred modern medicine for the treatment of health problems. However, when modern medicine appeared to be ineffective, or when the cost was too high, they turned to traditional medicine, and sometimes found this more effective. While some studies have found increased use of the services of traditional healers, the participants in this study did not seek these services but, rather, resorted to their own herbal concoctions to treat their ailments — an illustration of the active role that women play in their own health care. Women reported that they learned how to mix the herbal concoctions from their mother or from an elderly female member of their extended family. A typical example is what is locally known as *amalagala*, a product of crushed sweet-potato leaves mixed with water. This mixture is administered to pregnant women, who bathe in it or sit on it to lessen the risk of requiring a Caesarean section or of vaginal tearing during delivery. The women did not discuss trial and error for this concoction but unanimously reported confidence in its efficacy. Traditional medicine was reported to be used for treating birth complications, pediatric problems, and heart conditions. The views conveyed in the following statements were echoed by several women:

*During pregnancy I used to have pain in my abdomen. The medication I was given at the clinic did not help and the problem persisted. I had to resort to traditional medicine, which helped.*

*Before I stopped producing children, I used to spend sleepless nights trying to comfort my sick babies. This happened to all of my four children. I took them to various hospitals and their health problems persisted. I then resorted to the use of traditional medicine, which helped greatly.*

Some participants reported using family planning services secretly because their spouses were strongly opposed to the practice. Several women argued that they already had many children and felt physically

and emotionally weak. The physical weakness was related to workload, particularly around water collection, planting and tilling crops, and food processing and preparation. The emotional weakness refers to the stress of uncertainty, particularly with regard to having enough food for all of the children in times of drought and enough cash to cover the essentials, such as health care when a family member is ill. While men's opposition to their wives' use of family planning services is largely a function of culture, it is exacerbated by several factors, notably the lack of reproductive health education, especially in rural areas. The women suggested that they rarely discussed family planning with their spouses and that it is traditionally the man's role to decide how many children a couple will have. Under these circumstances, women indicated secret use of family planning services:

*We are on family planning programs secretly because our spouses won't allow us... Sometimes they [husbands] tell us that the Bible does not sanction the practice...but we seriously need the service.*

*I joined the family planning program without my husband's knowledge because at one time I delivered twice in a year and I was feeling weak.*

Secret use of family planning services by rural women may be considered a remarkable development in light of the fact that Ugandan rural women have traditionally favoured having many children as sources of future labour and security. This change in attitude could be an indicator of the perceived heavy toll of high fertility on women, as illustrated by the following comment:

*I wanted to join the family planning program but my husband refused to let me... I now have eight children... I have a painful abdomen. I think it is my uterus.*

### **Recommendations for Change**

Based on their experiences, the participants made a number of recommendations for improving their local health services. The women recommended that the ministry of health set up health-education programs, emphasizing that these should be targeted mainly at rural communities. They added that the focus should be on issues of particular concern to women, such as family planning, breast and cervical cancers, and other aspects of reproductive health. The women recommended that family planning education be targeted at rural men since men are a barrier to women's ability to more carefully control when to have children and how many children to have. The following view was echoed by several participants:

*Family planning education should be mainly for men, because they are the ones who stop their wives from using the services.*

In addition, some women recommended that confidential family planning services be offered in order to serve women whose actions are restricted by their husbands. They also recommended that rural health-care centres be well equipped and be staffed by well-trained resident health-care providers who are available 24 hours a day. They pointed to the need for laboratory and X ray facilities and suggested that required drugs be made available so that women do not have to purchase them on the open market. The participants recommended that health services for women, such as antenatal and maternity services, be extended to rural areas. They also recommended the deployment of more midwives to rural areas. The women proposed that traditional birth attendants undergo more training so that they will be able to carry out minor surgical procedures such as suturing, since birthing often takes place outside of health-care institutions. "I got torn during delivery at home but was never stitched up," said one participant, "and this really bothers me."

In view of the fact that some participants were not aware of the presence of community health workers in their area, the women recommended more deployment and training of community health workers, and more outreach by these workers, in order to reach all women in need of assistance. Most of the participants said they preferred female over male health-care providers because female providers have a better understanding of women's problems, especially with regard to reproductive health.

### **Discussion and Conclusion**

When women in rural Uganda require health care they encounter barriers, such as inaccessibility to health-care facilities, lack of time and money, and dependence on men. They have devised several strategies for coping with a particular health concern, including ignoring it, self-care/medication, use of herbal/traditional medicine, and secret use of family planning services.

However, these coping strategies have not been successful. Women in rural Uganda still report high levels of morbidity. Self-medication has always entailed the risk of wrong diagnosis and treatment, especially in the case of rural women who are in need of health education. The magnitude of this risk is conveyed by Whyte's (2001) finding that 63% of households in eastern Uganda and 83% of those in western Uganda owned a needle and syringe for home use, suggesting that self-medication is commonplace across the country. Indeed wrong diagnosis and treatment may explain the recurrence of syphilis, and possibly the exac-



erbatation of symptoms, as reported by the participants in this study. Even with correct diagnosis, self-medication may lead to under- or overdosing, as the participants lacked the training necessary to determine the right doses for treating their medical conditions. Indeed earlier studies (McCombie, 1996) have reported that underdosing is a common result of self-medication.

The present findings are also consistent with those of other studies conducted in Mukono District in central Uganda (Nakamate et al., 2003) and Kabarole District in western Uganda (Langlois, 2005). In these two studies, respondents were generally found to prefer modern medicine to traditional medicine. However, several respondents in our study reported using traditional methods when they could not afford modern medicine or when they believed it was ineffective. Although herbal or traditional medicine is used widely and is known to be effective in treating a variety of ailments, ranging from malaria (Asase, Oteng-Yeboah, Odamtten, & Simmonds, 2005) to skin disorders (Tadeg, Mohammed, Asres, & Gebre-Mariam, 2005), it may not be effective for more complicated health problems such as STDs or kidney disease. Several women in our study reported going to a health-care facility for diagnosis and treatment but continuing to experience the problem even after repeated visits and treatment. These experiences served to reduce the women's confidence in local health-care providers. Personnel in local facilities need more advanced training in order to diagnose and treat STDs, abdominal pain, genital sores, and mental stress.

The women who secretly accessed family planning services usually bought contraceptive pills at a drugstore without consulting family planning professionals. While they could obtain a prescription for birth control pills at family planning clinics, many women preferred to buy them over-the-counter at a drugstore. Women who obtained birth control pills at a drugstore faced less chance of being seen at a clinic and thus being associated with birth control. In addition, shopping at a drugstore was generally more convenient. In fact, many drugs that are prescription-only in North America are exported to Africa and are readily available over-the-counter in Uganda. Occasionally this situation is detrimental to the woman's health because the birth control pill is inappropriate. For example, researchers have reported that, for some women, use of contraceptive pills and injectable hormonal methods can have negative effects such as menstrual irregularities (Chapman & Gordon, 1999; Khefili, 1997) or infertility (Chapman & Gordon).

The women's recommendations for improved services, including well-equipped and well-staffed rural health centres, health education, and family planning education for rural men, would go a long way towards

addressing the problems and concerns of rural women. These recommendations, especially those concerning staffing, should be considered in the context of current human resource capacity. A World Health Organization report gives a figure of 19 nurses and 14 midwives per 100,000 people in Uganda (WHO, 2001). The shortage of doctors is corroborated by the findings of a 2004 study by Kinengyere (undated), which reports a doctor-to-patient ratio in Uganda of 1:10,000 in urban areas and 1:50,000 in rural areas. The shortage of health-care workers has been a function of poor remuneration, as a significant number of available professionals are reportedly not in active service (Kanyesigye, 2003). The successful implementation of the recommendations of our participants rests partly on the Uganda government's efforts to make the health profession attractive by offering adequate remuneration.

Nurses play a pivotal role in rural health-care facilities in Uganda. Matsiko and Kiwanuka (2003) report that registered nurses and midwives, respectively, are the most common local supervisors of rural health centres in Uganda. Yet the numbers of these health-care workers fall short of required staffing levels. For example, in a study of the treatment of women with obstetric fistula in 23 hospitals around the country, Karugaba (2003) found that the average nurse was expected to care for 70 or more patients, which had a negative effect on the both the quality and the quantity of care provided.

It is our view that the types of interventions recommended by the participants in this study cannot be effective unless they are carefully designed to focus on the problems and concerns of rural women. A carefully designed health education program, for instance, would entail a study of women's coping strategies, as this would inform the health education curriculum for the rural population. Preliminary studies to plan the design of health education programs could identify factors leading to drug resistance associated with self-medication. Future studies could examine the effectiveness of various forms of home remedies and traditional medicine on the key health problems faced by the women and how these interact with access to health services and formal medicine.

We propose that gender-sensitive policy interventions be based not only on the recommendations of rural women but also on their daily coping strategies. More broadly, given that rural women have been shown to play an active rather than passive role in addressing their own health needs, we favour policies that promote and nurture this sense of power and personal responsibility. Such policies would build on rather than disregard the women's indigenous knowledge, paving the way for women to become active participants in the policy interventions that affect them.

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## **L'influence de la distance géographique et sociale sur l'exercice des soins infirmiers et la continuité des soins dans une communauté autochtone éloignée**

**Denise S. Tarlier, Annette J. Browne et Joy Johnson**

Le but de cet article est d'explorer, à partir des conclusions d'une étude ethnographique, l'influence de la distance géographique et sociale sur l'exercice des soins infirmiers et la continuité des soins dans une communauté autochtone éloignée du Canada. Les auteures ont eu recours à des sources de données multiples afin de situer leur analyse dans le cadre unique que constituent les services de santé au sein de la communauté à l'étude. Leurs conclusions révèlent que l'éloignement géographique, les conditions sociales inéquitables qui influent sur la santé et le bien-être de la population autochtone, de même que le degré de préparation des infirmières face aux exigences d'un environnement complexe, engendraient des modèles de distanciation sociale en matière de relation thérapeutique. Ces modèles restreignent la capacité des infirmières à adopter une approche qui favoriserait la continuité des soins. Dans certains cas, la distanciation sociale s'est traduite par des pratiques d'étiquetage de l'Autre et par un désengagement à l'égard des patients. Transformer les déterminants de la santé autochtone dans les communautés éloignées constitue un premier pas important vers l'adoption de pratiques infirmières susceptibles de favoriser la continuité des soins et d'engendrer des améliorations durables en matière de santé.

Mots clés : communautés autochtones, exercice des soins infirmiers, étiquetage, désengagement, continuité des soins, relation thérapeutique

# **The Influence of Geographical and Social Distance on Nursing Practice and Continuity of Care in a Remote First Nations Community**

**Denise S. Tarlier, Annette J. Browne, and Joy Johnson**

The purpose of this article, which draws on the findings of a larger ethnographic study, is to explore the influences of geographical and social distancing on nursing practice and continuity of care in a remote First Nations community in Canada. Employing an ethnographic design, the authors use multiple data sources to ground the analysis in the unique context of health services in the selected community. The findings suggest that remote geographical location, the inequitable social conditions that shape the health and well-being of First Nations people, and nurses' level of preparedness to practise in this complex environment fostered patterns of social distancing in nurse-patient relationships. These patterns constrained nurses' ability to engage in practice that promotes continuity of care. In some cases, social distancing took the form of Othering practices and relational disengagement from patients. Changing the social determinants of Aboriginal people's health in remote communities is an important first step in supporting the changes in nurses' practice that are key to improving continuity of care and to effecting long-term, sustainable health improvements.

**Keywords:** Aboriginal peoples, First Nations, remote communities, nursing practice, primary health care nursing, Othering practices, relational disengagement, continuity of care, patient-provider interactions

Patients who experience fragmented health care are often described as “falling through the cracks” of health services. These patients typically receive care from multiple providers, often at all three levels of care (primary, secondary, and tertiary), and are often seen by providers at frequent intervals yet fail to achieve either optimal clinical outcomes or optimal continuity of care. While fragmentation of care challenges the delivery of quality health services in all settings, it is particularly critical in the context of health-care delivery in geographically remote Aboriginal<sup>1</sup> communities.

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<sup>1</sup> The term Aboriginal is used to refer, in an inclusive sense, to indigenous Canadian populations (Royal Commission on Aboriginal Peoples [RCAP], 1996). These are people who identify or are recognized as First Nations, Inuit, or Métis. The study site was a First Nations community where the majority of residents had “registered” First Nations status; therefore, the term First Nations is used in this work when referring specifically to the



Residents of remote communities in Canada experience both poorer health and poorer access to health services than Canadians living in urban, suburban, or even rural settings (Romanow, 2002; Statistics Canada, 2003). While acknowledging that a broadly accepted definition of *remote* has yet to be established (Pitblado, 2005), researchers have typically attempted to clarify the meaning of *remote* and distinguish it from *rural* by adding geographical descriptors such as isolated, semi-isolated, northern, or outpost. Geographic descriptors establish, in a general conceptual sense, the physical and logistical barriers that influence health in remote settings, such as distance, poor access, a small population base, and relatively few resources and amenities. Residents of remote communities are further removed (in both time and distance) from the level of definitive treatment that is available in larger population centres, and thus lack the safety net implied by proximity to secondary- and tertiary-level health services. These patients are also more likely to be affected by health-care delivery issues such as high staff turnover, lack of supports and resources within the community, and difficulty recruiting and retaining highly qualified personnel (Fontaine, 2005; Minore et al., 2005).

Aboriginal people make up a large proportion, if not the majority, of Canadians who live in remote communities (Statistics Canada, 2001). Relative to other Canadians, Aboriginal residents of remote communities are more vulnerable to experiencing fragmented care because the health and social inequities that exert a profound effect on health status (Adelson, 2005; Canadian Institute for Health Information [CIHI], 2004; RCAP, 1996) place them at increased risk of falling through the cracks of health-care delivery. The relatively poor health of Aboriginal people compared to that of other Canadians is linked to marked social and historical inequities (Adelson; RCAP; O'Neil, 1986, 1989; Waldram, Herring, & Young, 2006; Young, 1984) resulting from the historical social, political, and economic relationships between Aboriginal people and European settlers.

When health-services researchers describe a community as remote, the implication is that its residents (a) are predominantly Aboriginal, (b) have poorer health, and (c) have access to fewer health resources in their community than do other Canadians. Remoteness may also imply that remote Aboriginal communities have in a sense fallen through the

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study site and the First Nations residents of that community. The more inclusive term Aboriginal is used when referring to the wider context of Aboriginal health or social issues or to issues that are relevant to Aboriginal people generally. No differentiation is made or implied between Aboriginal people with registered Indian status and those without. Use of the term Aboriginal is not meant to be inclusive of the Aboriginal or indigenous people of countries other than Canada.

cracks in relation to both health-service delivery and the dominant society: they are remote by virtue of being socially, economically, and politically removed from mainstream society. For example, Aboriginal communities are not included in the databases developed for non-Aboriginal Canadians (e.g., the Canadian Community Health Survey database); thus, it is easier to lose sight of their health status in comparison to that of other Canadians. Neither are they part of provincial health-care systems. Being geographically distant from the places where provincial health services are located, remote Aboriginal communities are forced to rely on a federal system that has, in theory, developed to meet their health-care needs in the absence of available provincial services (Waldram et al., 2006). The distancing and isolation of remote Aboriginal communities from mainstream society have as much to do with the historical and sociopolitical positioning of Aboriginal communities and populations in Canada as with geographical location (Adelson, 2005; Waldram et al.). Thus, there is a complex interplay between geographical context and the historical socio-economic and political contexts of Aboriginal people's health, and it has profoundly influenced the health and social status of Aboriginal Canadians.

The purpose of this article is to examine one important aspect of the findings of a larger ethnographic study. The main objective of the study was to develop a broad understanding of how nurses, as the principal providers of primary care in a remote First Nations community yet recognized as just one part of a complex health-care system, influence continuity of care and clinical health outcomes. A comprehensive discussion of the larger study, including quantitative health-outcome data, can be found elsewhere (Tarlier, 2006). In this article, we explore how geographical and social distancing interacted to influence nursing practice and continuity of care. We focus on the conditions and factors that shaped nurses' ability to contribute to continuity of care in their practice within the remote First Nations community where the study was conducted. We define social distancing as nurse-patient interactions that are characterized by a sense of disengagement originating in nurses' feeling of disconnection from the broader social context of the Aboriginal community and patients' lives.

### **Literature Review**

Some improvements in the health status of Aboriginal people have been achieved in recent years, attributable primarily to public health strategies such as improved housing and disease prevention (National Aboriginal Health Organization [NAHO], 2003; Romanow, 2002). However, significant health disparities persist, stemming largely from the social and

economic conditions that shape people's lives and well-being (Adelson, 2005). For example, chronic diseases such as diabetes (Green, Blanchard, Young, & Griffith, 2003; Waldram et al., 2006; Young, Reading, Elias, & O'Neil, 2000) and heart disease (Shah, Hux, & Zinman, 2000), infectious diseases such as hepatitis A (Jinn & Martin, 2003), tuberculosis (CIHI, 2004; Indian & Northern Affairs Canada [INAC], 2003), and traumatic death and disability (CIHI; INAC; Karmali et al., 2005; Young, 2003) continue to be significantly more prevalent in the Aboriginal population than in the general population. These health disparities are reflected in health-status indicators such as Aboriginal infant-mortality rates a third higher than the national average (Adelson; CIHI; INAC; NAHO). Significantly, these statistics are not simply neutral indicators of health and well-being but reflect the profound impact of social inequities and the social determinants of health on the health of Aboriginal people (Adelson).

In many remote Aboriginal communities, nurses (sometimes referred to as outpost nurses) are the main providers of primary health care, yet they often have little preparation, over and above basic nursing education, to practise in a role that is considered both expanded and advanced nursing practice and that has traditionally been and continues to be considered a nurse practitioner role (Gregory, 1992; Martin-Misener, 2000; Stewart & MacLeod, 2005; Tarlier, 2006; Tarlier, Johnson, & Whyte, 2003). Nurses are responsible for providing primary care as well as community health nursing, public health care, and, often, the non-nursing health services that in less remote settings are typically provided by a multidisciplinary team. As nurses are the principal and often sole providers of health services in remote Aboriginal communities, any exploration of health-care delivery in these settings necessarily implies an exploration of nurses' role.

Gregory (1988) notes the dearth of literature, particularly research-based literature, related to outpost nursing in Canada. Authors of more recent works have made the same observation (Chaytor, 1994; McLeod, 1999; Tarlier et al., 2003). Until recently, the outpost nursing literature that does exist focused largely on how nurses and nursing practice are affected by the same issues that typify remote and Aboriginal health care: isolation, lack of support and resources, and sociopolitical and historical context (Gregory, 1988, 1992; Martin & Gregory, 1996; Tarlier et al.; Vukic & Keddy, 2002). In remote Aboriginal communities, nurses — the vast majority of whom are non-Aboriginal — are often isolated not only from the personal, professional, and social supports they have left behind in their home communities “down south,” but from the Aboriginal community itself. Most nurses are unprepared for the “culture shock” (Gregory, 1992, p. 188) that can be experienced upon arriving in a

community that is unexpectedly foreign in terms of culture, social conditions, language, and, often, the embodied inequities that shape people's health status in many remote reserve communities. Vukic (1997) links difficulties in building trusting nurse-patient relationships at the practice level to the sociopolitical context: "the difficulty in part stems from the constraining, structural, administrative, historical, cultural and political realities that have shaped northern community nursing" (p. 542).

Few studies have focused on nursing practice in remote First Nations communities or on evaluating health outcomes as a result of nursing practices. A multisite case study of continuity of care in three First Nations communities in northern Ontario (Minore, Boone, Katt, Kinch, & Birch, 2002; Minore et al., 2005) used a structure-process-outcome framework and retrospective chart review to extract patient data on three selected health conditions. The findings suggested that poor health outcomes were related to discontinuity of care. Factors contributing to the lack of continuity were high turnover of nursing staff, inadequate preparation and education of health-care providers, the failure of primary care providers to carry out "holistic assessments" of patients (Minore et al., 2002, p. 21), lack of follow-up care, and failure of providers to communicate patient information to each other. Continuity of care was also viewed as related to the organization of the health-services system. By using continuity of care to link the process and outcomes of health-care delivery and to identify gaps in care, the study by Minore et al. (2002) carried out key foundational work that the present study, focused more specifically on nursing practice, builds on.

## **Method**

One of the key challenges in conceptualizing this research lay in recognizing that whatever nurses' practice might contribute to health in remote Aboriginal communities, it is only one of many health determinants, including geographical location and historical and social inequities, that shape health disparities. Inevitably, the geographical, economic, and social contexts in which people live and in which health care is delivered exert strong influences on the structure of health-services delivery, health outcomes, and continuity of care. These interrelated issues were explored using ethnographic approaches, which were well suited to developing a contextualized understanding of the conditions that shaped nurses' ability to promote continuity of care in practice.

### ***Conceptual Underpinnings***

Two conceptual models provided a framework for conceptualizing the study and for the process of data collection and analysis: the Nursing

Role Effectiveness Model (NREM; Irvine, Sidani, & McGillis Hall, 1998) and conceptual work identifying features of continuity of care (Reid, Haggerty, & McKendry, 2002). The NREM is an adaptation of Donabedian's (1980) work, made specific to nursing practice. Situating the NREM within a primary health care (PHC) framework helped to conceptualize how, in addition to nurses' practice, health services structures, process, and outcomes were influenced by the broader context of Aboriginal health.

The recent conceptual work by Reid et al. (2002) on continuity of care asserts that this is a multi-faceted concept that encompasses all three of the identified types of continuity: informational, relational, and management. Informational continuity involves the transfer of information and the accumulated knowledge about a patient. Relational continuity refers to both ongoing patient-provider relationships and consistency of personnel. Management continuity depends on coordination and consistency in the approach to treatment management and flexibility, or an individualized approach to care. Situating the work of Reid et al. within the NREM as it was adapted for use in this research facilitated an understanding of continuity of care as an outcome of health services and nursing practice. The adapted NREM offered a framework from which to develop the study protocol, which outlined in detail the data to be collected, the sources of data, and the methods of data collection and analysis.

### ***Data Collection***

The study was conducted at a purposefully selected site that met four pre-established selection criteria: (a) primary care was provided chiefly by nurses working in an expanded and advanced nursing role and within a PHC framework, (b) the population was greater than 1,000, (c) a minimum of four nurses were employed in a nursing station, and (d) the community was isolated both geographically and in terms of access to health-care providers other than nurses (i.e., no physician in the community on a continuous basis). A First Nations community that met these four criteria was located in the northern region of a western Canadian province. Support for the research and permission to conduct the study in the community were obtained from the community Chief and the Band Council. Support for and permission to conduct the study in the community's nursing station were obtained from First Nations and Inuit Health Branch (FNIHB) Regional headquarters and from the nurse in charge of the nursing station. Ethical approval was obtained from a university Behavioural Research Ethics Board.

Data collection took place during three visits to the community over a 6-week period in the autumn and early winter of 2004. Due to the

expense and logistics of travel and the lack of alternative accommodation, the researcher (the first author) was immersed full-time in the study site while in the community. The researcher had extensive experience as an outpost nurse working and living in similar communities in the region, which facilitated her access to the community and her engagement with the nurses, community members, and FNIHB administrators.

Data were collected from multiple sources, including observation of nurse-patient encounters, participant observation of the day-to-day operations of the nursing station (e.g., staff meetings; informal interactions among nurses, other health-care workers, and nursing station staff), observations related to the broader community, and artifacts (e.g., documents, photographs, maps of the community). Both audiotaped and informal interviews were conducted with nurses, other health professionals, and para-professional and nursing station staff members, including Community Health Representatives, administrators, and clerical and maintenance staff who resided in the community. Thus, several of the interviewees were also local community members. Observations, including brief conversations with patients related to their experience of health care and continuity of care, and informal interviews were recorded as field notes.

Data collection during interviews was directed by “guiding questions” that were initially formulated to explore participants’ perspectives on how nursing practice and continuity of care were shaped by contextual and structural factors such as isolation, access to resources, and working conditions, as well as the broader contexts of the community and the organization of health services. Brief conversations with patients during observations of nurse-patient encounters were guided by questions aimed at exploring their experience of continuity of care. Consistent with ethnographic interviewing, the interviews were continuously modified in the field in response to early interpretations of the emerging data.

The participants are described in Table 1. The demographic characteristics of nurse participants ( $N = 15$ ) are summarized in Table 2.

<b>Table 1 <i>Participants</i></b>	
	<b><i>N</i></b>
Nurses	15
Other health professionals	2
Para-professional and support staff	4
Patients:	34
Women	20
Children	14

	<b>Position</b>	<b>Education</b>
Female: 13; male: 2 Age: early 20s to mid-50s European or Asian ancestry: 13 First Nations: 2	Permanent staff: 7 Relief staff: 7 Orientee: 1	Diploma: 6 BN/BSN: 6 PHC skills course: 6 Community Health Nurse upgrade course: 3 Unknown: 3

The length of time interviewees had spent in the community ranged from lifelong in the case of First Nations community members to weeks or months in the case of relief nurses. Of the non-First Nations nurses, two had worked in the community for a range of 2 to 4 years. While a number of the nurses employed in a relief capacity had worked in the community for a relatively short period (from less than 1 month to a few months), the majority had worked in other remote First Nations communities for varying lengths of time that in a few cases added up to several years.

Data from the chart contents as a whole were also collected. These data, referred to as "contextual notes," became a key part of the data set, providing a wealth of data that were particularly relevant to gaining an understanding of continuity of care at the study site.

### **Data Analysis**

Data analysis began in the field and was conducted concurrently with data collection. Initial analysis involved repeatedly reviewing the data, reworking, and rewriting, from jottings in the field to field notes that were continually expanded through the addition of interpretive memos. As key ideas were identified in the data, they were followed up and expanded upon in the field.

Data from each source were first analyzed independently using content analysis and subsequently interpreted in conjunction with the findings that emerged from other dimensions of the data set. The first level was based on a process of open coding and memoing, wherein data were coded line-by-line without reference to a priori theoretical assumptions (Emerson, Fretz, & Shaw, 1995). At a second, higher, level of analysis, data from the overall research process were analyzed thematically. The different levels of analysis undertaken for each data set were viewed not as discrete linear analytical events but as part of the iterative and ongoing development of ideas. Linking together the core themes and integrating

the findings of content analysis of each part of the data set facilitated the emergence of four over-arching themes. The adaptation of the NREM provided a conceptual structure within which to consider the three dimensions of continuity of care (Reid et al., 2002) that were used to guide analysis. These analytic strategies enabled a focused thematic interpretation of the data set as a whole.

### **Findings**

In this article we focus on the findings that were most relevant to understanding the interrelated nature of geographical and social location, and how it influences health, nursing practice, and continuity of care in the remote First Nations community where the study was conducted.

#### ***Nurses' Perceptions of the Remote Community: A World Apart***

When the nurse participants had first arrived at the study site, they understood that they were entering a community that was geographically distant from larger population centres. For the most part, they had expected that, because of its remote location and its First Nations population, the community would be “different” in some ways from the communities in which they customarily lived and worked. Indeed, several nurses noted that it was the difference, the opportunity to experience First Nations “cultures” and the sense of “adventure,” that had attracted them in the first place. Often, however, the nurses had not been prepared for the contextual contrasts they encountered on arriving in the community.

The community that served as the study site is located in the northern region of a western province, a 1- to 2-hour flight north of the nearest city. Like many remote communities, it is surrounded and isolated by water. It is accessible year-round by air, with daily scheduled service to and from the closest large service centre. However, transportation in and out of the community is often tenuous. Flights are sometimes “weathered out,” meaning that conditions prevent planes from landing or taking off. On any given day, high winds, storms, blizzards, fog, or extremely low temperatures may preclude flying. As in other northern communities, freeze-up and break-up present particular challenges to transportation within the community, as for 1 or 2 weeks each fall and again in the spring the ice is too thick to permit boat traffic yet not thick enough to allow people or vehicles to safely cross. The few roads in the community are unpaved and alternate between dust, mud, and ice, depending on the season. There are no sidewalks or shoulders to walk on. The dark forest grows right up to the verge, there are few streetlights to brighten the long stretches of road between buildings, and uneven



footing makes walking along the roads risky. Yet few residents own vehicles, so walking is a common mode of transportation.

In this particular community, the population varies between 2,000 and 3,000. The community's economic opportunities are limited, due to the long history of economic marginalization that affects many remote reserve communities in Canada, and its geographical location, far from any major industry or resources that could provide employment for a significant part of the population. Thus many residents are forced to rely on meagre social assistance payments as their main source of income. Less than 10% of the population is able to find full-time, year-round employment and the unemployment rate hovers around 30%, about five times the provincial rate of 6% (Statistics Canada, 2001). In 2001 the median average income of residents aged 15 and older was less than \$9,500, compared to more than \$12,400 for the province overall (Statistics Canada, 2001), and close to 40% of income earned in the community was government transfer payments (i.e., paid out largely as social assistance dispersed by local Band administration), versus 23% for the province as a whole (Statistics Canada, 2001). The community has both an elementary school and a high school up to Grade 12. However, barriers to high school completion persist: less than 2% of residents have been able to complete Grade 12. Of the residents who identified as First Nations, 97% spoke an Aboriginal language at home and 95% identified this as their first language (Statistics Canada, 2001).

At the time of the 2001 census, there were fewer than 500 houses in the community. Over 50% of these dwellings were more than 14 years old, over 40% were in need of minor repairs, and over 30% were in need of major repairs (Statistics Canada, 2001). This is a particular health concern, given Health Canada's (2003) definition of "adequate housing" as "housing units that do not require any minor or major renovations or replacement" (p. 65). Field observations suggested that more than one family in an extended family group reside in a small, two- or three-bedroom house. Local residents estimate that under 10% of houses in the community have running water, a condition of everyday life that is unknown to the majority of Canadians.

Both the First Nations community residents and the non-Aboriginal nurses frequently described the setting as "Third World." A nurse, who self-identified as First Nations and was a member of the community, described the conditions that many community residents lived with:

*Life is very difficult here. Running water and heat are big factors, in the morning especially, because people have to make a fire to warm up the house; sometimes when you go into the home early in the morning they're in bed just so they can stay warm. There are two or three families living*

*in one three-bedroom house. There's no running water, so hygiene is a factor. In some homes the water is frozen, so people have to build a fire and melt the water before they can wash up. Some of them don't change their clothes for a week because they don't have any water. How would they wash clothes? You need lots of water to wash clothes. They don't have dryers, they don't have towels to wash with, things like that. People don't eat properly because they're on a budget, on welfare. Their priority is to buy food.*

The lack of road access means that most goods are transported into the community by air, adding to the cost of groceries and basic supplies. One nurse described local costs as “exorbitant.” Field observations substantiated the high cost of basic necessities; for example, a case of infant formula (12 tins) cost \$58 (compared to \$26 for the same case in an urban centre), a box of disposable diapers cost \$35 (compared to less than \$20), and a box of laundry soap cost \$25 (compared to about \$8). Moreover, since the store is located across the water, far from where most First Nations residents live, transportation is by boat, or across the ice by foot, snowmobile, or vehicle. The water-taxi costs \$5 to \$8 per person one way, in a small open boat with no lifejackets on board; thus transportation is not only costly and inconvenient but also hazardous. The simple, everyday chore of purchasing necessities at the local store entails a degree of hardship that would be considered unacceptable in most Canadian communities.

Non-Aboriginal residents such as nurses, teachers, store personnel, and Royal Canadian Mounted Police officers, who together make up less than 1% of the population, have come to the community specifically to provide services. Therefore, notably, they are employed. Much of this 1% live together, segregated on one side of the water (the side where most of the services and resources are located), while the majority of the First Nations residents live on the “reserve side.”<sup>2</sup> In addition to having better access to local services, the small, mainly non-Aboriginal, off-reserve community enjoys noticeably better housing and roads that, while not paved, are at least graded and gravelled. Most of the nurses, however, live on the reserve side, where they are accommodated in a nurses' residence that provides a standard of living similar to what nurses are accustomed to in the south or in larger centres. Thus, the nurses enjoyed a substantially higher standard of living than most of their patients. In this remote First Nations reserve community, the historical sociopolitical context of

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<sup>2</sup> The word *reserve* refers to the Crown lands historically assigned to specific Aboriginal groups. The designation and assignation of Aboriginal people to reserved lands reflects the historic colonial subjection of Aboriginal people in Canada (Adelson, 2005).

Aboriginal people's lives has fused with the implications of geographical isolation to create a context of profound inequity in the social determinants of health.

### *Nurses' Practice in the Context of Difference*

Nurses' work, influenced by the broader community context of inequity and marginalization, occurred at the margins of mainstream nursing practice. Nurses newly arrived in the community found themselves in a world that was drastically different from the one they were accustomed to in urban or suburban, predominantly non-Aboriginal settings. The substandard housing, the lack of running water, the high cost of food, supplies, and transportation, and the reality of poverty within the community were among the contextual issues raised repeatedly by all participants, suggesting that little has changed since Gregory (1992) reported on similar findings 15 years ago. The First Nations health professionals and administrators who participated in this study clearly identified the need for non-Aboriginal nurses to be better prepared to work within the context, culture, and enculturated social conditions of a remote Aboriginal community. While most of the nurses had received a 3-week orientation, including an introduction to the isolation and the environment they could expect to find, they nevertheless felt unprepared. One recently arrived nurse stated, "*Nothing* prepares you for the reality of it."

For nurses, it was also a different world because the work expectations were quite different from those in the settings they were familiar with. Few perceived any part of their formal nursing education as having specifically prepared them to work as a primary care provider in a remote setting or in the context of Aboriginal health, cultures, and communities. This suggests that outpost nursing requires knowledge and skills well beyond what can be learned in basic nursing education programs. One participant felt unprepared for the reality of practice despite having several years' experience in acute critical care nursing: "I didn't really know what was expected of me until I got up here and saw — oh my god, this is what I've got to do. It freaked me out."

In addition to arriving ill-prepared for primary care practice, the nurses were faced with an exceptionally challenging patient population in terms of complex disease management and co-existing social and health issues. Community residents lived with everyday risk factors for poor health that would be considered unacceptable in mainstream communities, such as overcrowded housing conditions without running water. Nurses were expected to provide primary care in a setting that was defined not only by health and social inequities but also by an overwhelming burden of illness and injury. One nurse described her initiation

to the work as follows: "When I came here, everything seemed to be stressing me out. It was the isolation, being in a different culture... but the work aspect of it had me so stressed out that it was affecting everything else." Contextual and practice issues such as these contributed to a high turnover rate among nursing staff at this site. A review of relevant documents revealed that over 70 nurses had been employed in the nursing station in the 2-year period immediately preceding data collection.

Observational and interview data show that nurses were confronted daily with patient situations they felt helpless to remedy, such as children who were brought in for treatment of impetigo but who lived in a home without running water, or diabetic patients who could not afford to make healthier food choices. While nurses may have appreciated in theory the link between social inequities in the community and the health disparities they encountered on a daily basis, few of the nurses in this study possessed either previous experience in community health nursing or the knowledge and skills needed to address health issues at the community level. Thus nurses focused on what they felt they could manage, which was the day-to-day, task-oriented work of treating immediate health problems within a biomedical model of care, yet knowing that the treatment they were offering was often only a band-aid solution, given the root causes of poor health in the community. In discussing how nurses managed the broader challenges imposed by embodied health and social inequities, one nurse participant stated:

*Diabetes is a huge, complex health issue, and the nutrition is really poor, and the poor sanitation is another huge issue, and you see a lot of really preventable things come in the door, and some days it just seems like you see the same thing over and over and over again, and that's frustrating... we just deal with one situation at a time.*

Most nurses felt better prepared to respond to the prevalence and significance of poor health in the community by focusing on acute episodic care of patients at the individual level, rather than by approaching the issues that contributed to poor health from a more comprehensive community health nursing perspective. Nurses focused on treatment or curative services within a biomedical model, at the expense of health prevention and promotion activities within a PHC or community-development model. This suggests that they experienced role confusion related to understanding the broad, community basis of their nursing work. This dynamic allowed nurses to cope with their work environment, but it also fostered unintentional complacency about the prevalence of poor health and the issues that contributed to it. While most nurses appeared to link health with its social determinants in theoretical terms, at the practice level they often failed to link the prevailing

social and health conditions with patients' use of health services, which was in turn a reflection of continuity of care. For example, nurses often failed to see that social conditions in the community, such as lack of transportation or child care, presented challenges for mothers, who may have missed an appointment for prenatal or postpartum follow-up or for infant immunization. Nurses often ascribed behaviours such as failing to return for follow-up to a failure to take responsibility for one's own health. In effect, a degree of complacency blinded nurses to the health disparities that were the real health challenges facing their patients.

### ***The Effects of Social Distancing on Nursing Practice and Continuity of Care***

It became evident that the majority of nurses lived in the familiar world of the nursing station, remaining largely unaware of the unfamiliar world of the surrounding community. One First Nations nurse remarked that if non-Aboriginal nurses "come from a middle-class town or city that's quite different to here, they can't completely know what the reserve is like, so they never really get accustomed to it." Nurses encountered the realities imposed by the community context on a daily basis, yet they lived and worked within the protective bubble of the nursing station and residence, isolated and insulated from the community. Nurses were not really a part of the community or of the *other* world they associated with it; the local community was not *their* world. This paradox allowed nurses to maintain a distance from the reality they encountered in the clinic and in the community. As with previous research that identified nurses working in outpost settings as being "other" in the remote Aboriginal community (Tarlier, 2001; Vukic, 1997; Vukic & Keddy, 2002), distance between nurses and the community created space for nurses to remain disconnected from the community and disengaged from patients' lives.

Their disconnection and disengagement at the community level influenced nurses' engagement in health-care encounters at the individual level. Nurse-patient encounters suggest a process of relational disengagement, reflecting the challenges that influenced nurses' ability to engage in responsive relationships with patients (Tarlier, 2004). Othering, defined as a process of differentiation wherein people are set apart on the basis of perceived or supposed difference from the dominant culture (Browne, 2005, 2007; Johnson et al., 2004), was observed as contributing to nurses' disengagement from both the community and individual First Nations patients. These patterns of social distancing are complex. For example, the nurses experienced the process of Othering in relation to the community, yet at the same time engaged in a process of Othering themselves, from within the predominately non-First Nations environment of the nursing station.

Observational and interview data suggest that Othering is reflective of the difference that non-Aboriginal health-care providers perceived between their own worlds and the world of the local community. For example, one nurse who had relatively little experience working in remote First Nations communities remarked, "I don't think it matters how close you get or how much you're involved in the social activities; we're white, they're Aboriginal." As Browne (2005) points out, such framing of intercultural relationships in terms of "us"/"them" binaries (p. 79) reflects both "popularized assumptions" (p. 79) and racialized discourses that permeate social discourses in Canada and play a role in shaping many people's constructions of Aboriginal people. Thus, the Othering practices observed in the data represent individual nurses' mirroring of broader social discourses about Aboriginal people, rather than being an intentional or conscious effort to engage in practices or behaviours that reflect Othering. At the same time, the process of Othering affected the extent to which nurses were able to convey acceptance of and respect for the patients they encountered in the nursing station. Othering thereby mitigated the formation of responsive nurse-patient relationships and contributed to a sense of distance between nurses and patients. According to Reid (2002), the strength of the relationship between patient and provider (or provider teams), which includes characteristics such as respect, trust, communication, and comfort, is an important aspect of relational continuity of care. Thus, distance in interpersonal relationships compromised relational engagement, which was the linchpin holding together the process of providing care and informational and management continuity.

In the absence of relational engagement, the process of care was characterized by a sense of disengagement within nurse-patient encounters, which was one factor creating gaps in continuity of care. The consequences of disengagement, and its influence on continuity of care, can be significant; for example, as reported elsewhere, such patterns of relating and gaps in continuity of care can have discernable effects on maternal-infant health outcomes (Tarlier, 2006). Thus, geographical and social distancing interact to influence nursing practice and, in turn, continuity of care.

## **Discussion**

At the meso and micro levels of health-service delivery, community relations and nurse-patient encounters in the context of this remote community magnified the ways in which Othering practices contributed to social distancing (also described in Browne, 2005, 2007, and Tarlier, 2004) and constrained the extent to which continuity of care could be enacted in everyday nursing practice. At a societal level, Othering perpet-

uates social inequities and marginalizing practices in health care (Browne, 2005, 2007; Browne & Fiske, 2001). Clearly, it is important that these issues, particularly the role of social distancing, be considered in relation to continuity of care in geographically isolated Aboriginal communities, where health disparities are greatest.

Nurse-patient encounters do not occur in a vacuum but are situated within a context that influences both nurses and patients. In remote Aboriginal communities, context is shaped by the implications of being geographically distant from the resources, supports, and amenities that are taken for granted by most Canadians and by the social and historical realities and conditions that inform the social location of Aboriginal people in Canada. Moreover, the system of delivering health services to Aboriginal Canadians is situated within and structured by the historical and sociopolitical context of Aboriginal health. Each of these contexts influences the unfolding of nursing practice in ways that have implications for the health of the residents of remote First Nations communities.

Conceptualizing nursing practice and continuity of care within a PHC framework serves to highlight these links among the social and environmental contexts, the structure of health services, and the processes of achieving continuity of care and health. PHC enables a broad view of the multiple factors — both within and external to the health-care system — that influence health (O’Neil, 1986). While the present findings suggest that specific aspects of context shape nurses’ practice in a remote First Nations community and their ability to influence continuity of care, the conceptual underpinnings of the study serve to remind us that no single circumstance can be identified as “causing” the findings related to continuity and health outcomes.

Health-services researchers postulate that improving continuity of care serves to decrease fragmentation of care (Haggerty et al., 2003; Sparbel & Anderson, 2000). If fragmented care is exemplified by the idea of patients “falling through the cracks” of health-care delivery, continuity of care may be represented by the idea of ensuring the safe and efficient passage of patients as they navigate the health-care system. In the context of nursing practice in remote Aboriginal communities, improving the ability of nurses to contribute to continuity of care represents a critical strategy for improving health.

Based on the three aspects of continuity of care identified by Reid et al. (2002), the findings of this study reveal that gaps in continuity (Tarlier, 2006) were influenced by factors in the context, structure, and processes of health-services delivery at the study site, as well as by factors within nursing practice. For example, management continuity was often compromised by nurses’ lack of preparation to provide community-based primary care in a First Nations community, which was in part attribut-



able to the unavailability of appropriate educational opportunities at the organizational level. Informational and relational continuity were affected by the high staff turnover and the inconsistency of staffing at the organizational level and by relational disengagement between nurses and patients at the individual level.

The process of Othering acted as a barrier to nurse-patient engagement and the formation of respectful, responsive relationships between nurses and individual patients. Similarly, in a study of First Nations women's beliefs about prenatal care, Sokoloski (1995) identified the discriminatory attitudes of health-care providers as a barrier to prenatal care; First Nations women were more likely to be satisfied with care and to attend prenatal visits when health-care providers engaged wholly with them during interactions. In the present study, as in Browne's (2005, 2007) study of encounters between nurses and First Nations women, nurses did not intentionally or even consciously engage in Othering practices. However, their lack of insight related to Othering practices contributed to distance in nurse-patient interactions, precluding the formation of engaged, responsive relationships with patients and possibly inadvertently compromising patients' use of health services and thus the continuity of care.

One of the external factors identified by Donabedian (1980) in his original work applying the structure-process-outcome framework to evaluation of health services was inequity in the social valuation (and thus access to health services) of "different segments of the population" (p. 16), or, in contemporary language, populations that are marginalized by social and health inequities. As Donabedian suggests, and as the present findings confirm, the structure and processes of health care do not imply singular cause-and-effect relationships; rather, they imply a web of multi-causal interrelationships that are shaped by the complex inter-workings of multiple health and health-care influences.

In its most essential definition, PHC has the expressed goal of enabling populations to achieve equitable health by effecting meaningful and sustainable change in the social and economic dimensions that influence health. The social inequity and marginalization that emerged as the contextual backdrop of this study must be addressed through broad health-policy changes guided by the PHC principles set down by the World Health Organization (1978). Health policy — and the delivery of nursing care within communities — must be realigned to better reflect the essential philosophy and spirit of PHC. Initiating new structures within federal health policy-making that give Aboriginal people a greater voice in policy formulation at the highest levels is congruent with the philosophical mandate of PHC and is a necessary step in breaking the grip of a system that has never really been freed of its colonial roots.



For nurses to become fully invested in the process of creating change in the context of Aboriginal health, they must have the knowledge and skills needed to support their role as brokers of a PHC model, in the unique yet diverse contexts of practice they will encounter in remote Aboriginal communities. Nurses' practice in these communities calls for a profound understanding of the principles of PHC and community development, as well as knowledge related to the historical and contemporary sociopolitical contexts of Aboriginal health, the social dynamics that underlie the process of Othering, issues related to geographical location and health, and cultural safety. This is no small challenge, given that nursing education tends not to focus on the sociopolitical context of health or health-care inequities, marginalizing practices in health care, or the complex processes of Othering (Browne, 2005). However, this kind of knowledge would enable nurses to develop an awareness of the multiplicity of complex factors and social conditions that affect the health of Aboriginal people. Fostering a strong foundation of clinical knowledge is equally important if nurses are to strive towards improving continuity of care in Aboriginal communities; nurses require advanced nursing practice skills as primary care providers in order to provide effective and efficient primary care and to engage effectively with patients. This is particularly true for nurses working in communities where geographical and social distances call for a multiplicity of skills, knowledge, and nursing competencies.

As the present findings suggest, nursing practice in remote Aboriginal communities is broad and complex and requires formal knowledge and skills that are not only beyond basic nursing education but also beyond nurses' usual informal experiential learning. By better understanding their role as primary care providers working within a PHC model of health, nurses will be better positioned not only to exert a positive influence on continuity of care and health outcomes but also to facilitate change in the broader picture of health determinants that so profoundly influence health in remote Aboriginal communities. There is an urgent need for research on the development, delivery, and evaluation of formal educational opportunities to prepare nurses for practice in remote Aboriginal communities, as well as research to further explore and substantiate the relationships between nurses' preparation, continuity of care, and health outcomes. In keeping with the fundamental principles of PHC, future research should also focus on incorporating the perspectives of Aboriginal stakeholders, including those at the local community level.

It is time to critically examine the policies and structures that have shaped both Aboriginal health services and the preparation of nurses to provide care in remote Aboriginal communities, to rectify those policies and structures that support or perpetuate the inequitable delivery of

services and strengthen and build upon those that support the fundamental principles of PHC and that effect change in the social determinants of the health of Aboriginal people. Such actions will support the changes to nursing practice that are key to improving continuity of care and to effecting long-term, sustainable improvements in both health and nursing practice in remote Aboriginal communities.

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Résumé

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**La concurrence dirigée en matière de services de prestation de soins à domicile et ses effets sur les infirmières**

**Diane Doran, Jennie Pickard, Janet Harris, Peter C. Coyte, Andrew R. MacRae, Heather S. Laschinger, Gerarda Darlington et Jennifer Carryer**

Cette étude avait pour but d'explorer le rapport entre les caractéristiques des contrats de soins à domicile (en tant qu'indicateurs des relations de travail), la satisfaction des infirmières au travail et la perception de la sécurité d'emploi. Une collecte de données fondée sur un modèle transversal a été menée auprès de 11 centres d'accès aux soins communautaires (CASC), de 11 agences de prestation de soins infirmiers situés dans la province canadienne d'Ontario et de 700 infirmières. Un sondage envoyé par la poste aux CASC a servi à recueillir des données sur la durée des contrats accordés aux agences, les possibilités de renouvellement, le volume de service qui leur est confié et leur niveau de profit. Un deuxième sondage par la poste auprès des infirmières a permis de recueillir des données sur leur âge, leur sexe et leur situation d'emploi, ainsi que le nombre d'années de service au sein de la communauté et de l'agence pour laquelle elles travaillaient au moment de l'étude. On a recueilli des données sur leur satisfaction au travail à l'aide de la *Nursing Job Satisfaction Scale*. On a évalué la perception de la sécurité d'emploi à l'aide d'un seul élément mesuré sur une échelle de Likert de cinq points. On a relevé des différences notables entre les agences de prestation sur le plan de la perception de la qualité des soins chez les infirmières, de la satisfaction au travail, de la satisfaction à l'égard du temps consacré aux soins et de la sécurité d'emploi. Les aînées ont rapporté une plus grande satisfaction au travail que leurs cadettes. Les infirmières payées sur une base horaire s'estiment plus satisfaites du temps consacré au travail que celles qui sont payées à la visite. Sur le plan de la sécurité d'emploi, celles qui travaillent à titre occasionnel se sont dites moins satisfaites que celles qui travaillent à temps plein. Des différences ont été relevées entre les différentes agences de prestation, mais on n'a établi aucun lien avec le niveau de profit. D'autres travaux de recherche seront nécessaires pour déterminer les meilleures pratiques que peuvent adopter les agences afin d'accroître la satisfaction de leur personnel.

Mots clés : soins à domicile, qualité des soins, satisfaction au travail

# **The Relationship Between Managed Competition in Home Care Nursing Services and Nurse Outcomes**

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The objective of this study was to investigate the relationship between the characteristics of home-care contracts, as indicators of employment relationships, and nurses' job satisfaction and perceived job security. A cross-sectional design was used to collect data on the study variables. The setting was 11 Community Care Access Centres and 11 nursing provider agencies in the Canadian province of Ontario. The sample included 700 nurses. A mailed survey was used to collect data from CCACs on length of contract awarded to provider agencies, potential for renewal, volume of service awarded, and profit status of the agency. Data were collected, via a mailed survey, on nurses' age, gender, work status, and years of employment in the community and at the current agency. The Nursing Job Satisfaction Scale was used to collect data on nurses' job satisfaction. Perceived job security was assessed using a single item measured on a 5-point Likert scale. Significant differences were found among provider agencies in nurses' perception of the quality of care, work enjoyment, satisfaction with time for care, and job security. Older nurses rated work enjoyment higher than younger nurses. Nurses paid on an hourly basis were more satisfied with their time for care than those paid on a per-visit basis. Nurses employed on a casual basis were less satisfied with job security than those employed on a full-time basis. Differences in nurse outcomes were observed among nursing provider agencies, but these were not related to the profit status of the agency. Further research is needed on the best practices within agencies that result in more satisfied staff.

**Keywords:** Home care, community nursing, quality of care, job satisfaction

Home care has become an increasingly important component of health services. Various models for managing and delivering home care have evolved. Until 1995, communities in the Canadian province of Ontario had home-care programs that either employed nurses directly or contracted with not-for-profit and for-profit nursing agencies to provide nursing care. In 1997 the Ministry of Health and Long-Term Care established 43 Community Care Access Centres across the province to provide a single point of access to home care and coordination of long-term placement. By 2002 two of these CCACs had been merged, leaving a total of 42. The creation of CCACs was accompanied by both divestment

of direct-service professional staff from public/government agencies and the adoption of managed competition/competitive bidding, commonly referred to as a Request For Proposals (or RFP) process for nursing service contracts. The RFP sets out a CCAC's requirements in areas such as client services, financial management, and organization (Carefoote, 1998).

The purpose of this study was to investigate the impact of managed competition in Ontario on the quality of nurses' worklife and job security.

Managed competition was introduced in Ontario with the goal of achieving quality care at greater efficiency. Only a few studies have investigated the impact of managed competition on caregivers and provider agencies. Denton, Zeytinoglu, and Davies (2003) studied occupational illnesses among nurses, personal-support workers, and therapists working in clients' homes. They focused on home-care workers, which included both visiting home-care workers such as nurses and personal-support workers employed by a nursing provider agency under contract with a CCAC, and office workers, which included case managers, coordinators, supervisors, and managers working directly for an Ontario CCAC. High levels of stress, burnout, and physical health problems were documented, many of which were deemed to be preventable. The study concluded that restructuring and organizational changes in Ontario were significant factors in increasing job dissatisfaction, absenteeism, fear of job loss, and propensity to leave. However, because the investigators conducted their study at one point in time, after the introduction of managed competition, there is no way to rule out other possible contributors to job dissatisfaction and absenteeism. Abelson, Gold, Woodward, O'Conner, and Hutchison (2004) observe that implementation of the competitive contracting model in Ontario has resulted in high transaction costs incurred by purchaser and provider agencies, as well as quality of care and continuity concerns raised by individual clients and by providers who must establish and build new relationships following the awarding of new contracts and agency transfers. They report that transaction costs were incurred by provider agencies that required dedicated staff time at the managerial level to oversee the competitive bidding process. CCACs incurred weeks of dedicated case-manager time to communicate and oversee the changes that resulted from the awarding of the contracts. Case managers also incurred opportunity costs in working to ensure a smooth transition between "old" and "new" agencies.

When the Massachusetts Department of Public Health employed a form of competitive bidding for mental health services, Schlesinger, Dorwart, and Pulice (1986) concluded that the contracting process added administrative complexity and that the initial cost savings were relatively



small. To the extent that cost savings existed, they primarily reflected lower wages paid by for-profit agencies, as opposed to public agencies. However, along with these lower wages came higher employee turnover and reduced continuity of care. Similar results are reported by Shapiro (1997) for Manitoba. In the Manitoba study, contracting out led to lower service costs. However, it did so at the expense of lower employee wages, higher staff turnover, and lower job security. In addition, there were high administrative costs associated with managing the service contract.

In summary, debate has been prevalent in the health-care literature about the benefits of competitive bidding for health-service delivery. None of the research has involved a comprehensive evaluation of the impact of managed competition on the quality of nurses' worklife. The present study was designed to address this gap in the literature. It investigated the impact of aspects of managed competition — specifically, the profit status of the provider agency awarded a nursing service contract, the volume of service, and duration of the contract — on nurses' job satisfaction and perception of job security.

### **Theoretical Perspective and Study Variables**

Social exchange theory (Blau, 1964) was used as the theoretical basis for the study because it enables conceptualization of the interplay between characteristics of the employment relationship and employees' responses in terms of affective and behavioural outcomes. Social exchange theory describes employment relationships as based on a balance between inputs and outputs in social transactions where reciprocity is sought (Blau, 1964; Coyle-Shapiro & Kessler, 2000). In order to retain and recruit nurses, employers need to develop strong employment relationships. Positive employment relationships are developed through the social exchange process. Variables such as work conditions, access to benefits, and employment within one's preferred employment pattern (e.g., full-time vs. part-time employment) have been used to characterize the employment exchange relationship (Malette, 2005; Van Dyne & Ang, 1998). Strong employment relationships have been identified as influencing job satisfaction and workplace morale, which can affect the quality of nursing care provided (Lowe & Schellenberg, 2001).

The employment relationship variables in this study were nursing provider agency profit status, duration of the service contract with a CCAC, volume of service, potential for contract renewal, employment pattern (full-time, part-time, or casual), and method of remuneration. Profit status was selected for investigation because it has been associated with variation in wages paid by for-profit agencies (Schlesinger, Dorwart, & Pulice, 1986), which could affect nurses' job satisfaction and

intention to leave (Irvine & Evans, 1995). Duration of service contract and potential for renewal were selected because of evidence that longer contracts produce greater stability in employment, resulting in higher staff morale (Schlesinger, Dorwart, & Pulice; Shapiro, 1997). Volume of service was selected because it, too, could provide agencies with the opportunity to build stable staffing resources. Employment pattern was selected because of concerns raised about the casualization of the nursing workforce, although evidence concerning its impact on nurses' quality of worklife is controversial, with some nurses preferring part-time over full-time work (Mallette, 2005). Method of remuneration was selected because of research evidence that contracting out results in lower wages (Shapiro). In Ontario, home-care nurses are paid either by the hour or by visit. Under an hourly remuneration scheme, nurses are paid for hours worked; under a per-visit scheme, they are paid by the visit. The per-visit rate could under- or over-represent actual hours worked. The nursing outcome variables selected for investigation were nurses' perception of job security and job satisfaction as measured by three variables: satisfaction with the quality of care, satisfaction with time for care, and work enjoyment. In order to control for individual nurse factors that could explain variation in these outcomes, the following nurse characteristic variables were included: years of employment with the agency, years of employment in community nursing, age, and hours worked per week.

The study was exploratory rather than hypothesis testing because of the lack of strong empirical literature on which to generate hypotheses. Research questions were generated to guide the data collection and analysis based on social exchange theory and the findings from the literature review.

Five research questions were explored: Do nurses employed by for-profit as opposed to not-for-profit agencies report lower levels of (a) satisfaction with the quality of care, (b) satisfaction with time for care, (c) work enjoyment, and (d) job security? Is longer duration of the nursing provider contract and potential for renewal associated with higher (a) satisfaction with the quality of care, (b) satisfaction with time for care, (c) work enjoyment, and (d) job security? Is higher volume of service contract associated with higher (a) satisfaction with the quality of care, (b) satisfaction with time for care, (c) work enjoyment, and (d) job security? Is nurses' employment pattern (i.e., full-time, part-time, casual) associated with (a) satisfaction with the quality of care, (b) satisfaction with time for care, (c) work enjoyment, and (d) job security? Is nurses' method of remuneration (i.e., hourly or per-visit) associated with (a) satisfaction with the quality of care, (b) satisfaction with time for care, (c) work enjoyment, and (d) job security?

## **Method**

Data were collected over a 12-month period in 2002–03. A survey design was used to collect data on nursing outcome variables and employment characteristic variables. The study received ethical approval from the research ethics board of the University of Toronto.

### ***Setting and Sample***

The setting consisted of CCACs and their nursing provider agencies. All CCACs in the province were eligible to participate. A total of 11 CCACs were randomly selected from among the 42 in the province, ensuring regional representation. If a CCAC declined, another CCAC in the same region was invited to participate. Eleven CCACs declined to participate due to either multiple concurrent commitments or impending changes in provider contracts related to a competitive bidding cycle. All nursing provider agencies holding contracts with the participating CCACs were invited to take part. One agency with a single contract declined to participate, resulting in a total of 11 nursing agencies with 34 contracts represented. There were more contracts than agencies because provider agencies held contracts with more than one CCAC.

The sample consisted of Registered Nurses (RNs) and Registered Practical Nurses (RPNs). Nurses were eligible to participate if they had worked a minimum of 6 months with a provider agency that consented to participate in the study. A sample size of 700 nurses was sought, based on an estimated small effect size, a power of 95%, and a significance level of 0.01 (adjusting for multiple tests of significance). Of the 1,430 questionnaires distributed, 700 were returned completed, for a response rate of 49.0%. Nurses were on average 45 years old ( $\pm 9.64$ ), female (98%), and married (77%), with 8.2 years ( $\pm 6.22$ ) of community nursing experience, 6.0 years ( $\pm 5.32$ ) with their current employer, working 29 hours ( $\pm 12.1$ ) per week. There were 479 RNs (68.5%), 211 RPNs (30.2%), and nine advanced practice nurses (1.3%). The sample was evenly split between nurses working with for-profit ( $n = 348$ ; 49.7%) and not-for-profit ( $n = 352$ ; 50.3%) agencies. With respect to employment pattern, 212 nurses worked full-time (30.4%), 266 part-time (38.3%), and 219 casual (31.4%).

### ***Measures***

***Nurse characteristic variables***, consisting of age, gender, work status, and years of employment within the community and at the current agency, were obtained from the nurse survey.

***Employment relationship variables***, consisting of profit status, contract volume, duration, and potential for renewal of the nursing provider

agency were collected from a survey sent to CCACs. Contract volume was measured as the total annual number of nursing visits in the most recent contract. The duration of the contract and the potential length if renewed were measured in months. Method of remuneration was assessed with one item in the nurse survey.

**Nursing job satisfaction** was measured using the Nursing Job Satisfaction Scale (Atwood, Hinshaw, & Gerber, 1987), whose three subscales reflect nurses' perception of quality of care, work enjoyment, and time to do one's job. Items are rated on a five-point scale. Examples of items measuring satisfaction with the quality of care include: whether it is difficult to provide high-quality care, whether it is difficult to give good care, satisfaction with the technical care, ability to provide individual care, and ability to keep the client comfortable. Examples of items measuring work enjoyment include agreement with the statements: satisfied with my job for the time being, definitely dislike my work (reverse scored), and find real enjoyment in my work. Examples of items measuring satisfaction with time for care include agreement with: usually have enough time to do a good job, have to work overtime to get paperwork done, and could deliver better care if I had more time. The construct validity of the scale is supported and its reliability and validity are documented (Cronbach's alpha = 0.88) (Atwood et al.). In the present study, Cronbach's alpha for the three subscales of the Nursing Job Satisfaction Scale was: for the RN sample ( $n = 479$ ): satisfaction with quality of care (0.81), work enjoyment (0.87), and satisfaction with time for care (0.89); for the RPN sample ( $n = 211$ ): satisfaction with quality of care (0.81), work enjoyment (0.84), and satisfaction with time for care (0.89).

**Perception of job security** was assessed by a single item measured on a five-point Likert scale.

### **Data Collection**

The Executive Director of each CCAC was contacted by mail and invited to participate in the study by signing and returning a consent form in a self-addressed stamped envelope. If the Executive Director declined to participate, another CCAC was randomly selected from the same region until each region of the province was represented. Following enrolment of CCACs, all of the affiliated nursing agencies were invited to participate by signing and returning a consent form. Provider agencies were asked to distribute questionnaires to nurses by preparing two mailing labels for each eligible nurse. An agency representative advised the Research Coordinator of the number of eligible nurses, who then provided packages containing the nurse invitation to participate, a questionnaire, and a stamped envelope self-addressed to the research team.

Agencies were asked to send a package by mail (postage paid) to every nurse who had been employed by their agency for 6 months or more. In order to protect nurse confidentiality, nurses were not identified by name. Return of a completed questionnaire indicated consent to participate in the study. After approximately 2 weeks, the agencies were asked to distribute a one-page flyer to the same nurses, thanking those who had already returned their questionnaires and reminding others that a response would be valued by the research team.

### ***Data Analysis***

The SAS statistical program was used to analyze the data. Means and standard deviations were calculated to describe the distribution of the study variables. Hierarchical linear modelling (HLM) was conducted to explore the research questions. The HLM assessed the relationships between the employment relationship variables measured at the agency level and outcome variables measured at the individual level. Nurse characteristic variables that were significantly correlated ( $p < .05$ ) with the outcome variables were entered as covariates at the individual level. HLM was conducted in order to account for the fact that nurses were nested within agencies. Agencies were, in turn, nested in contracts. Contracts were nested within CCACs. However, agencies were not nested in CCACs, because the same agency could have a service contract with more than one CCAC. In order to represent the multiple levels of data, the researchers had to decide whether to model the results at three levels or two. Three levels would have nurses nested within contracts, which in turn are nested in CCACs. Two levels would have nurses nested within agencies.

The two-level model was chosen, for several reasons. First, at no time was significant variation in outcome variables observed between CCACs, suggesting that modelling variation at the CCAC level was not important for the data. Second, the model included other variables that represented the contract characteristics, such as volume of service and length of contract. Third, and probably most importantly, the predictor variables entered to explain variation in the outcome variables were the same for the two-level and the three-level models. From a theoretical perspective, it is usually desirable to represent the findings by the most parsimonious model. It is possible that some nurses worked with the same agency under more than one contract. This was unlikely to confound the analysis, because agencies with multiple contracts typically hold contracts with more than one CCAC. Because CCACs are geographically distributed across the province, it is unlikely that nurses worked outside their own geographic region.

<b>Table 1 Fixed Effect Results</b>			
<b>Variable</b>	<b>Coefficient</b>	<b>T Value</b>	<b>P Value</b>
<b><i>Satisfaction with Quality of Care</i></b>			
Profit status of agency	0.244	1.14	0.26
Age of nurse	-0.001	-0.30	0.76
Length of employment with agency	0.006	1.12	0.27
Hours worked	0.004	1.71	0.09
Casual work status	0.02	0.31	0.76
Employed part-time	0.06	0.80	0.43
Length of contract	-0.003	-0.69	0.49
Potential length of contract if renewed	0.003	1.28	0.20
Volume of contract	-0.01	-1.42	0.16
<b><i>Work Enjoyment</i></b>			
Profit status of agency	0.13	0.81	0.42
Age of nurse	0.006	2.31	0.02
Length of employment with agency	-0.005	-1.0	0.32
Employed full-time	-0.06	-1.00	0.31
Employed part-time	0.05	0.90	0.37
Length of contract	0.002	0.90	0.61
Potential length of contract if renewed	-0.001	-0.61	0.54
Volume of contract	-0.01	-1.56	0.12
<b><i>Satisfaction with Time for Care</i></b>			
Profit status of agency	0.26	0.88	0.38
Age of nurse	-0.001	0.34	0.73
Length of time employed with agency	-0.01	-1.72	0.09
Employed full-time	0.12	1.40	0.16
Employed part-time	0.06	0.79	0.43
Length of contract	-0.007	-1.26	0.21
Potential length of contract if renewed	0.002	0.74	0.46
Volume of contract	-0.02	-1.90	0.06
Pay determined	0.21	2.37	0.02

<b>Perception of Job Security</b>			
Profit status of agency	0.23	0.60	0.55
Age of nurse	0.002	0.30	0.76
Employed full-time	-0.55	-3.85	0.001
Employed part-time	-0.07	-0.59	0.56
Length of contract	-0.005	-0.58	0.57
Potential length of contract if renewed	-0.002	-0.47	0.64
Volume of contract	-0.001	-0.04	0.99

## Results

### **Descriptive Results**

Eighteen (52.9%) of the nursing provider contracts were held by for-profit agencies. On average, there were three nursing service contracts per CCAC (*range* = 2 to 5), with an average volume of 56,352 ( $\pm$  27,760) nursing visits, length 35 ( $\pm$  7.4) months, and potential length 52 ( $\pm$  14.6) months. The length of contracts was comparable to the provincial mean of 33 months and potential length if contract renewed of 49 months. The method of remunerating nurses was evenly split between hourly (46%) and per-visit (50%). The percentage does not add up to 100 because a few nurses reported remuneration based on both an hourly and a per-visit basis (3%).

Nurses' scores on the quality of care variable ranged from 1.33, indicating low quality, to 5.00, indicating very high quality. The mean score of 3.84 (*SD* = 0.65) suggests a moderate level of satisfaction with quality of care. Nurses were least satisfied with their ability to provide high-quality care (3.48) and most satisfied with the technical nature of care (3.99) and their ability to keep clients comfortable (4.11). Nurses were on average not satisfied with time for care. The mean score was 2.83 (*SD* = 0.82). They were least satisfied with time for paperwork (2.73) and time to discuss patient-care problems with other nursing personnel (2.70). A mean score of 3.84 (*SD* = 0.54) indicated that nurses were moderately satisfied with work enjoyment. Of the items measuring work enjoyment, nurses expressed least satisfaction with the conditions of the job (1.69) and balance between work and leisure (2.14). A mean score of 2.62 (*SD* = 1.28) indicated a low level of satisfaction with job security.

### **Hierarchical Linear Modelling (HLM) Results**

The results of the HLM analysis are presented in Table 1. There were significant differences in nurses' satisfaction with the quality of care

among provider agencies ( $p < 0.05$ ); however, none of the other variables selected for analysis significantly predicted nurses' satisfaction with quality of care.

**Work enjoyment.** The HLM models indicated significant differences in nurses' work enjoyment among agencies ( $p < 0.05$ ). The average work enjoyment for nurses employed by for-profit and by not-for-profit agencies did not differ significantly. Older nurses rated work enjoyment higher than younger nurses.

**Satisfaction with time for care.** The HLM models indicated significant differences in nurses' satisfaction with time for care among agencies ( $p < 0.05$ ). Nurses who had been with the same agency longer were less satisfied with time for care than those who had been with the same agency for a shorter period. Nurses paid on an hourly basis were more satisfied with their time for care than those paid on a per-visit basis. Total volume of the contract was negatively related to nurses' satisfaction with time for care.

**Satisfaction with job security.** There were significant differences in nurses' perception of job security among provider agencies ( $p < 0.05$ ). The only other predictor of satisfaction with job security was employment status: nurses who were employed on a casual basis perceived less job security than those employed full-time.

In summary, there were significant differences in all of the nurse outcome variables among provider agencies. When these differences were explored, none of the employment relationship variables were found to predict satisfaction with quality of care. Three employment relationship variables predicted satisfaction with time for care: length of employment with the agency, remuneration based on an hourly rather than a per-visit rate, and volume of the service contract. Only one employment relationship variable predicted satisfaction with job security: casually employed nurses were less satisfied with job security than nurses employed full-time.

## Discussion

Several dominant themes have emerged in the literature concerning the impact of managed competition on the quality of home health services and outcomes for nurses. The discussion has reflected concern that restructuring of home health services has resulted in increased stress and burnout and decreased physical health and job satisfaction for home-care workers (Denton et al., 2003). It has led to increased absenteeism and fear of job loss (Denton et al.), undermined trust (Browne, 2000), and perhaps compromised continuity of care (Browne).



Nurses who participated in this study reported moderate work enjoyment and low job security. They were least satisfied with their ability to provide quality care, time for paperwork, time to discuss patient care problems with other nurses, conditions of the job, and balance between work and leisure. They were highly satisfied with the technical nature of care and their ability to keep clients comfortable. Approximately one third of the nurses worked full-time, one third worked part-time, and one third were casual/relief. Nurses who worked casual hours were less satisfied with their job security than those who worked full-time.

In general, these findings suggest that home-care nurses are moderately satisfied with their work but lack job security and are experiencing time pressures to complete their daily work. There were significant differences in nurses' perceptions among agencies on all dimensions of job satisfaction. Specifically, nurses working with some agencies reported higher quality of care, work enjoyment, satisfaction with time for care, and satisfaction with job security. When the differences among agencies were explored, they were found to be unrelated to whether the nurse worked for a for-profit or a not-for-profit agency. Older nurses reported more work enjoyment than younger nurses. Satisfaction with time for care was inversely related to the length of time the nurse had worked with the agency: nurses who had worked longer were less satisfied with time for care. This finding may reflect the fact that nurses who had worked with an agency for a long time had experienced different time pressures and expectations in the past, prior to the introduction of technology that has resulted in major changes in the acuity of clients being cared for in the community. There has also been an increased need for care around the clock, 7 days a week. Also worthy of note is the fact that nurses who were paid on a per-visit basis were less satisfied with their time for care than nurses who were paid on an hourly basis, suggesting the need to examine and perhaps revise the models for remuneration of home-care nurses.

Flynn and Deatricks (2004) report on the following important agency attributes, as identified by home-care nurses in the United States: preceptor-based orientation, real-time phone support, interdisciplinary coordination, scheduled time off, realistic workload, adequate staffing, supportive administrative practices, competent supervisors, and patient-centred vision. With the exception of "realistic workload," which conceptually overlaps with the measure of "satisfaction with time for care," these types of work conditions were not explored in the present study. However, because there were differences in nurses' perceptions among agencies, a more thorough understanding of the work conditions that contribute to nurses' job satisfaction in the home-care setting is an

important area for future research. Future studies could investigate the impact of both work-environment variables and employment relationship variables on home-care nurses' work enjoyment, satisfaction with the quality of and time for care, and perceptions of job security. The work-environment variables suggested by Flynn and Deatrlick in their study with US home-care nurses could be explored in studies with Ontario home-care nurses.

Social exchange theory was used to guide the selection of variables and research questions. Variables such as work conditions, access to benefits, and employment within one's preferred employment pattern (e.g., full-time vs. part-time) have been used to characterize the employment exchange relationship (Mallette, 2005; Van Dyne & Ang, 1998). Three of the employment relationship variables selected for investigation in this study were significantly associated with one or more of the nurse-satisfaction variables — namely, length of employment with the agency, volume of service, and method of remuneration. These findings suggest that social exchange variables are important for understanding nurses' job satisfaction, although further research is needed to determine whether other employment relationship variables are important to understanding community nurses' job satisfaction. For instance, Mallette's findings suggest that knowing whether a nurse is employed in a preferred employment pattern (i.e., voluntary employment status) is more important for understanding nurses' affective response to their work than whether the nurse is employed in a casual, part-time, or full-time position.

### ***Study Limitations***

This study took place just after the Ontario government reorganized home-care nursing services and introduced management competition through the competitive awarding of home-care contracts. Home-care nursing provider agencies were adapting to these changes at the time of data collection. The impact of this transition to managed competition on the study results is unknown. However, it might be useful to repeat the study when the market response to managed competition has further stabilized. The employment relationship variables were aggregated to the agency level. Therefore the variability among these aggregate measures was limited to a sample size of 11 agencies. This leads to the recommendation that future studies be conducted with a larger agency sample size.

### **Conclusion**

Debate about the comparative performance of for-profit and not-for-profit home-care providers has been prevalent in the health-care literature (Rosenau & Linder, 2001). Much of this debate has yet to be

informed by the findings of evaluation studies. The present study has begun to address this gap in the literature. It investigated the impact of the competitive model of awarding home-care nursing contracts in Ontario on nurses' job satisfaction and job security. No differences in nurses' satisfaction with the quality of care, work enjoyment, satisfaction with time for care, or job security were observed between agency ownership types. For the most part, none of the contract characteristic variables, such as contract volume and length, explained variation in nurses' satisfaction with the quality of care, work enjoyment, or satisfaction with time for care. However, three of the employment relationship variables were associated with higher levels of satisfaction on one or more of the job-satisfaction variables: full-time employment, remuneration on an hourly basis, and volume of service.

The policy implications of these findings are several. The results suggest that the quality of nurses' worklife does not suffer under for-profit delivery of home-care nursing. Nurses from both types of agency expressed moderate levels of work enjoyment and low levels of satisfaction with time for care and job security. Policy implications include the need to promote opportunities for full-time employment and remuneration of nurses on an hourly rather than a per-visit basis. Differences observed at the agency level suggest the need for further investigation of the best practices within agencies that result in more satisfied staff. It is also possible that the concern about having adequate time to provide care is not sector-specific but is common to nursing in other settings such as acute care.

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*Résumé*

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## **La préférence du personnel des soins prolongés pour les questionnaires électroniques**

**G. Peggy McFall et Doris L. Milke**

Le personnel des soins infirmiers a-t-il l'impression de participer à un nombre trop élevé de recherches? Les questionnaires électroniques sont-ils une méthode pratique de collecte de données? On a demandé à des membres du personnel du plus important établissement de soins prolongés au Canada de répondre à ces questions dans le cadre d'un sondage (mené en versions électronique et papier). Vingt-cinq directeurs des soins infirmiers et 32 autres professionnels du secteur ont indiqué qu'ils préféreraient les questionnaires électroniques. Ils ont rapporté être satisfaits de leur apport aux travaux de recherche et précisé que le principal facteur qui limitait leur participation était la charge de travail. Le recours aux questionnaires électroniques pourrait donc avoir un effet positif sur la relation entre chercheurs et personnel infirmier, condition essentielle de la qualité de la recherche menée en soins infirmiers.

Mots clés : collecte de données, personnel

# **Preference of Continuing Care Staff for Electronic Surveys**

**G. Peggy McFall and Doris L. Milke**

Do care staff feel they participate in too much research, and are electronic surveys a convenient way of collecting data? Care staff at Canada's largest public provider of facility-based continuing care were asked these questions in a questionnaire (i.e., electronic survey or paper survey) developed for this study. A total of 25 nursing managers and 32 other professional care staff indicated that they preferred electronic surveys and were satisfied with the extent of their research participation. They also indicated that workload was the main deterrent to their research participation. Use of electronic surveys could positively affect the researcher/care staff relationship that is so important to the quality of health-care research.

**Keywords:** Data collection, computers, staff, applied research

Evidence-based practice in nursing care involves the inclusion of the best available research evidence in the decision matrix of good patient/client care. Gathering research in applied settings is a challenge, however, because care staff are often extremely busy and reluctant to take the time required to participate in data collection. The barrier to research participation most often cited by nursing staff is lack of time (Happell, 2004; Hutchinson & Johnston, 2003; Valente, 2003). This concern is validated by evidence that nurses are working harder and have a wider variety of duties now than in the past (Bojtor, 2003; Fitch, 2004). It is essential that the research process be made as attractive as possible to staff members who are directly involved in the provision of care. One way to do so is to decrease the time required for data collection.

Initially, staff members may be motivated to participate in research by the exciting prospect of contributing to research knowledge. If their participation does not produce results, however, they may be reluctant to take part in other studies and their relationship with researchers may become strained. The importance of the researcher/nursing staff relationship is well documented (Conn, Burks, Rantz, & Knudsen, 2002; Engle, 1999; Ruckdeschel & Van Hitsma, 1997). Collaboration between researchers and practitioners is essential to the development of good, robust research. To maintain a positive relationship with staff, researchers must ensure that data collection is manageable (Hutchinson & Johnston, 2003). This study focuses on ways to decrease the time needed for data

collection. Specifically, as care staff must take their workload into consideration, how can we tip the balance in favour of research?

Bojtor (2003) argues that, in health care, technology may be adding new tasks to an already busy work day. However, other researchers have shown that computer technology can significantly reduce the workload of nursing staff (Adderley, Hyde, & Mauseth, 1997; Wong et al., 2003). When an information technology system was implemented on an intensive-care unit, the proportion of time per shift that research nurses spent documenting tasks was reduced from 35% to 24%, and the time saved was translated into direct patient care (Wong et al.). A veterans-care facility implementing a paperless system found that computerization allowed more time for direct patient care; in addition, it decreased wait times for processing orders, eliminated transcription errors, and permitted faster communication among departments and between doctors and nurses (Adderley et al.). Electronic records used for monitoring cataract surgery patients have been cited as a major factor in improving access to cataract surgery (Johnston, Sparrow, Canning, Tole, & Price, 2005). These results indicate that technology can decrease the patient-care workload with regard to charting and sharing information. Therefore, it seems reasonable to assume that adopting computer applications in research, such as well-planned electronic surveys, will decrease the workload of direct-care staff and thus improve patient care.

Hanscom, Lurie, Homa, and Weinstein (2002) found that electronic surveys increased the consistency and completeness of the data collected and eliminated the need for manual data entry. Electronic surveys have been shown to be more convenient than paper surveys for researchers in several professions, by reducing costs, providing faster response times, and resulting in a more flexible and more easily standardized survey (Courtney & Craven, 2005; Jones & Pitt, 1999; Kiesler & Sproull, 1986; Raziano, Jayadevappa, Valenzuela, Weiner, & Lavizzo-Mourey, 2001; Schleyer & Forrest, 2000; VanDenKerkhof, Parlow, Goldstein, & Milne, 2004). However, there has been little investigation of whether electronic surveys are more convenient for study participants. The present study examined whether electronic surveys allowed care staff to collect data more quickly and with less interference in day-to-day tasks.

We addressed four research questions: 1. *Do electronic surveys result in faster response times and higher response rates than traditional paper surveys?* 2. *Do care staff feel sufficiently competent with computers to use them for data-collection tasks such as completing electronic surveys?* 3. *Do care staff believe they spend too much time on research activities?* 4. *Do electronic surveys make it more convenient to participate in research?*



## **Method**

The study used a two (electronic survey, paper survey) by two (nursing managers, other professional staff) between-subjects design. The factor of survey type allowed for exploration of response times and rates. The factor of staffing designation was used because nursing managers, who typically have a baccalaureate degree, were expected to have more computer and research experience than other nursing staff. In addition, at the time of the study there were constraints on computer access for frontline nursing staff whereas all nursing managers had computer access. The nursing managers in this study not only managed and coordinated the provision of care (24 hours a day, 7 days a week) for residents in an assigned unit, directing and supervising staff, but also served as the residents' case managers, coordinating the provision of interdisciplinary care (Capital Care Group, 1997). They therefore had a holistic view, the most complete picture of each resident's care. Ethical approval was obtained from the Arts, Science, and Law Human Research Ethics Board of the University of Alberta. The participants received no compensation for completing the survey, although it was assumed that they would be participating as part of their work day.

### ***Setting***

Prior to the study, CapitalCare in Edmonton, Alberta, Canada's largest public provider of facility-based continuing care, identified several issues concerning the use of technology among their care staff. As one component of an initiative to improve dementia care, 32 nursing managers were sent an electronic survey that had two goals: to encourage staff use of some recently introduced assessment tools, and to evaluate the extent to which these tools were being used. This was a novel way of collecting information from nursing managers, and it became apparent that some managers had rudimentary computer skills. Researchers also noticed that the completed electronic survey had a better return time and a higher response rate than the usual paper surveys. Researchers and best-practice leaders at CapitalCare were interested in determining whether another electronic survey would produce similar results. They also wished to investigate staff computer skills, particularly aspects that would make electronic data collection possible (implementation of computerized Minimum Data Set [MDS] -2.0/Resident Assessment Instrument-2.0 [RAI] was scheduled for 2006-07).

### ***Participants***

All nursing managers and other professional staff at CapitalCare who fit the study definition of care staff and had access to a computer were

invited to participate (computer access was required for random assignment of the study conditions). Care staff were defined as staff members who were directly involved with residents on a regular basis. Of the 79 people who fit this criterion, 31 were labelled as nursing managers. This group performed managerial duties and were directly involved in resident care, and all but one was a registered nurse. These staff members were known to have some computer knowledge. They used computers in their daily work and had previously been electronically surveyed by CapitalCare. The remaining 48 potential participants were labelled as other professional staff. This group included rehabilitation staff (occupational and physical therapists), recreational therapists, social workers, and dietitians who interacted directly with patients. Their computer experience was unknown. All participants were recruited via an information letter that accompanied the survey.

Of the possible 79 participants, 59 responded. They included 25 nursing managers (11 completed the electronic survey and 14 the paper survey), 32 other professional staff (17 completed the electronic survey and 15 the paper survey), and two who did not indicate their staffing group; these two participants were included in the response rates and times but were excluded from all other analyses. The nursing managers had been employed in long-term care an average of 14 ( $SD = 7.5$ ) years and other professional staff an average of 9.7 ( $SD = 7.3$ ) years.

### **Materials**

A 12-item questionnaire (<http://www.webcitation.org/5FI5DjK7z>) was developed with the technical support of the Department of Psychology Instructional Technology and Resources Laboratory, University of Alberta, and the Information Systems staff of CapitalCare's Corporate Planning Department. It included questions about manager and staff computer skills and their perception of the research workload and the convenience of electronic surveys. The questions were primarily based on a five-point Likert scale, with some yes/no, ranking, choice, and fill-in-the-blank items. For the purposes of determining face validity and resolving any technical difficulties, the questionnaire was pretested using 10 CapitalCare staff members who met the inclusion criteria but were not included in the study. The questionnaire was completed in less than 10 minutes and no major difficulties were encountered.

### **Procedure**

Nursing managers and other professional staff were randomly assigned to either the electronic or the paper survey group. The two survey types were timed to be received at approximately the same time. The electronic survey group received a link to the questionnaire by e-mail and the paper

survey group received the questionnaire via interoffice mail. Previously at CapitalCare, questionnaires had been received by e-mail, printed, completed, and mailed back. In this study, the procedure served to prevent any overlap between the electronic and paper survey types.

The electronic survey was administered and submitted entirely via e-mail. The e-mail included a link to the questionnaire and instructions for completing it. Participants were instructed to open the questionnaire by double clicking on the link. When they opened the link, the first screen was an information letter, with the link that opened the questionnaire evident at the bottom. On completing the survey, participants were instructed to click the submit button to send it to the research database. The time of receipt in the database was recorded.

The paper survey was administered and submitted entirely via interoffice mail. The package sent to participants included a letter describing the survey, similar to the e-mail sent to the other group. The questionnaire was stapled to this sheet. A self-addressed envelope was also included. Participants were instructed to complete the survey, place it in the envelope, and return it via interoffice mail.

All participants were asked to complete the questionnaire within 2 weeks of receipt. A date sticker was included with the e-mail for the electronic survey group and with the instruction letter for the paper survey group. One week later, a reminder was sent to all participants via e-mail and interoffice mail, respectively.

### ***Analysis***

Descriptive data were reported for most questions. ANOVAs and *t* tests were conducted where appropriate using  $\alpha = 0.05$ . Participants indicated the number of hours they used a computer at work on a seven-point scale: 1 (0–4), 2 (5–9), 3 (10–14), 4 (15–19), 5 (20–24), 6 (25–29), 7 ( $\geq 30$ ). They rated frequency of participation in research as 1 (daily), 2 (once a week), 3 (once a month), 4 (once every 3 months), 5 (once a year). Dichotomous questions were coded 0 (no) and 1 (yes). When ANOVA was used to analyze the data based on the Likert or dichotomous scale, the means of the scale was reported.

### **Results**

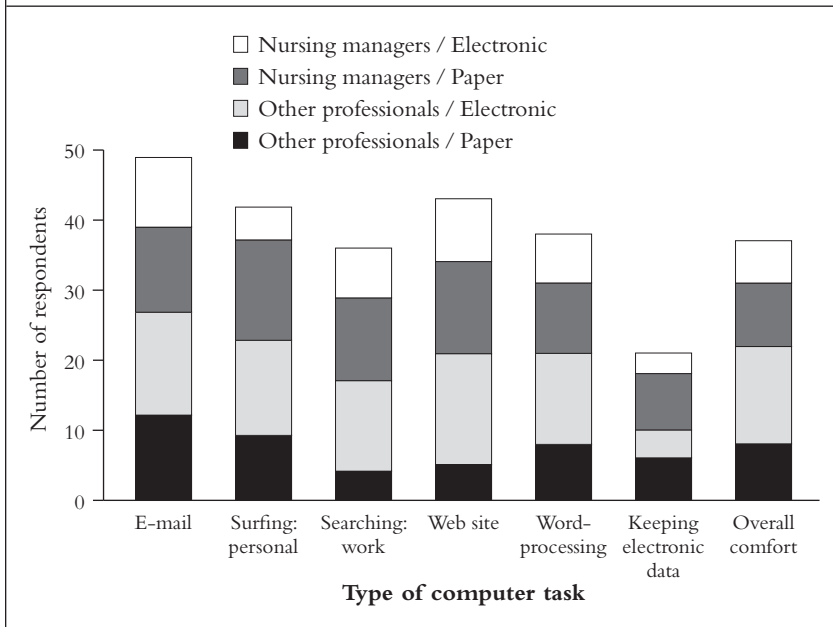
The response rates were 28/39 (72%) for the electronic survey and 31/40 (78%) for the paper survey. Of the surveys sent to nursing managers, the return rate was 11/15 (73%) for the electronic survey and 14/16 (88%) for the paper survey. Of those sent to other professional staff, the return rate was 17/24 (71%) for the electronic survey and 15/24 (62%) for the paper survey.

The mean response time was 3.8 ( $SD = 4.5$ ) days for the electronic survey and 5.5 ( $SD = 5.3$ ) days for the paper survey. Although the response time for the paper survey was slower, it was not significantly different:  $t(57) = 1.35, p = .183$ .

When participants were asked if they had a computer at home, 90% said yes. Nursing managers used a computer at work significantly more ( $M = 3.6, SD = 1.5$ ) than other professional staff ( $M = 1.9, SD = 1.1$ ),  $F(1,50) = 41.8, p < .001$ . One respondent said, "The number of hours of using the computer weekly varies. Some weeks would be up to two hours daily and other weeks less."

The majority of respondents ( $> 60\%$ ) indicated that they were comfortable to extremely comfortable with all categories of computer use (see Figure 1) except for keeping patient data electronically. Three out of 11 nursing managers responding electronically (27%) and 8/14 responding via paper (57%) reported being comfortable or extremely comfortable. Four out of 17 other professional staff responding electronically (24%) and 6/12 responding via paper (50%) reported being comfortable or extremely comfortable. There was no significant effect of staffing designation for this item:  $F(1,49) = 0.50, p = .483$ .

**Figure 1 Respondents Who Rated Themselves Comfortable or Extremely Comfortable With Computers (N = 57)**



Of all nursing managers surveyed, 90% said they had completed an electronic survey before. Of other professional staff surveyed, 10/15 responding electronically (67%) and 8/14 responding via paper (57%) said they had completed an electronic survey before. Significantly more electronic surveys had been completed before by nursing managers ( $M = .92$ ,  $SD = .28$ ) than by other professional staff ( $M = .62$ ,  $SD = .49$ ),  $F(1,49) = 6.4$ ,  $p = .014$ .

Of those who had participated in research over the previous year, nursing managers had done so more often ( $M = .80$ ,  $SD = .41$ ) than other professional staff ( $M = .55$ ,  $SD = .51$ ),  $F(1,52) = 4.08$ ,  $p = .049$ . Eighty percent of nursing managers, compared to only 50% of other professional staff, indicated they had participated in research over the previous year. Of all staff members who had participated in research over the previous year, a majority (84%) had done so quarterly or less often.

The majority of respondents (58%) identified workload as the main barrier to their willingness to participate in research. There was no significant difference between staffing groups for this question:  $F(1,51) = 1.49$ ,  $p = .227$ . Other factors affecting willingness to participate in research were the value of the research (18%) and the applicability of the research to their worksite (16%).

When participants were asked about their opportunities to take part in research, there was no significant effect between nursing managers ( $M = 2.7$ ,  $SD = 0.99$ ) and other professional staff ( $M = 2.3$ ,  $SD = 0.94$ ),  $F(1,49) = 1.57$ ,  $p = .216$ . Of particular interest to CapitalCare was the basic breakdown for this question. Rehabilitation staff ( $M = 2.1$ ,  $SD = 0.95$ ,  $n = 13$ ) and recreational therapists ( $M = 2.0$ ,  $SD = 1.0$ ,  $n = 7$ ) reported having the fewest opportunities and dietitians the most ( $M = 3.2$ ,  $SD = 0.50$ ,  $n = 4$ ). Nursing managers ( $M = 2.7$ ,  $SD = 1.0$ ,  $n = 24$ ) and social workers ( $M = 2.8$ ,  $SD = 0.44$ ,  $n = 5$ ) reported having “just the right” number of opportunities. One respondent commented: “As I do not have my masters I am not involved in research as I define it. However, staff do lots of informal research at their own level and on their own terms, particularly if taking [practicum] students from the University of Alberta.” Another wrote: “Research initiatives are excellent. Some suggestions I have are [either] invest more time to explain the projects and their potential applications and benefits to our programs using layman terms, or reduce abstract objectives to more manageable ideas for us.” A third was more pointed: “I like to partake in research on my unit when it directly applies to my area.”

When asked to give their first choice in terms of electronic or traditional surveys, a majority of participants chose some form of electronic survey (see Table 1). One respondent who had just purchased a computer wrote: “Hopefully in a year’s time with a few lessons from the right

**Table 1 Respondents' First Choice for Completing a Survey**

	<b>Nursing Managers / Electronic (%)</b>	<b>Nursing Managers / Paper (%)</b>	<b>Other Professional Staff / Electronic (%)</b>	<b>Other Professional Staff / Paper (%)</b>	<b>Total (%)</b>
Desktop Icon*	3/11 (27)	5/14 (36)	2/17 (12)	4/15 (27)	14/57 (25)
E-mail/e-mail return	2/11 (18)	7/14 (50)	8/17 (47)	(2/15 (13)	19/57 (33)
E-mail/postal return	1/11 (9.1)	2/14 (14)	0/17 (0)	1/15 (6.7)	1/57 (7.0)
Web site	2/11 (18)	1/14 (7)	8/17 (47)	3/15 (20)	14/57 (25)
Paper	2/11 (18)	2/14 (14)	1/17 (5.9)	5/15 (33)	10/57 (18)
Telephone	0/11 (0)	1/14 (7)	0/17 (0)	0/15 (0)	1/57 (1.8)
In person	1/11 (9.1)	1/14 (7)	0/17 (0)	0/15 (0)	2/57 (3.5)

\* Desktop Icon was a Web site survey previously used by the institution. It was accessed via a desktop icon placed by the IT department. No Web site was apparent.

person I will be more comfortable. Most certainly then my responses to this questionnaire would be decidedly different.” Of the various means presented in the questionnaire for completing and returning surveys, overall the participants reported liking the Web site survey the most, finding it the most convenient and the least time-consuming, and liking the e-mail survey returned in paper form the least, finding it time-consuming and the least convenient (see Table 2).

## **Discussion**

The main findings of the study are as follows: (1) the response rates and response times were the same for the electronic and paper surveys; (2) participants felt comfortable using computers in all but one factor: keeping patient data electronically; (3) nursing managers and other professional staff indicated an ability to manage their research load, although some staffing groups, rehabilitation in particular, seemed to have few research opportunities; and (4) participants expressed a liking for electronic surveys, indicating Web site surveys as the preferred form. Respondents also indicated that they found electronic surveys more convenient than traditional surveys.

A central question of this study was whether, among nursing managers, electronic surveys result in faster response times and higher response rates than traditional paper surveys. Several recent studies have found a higher response rate for paper surveys but a faster response time for electronic surveys (Jones & Pitt, 1999; Kiesler & Sproull, 1986; Raziano et al., 2001). The present findings are consistent with these results: the response times were faster for the electronic survey than for the paper survey. Two studies report lower response rates for electronic surveys (Faulx et al., 2005; VanDenKerkhof et al., 2004). In the present study, response rates for the two surveys were very similar. As more research participants become comfortable with computers, electronic surveys may achieve better response rates than paper surveys.

Ajetunmobi (2002) notes that questionnaire response rates for health-care workers are notoriously low. However, others suggest that care staff will participate in more research, and will incorporate more research into their clinical practice, if they have a vested interest in the research (Gillibrand, Burton, & Watkins, 2002; Happell, 2004). It is possible that the electronic survey in the present study, which dealt with research and the use of computers, was of interest to CapitalCare staff and thus prompted response. Another factor that may have contributed to the relatively high response rate for the electronic survey was its brevity in comparison with other surveys that these personnel had recently been asked to complete.

<b>Table 2 Respondents' Preferences Among Various Electronic Surveys</b>						
		<b>Desktop Icon M (SD)</b>	<b>E-mail/ E-mail Return M (SD)</b>	<b>E-mail/ Paper Return M (SD)</b>	<b>Web Site M (SD)</b>	
<b>Nursing managers</b>	Liked survey	0.88 (0.33)	0.89 (0.32)	0.59 (0.51)	0.93 (0.26)	
	Survey convenient	0.73 (0.46)	0.83 (0.38)	0.33 (0.49)	1.00 (0.00)	
	Took less time	0.71 (0.47)	0.65 (0.49)	0.31 (0.48)	0.75 (0.45)	
<b>Other professional staff</b>	Liked survey	1.00 (0.00)	0.94 (0.25)	0.33 (0.50)	0.93 (0.27)	
	Survey convenient	0.88 (0.35)	0.81 (0.40)	0.13 (0.35)	0.85 (0.38)	
	Took less time	0.88 (0.35)	0.81 (0.40)	0.13 (0.35)	0.92 (0.28)	



CapitalCare staff were found to be very comfortable with computers and to use them both at work and at home. CapitalCare was actively involved in computer training and increasing computer availability to staff but had not formally surveyed staff to determine the level of computer training required. The one area where participants indicated a low level of comfort was keeping patient data electronically. This low comfort level may be due to the fact that only some staff had been involved in the pilot study introducing MDS/RAI, which is based on electronic patient records, during the province's gradual implementation of the program.

Despite the fact that care staff indicated workload as the number one factor affecting their willingness to participate in research, they also indicated satisfaction with the opportunity to participate in research. Hutchinson and Johnston (2003) report that 79% of their respondents indicated that workload was a moderate or great barrier to research utilization. In the present study, however, care staff seemed able to manage both their workload and their research activities. Rehabilitation and recreational staff indicated a preference for more opportunities to do research, and subsequently a CapitalCare clinical specialist initiated a brown-bag lunch to discuss research topics with this professional group. The dietitians indicated the most opportunities to engage in research, likely because one dietitian at CapitalCare was a co-principal investigator in a funded study and offered other dietitians research opportunities. Although the focus here has been data collection, nursing staff and other professional staff can play a pivotal role in many phases of research: suggesting methods of data collection, identifying issues that merit investigation, and the determination of the outcomes measured (Camberg et al., 1999; Conn et al., 2002; Courtney & Craven, 2005; Engle, 1999; Gillibrand et al., 2002; Ruckdeschel & Van Hitsma, 1997).

Another question posed was whether electronic surveys increased the convenience of taking part in research. Consistent with the findings reported in the literature, the majority of participants found electronic surveys more convenient and less time-consuming than traditional paper surveys (Adderley et al., 1997; Dumas, Dietz, & Connelly, 2001; Wong et al., 2003). The majority of participants indicated a preference for electronic questionnaires. However, it should be noted that the participants expressed a preference for returning the survey electronically, not just receiving it that way. When asked about a survey attached to an e-mail to be completed and returned in paper form, only 50% said they liked this format and found it more convenient than traditional paper surveys. This is an important distinction, and the electronic method used in this study may have contributed to the high response rate.

One limitation of the study is that only care staff who had computer access were invited to participate. This was due to computer access constraints within CapitalCare; specifically, the roll-out of computers within the organization had just begun when the study was conducted and therefore employee access to computers was limited. The study participants may have been CapitalCare's most computer-competent care staff. It would be interesting to extend the research by administering a paper survey to those who do not yet have access to a computer at work. It would seem that the less computer-competent a staff member is, the less comfortable he or she will be with electronic surveys. This would indeed be a barrier to research conducted using electronic data collection.

Overall, the results of this study suggest that electronic surveys are an important tool in the collection of research data. Because CapitalCare is Canada's largest public provider of facility-based continuing care, this finding may be generalizable to other facilities. However, a wide variety of technologies are being used in care institutions, and until there is an affordable way to implement computer management systems (see Howard, 2003, for suggestions), these findings may have limited applicability.

The electronic survey was well received. The implications are that research, quality assurance, and evaluation surveys should be administered electronically to nursing and other direct-care staff. The findings of a recent review of electronic data collection by Courtney and Craven (2005) suggest that while electronic surveys may be affected by many of the same trustworthiness issues as paper surveys, such as a bias towards socially desirable answers, electronic methods are highly beneficial for researchers. Because electronic surveys are more convenient for researchers, are accepted by participants, and have comparable response rates and times, one can conclude that they are the best way to administer questionnaires to long-term-care staff, especially as computer experience increases and as employers implement computer technology and provide computer training.

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*Résumé*

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## **La préférence du personnel des soins prolongés pour les questionnaires électroniques**

**G. Peggy McFall et Doris L. Milke**

Le personnel des soins infirmiers a-t-il l'impression de participer à un nombre trop élevé de recherches? Les questionnaires électroniques sont-ils une méthode pratique de collecte de données? On a demandé à des membres du personnel du plus important établissement de soins prolongés au Canada de répondre à ces questions dans le cadre d'un sondage (mené en versions électronique et papier). Vingt-cinq directeurs des soins infirmiers et 32 autres professionnels du secteur ont indiqué qu'ils préféreraient les questionnaires électroniques. Ils ont rapporté être satisfaits de leur apport aux travaux de recherche et précisé que le principal facteur qui limitait leur participation était la charge de travail. Le recours aux questionnaires électroniques pourrait donc avoir un effet positif sur la relation entre chercheurs et personnel infirmier, condition essentielle de la qualité de la recherche menée en soins infirmiers.

Mots clés : collecte de données, personnel

# **Preference of Continuing Care Staff for Electronic Surveys**

**G. Peggy McFall and Doris L. Milke**

Do care staff feel they participate in too much research, and are electronic surveys a convenient way of collecting data? Care staff at Canada's largest public provider of facility-based continuing care were asked these questions in a questionnaire (i.e., electronic survey or paper survey) developed for this study. A total of 25 nursing managers and 32 other professional care staff indicated that they preferred electronic surveys and were satisfied with the extent of their research participation. They also indicated that workload was the main deterrent to their research participation. Use of electronic surveys could positively affect the researcher/care staff relationship that is so important to the quality of health-care research.

Keywords: Data collection, computers, staff, applied research

Evidence-based practice in nursing care involves the inclusion of the best available research evidence in the decision matrix of good patient/client care. Gathering research in applied settings is a challenge, however, because care staff are often extremely busy and reluctant to take the time required to participate in data collection. The barrier to research participation most often cited by nursing staff is lack of time (Happell, 2004; Hutchinson & Johnston, 2003; Valente, 2003). This concern is validated by evidence that nurses are working harder and have a wider variety of duties now than in the past (Bojtor, 2003; Fitch, 2004). It is essential that the research process be made as attractive as possible to staff members who are directly involved in the provision of care. One way to do so is to decrease the time required for data collection.

Initially, staff members may be motivated to participate in research by the exciting prospect of contributing to research knowledge. If their participation does not produce results, however, they may be reluctant to take part in other studies and their relationship with researchers may become strained. The importance of the researcher/nursing staff relationship is well documented (Conn, Burks, Rantz, & Knudsen, 2002; Engle, 1999; Ruckdeschel & Van Hitsma, 1997). Collaboration between researchers and practitioners is essential to the development of good, robust research. To maintain a positive relationship with staff, researchers must ensure that data collection is manageable (Hutchinson & Johnston, 2003). This study focuses on ways to decrease the time needed for data

collection. Specifically, as care staff must take their workload into consideration, how can we tip the balance in favour of research?

Bojtor (2003) argues that, in health care, technology may be adding new tasks to an already busy work day. However, other researchers have shown that computer technology can significantly reduce the workload of nursing staff (Adderley, Hyde, & Mauseth, 1997; Wong et al., 2003). When an information technology system was implemented on an intensive-care unit, the proportion of time per shift that research nurses spent documenting tasks was reduced from 35% to 24%, and the time saved was translated into direct patient care (Wong et al.). A veterans-care facility implementing a paperless system found that computerization allowed more time for direct patient care; in addition, it decreased wait times for processing orders, eliminated transcription errors, and permitted faster communication among departments and between doctors and nurses (Adderley et al.). Electronic records used for monitoring cataract surgery patients have been cited as a major factor in improving access to cataract surgery (Johnston, Sparrow, Canning, Tole, & Price, 2005). These results indicate that technology can decrease the patient-care workload with regard to charting and sharing information. Therefore, it seems reasonable to assume that adopting computer applications in research, such as well-planned electronic surveys, will decrease the workload of direct-care staff and thus improve patient care.

Hanscom, Lurie, Homa, and Weinstein (2002) found that electronic surveys increased the consistency and completeness of the data collected and eliminated the need for manual data entry. Electronic surveys have been shown to be more convenient than paper surveys for researchers in several professions, by reducing costs, providing faster response times, and resulting in a more flexible and more easily standardized survey (Courtney & Craven, 2005; Jones & Pitt, 1999; Kiesler & Sproull, 1986; Raziano, Jayadevappa, Valenzula, Weiner, & Lavizzo-Mourey, 2001; Schleyer & Forrest, 2000; VanDenKerkhof, Parlow, Goldstein, & Milne, 2004). However, there has been little investigation of whether electronic surveys are more convenient for study participants. The present study examined whether electronic surveys allowed care staff to collect data more quickly and with less interference in day-to-day tasks.

We addressed four research questions: 1. *Do electronic surveys result in faster response times and higher response rates than traditional paper surveys?* 2. *Do care staff feel sufficiently competent with computers to use them for data-collection tasks such as completing electronic surveys?* 3. *Do care staff believe they spend too much time on research activities?* 4. *Do electronic surveys make it more convenient to participate in research?*

## **Method**

The study used a two (electronic survey, paper survey) by two (nursing managers, other professional staff) between-subjects design. The factor of survey type allowed for exploration of response times and rates. The factor of staffing designation was used because nursing managers, who typically have a baccalaureate degree, were expected to have more computer and research experience than other nursing staff. In addition, at the time of the study there were constraints on computer access for frontline nursing staff whereas all nursing managers had computer access. The nursing managers in this study not only managed and coordinated the provision of care (24 hours a day, 7 days a week) for residents in an assigned unit, directing and supervising staff, but also served as the residents' case managers, coordinating the provision of interdisciplinary care (Capital Care Group, 1997). They therefore had a holistic view, the most complete picture of each resident's care. Ethical approval was obtained from the Arts, Science, and Law Human Research Ethics Board of the University of Alberta. The participants received no compensation for completing the survey, although it was assumed that they would be participating as part of their work day.

### ***Setting***

Prior to the study, CapitalCare in Edmonton, Alberta, Canada's largest public provider of facility-based continuing care, identified several issues concerning the use of technology among their care staff. As one component of an initiative to improve dementia care, 32 nursing managers were sent an electronic survey that had two goals: to encourage staff use of some recently introduced assessment tools, and to evaluate the extent to which these tools were being used. This was a novel way of collecting information from nursing managers, and it became apparent that some managers had rudimentary computer skills. Researchers also noticed that the completed electronic survey had a better return time and a higher response rate than the usual paper surveys. Researchers and best-practice leaders at CapitalCare were interested in determining whether another electronic survey would produce similar results. They also wished to investigate staff computer skills, particularly aspects that would make electronic data collection possible (implementation of computerized Minimum Data Set [MDS] -2.0/Resident Assessment Instrument-2.0 [RAI] was scheduled for 2006-07).

### ***Participants***

All nursing managers and other professional staff at CapitalCare who fit the study definition of care staff and had access to a computer were



invited to participate (computer access was required for random assignment of the study conditions). Care staff were defined as staff members who were directly involved with residents on a regular basis. Of the 79 people who fit this criterion, 31 were labelled as nursing managers. This group performed managerial duties and were directly involved in resident care, and all but one was a registered nurse. These staff members were known to have some computer knowledge. They used computers in their daily work and had previously been electronically surveyed by CapitalCare. The remaining 48 potential participants were labelled as other professional staff. This group included rehabilitation staff (occupational and physical therapists), recreational therapists, social workers, and dietitians who interacted directly with patients. Their computer experience was unknown. All participants were recruited via an information letter that accompanied the survey.

Of the possible 79 participants, 59 responded. They included 25 nursing managers (11 completed the electronic survey and 14 the paper survey), 32 other professional staff (17 completed the electronic survey and 15 the paper survey), and two who did not indicate their staffing group; these two participants were included in the response rates and times but were excluded from all other analyses. The nursing managers had been employed in long-term care an average of 14 ( $SD = 7.5$ ) years and other professional staff an average of 9.7 ( $SD = 7.3$ ) years.

### **Materials**

A 12-item questionnaire (<http://www.webcitation.org/5FI5DjK7z>) was developed with the technical support of the Department of Psychology Instructional Technology and Resources Laboratory, University of Alberta, and the Information Systems staff of CapitalCare's Corporate Planning Department. It included questions about manager and staff computer skills and their perception of the research workload and the convenience of electronic surveys. The questions were primarily based on a five-point Likert scale, with some yes/no, ranking, choice, and fill-in-the-blank items. For the purposes of determining face validity and resolving any technical difficulties, the questionnaire was pretested using 10 CapitalCare staff members who met the inclusion criteria but were not included in the study. The questionnaire was completed in less than 10 minutes and no major difficulties were encountered.

### **Procedure**

Nursing managers and other professional staff were randomly assigned to either the electronic or the paper survey group. The two survey types were timed to be received at approximately the same time. The electronic survey group received a link to the questionnaire by e-mail and the paper

survey group received the questionnaire via interoffice mail. Previously at CapitalCare, questionnaires had been received by e-mail, printed, completed, and mailed back. In this study, the procedure served to prevent any overlap between the electronic and paper survey types.

The electronic survey was administered and submitted entirely via e-mail. The e-mail included a link to the questionnaire and instructions for completing it. Participants were instructed to open the questionnaire by double clicking on the link. When they opened the link, the first screen was an information letter, with the link that opened the questionnaire evident at the bottom. On completing the survey, participants were instructed to click the submit button to send it to the research database. The time of receipt in the database was recorded.

The paper survey was administered and submitted entirely via interoffice mail. The package sent to participants included a letter describing the survey, similar to the e-mail sent to the other group. The questionnaire was stapled to this sheet. A self-addressed envelope was also included. Participants were instructed to complete the survey, place it in the envelope, and return it via interoffice mail.

All participants were asked to complete the questionnaire within 2 weeks of receipt. A date sticker was included with the e-mail for the electronic survey group and with the instruction letter for the paper survey group. One week later, a reminder was sent to all participants via e-mail and interoffice mail, respectively.

### ***Analysis***

Descriptive data were reported for most questions. ANOVAs and *t* tests were conducted where appropriate using  $\alpha = 0.05$ . Participants indicated the number of hours they used a computer at work on a seven-point scale: 1 (0–4), 2 (5–9), 3 (10–14), 4 (15–19), 5 (20–24), 6 (25–29), 7 ( $\geq 30$ ). They rated frequency of participation in research as 1 (daily), 2 (once a week), 3 (once a month), 4 (once every 3 months), 5 (once a year). Dichotomous questions were coded 0 (no) and 1 (yes). When ANOVA was used to analyze the data based on the Likert or dichotomous scale, the means of the scale was reported.

### **Results**

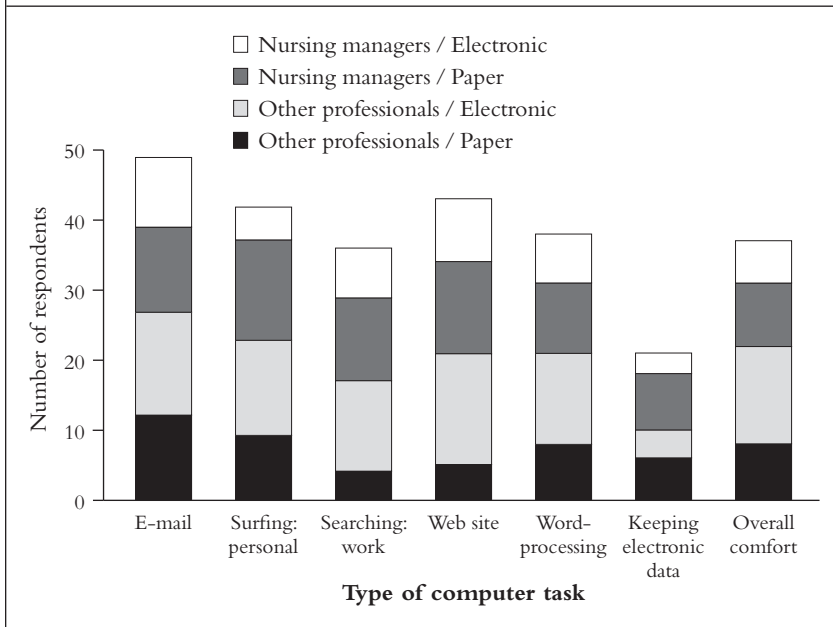
The response rates were 28/39 (72%) for the electronic survey and 31/40 (78%) for the paper survey. Of the surveys sent to nursing managers, the return rate was 11/15 (73%) for the electronic survey and 14/16 (88%) for the paper survey. Of those sent to other professional staff, the return rate was 17/24 (71%) for the electronic survey and 15/24 (62%) for the paper survey.

The mean response time was 3.8 ( $SD = 4.5$ ) days for the electronic survey and 5.5 ( $SD = 5.3$ ) days for the paper survey. Although the response time for the paper survey was slower, it was not significantly different:  $t(57) = 1.35, p = .183$ .

When participants were asked if they had a computer at home, 90% said yes. Nursing managers used a computer at work significantly more ( $M = 3.6, SD = 1.5$ ) than other professional staff ( $M = 1.9, SD = 1.1$ ),  $F(1,50) = 41.8, p < .001$ . One respondent said, "The number of hours of using the computer weekly varies. Some weeks would be up to two hours daily and other weeks less."

The majority of respondents ( $> 60\%$ ) indicated that they were comfortable to extremely comfortable with all categories of computer use (see Figure 1) except for keeping patient data electronically. Three out of 11 nursing managers responding electronically (27%) and 8/14 responding via paper (57%) reported being comfortable or extremely comfortable. Four out of 17 other professional staff responding electronically (24%) and 6/12 responding via paper (50%) reported being comfortable or extremely comfortable. There was no significant effect of staffing designation for this item:  $F(1,49) = 0.50, p = .483$ .

**Figure 1 Respondents Who Rated Themselves Comfortable or Extremely Comfortable With Computers (N = 57)**



Of all nursing managers surveyed, 90% said they had completed an electronic survey before. Of other professional staff surveyed, 10/15 responding electronically (67%) and 8/14 responding via paper (57%) said they had completed an electronic survey before. Significantly more electronic surveys had been completed before by nursing managers ( $M = .92$ ,  $SD = .28$ ) than by other professional staff ( $M = .62$ ,  $SD = .49$ ),  $F(1,49) = 6.4$ ,  $p = .014$ .

Of those who had participated in research over the previous year, nursing managers had done so more often ( $M = .80$ ,  $SD = .41$ ) than other professional staff ( $M = .55$ ,  $SD = .51$ ),  $F(1,52) = 4.08$ ,  $p = .049$ . Eighty percent of nursing managers, compared to only 50% of other professional staff, indicated they had participated in research over the previous year. Of all staff members who had participated in research over the previous year, a majority (84%) had done so quarterly or less often.

The majority of respondents (58%) identified workload as the main barrier to their willingness to participate in research. There was no significant difference between staffing groups for this question:  $F(1,51) = 1.49$ ,  $p = .227$ . Other factors affecting willingness to participate in research were the value of the research (18%) and the applicability of the research to their worksite (16%).

When participants were asked about their opportunities to take part in research, there was no significant effect between nursing managers ( $M = 2.7$ ,  $SD = 0.99$ ) and other professional staff ( $M = 2.3$ ,  $SD = 0.94$ ),  $F(1,49) = 1.57$ ,  $p = .216$ . Of particular interest to CapitalCare was the basic breakdown for this question. Rehabilitation staff ( $M = 2.1$ ,  $SD = 0.95$ ,  $n = 13$ ) and recreational therapists ( $M = 2.0$ ,  $SD = 1.0$ ,  $n = 7$ ) reported having the fewest opportunities and dietitians the most ( $M = 3.2$ ,  $SD = 0.50$ ,  $n = 4$ ). Nursing managers ( $M = 2.7$ ,  $SD = 1.0$ ,  $n = 24$ ) and social workers ( $M = 2.8$ ,  $SD = 0.44$ ,  $n = 5$ ) reported having “just the right” number of opportunities. One respondent commented: “As I do not have my masters I am not involved in research as I define it. However, staff do lots of informal research at their own level and on their own terms, particularly if taking [practicum] students from the University of Alberta.” Another wrote: “Research initiatives are excellent. Some suggestions I have are [either] invest more time to explain the projects and their potential applications and benefits to our programs using layman terms, or reduce abstract objectives to more manageable ideas for us.” A third was more pointed: “I like to partake in research on my unit when it directly applies to my area.”

When asked to give their first choice in terms of electronic or traditional surveys, a majority of participants chose some form of electronic survey (see Table 1). One respondent who had just purchased a computer wrote: “Hopefully in a year’s time with a few lessons from the right

**Table 1 Respondents' First Choice for Completing a Survey**

	<b>Nursing Managers / Electronic (%)</b>	<b>Nursing Managers / Paper (%)</b>	<b>Other Professional Staff / Electronic (%)</b>	<b>Other Professional Staff / Paper (%)</b>	<b>Total (%)</b>
Desktop Icon*	3/11 (27)	5/14 (36)	2/17 (12)	4/15 (27)	14/57 (25)
E-mail/e-mail return	2/11 (18)	7/14 (50)	8/17 (47)	(2/15 (13)	19/57 (33)
E-mail/postal return	1/11 (9.1)	2/14 (14)	0/17 (0)	1/15 (6.7)	1/57 (7.0)
Web site	2/11 (18)	1/14 (7)	8/17 (47)	3/15 (20)	14/57 (25)
Paper	2/11 (18)	2/14 (14)	1/17 (5.9)	5/15 (33)	10/57 (18)
Telephone	0/11 (0)	1/14 (7)	0/17 (0)	0/15 (0)	1/57 (1.8)
In person	1/11 (9.1)	1/14 (7)	0/17 (0)	0/15 (0)	2/57 (3.5)

\* Desktop Icon was a Web site survey previously used by the institution. It was accessed via a desktop icon placed by the IT department. No Web site was apparent.

person I will be more comfortable. Most certainly then my responses to this questionnaire would be decidedly different.” Of the various means presented in the questionnaire for completing and returning surveys, overall the participants reported liking the Web site survey the most, finding it the most convenient and the least time-consuming, and liking the e-mail survey returned in paper form the least, finding it time-consuming and the least convenient (see Table 2).

## **Discussion**

The main findings of the study are as follows: (1) the response rates and response times were the same for the electronic and paper surveys; (2) participants felt comfortable using computers in all but one factor: keeping patient data electronically; (3) nursing managers and other professional staff indicated an ability to manage their research load, although some staffing groups, rehabilitation in particular, seemed to have few research opportunities; and (4) participants expressed a liking for electronic surveys, indicating Web site surveys as the preferred form. Respondents also indicated that they found electronic surveys more convenient than traditional surveys.

A central question of this study was whether, among nursing managers, electronic surveys result in faster response times and higher response rates than traditional paper surveys. Several recent studies have found a higher response rate for paper surveys but a faster response time for electronic surveys (Jones & Pitt, 1999; Kiesler & Sproull, 1986; Raziano et al., 2001). The present findings are consistent with these results: the response times were faster for the electronic survey than for the paper survey. Two studies report lower response rates for electronic surveys (Faulx et al., 2005; VanDenKerkhof et al., 2004). In the present study, response rates for the two surveys were very similar. As more research participants become comfortable with computers, electronic surveys may achieve better response rates than paper surveys.

Ajetunmobi (2002) notes that questionnaire response rates for health-care workers are notoriously low. However, others suggest that care staff will participate in more research, and will incorporate more research into their clinical practice, if they have a vested interest in the research (Gillibrand, Burton, & Watkins, 2002; Happell, 2004). It is possible that the electronic survey in the present study, which dealt with research and the use of computers, was of interest to CapitalCare staff and thus prompted response. Another factor that may have contributed to the relatively high response rate for the electronic survey was its brevity in comparison with other surveys that these personnel had recently been asked to complete.

<b>Table 2 Respondents' Preferences Among Various Electronic Surveys</b>						
		<b>Desktop Icon M (SD)</b>	<b>E-mail/ E-mail Return M (SD)</b>	<b>E-mail/ Paper Return M (SD)</b>	<b>Web Site M (SD)</b>	
<b>Nursing managers</b>	Liked survey	0.88 (0.33)	0.89 (0.32)	0.59 (0.51)	0.93 (0.26)	
	Survey convenient	0.73 (0.46)	0.83 (0.38)	0.33 (0.49)	1.00 (0.00)	
	Took less time	0.71 (0.47)	0.65 (0.49)	0.31 (0.48)	0.75 (0.45)	
<b>Other professional staff</b>	Liked survey	1.00 (0.00)	0.94 (0.25)	0.33 (0.50)	0.93 (0.27)	
	Survey convenient	0.88 (0.35)	0.81 (0.40)	0.13 (0.35)	0.85 (0.38)	
	Took less time	0.88 (0.35)	0.81 (0.40)	0.13 (0.35)	0.92 (0.28)	

CapitalCare staff were found to be very comfortable with computers and to use them both at work and at home. CapitalCare was actively involved in computer training and increasing computer availability to staff but had not formally surveyed staff to determine the level of computer training required. The one area where participants indicated a low level of comfort was keeping patient data electronically. This low comfort level may be due to the fact that only some staff had been involved in the pilot study introducing MDS/RAI, which is based on electronic patient records, during the province's gradual implementation of the program.

Despite the fact that care staff indicated workload as the number one factor affecting their willingness to participate in research, they also indicated satisfaction with the opportunity to participate in research. Hutchinson and Johnston (2003) report that 79% of their respondents indicated that workload was a moderate or great barrier to research utilization. In the present study, however, care staff seemed able to manage both their workload and their research activities. Rehabilitation and recreational staff indicated a preference for more opportunities to do research, and subsequently a CapitalCare clinical specialist initiated a brown-bag lunch to discuss research topics with this professional group. The dietitians indicated the most opportunities to engage in research, likely because one dietitian at CapitalCare was a co-principal investigator in a funded study and offered other dietitians research opportunities. Although the focus here has been data collection, nursing staff and other professional staff can play a pivotal role in many phases of research: suggesting methods of data collection, identifying issues that merit investigation, and the determination of the outcomes measured (Camberg et al., 1999; Conn et al., 2002; Courtney & Craven, 2005; Engle, 1999; Gillibrand et al., 2002; Ruckdeschel & Van Hitsma, 1997).

Another question posed was whether electronic surveys increased the convenience of taking part in research. Consistent with the findings reported in the literature, the majority of participants found electronic surveys more convenient and less time-consuming than traditional paper surveys (Adderley et al., 1997; Dumas, Dietz, & Connelly, 2001; Wong et al., 2003). The majority of participants indicated a preference for electronic questionnaires. However, it should be noted that the participants expressed a preference for returning the survey electronically, not just receiving it that way. When asked about a survey attached to an e-mail to be completed and returned in paper form, only 50% said they liked this format and found it more convenient than traditional paper surveys. This is an important distinction, and the electronic method used in this study may have contributed to the high response rate.



One limitation of the study is that only care staff who had computer access were invited to participate. This was due to computer access constraints within CapitalCare; specifically, the roll-out of computers within the organization had just begun when the study was conducted and therefore employee access to computers was limited. The study participants may have been CapitalCare's most computer-competent care staff. It would be interesting to extend the research by administering a paper survey to those who do not yet have access to a computer at work. It would seem that the less computer-competent a staff member is, the less comfortable he or she will be with electronic surveys. This would indeed be a barrier to research conducted using electronic data collection.

Overall, the results of this study suggest that electronic surveys are an important tool in the collection of research data. Because CapitalCare is Canada's largest public provider of facility-based continuing care, this finding may be generalizable to other facilities. However, a wide variety of technologies are being used in care institutions, and until there is an affordable way to implement computer management systems (see Howard, 2003, for suggestions), these findings may have limited applicability.

The electronic survey was well received. The implications are that research, quality assurance, and evaluation surveys should be administered electronically to nursing and other direct-care staff. The findings of a recent review of electronic data collection by Courtney and Craven (2005) suggest that while electronic surveys may be affected by many of the same trustworthiness issues as paper surveys, such as a bias towards socially desirable answers, electronic methods are highly beneficial for researchers. Because electronic surveys are more convenient for researchers, are accepted by participants, and have comparable response rates and times, one can conclude that they are the best way to administer questionnaires to long-term-care staff, especially as computer experience increases and as employers implement computer technology and provide computer training.

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### Authors' Note

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## *Special Happenings*

### **Poverty and Human Development**

The special Happenings section in this issue of the Journal is a response to a call by the Council of Science Editors. The Council has asked all science editors worldwide to publish a special issue on Poverty and Human Development in order to raise global awareness about the devastating human toll of poverty.

In the year 2000 the United Nations received the greatest-ever commitment from countries rich and poor to do everything in their power to eradicate poverty, promote human dignity and equality, and achieve peace, democracy, and environmental sustainability. World leaders committed their support for the Millennium Declaration, which established a concrete objective: the Millennium Development Goals (MDGs) for advancing human development and reducing extreme poverty by the year 2015. These goals provide a global framework for raising inadequate incomes, reducing widespread hunger, achieving gender equality, managing environmental sustainability, and ensuring access to education, health care, and clean water.

There is growing concern that the MDGs will not be reached by the target date. For example, it is currently projected that child mortality — which is considered a very sensitive and accurate marker of poverty — will not be reduced by 2015, with 41 million children expected to die before their fifth birthday from the effects of poverty, a preventable cause of child death (Watkins, 2005).

This present initiative of the Council of Science Editors is a call to action for scientists to address the problem. The Council has offered science and health-care editors a unique opportunity to use their knowledge and expertise to promote the Millennium Development Goals.

When the invitation for a global initiative on Poverty and Human Development was extended to science editors, we at *CJNR* signed on immediately, along with more than 230 other journals. There are many different ways to raise awareness about the issue, such as through editorials or the publication of reports and research studies. We decided that *CJNR*'s contribution would be to feature work being carried out on Poverty and Human Development by publishing synopses of various projects in the Journal's Happenings section.

We announced the publication of this special Happenings section by writing to deans and directors of schools and asking them to inform their faculty members about it. We also publicized it through our regular

listservs and in the pages of *CJNR* and by posting it on our Web site. Although the time frame was short, we were delighted at the number of submissions we received. Unfortunately, space did not allow us to publish all of these. We gave priority to large-scale projects and studies that, when taken together, reflected the range and quality of the work being carried out both in Canada and abroad.

The projects described in the pages that follow illustrate the ways in which Canadian nurses are contributing towards the achievement of the Millennium Development Goals. These projects, whether completed or in progress, offer important new knowledge and innovation in terms of access to primary health care and social service programs for homeless youths and low-income families in Canada (MDG 4, 5), homeless members of minority groups and psychiatric survivors, in terms of decreasing child mortality in Indonesia (MDG 4), and in terms of combating HIV/AIDS (MDG 6) through collaborative partnerships to build capacity in HIV policy in Africa, the Caribbean, and Vietnam.

Human development is about freedom and about building human capacity. Canadian nurse researchers have made significant achievements in building human capacity both in Canada and in developing countries such as Vietnam, Indonesia, and Caribbean and African nations, and they are making important contributions to the promotion of human development by addressing the devastating effects of poverty.

The journals around the world that have signed on to this initiative by the Council of Science Editors will be releasing their contributions simultaneously on October 22, 2007. Although this special Happenings section appears in print in our September issue, we will be posting it on the *CJNR* Web site on October 22. This is our way of showing our unequivocal support for the Millennium Development initiative, applauding the Council for its leadership, and joining with other science editors to remind world leaders that 2015 is close at hand and they must take heed.

**Anne W. Snowdon, Special Feature Editor**  
**Laurie N. Gottlieb, Editor-in-Chief**

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# The Comparative Costs and Effects of Four Models to Augment Services for Low-Income Families

Jane Drummond, Maria Mayan,  
Laurie Schnirer, and Sylvia So

## Purpose

A pervasive challenge faced by Canadian health and social service providers is to *promote health for low-income families in a proactive and cost-effective manner*. Families with low incomes experience an array of health and social problems that prevent access to available services, compromise their resilience, and lead to negative family outcomes; for some populations, linkage to the services they need can result in improved health and well-being while reducing long-term costs to the public (Browne et al., 1999, 2001; Oliver & Ebers, 1998; Osborn & Hagedoorn, 1997). However, little rigorous research has been conducted to examine the effects of different integration-of-service delivery models, such as (a) how low-income families use and benefit from the services, and (b) the long-term costs and benefits of the services for society. Families First Edmonton is seeking to determine the best way to deliver existing services to low-income families.

## Goals

Families First Edmonton is an innovative, transdisciplinary project developed to improve the delivery of health and social services to low-income families by helping the families to become aware of and linked to the services they need. Its goals are to: (a) test the social, health, and economic impact of four service-delivery models on low-income children and families and their communities; (b) establish the relative cost-effectiveness of service delivery; (c) delineate the collaboration among systems necessary for the delivery of programs; and (d) describe best practices supporting program delivery.

## Methods

Families First Edmonton is a randomized, single-blind, longitudinal trial with a two-by-two factorial design. Families can volunteer to participate in the project if they reside in the city of Edmonton, have at least one

child 12 years of age or younger, and are receiving low-income assistance from the provincial, municipal, or regional government. Participant families ( $N = 1,200$ ) are assigned randomly to one of four service-delivery models and receive services for 2 years.

- *Family Health Lifestyle* families can access any available services. A Family Support Coordinator helps the family to solve problems and links it to education, health, and social services.
- *Recreation Coordination* families can access any available services. A Recreation Coordinator helps the family to place children in recreational programs that are provided free of charge.
- *Comprehensive* families can access any available services as well as a combination of the programs available to the *Family Health Lifestyle* and *Recreation Coordination* families.
- *Self-Directed* families receive the same programs and services they do now.

At the end of service delivery, researchers follow the families for an additional 3 years to assess the long-term impact. These service delivery models and the practices associated with them are designed primarily to (a) build and sustain linkages to established government and community services that are initiated by low-income families, and (b) reduce overall costs to the health and social service sectors by increasing cost-effective use of preventive and health promotion services.

### **Committed Partners**

Families First Edmonton was conceived in February 2001 and was built on long-term planning and ongoing collaboration with community, municipal, regional, and provincial organizations. The research is being coordinated by the Community–University Partnership for the Study of Children, Youth, and Families, which facilitates collaborative, community-based initiatives in research and knowledge sharing. The 12 partners are drawn from municipal, regional, and provincial governments, the community, and academia. The service is being delivered by the Families Matter Partnership Initiative, a project of the Edmonton YMCA, Multicultural Health Brokers Co-op of Edmonton, KARA Family Resource Centre, and Bent Arrow Traditional Healing Society.

Families First Edmonton is designed to generate knowledge that is meaningful for Canadian health-care policy-makers, practitioners, and families and that is essential for the adaptation and implementation of lessons learned across Canada and elsewhere. To learn more, visit [www.familiesfirstedmonton.ualberta.ca](http://www.familiesfirstedmonton.ualberta.ca).



# **Strengthening Nurses' Capacity in HIV Policy Development in Sub-Saharan Africa and the Caribbean: An International Program of Research and Capacity Building**

**Nancy C. Edwards and Susan Roelofs**

A multidisciplinary team of 20 researchers and research users from six countries — Canada, Jamaica, Kenya, Uganda, South Africa, and Barbados — are collaborating on a 4-year (2007–11) program of research and capacity building (Edwards et al., 2007), to address the HIV and AIDS pandemic in Sub-Saharan Africa and the Caribbean, the two regions with the highest global HIV prevalence rates. Nurses are at the forefront of HIV prevention and AIDS care in these countries but have limited involvement in related policy decisions. This initiative uses a participatory action research approach to situate nurses as leaders in building capacity and initiating collaborative action with other health professionals and decision-makers to improve health systems for HIV and AIDS.

## **Purpose**

To strengthen the contribution of Sub-Saharan and Caribbean nurses to health policy development and health systems reform, in order to improve the effectiveness of HIV and AIDS policies and practices.

## **Objectives**

To strengthen health systems in Sub-Saharan Africa and the Caribbean by improving the quality of HIV and AIDS nursing care, supporting the scaling-up of innovative HIV and AIDS programs and practices, and fostering dynamic and sustained engagement of nurse researchers and research users in the policy-development process.

## **Partners**

Formal partners include academic researchers, service providers, and nursing-association leaders and their respective institutions in Canada, Jamaica, Kenya, Uganda, South Africa, and Barbados. National advisory

committees in partner countries and an international advisory committee will also contribute to program implementation and evaluation.

### **Research Projects**

Project 1: Nursing practice in HIV prevention and AIDS care in Sub-Saharan Africa and the Caribbean. Project 2: The interface among health-system priorities, capacity building, and policy innovation in Sub-Saharan Africa and the Caribbean. Project 3: Dynamic collaborations to strengthen health-care systems for HIV and AIDS in Sub-Saharan Africa and the Caribbean. Project 4: International comparative case studies.

### **Capacity Building**

Three leadership hubs in each country will foster dynamic collaboration among frontline nurses and managers, researchers, decision-makers, and community representatives. Hubs will act as levers for change to translate enhanced capacity into policy and action. A 2-month intensive research internship for junior nurse researchers from partner countries will be held annually, building a critical mass of nurse researchers with a leadership role in addressing local health priorities. Interns will collaborate with local decision-makers and with local and Canadian research mentors. Other capacity-building initiatives include knowledge-translation workshops for leadership hubs, focused mentorship activities, and opportunities for graduate student and junior researcher involvement.

### **Stage**

The project commenced in February 2007. The ethics approval process is underway. A team workshop was held in Ottawa in June, attended by representatives from all countries. National advisory committee members have been selected and inaugural meetings began in July. Site visits to Sub-Saharan Africa and the Caribbean, hiring of local research staff, and commencement of data collection are planned for the autumn. The first international cohort of research interns will be selected in October 2007 for the June-July 2008 internship in Ottawa. Canadian nurses with an interest in international health may also apply for the internship.

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**Authors' Note**

This project is being carried out with the aid of a grant from the International Development Research Centre, Ottawa, on behalf of the Global Health Research Initiative. This synopsis is drawn from the project proposal developed by the full research team.

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# **Diversity and Homelessness: Minorities and Psychiatric Survivors**

**Cheryl Forchuk, Elisabeth Jensen, Rick Csiernik,  
Carolyn Gorlick, Susan L. Ray, Helene Berman,  
Pamela McKane, and Libbey Joplin**

This study explores the intersecting vulnerabilities in individuals who are homeless and have psychiatric challenges. Psychiatric survivors are often perceived as a homogeneous group with similar needs. However, survivors with further minority status are likely to have additional concerns and needs that may not be met by the current systems of care. People further marginalized by visible/cultural minority-group status, sexual orientation, and/or disabilities are being studied through this line of research. While possessing any of these vulnerabilities can increase the risk for poverty and homelessness, the interaction among them is poorly understood, particularly in relation to housing and homelessness.

## **Goals**

A key objective of the Homelessness and Diversity Issues in Canada initiative is to support policy-relevant research on homelessness in Canada as it relates to diversity. The project directly addresses this objective by examining the interplay between two issues related to diversity (mental illness and membership in a visible or cultural minority group) and homelessness. Students will have the opportunity to participate in research related to this understudied area. The participatory and interdisciplinary approach promotes the sharing of knowledge among researchers and the users of research.

## **Methods**

The project has three stages:

1. Secondary analysis of data collected through the Community University Research Alliance on Housing and Mental Health. This data set includes interviews with 300 individuals conducted in 2004 and again in 2005. Of this sample, more than a quarter of respondents were interviewed in shelters. The data will be explored for racial/ethnic differences.

2. Critical ethnography, including focus groups and interviews with key informants representing minority groups and service providers working with members of minority groups.
3. Policy analysis will be informed by the first two phases. It will also include examination of municipal, provincial, and federal policies that relate to diversity issues (including refugee status, immigration, multi-cultural issues, and Aboriginal issues), housing and homelessness issues, income support, and mental health services.

## **Results**

The quantitative results suggest that consumers consider their multiple disabilities as well as poverty to be major sources of their diversity. In particular, serious vision and learning problems influence their ability to procure employment and secure housing. The focus groups have led to several interesting findings. Families are increasingly joining the ranks of the homeless and believe they are not being well served by services for the homeless. Children's educational and health needs are not being adequately addressed by the current system. However, an overriding theme is that when participants experience feelings of being different, these most frequently arise from issues of class, rather than race, ethnicity, religion, age, marital status, or gender; while these other factors are important, being poor is what they consider the principal cause of their marginalization. The existence of disabilities is integrally related to the poverty. The language of "diversity" is often researcher-driven, and the central themes and challenges that have emerged from the participants' voices stem from the sense of chronic transience and uprooting, family disruption, and disconnections.

## **Community Partners**

All the local shelters in London, Ontario (e.g., Men's Mission, Salvation Army, Unity Project), took part in the Diversity and Homeless study, as did culture-specific organizations such as Atlohsa, an Aboriginal shelter. Other participating community agencies included London Intercommunity Health Centre, London Community Resource Centre, Cross Cultural Learner Centre, Association for the Elimination of Hate, and Across Languages. These organizations are not culture-specific but serve culturally diverse populations. The shelters and cultural agencies were approached for assistance with the focus groups and interviews in particular. They played a key role in identifying policies that have an impact on the area of study.

### **Impact**

The results of this study have been disseminated to the general public, scholars, politicians, and decision-makers through presentations at various conferences both locally and internationally. The study is raising awareness and increasing knowledge about the service needs of psychiatric consumers who are marginalized by virtue of their visible/cultural minority group status, sexual orientation, and/or disabilities. The study hosted an “all candidates” meeting in 2005 to address issues related to diversity and homelessness. In addition, a group of pro bono law students from the University of Western Ontario have been analyzing policies related to mental illness, housing, homelessness, income support, and diversity issues.

### **Authors' Note**

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

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# **An Action Research Approach to Developing Culturally Relevant Interventions: The Stigma of HIV in a Vietnamese Community**

**Alice Gaudine, Lan Gien, Tran T. Thuan, and Do V. Dung**

This was a collaborative project between faculty at Memorial University of Newfoundland and the University of Medicine and Pharmacy of Ho Chi Minh City, Vietnam, and representatives of a poor community located on the outskirts of a major city in Vietnam. The project used an action research approach in working with a community to identify a health issue they wished to address. First, the faculty members formed an advisory committee of 10 key members of the community and helped them to reach consensus on the issue to be addressed. Next, they collected primary data on the issue and summarized the data for the advisory committee. The faculty members and the advisory committee held meetings at which they agreed on community interventions to address the health issue. It is anticipated that these interventions will be implemented in fall 2007.

The project had three objectives. The first was for Canadian and Vietnamese faculty to work with an advisory committee comprising representatives of a poor community in Vietnam to identify a community health issue. (The issue, which was chosen by consensus, was the stigmatizing of persons with HIV.)

The second objective was for the faculty members to gather data describing the health issue, identify its underlying causes, and elicit suggestions for improving the situation from the perspective of community members. The advisory committee had input into data-collection methods (the participants would include persons with HIV and their family members, community members, and health professionals). Semi-structured interviews were used to explore participants' perception of the stigma and their suggestions for addressing the problem. Interviews were conducted with 10 community members with HIV, 10 family members of persons with HIV, 10 other community members, and 5 health professionals working in this community. Three focus groups were held: one for persons with HIV, one for persons who had a family member with HIV, and one for community members and health professionals. Interviews and focus groups were audiotaped, tran-

scribed verbatim, and translated into English. Faculty members then categorized the participants' perceptions of the stigma into themes and categorized the participants' suggestions for interventions.

The findings reveal that many community members equated HIV infection with heroin addiction and prostitution. While the community members said they understood how HIV was transmitted, most said they had some fears about becoming infected. The descriptions of the stigma provided by persons with HIV and family members led to the emergence of themes including *shunned by neighbours*, *viewed as poor parents*, and *ignored by health professionals*. Suggestions for reducing the stigma surrounding HIV obtained from different sources included the following: providing community members and health professionals with information about the stigma; educating families, the general public, and health professionals about HIV; and altering the behaviours of persons with HIV.

The third objective of the project was for faculty members to work with community representatives to identify and implement ways of addressing the health issue. Several meetings were held during which the faculty members presented the findings from the interviews and focus groups to the advisory committee and suggested possible interventions for reducing the stigma of HIV in the community. The suggested interventions included four types of education session: (1) for family members, on how to care for the infected person; (2) for health workers, on counselling skills; (3) for persons with HIV, on their own role in reducing the stigma; and (4) for hospital nurses, on the stigma of HIV and their role in the stigma. It is anticipated that these interventions will be implemented in fall 2007 and will be evaluated by measuring their comfort level among persons with HIV.

The overall goal of this project was to demonstrate how faculty can work with community leaders in a poor Vietnamese community to address a health issue. Challenges in using an action research approach to community development will be identified.

### Authors' Note

This project was funded by the International Development Research Centre (Canada). We wish to acknowledge the dedication and assistance of Dr. Maureen Laryea in planning the study.

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# Identification of Modifiable Risk Factors for Acute Respiratory Infection in Indonesian Children Under 5 Years of Age

Nani Nurhaeni, Donna Moralejo, and Karen Webber

## Country and Partners

This study was part of a larger AUCC-UPCD-CIDA Tier 2 Linkage Project conducted collaboratively by the School of Nursing, Memorial University of Newfoundland, and the Faculty of Nursing, University of Indonesia. The two study villages were located in West Java province, a rural area. The population of the two villages was 13,119, including 2,108 children under age 5. The majority of village men were farmers, fruit sellers, motorcycle drivers, or labourers, or had no permanent job.

## The Study Problem and the Purpose of the Study

Acute respiratory infection (ARI), especially pneumonia, is a major cause of morbidity and mortality in Indonesian children under 5 years of age. Strategies related to immunization, case identification, and case management have been only partially effective in reducing ARI morbidity and mortality in developing countries. These approaches are expensive and may not be feasible in villages with limited access to health services and resources. Studies in other countries have identified a number of risk factors for ARI, including young age, malnutrition, incomplete immunization, population density, exposure to environmental tobacco and household smoke, and low maternal education. No studies had been done in Indonesia, however, and the studies that have been conducted have not focused on factors that might feasibly be modified. The research questions, therefore, were: 1. *What risk factors are associated with high frequency of ARI in young Indonesian children?* 2. *Which risk factors might be readily modified by families to reduce the incidence of ARI?*

## Methods

The participants were parent-child dyads living in the study villages; all children were under 5 years of age. The local village health workers identified and made initial contact with potential participants. The researchers then met with them, at their convenience, and obtained written consent.

Data were collected using four questionnaires, written in the local language and administered verbally by the researchers. These concerned: (1) demographics; (2) history and health assessment (assessed immunization, body weight, vital signs, general appearance, and history of recent illness); (3) environmental assessment (assessed smoking and cooking habits, ventilation and handwashing facilities, and household design); and (4) use of health services (assessed use of services and responsibilities for decision-making). From the history obtained from the parent about episodes of ARI over the previous year, the children were categorized as having a high (more than six episodes) or low (six or fewer episodes) frequency of ARI.

## Results

There were 120 parent-child dyads in the final convenience sample; the mean age of the children was 29.3 months (*range* = 3–60 months). Logistic regression showed that three variables were significant predictors for high (vs. low) frequency of ARI when other factors were controlled: (1) mother's education less than Grade 3 (OR = 1.19; CI = 1.03–1.37;  $p = .0167$ ), (2) being carried on the mother's back when the mother was cooking, per each half-hour increase in carriage (OR = 2.11; CI = .96–4.6;  $p = .0498$ ), and (3) having no ventilation for the stove (OR = 2.67; CI = 1.17–6.1;  $p = .0378$ ). In bivariate analysis, two other variables were significantly different for high frequency of ARI: having four or more people share the bedroom with the child, and exposure to a large amount of kitchen smoke. These factors did not remain significant in regression, the latter being related to ventilation, being carried, and whether a window was open during cooking.

Almost half of the children (47.5%) were carried by their mothers in the kitchen, but the mothers could readily identify a person, usually a sibling or grandparent, who could take care of the child while she cooked. Households used either a kerosene stove (75.8%) or wood stove (24.2%), with 67.5% having ventilation for the stove. In 59.2% of the houses, the kitchen opened into the living room; only 64.2% of houses had at least one window that could be opened to clear kitchen smoke. The majority of the mothers (91.9%) could identify ways to improve ventilation while cooking. Few mothers (4.2%) said that it would be possible to separate a sick child from their other children, and only 35.2% could identify a strategy for reducing exposure to environmental tobacco smoke.

Immunization was incomplete for 30% of the children older than 12 months, and 67.5% of the children were underweight. Only 7.5% of households had no smokers. While not associated with higher risk for

ARI in this study, probably due to small sample size and lack of statistical power, these are important risk factors that could be modified through additional education and action.

### **Implications and Conclusions**

The study identified key factors that could potentially be modified through a community-based intervention program. The findings led, as part of the larger project, to the development of a health-education program that emphasized reducing exposure to kitchen smoke (e.g., by improving ventilation and carrying children less when cooking) and other health promotion strategies (e.g., improving nutrition and immunization status, reducing contact with a sick child, and asking smokers to smoke away from the children).

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# **Support Intervention for Homeless Youths**

**Miriam Stewart, Linda Reutter,  
and Nicole Letourneau**

## **Purpose and Goals**

Homelessness is a significant problem among youths in major urban centres. It is associated with alcohol and drug use, violence, and gangs (Baron, 1999), crime (by both victims and perpetrators) (Gaetz, 2004), decreased physical and mental health (Commander, Davis, McCabe, & Stanyer, 2002), and sexual assault (Baron, 1997). Despite the reported beneficial effects of social support in decreasing depressive symptoms (Commander et al.) and enhancing mental health (Votta & Manion, 2004), most service agencies offer structural support (i.e., shelter and food) at the expense of emotional, affirmational, and informational support. There is a paucity of data on the provision of social support for homeless youths through peer and group mentoring, both in Canada and globally, and limited understanding of how to design and implement mentoring interventions to reduce negative outcomes for youths at risk (Bellamy, Springer, Sale, & Espiritu, 2004).

The purpose of this study by a team of nurse researchers was to (1) assess the support needs and support intervention preferences of homeless youths; and (2) pilot test a comprehensive support-education intervention for homeless adolescents that optimizes peer influence, reduces isolation, and enhances functioning.

In Phase I of the study, we assessed support needs and support intervention preferences from the perspective of homeless youths and personnel from various community agencies that serve homeless youths in Edmonton, Alberta, Canada. The 2006 homeless count in Edmonton revealed 2,618 homeless persons, 21% of whom were under the age of 30 (Homeless Count Committee, 2006). We conducted in-depth individual interviews with 19 homeless youths and 18 service providers, to elicit perceptions of coping strategies (e.g., support seeking) for managing stressful situations, services/supports available and accessed, experiences with support programs, priority support needs, and preferred support interventions, including intervention level (e.g., dyad or group), mode (e.g., face-to-face), and agents (e.g., peers, professionals). These interviews revealed that resources were needed to provide all forms of support — emotional, affirmational, instrumental (practical), and informational.

Follow-up group interviews were conducted with service providers ( $n = 9$ ), homeless youths ( $n = 14$ ), and previously homeless youths who had made the transition from homelessness ( $n = 3$ ), to elicit feedback on the relevancy of the proposed intervention, including format and logistical issues. Qualitative data from the follow-up interviews affirmed that the most beneficial type of support intervention would include group support with the opportunity for one-on-one support.

Perceived support needs and support preferences elicited during Phase I interviews guided the development of the Phase II support intervention program. Fifty-six homeless youths between the ages of 16 and 24 who either were experiencing homelessness or were in transition from homelessness participated in the support intervention. The intervention consisted of weekly sessions of approximately 2 to 3 hours over a period of 26 to 31 weeks. Time was allotted for one-to-one interaction between youths and mentor(s) during each group session, which was centred on a recreational group activity. Intervention agents (i.e., group facilitators, mentors) included both peers (former homeless youths) and professionals (social service or health professionals who had expertise working with street youths). The peer mentors built relationships with the youths based on their similar life experiences, and the community and professional mentors were able to connect with the youths through role modelling, provision of information, encouragement, and understanding. It was hypothesized that, following the support intervention, homeless youths would report decreased support needs, increased support satisfaction, decreased loneliness, increased support-seeking coping, and decreased high-risk health-related behaviours. At pre-, mid-, and post-intervention points, we collected qualitative data on the impact of the intervention, support intervention processes, satisfaction with the intervention, and suggestions for improvements; and quantitative data on coping strategies, healthy behaviours, perceived self-worth, feelings of loneliness and isolation, and increase in and satisfaction with social support.

### **Partners**

Partnerships were developed with 14 agencies/organizations at the local ( $n = 11$ ), provincial ( $n = 1$ ), and national level ( $n = 2$ ) (see Appendix 1). These partner agencies provided input on recruitment, screening, and training strategies for intervention agents (peer and professional mentors); strategies for recruiting youth participants; and methods for addressing logistical issues (e.g., transportation, volunteer insurance, program location). The three community partners provided space for the intervention and professional mentors. A Community Advisory Committee was set up to guide the implementation of the intervention (see Appendix 1).

### Stage of the Project

Qualitative data revealed enhanced emotional and mental well-being, diminished stress, increased sense of equality and esteem, and decreased sense of loneliness following the support intervention. The quantitative data reinforced the finding of a significant decrease in loneliness over time and, although not statistically significant, an increase in size of social network following the support intervention. These homeless youths also reported an expanded repertoire of coping skills. Some youths reciprocated by offering support to other support-group participants. The youths reaped benefits from the intervention through social learning and social comparison because they could relate to other youths who had similar experiences and goals. The youths recommended that funding be provided for similar support interventions. The intervention fostered research capacity through (a) recruitment, screening, and training tools developed for intervention agents; (b) opportunities for peer and professional mentors to gain experience working with at-risk populations and increase their knowledge of homeless youths and available resources; (c) opportunities for peer/professional mentors and partner agencies to become involved in research and expand their capacity and skill development within a participatory action approach; and (d) opportunities for partner agencies to adopt a pilot-tested program. This study provides knowledge critical for designing effective mentoring support interventions for homeless youths/youths at risk. The study also provides insights into the challenges encountered in research with this highly vulnerable population.

Dissemination of the findings included a report to the funder; presentations at local, regional, national, and international forums; and preparation of papers.

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**Appendix 1 *Community Partners and Community Advisory Committee***

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**Community Partners**

Boyle Street Co-op

Old Strathcona Youth Co-op

Edmonton City Centre Church Corporation's Kids in the Hall program

**Community Advisory Committee**

Edmonton City Centre Church Corporation  
(Crossroads, Kids in the Hall)

Catholic Social Services

Youth Coalition Against Poverty

Boyle Street Co-op

Government of Canada – Human Resources Development Canada

City of Edmonton Community Services

Edmonton Inner City Youth Housing Project

Association for Youth-in-Care – Edmonton

Youth Emergency Shelter Society

Alberta Mentoring Partnership

Old Strathcona Youth Co-op

Big Brothers Big Sisters

# “Left Out”: Perspectives on Social Exclusion and Social Isolation in Low-Income Populations

Miriam Stewart, Linda Reutter, Gerry Veenstra,  
Rhonda Love, and Dennis Raphael

## Purpose and Goals

Experiences and perceptions of exclusion/inclusion and isolation/belonging, and their influence on perceived health and quality of life, have seldom been explored from the perspectives of both low-income and higher-income participants in a single study, and rarely using a mix of qualitative and quantitative methodologies. The purpose of this study was to examine the impact of socio-economic status on exclusion/inclusion and isolation/belonging, as well as to identify strategies (policies and programs) for enhancing inclusion and belonging for those living in poverty. The research objectives were: (1) to explore the *concepts* of social exclusion/inclusion and isolation/belonging as key dimensions of social cohesion; (2) to describe *experiences* of exclusion/inclusion and isolation/belonging, particularly among low-income people; (3) to describe *processes/practices* of social exclusion and social isolation; and (4) to identify implications for *policies* and *programs*. The two urban sites of Toronto, Ontario, and Edmonton, Alberta, were selected for the study because the social and economic policies in the Canadian provinces of Ontario and Alberta have resulted in substantial cuts to the social safety net. Statistics Canada's Low Income Cut Offs were used to determine poverty status (low income).

The experiences of exclusion/inclusion and isolation/belonging were elicited through mixed methods (i.e., qualitative, quantitative, and participatory approaches). Initially, we conducted individual interviews with low-income ( $n = 59$ ) and higher-income ( $n = 60$ ) people in four neighbourhoods at each site and six group interviews with low-income people ( $n = 35$ ) at each site (total =  $n = 154$ ). Phase II consisted of a telephone survey (modified random-digit dialling) conducted in the same neighbourhoods with low-income and higher-income people ( $n = 1,671$ ). In Phase III, three group interviews (one national and one each in Toronto and Edmonton) were conducted with policy-makers/influencers and program planners representing a range of health and health-related organizations ( $n = 23$ ).

## **Partners**

We formed partnerships with local ( $n = 8$ ), provincial ( $n = 1$ ), and national ( $n = 1$ ) agencies/organizations (see Appendix 1). Partners provided input on the research objectives, helped to formulate guidelines for the advisory committee, and advised on proposed research activities, data-collection guides, and mechanisms for communication and dissemination. This fostered research that was relevant, responsive, and applicable for use in transforming policies and programs to enhance inclusion and belonging among low-income people. Representatives from partner organizations and other agencies served on a Community Advisory Committee, which met periodically with researchers to review and revise interview guides, assist with identification and recruitment of participants, help select specific neighbourhoods in which to situate the study, and provide space in a supportive environment for interviews.

## **Stage of the Project**

The report for this nurse-led study was completed in 2003. Survey data revealed significant relationships between self-rated health and measures of exclusion and inclusion, in that poorer health was associated with social exclusion and lack of inclusion. Both qualitative and quantitative findings revealed that inadequate financial resources, ill health, "lack of time," user fees, and unwelcoming behaviours serve to inhibit low-income people from participating in community activities. Poor health as a barrier to participation was reported by three times as many low-income as higher-income respondents (33% vs. 10%), and unwelcoming behaviours were cited by almost twice as many low-income as higher-income respondents (18% vs. 10%). Higher-income people were more likely than low-income people to belong to clubs and professional organizations.

Income was a consistent predictor of isolation and sense of belonging to the community; low-income people experienced greater isolation and less sense of belonging than higher-income people. Age, educational attainment, household income, social support received, and social support given had significant positive relationships with our measure of belonging. Better educated, wealthier respondents, and those receiving social support, were less likely than their counterparts to feel isolated. Qualitative data revealed that, for both income groups, the opportunity to receive and give supports and the benefits of reciprocity fostered a sense of belonging, although low-income people received and provided less support.

Survey participants had considerable understanding of the effects of poverty, with 91% linking poverty to health; however, only 68% acknowledged poverty's effect on exclusion from community life. Participants were most likely to attribute poverty to structural causes and least likely to favour individualistic attributions. Yet the qualitative data revealed that low-income people overwhelmingly thought that others viewed them as a burden to society — lazy and irresponsible. Participants' exposure to poverty through formal talks (courses, workshops) was strongly related to understanding the effects of poverty and to structural attributions for poverty. Most participants, in all phases of the study, favoured structural solutions to poverty as opposed to tackling the effects of poverty.

The study contributes to the knowledge base on psychosocial, socio-economic, and political facilitators of and barriers to participation in activities, by comparing the experiences of low-income and higher-income people residing in different cities within economically homogeneous and heterogeneous neighbourhoods. The findings illustrate how the multiple causes, processes, and outcomes of social exclusion are intertwined, thereby providing in-depth information regarding the effects of poverty on quality of life. The qualitative findings give visibility to the perceptions of low-income and higher-income people regarding the impacts of poverty on social exclusion and isolation, and explicate the strategies used by low-income people to manage exclusion. Our findings indicate that individual citizens and decision-makers are knowledgeable about policies and programs that could redress/reduce material deprivation and social exclusion and that could identify strategies for enhancing social inclusion and belonging among people living in poverty. The involvement of community partners in the various processes of the research and the participation of low-income people in making recommendations for practice, programs, and policies reflect an inclusive process that values community input in decision-making.

A final report to funders was submitted November 2003. Two articles have been published (Reutter et al., 2005, 2006) and two articles have recently been submitted. Several presentations have been made at local ( $n = 1$ ), national ( $n = 3$ ), and international ( $n = 4$ ) forums and conferences.

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### Appendix 1 *Community Partners*

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#### **Edmonton**

Edmonton Social Planning Council  
Edmonton Community Services  
Health Canada (Health Promotion Branch)  
Alberta Human Resources and Employment  
Capital Health Community Health Services

#### **Toronto**

Centre for Social Justice  
East End Community Health Centre  
Four Villages Community Health Centre  
Lakeshore Area Multi-service Project  
South Riverdale Community Health Centre

## Book Review

### ***The Complexities of Care: Nursing Reconsidered***

Edited by Sioban Nelson and Suzanne Gordon  
Ithaca, NY: Cornell University Press, 2006. 211 pp.  
ISBN 978-0-8014-4505-7

**Reviewed by Franco A. Carnevale**

Caring is likely the feature of nursing that is most strongly evoked by both providers and recipients of nursing services. A large proportion of nurses would likely say that they chose nursing as a career because they wanted to care. Indeed, a significant body of scholarly literature has articulated theoretical frameworks, clinical accounts, and research evidence relating caring to important patient and family outcomes.

However, a counter-literature has been pointing to the perils of nursing's commitment to a caring discourse. Some feminist analyses have argued that this characterization of nurses — and women, for that matter — perpetuates a longstanding societal expectation of self-sacrifice in service to the interests of others (without recognition and compensation).

*The Complexities of Care: Nursing Reconsidered*, edited by Sioban Nelson and Suzanne Gordon, makes an important contribution to this debate. The principal aim of the book is to demonstrate that nursing's emphasis on the virtuousness of caring and of the profession, rather than on the complex knowledge and concrete contributions that nurses make on a daily basis, has unintended consequences. The book examines the interaction among caring discourse, nursing practice, and the economic and political environment of nursing in order to show how nursing's "virtue script," in the context of less time for caring work, perpetrates the invisibility of nursing's sophisticated technological work. Nurses believe they are failing because they are unable to provide the caring that they and others expect — disregarding their extraordinary "body work" with its significant impact on patient outcomes.

The works collected in this volume are persuasive, drawing on a variety of scholarly disciplines. Nelson has already made numerous contributions through her critical historical studies of nursing, while Gordon is an award-winning journalist recognized for her examination of how nursing work is portrayed.

The first chapter, authored by Nelson and Gordon, examines the power of nursing's virtue script, which has historically served to senti-

mentalize and trivialize complex work, thus undermining the profession's recruitment strategies. In chapter 2, the sociologist Dana Weinberg analyzes the breakdown of nursing at Boston's Beth Israel Hospital, whose nursing department was one of the most acclaimed in the United States. Weinberg shows how allegiance to a narrow caring discourse — which was not greatly valued by the hospital's administration — served to disable the nursing department's defence of its highly effective services.

Next, Diana Mason, Editor-in-Chief of the *American Journal of Nursing* discusses how nursing has systematically conveyed a particular image of itself. She demonstrates that nurses have vigorously resisted attempts to portray the grittier, less virtuous side of nursing. In chapter 4, the philosopher Lydia Moland highlights the moral dilemmas that emerge when nurses are unable to reconcile their caring values with the tough demands of their daily work.

In the fifth chapter, Sioban Nelson challenges the “equating” of ethical expertise with clinical expertise by scholars such as Patricia Benner. For Nelson, this conflation of ethical and clinical expertise blurs our understanding of nursing work and the significant influence that contextual factors exert on nursing practice, emphasizing nurses' idealistic accounts of what they (ought to) do rather than how they actually manage patient problems in complex, frequently confounding, clinical realities. In the succeeding chapter, the British nursing scholar Tom Keighley discusses the ways in which nursing “health” discourses obscure the daunting challenges involved in caring for sick and vulnerable patients.

In chapter 7, the other co-editor of *The Complexities of Care*, Suzanne Gordon, examines nursing's commitment to “holism.” Gordon points out that the nursing dialogue on holism conceals the broad range of medical, technical, and emotional expertise that is involved in everyday nursing practice. Two Australian nursing researchers, Sanchia Aranda and Rosie Brown, raise concerns in chapter 8 about the shift in palliative care nursing from the role of caregiver to that of case manager. They assert that this shift will erode nurses' sophisticated clinical assessment skills as well as their important role as mentors to other care providers.

In chapter 9, the Australian nursing scholar Marie Heartfield discusses shifts in nursing work on short-stay units. She argues that nurses are required to practise in an uncaring manner because of the restructuring of certain services without a corresponding re-examination of nurses' commitment to caring. In chapter 10, the nursing-workforce researcher Sean Clarke examines key epistemological and methodological questions about nursing work. Pointing to landmark research demonstrating that nursing staffing levels affect patient outcomes, Clarke reveals just how little is known about what nurses actually do and how they do it. In the

final chapter, the editors call on the profession to acknowledge the complex abilities involved in nursing and to demonstrate to society their significance for patient safety and outcomes.

This book makes a truly valuable contribution to our examination of the epistemological foundations of nursing. A wide range of sources and analyses are drawn together to highlight a consistent thesis: the construal of nursing as primarily and sometimes exclusively caring work belies the complexity of other realms of nursing practice that could contribute significantly to the well-being not only of patients but of nursing itself.

This collection of articles is so exceptional that I raise only one point of criticism. *The Complexities of Care* tends to treat caring and body work dichotomously, thus setting up a debate between the proponents of moral virtue and those of technical proficiency. I agree with the authors that this dichotomy is congruent with modern Western thinking, whereby exceptional practitioners are commonly judged as possessing *either* a virtuous character *or* excellent technical skills, never both. However, I propose that future work in this area consider recent work in *virtue ethics*, drawing on Aristotle's conception of virtue: the features of a *virtuoso* in the classical sense cannot be reduced to one's character or to one's technical skills. I believe that some contemporary proponents of nursing excellence in terms of a moral discourse, such as Benner, are not suggesting that caring should trump technical mastery but, rather, are calling for a recognition of the moral commitments that underlie complex technical care (as well as the sophisticated expertise involved in caring) — these are irreducible in a complete representation of nursing excellence.

This book is a call for rethinking and action on the part of nursing scholars, educators, researchers, administrators, and clinicians.

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