

EDITORIAL

Open Access: A Hot Topic in the Publishing World

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

Governments and academic communities have been the most vocal advocates for open access. Their argument goes something like this: Public institutions and government grants, as well as private endowments, support and underwrite the cost of research; therefore, the results of that research should be accessible and available to those who, ultimately, have paid for it — that is, the public. Commercial, for-profit publishing houses are viewed as profiting unduly from the work of the academic community, publishing manuscripts that are largely the product of public funding. This user-pay model functioned well until the mid-1980s. However, subscription rates then rose significantly, making many serials unaffordable for smaller institutions, while the larger institutions were able to continue subscribing to the most prestigious medical and scientific journals only by cutting back their holdings. (Subscription rates for for-profit journals increased by 227% between 1986 and 2002 [Frankish, 2004].)

Governments have taken steps to rectify the situation by developing national policies of open access to scientific and medical journals. For example, the US House of Representatives Appropriations Subcommittee has decreed that an electronic copy of any manuscript accepted by a peer-review journal that has received support from the National Institutes of Health (NIH) be deposited in PubMed Central — the free archive maintained by the US National Library of Medicine — and that the NIH make the manuscript available to the public free of charge after an interval, chosen by the author, of anywhere up to 12 months following publication (Barrett, 2005); the NIH has until the end of 2005 to submit to Congress an implementation plan for this scheme. In Great Britain, the House of Commons Science and Technology Committee has recommended that every institution of higher learning in the United

Kingdom set up a repository to enable its researchers to self-archive their publications (Frankish, 2004). At the international level, meanwhile, the Public Library of Science is a not-for-profit organization of “scientists and physicians committed to making the world’s scientific and medical literature a freely available public resource.”

Opponents of open access come primarily from for-profit publishing houses, who maintain that they provide an invaluable service by selecting, editing, and publishing the work of scholars. These services are expensive: the cost of publishing an article is in excess of \$3,000. They further justify their profits by citing the risks they take and the losses they absorb. Commercial publishers operate from a business model. They further argue that they are good corporate citizens — funding conferences and educational outreach programs and underwriting scholarships — that in fact they are partners with universities and government.

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

Let us look first at the issue of payment. In the fee-for-access system, the user pays through individual and institutional subscriptions. In the open-access system, some other means has to be found to cover the cost of publishing a manuscript. Several economic models have been floated and tested (Willinsky, 2003). One of the most discussed is a model in which the payer is not the user but the author. In other words, the publisher (whether commercial or not-for-profit) continues to provide the services of peer review, editing, and production, but instead of the user it is the author who pays. How does this work?

What is being proposed is that research grants cover the cost of publication as well as the cost of the research itself. The rationale is that if the public pays salaries and other costs associated with research, why not the final step in the research process, publication of the results? The weaknesses in this proposal are obvious. For instance, not every publication is supported by grant money. Who will pay for the publication of theoretical articles, articles by students, articles reporting the findings of low-budget research, articles publishing data long after the grant has expired? In addition, because each grant will have to be larger in order to cover publication costs, the number of available grants will be smaller — unless of course the budgets of the various granting agencies are increased significantly.

Because few can argue against the principle of open access, the more established and prestigious journal publishers are now making publications available, free of charge, after a certain period following publication — usually 6 or 12 months — while retaining the old system of having

the user pay. This system functions well in disciplines where knowledge becomes (or is perceived to become) outdated more quickly than it is in the behavioural sciences and where competition is particularly fierce.

Another model being tried is for authors to post their manuscripts on the Internet, thus eliminating the middleman. However, this model immediately raises a red flag: What will happen to standards and quality control? The Internet is replete with unsubstantiated, erroneous information. Some online publishers have review panels but it is difficult to know which articles have undergone a review process and which have not.

Under the user-pay system, several mechanisms are in place to ensure that standards are being met. Publishing houses have been responsible for enforcing standards. The tried and true method is rigorous (and costly) peer review. This system relies heavily on experts to review and adjudicate the quality and veracity of the research. Although much criticism has been levelled at the peer-review process, an ideal replacement has yet to be proposed. When a manuscript is submitted to an established, reputable publishing house, many eyes will have scrutinized it before the paper appears in print or online. A key role of the journal editor is to review the reviewers, in order to ensure that quality is preserved and to protect against conflict of interest. The next level of quality assurance is the editing and production process. Copy editors are trained to catch inconsistencies and errors of omission and commission; they also make a manuscript more readable and thus more accessible to the reader.

Another of the many issues that have been raised is the storing of information — archiving. Archiving of material is an important function, currently assumed by publishers, that allows users to access published material quickly and efficiently. Systems have been developed to enable databases such as CINAHL, MEDLINE, and PsycINFO to index and catalogue manuscripts. At the moment, each journal must undergo a complex process before it is eligible for inclusion in one of these important indexing services.

Coalitions of scientists, granting agencies, and publishers have been looking into this issue. Their task is to propose the most efficient ways of making information available while safeguarding standards with regard to electronic publication. To date there have been much talk and some trials but no single “best” solution. It is too early to determine sustainability and long-term effects based on any of the trials. The idea of open access is a noble one, but, as Peter Blank observes, “the devil is in the details. How do we get universal access to medical literature?” (“The Gathering Storm,” 2005, p. 5).

Among editors of nursing journals, the debate on open access has yet to heat up. The topic was touched on last summer at the annual meeting

of INANE (yes! the acronym for the International Nursing Association of Nurse Editors) and there has been some exchange on the Association's listserv.

The majority of nursing journals are published by large commercial concerns. There are few surviving academic not-for-profit journals such as *CJNR*. We keep our subscription rates comparatively low and survive through an SSHRC grant, institutional and individual subscriptions, revenues from copyright permission, and volunteerism (all editors with the exception of the managing editor volunteer their time), and by running a very tight ship. The effect of the shift from open access to user pay will be very different for small, independent nursing journals and association journals as compared to large journals or those published by commercial firms. Some journals, such as the *Canadian Medical Association Journal*, rely heavily on revenues from paid advertisements in their print version to support their more academic online version.

It is too early to say how open access will affect *CJNR* and journals like it. In the meantime we are online through Ingenta and can be downloaded by all individual subscribers and those whose institutions subscribe to this service. We will observe from the sidelines, keep informed, participate in the debate, and watch as the process plays out. Open access will not go away. Stay tuned — the rocky road of uncertainty will continue for some time to come.

Laurie N. Gottlieb
Editor-in-Chief

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GUEST EDITORIAL

Knowing Is Not Enough: We Must Do

Susan McClement and Lesley F. Degner

It is a simple fact that every person will die. What is less of a given is the extent to which those with life-limiting illnesses will receive the type of care encapsulated in the World Health Organization (2002) definition of palliative care:

An approach that improves the quality of life of individuals and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (p. 1)

Though there are many ways of “knowing” in nursing (Silva, Sorrell, & Sorrell, 1995), achievement of the “deliverables” embedded within this definition is contingent, in large measure, upon the generation of a sound body of empirical knowledge to guide practice. A major component of palliative care research is nursing research, the ultimate goal of which is to improve patient care (Ferrell & Grant, 2001). As in all areas of nursing, a solid research base will inform and enhance palliative nursing practice and the appropriate standards to be adhered to within it.

The pioneering nurse researcher Jeanne Quint Benoliel observed that, historically, palliative nursing care depended on “the good will and personal skills of individualized nurses; yet what they offered was invisible, unrecognized, and unrewarded” (Quint, 1967, p. ix). Good will and personal skill still hold currency in the provision of palliative nursing care. It is only in concert with sustained research efforts, however, that the full potential and promise of palliative nursing can be made visible, recognized, and celebrated.

The German dramatist, novelist, poet, and scientist Johann Wolfgang von Goethe (1749–1832) understood well the reciprocal relationship between knowledge and practice. Goethe asserted: “Knowing is not enough; we must apply. Understanding is not enough; we must do. Knowing and understanding in action make for honor. And honor is the heart of wisdom.” (<http://www.p-mmm.com/sayings.htm>) This issue of the Journal contains papers reflective of knowing, understanding, application, and wisdom as regards palliative care research.

The concept analysis paper by Marie Bakitas speaks to the importance of conceptual clarity in conducting empirical work, and the need to both understand and attend to the ways in which historical, legal, bioethical, and clinical influences shape our understanding of concepts and affect our ability to integrate them into programs of palliative care research. The integrative review by Dr. Joan Bottorff and colleagues of methodological issues in researching palliative care nursing practice illuminates our understanding of the ways in which nursing knowledge has been generated, and sensitizes us to the importance of keeping the efficacy of nursing interventions front and centre in the research agenda, particularly in the context of interdisciplinary work. The grounded theory study by Drs. Duggleby and Wright of how palliative care patients live with hope enables us to better understand this dynamic process, and illustrates the coalescence between the facets of knowing, understanding, and application that ideally characterize the research enterprise.

This issue of *CJNR* is augmented by several invited papers. In her Discourse, Dr. Linda Kristjanson speaks to the wisdom and importance of distinguishing between the different types of palliative care that patients and families receive in order to construct contextually appropriate and meaningful research questions. She offers a sound argument against reliance on prognostication as the defining index by which palliative care services are made available, and she challenges us to develop innovative research approaches that will inform the development of models of palliative care nursing for those with diseases other than cancer.

In the Designer's Corner, Dr. Julia Addington-Hall provides readers with a clear statement of the benefits of palliative care research and stresses the need for health-services research, particularly as it relates to funding sustainability for palliative care. She thoughtfully outlines the multitude of ethical considerations and tensions inherent in conducting palliative care research and provides cogent guidance for ways of responding to them. Dr. Addington-Hall reminds us of the need for academics to partner with clinicians and service users in order to ensure research excellence.

In *Translating Research*, Dr. Lesley Degner takes a lesson from the history books to remind us that successful implementation of a change in evidence-based practice must be nested solidly within a theoretical framework that takes into account elements of professional and organizational behavioural change. She provides an overview of four theories that may prove instructive to those seeking to initiate knowledge-translation projects in palliative care settings. The relevance and timeliness of Dr. Degner's contribution is underscored by the brisk evolution of evidence-based practice as a means of improving patient care and

closing the chasm between optimal end-of-life care and that which exists (Rutledge, 2005).

In the Happenings section of the Journal, Dr. Doris Howell outlines several recent initiatives that have the potential to significantly advance research in palliative and end-of-life care. These include the commitment of funds by the Canadian Institutes of Health Research to support interdisciplinary research on a variety of topics salient to end-of-life care, and the establishment of an endowed research Chair in Cancer Nursing at the University Health Network and the University of Toronto's Faculty of Nursing. Dr. Howell has been awarded that prestigious Chair, and as part of her mandate will develop a patient-focused outcomes research program focusing on the effectiveness of health-care delivery and nursing intervention research in symptom assessment and management. Dr. Susan McClement describes the development and future directions of a recently funded interdisciplinary unit in Manitoba dedicated to psychosocial research in end-of-life care for patients with a variety of life-limiting illnesses.

Finally, graduate nursing student Annemarie Hoffmann critiques for us the feature documentary film *The Man Who Learned to Fall*. Her characterization of the vivid and realistic way in which this documentary captures the experiences, challenges, joys, and sorrows of a person living with amyotrophic lateral sclerosis and his family reminds us of the reasons why we strive for excellence in palliative care nursing and research in the first place.

While dying is part of the human condition, dying poorly certainly ought not to be (Chochinov, 2004). Goethe was right: knowing and understanding are not enough; we must do.

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Discourse

Directions in Palliative Care Nursing Research: Impeccable Care, Timing, and Complexity

Linda J. Kristjanson

Notable advances have been made in the past three decades in palliative care nursing. The features that distinguish palliative care — attention to the whole person and to all aspects of a patient's suffering as well as a multidisciplinary approach to care — have resulted in marked improvements in the standard of care for those with advanced and incurable cancer (Woodruff, 2004). Palliative care research has resulted in better knowledge of symptom assessment and treatment, improved psychosocial care, and a more refined approach to managing family care needs. The need for palliative care is enormous and will continue to increase, placing tremendous pressures on existing services. Until recently, palliative care tended to concentrate on the needs of cancer patients and their families, focusing on the terminal stages of a person's life. However, the field is being challenged to provide high-quality care to a wider range of patients, receiving care in a variety of settings, with more complex symptoms and co-morbidities, at earlier stages of their illness. These challenges are captured well in the most recent World Health Organization (2002) definition of palliative care:

An approach that improves the quality of life of individuals and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (p. 1)

This definition improves on previous ones, which were cancer-centric, too narrow, and too time-specific. It presents palliative care nursing research with three specific challenges:

- to produce empirical evidence that will inform impeccable nursing assessment and treatment of pain and other problems — physical, psychosocial, and spiritual

- to conduct research that will guide decisions about when to offer a palliative approach to patients who may have very different life-threatening disease trajectories
- to investigate the palliative care needs of individuals with non-malignant life-threatening conditions, prompting us to consider a broader and more complex range of palliative conditions

These three research challenges are examined below, with a focus on how palliative care nursing research ought to respond.

Impeccable Assessment and Treatment

When a person is facing a life-threatening progressive illness, the close attention of those whose role it is to provide care is critical. In fact, the attention given to the patient's comfort, complex symptoms, and confusing feelings, as well as difficult family dynamics, is what makes palliative care effective. It is impossible to be an expert palliative care nurse and skim over the patient's concerns, minimize distress, or ignore minor difficulties. Indeed, it is the nurse's detailed attention to the small aspects of a patient's physical, emotional, and spiritual state that makes a difference. As one family member stated to me when referring to the palliative care provided to her mother, "Nothing was too much trouble for the nurses." If palliative care nurses are to truly pay impeccable attention to the needs of our patients and their families, they must systematically and vigorously address the need for sound research to inform our practice. However, research efforts to improve assessment and resolution of the problems faced by patients and their families will be more refined and tailored if researchers are able to distinguish among a *palliative approach*, *specialized palliative services*, and *end-of-life or terminal care* (Kristjanson, Toye, & Dawson, 2003). These different types of palliative care responses provide a context for different types of research questions and variations in assessment and treatment.

A Palliative Approach

A palliative approach is one in which the person's condition is not amenable to cure and the symptoms of the disease require effective symptom management. Active treatment of the disease may still be required and may be provided concurrently with a palliative approach. However, the primary goal of a palliative approach is to ensure that the patient is comfortable and maintains a level of functioning.

Specialized Palliative Services

This form of palliative care involves referral to a specialist palliative care team or health professional. It does not replace a palliative approach but,

rather, augments it with focused, specific input as required, usually in one of two ways: assessment and treatment of complex symptoms, or provision of information and advice to staff about complex issues (e.g., ethical dilemmas, family issues, or psychological or existential distress).

End-of-Life or Terminal Care

This form of palliative care is appropriate when the individual is in the final days or weeks of life, and care decisions and goals are focused on his or her physical, emotional, and spiritual comfort and on support for the family.

The ability to differentiate among these three types of palliative care is important in formulating research questions about who receives palliative care, how to structure services, when to offer palliative care, and how to resource palliative care. This distinction provides direction for palliative care nursing research to ensure that studies undertaken address the range of palliative services/interventions that may be needed.

When to Move to a Palliative Approach

It is important to first dismiss the idea that one can easily and clearly distinguish curative from palliative care, or that patients move neatly from one modality to another. Introcaso and Lynn (2002) report that the best way to identify those patients who need a palliative approach is to ask the following question: "Which of your patients is sick enough that death within a few months would not be surprising?" This question is a useful one clinically because it identifies patients with eventually fatal illnesses at a time when they will need comprehensive services and support for the rest of their lives.

The rapidity and stages of decline vary considerably with the type of illness. For example, the course of lung cancer may be very brief, the illness trajectory associated with dementia can be relatively long, and the debilitating effects of amyotrophic lateral sclerosis may be endured for months only or for several years. Individuals with organ failure such as renal disease may experience a more predictable terminal phase of illness, while those with chronic obstructive airway disease could well suffer many exacerbations followed by periods of recovery.

We cannot depend on prognosis as the basis for accessing palliative services or for determining what constitutes a palliative care research question or topic. Prognostication is frequently uncertain, may be riddled with error, and may not be the best marker of palliative care need (Christakis, 1999). Rather, in end-of-life care we must ask how we can provide comprehensive, reliable palliative nursing because the person is very sick and death may be an outcome of his or her progressive illness.

This framework shapes the type of nursing research questions we ask and the focus of our inquiries.

Who Is Likely to Need Palliative Care in the Future?

The number of cancer patients requiring palliative care will not diminish, and cancer is likely to remain the most common cause of premature death (death before age 65) and the second most common cause of death overall (Clinical Oncology Society of Australia, Cancer Council Australia, and National Cancer Control Initiative, 2003). However, we must also consider palliative services for those with other progressive degenerative illnesses, for children, and for segments of the aged population.

Neurodegenerative Illnesses

People living with neurological diseases such as amyotrophic lateral sclerosis, multiple sclerosis, Huntington's disease, and Parkinson's disease face long-term physical and psychological challenges. Neurodegenerative diseases have the capacity to evoke the most negative and despondent attitudes on the part of many health-care professionals. These attitudes can be readily transmitted to patients and their families. The fact that we cannot significantly alter disease progression is sometimes interpreted to mean that there is nothing more to be done. This is inaccurate and regrettable. It is precisely because we cannot reverse or even retard the disease process that we must do everything possible to alleviate symptoms and offer appropriate psychological and spiritual support. The illness trajectory for people with neurodegenerative diseases may be years or decades and entail lengthy periods of dependency. A range of technologies and health-care options may be used to ensure adequate nutrition, communication, cardiac and respiratory functioning, bowel motility, and skin integrity. All such interventions require learning and adjustment on the part of the patient and family. This is where a *palliative approach* has much to offer. The psychological and social factors associated with neurodegenerative diseases are as important as physical care, and the healthy recovery of family members after their eventual bereavement is also essential. These needs all fall within the practice domain of palliative care nurses.

Development and testing of a hybrid "package" of care with the correct mixture of rehabilitative care, respite, and palliative support appears necessary. As well, tailoring this package to a range of settings, perhaps "following" the patient as a supportive framework, may be helpful. This approach to care might then provide a useful template for planning supportive palliative care for individuals with other non-

malignant conditions. Palliative care nurses should play an active role in undertaking research aimed at addressing the needs of these populations.

A Palliative Approach for Children

The development of palliative services for adults has not been paralleled in pediatrics. It is not that death is less common amongst children than amongst adults. The dying child has been avoided in the literature and in practice, perhaps for emotionally charged reasons. The provision of pediatric palliative care is patchy and inconsistent. One of the reasons for this may be that many of the fatal diseases that afflict children are rare and the children suffering from them are distributed over a broad geographic area.

Most child deaths are due to uncontrollable malignant disease following unsuccessful attempts at curative treatment, and although cure rates for cancer have increased markedly in recent years, nearly one third of childhood malignancies result in death. However, pediatric palliative care needs extend beyond cancer diagnoses and may be appropriate for a range of progressive, life-threatening illnesses (e.g., neurodegenerative and metabolic disorders, organ failure).

To date, a sound model for pediatric palliative care has not been reported in the empirical literature. As well, research to document the needs of various subgroups of pediatric patients and their families has been lacking. Models of palliative care for children may be quite different from those for adults and likely would feature a greater emphasis on respite services, long-term support, family interventions focused on siblings, and community home support. Nurses can play an active role in addressing this gap in knowledge by providing the evidence needed to help guide care decisions and service developments for pediatric populations.

A Palliative Approach in the Care of the Aged

Unique and challenging issues emerge in the provision of palliative care for the elderly. The illness trajectory may be prolonged and is likely to involve co-morbidity and cognitive and communication impairment. Institutional care may be required because of the often severe and long-term nature of functional incapacity and the frailty of elderly family caregivers. In the year 2000 the overall prevalence of dementia worldwide was approximately 25 million persons; about 6.5% of the population 65 years of age and older suffered from dementia and the number of new cases that year was estimated to be 4.6 million. Forecasts indicate a considerable increase in the number of demented elderly, to 63 million in 2030 and 114 million in 2050 (Wima, Winblad, Aguero-Torres, & von Strauss, 2003). Alzheimer disease averages about 7.5 years from onset to

death, but might last anywhere from 3 to 25 years (Kemp, 1995); each stage brings with it unique difficulties, further deterioration for the patient, and anguish for the family. A palliative approach to care for these individuals and their families is extremely relevant, providing attentive physical care, symptom relief, psychological support related to loss and grief, and sensitive discussions related to advance care directives.

Traditional models of palliative care have tended to focus on the care of patients with cancer. Although cancer is for the most part a disease of the elderly, these models do not necessarily meet the palliative care needs of the wider population of elders. The question is, therefore, how to provide the best possible palliative care for this population?

Recently, the Australian Department of Health and Aged Care funded the Australian Palliative Residential Aged Care project (www.apracproject.org) to examine how a palliative approach to care might be incorporated into residential aged care. This project involved the identification of evidence-based guidelines for a palliative approach in residential aged-care facilities, development of competencies for all aged-care staff, and educational programs to meet these competencies. Funding has now been provided to implement the guidelines and educational programs, with more than 10,000 copies of the guidelines produced for the aged-care sector. This project has fostered broad-reaching public expectations about the importance of a palliative approach at end of life and has stimulated new research into how to apply a palliative approach in aged care.

Palliative care nurses and their nursing research colleagues in gerontology are coming together to generate the empirical evidence required to address the end-of-life care needs of the older population. End-of-life care for this burgeoning sub-population will become our greatest health-care challenge, and palliative care nurses have an important proactive role to play in informing health-policy decisions about how to best meet this challenge.

Conclusion and Future Directions

Although notable progress has been made in recent decades in the area of palliative care nursing research, some of the symptoms (e.g., fatigue) and concerns of our patients and their families are not being well addressed. In addition, a number of patient groups are being undertreated. The following questions illustrate several research areas that warrant further work:

- What are the most effective ways to assess and manage fatigue?
- What are the most appropriate models of palliative care for children and their families?

- What are the most valid and reliable and clinically sensitive ways to assess pain and other symptoms of distress in individuals who are cognitively impaired?
- What is the most effective way of responding to the grief of surviving family members?
- How do we address the grief and loss of individuals with cognitive dementia?
- How can we best integrate advance care planning into care in such a way that families and patients feel supported and comfortable with the decisions they have made?
- How should we manage questions about nutrition and fluid support for people in the advanced stages of a terminal illness?
- How might we best address the needs of individuals from minority cultural groups?
- What approaches to palliative care are most helpful to individuals with non-malignant diseases (e.g., amyotrophic lateral sclerosis, multiple sclerosis, Huntington's disease, Parkinson's disease)?
- What are the most effective ways to provide palliative care to individuals who live alone and do not have the support of friends, family, or neighbours?
- What health-policy research must be undertaken to prepare for the aging population and shifting demographics that will require more caregivers for those who need support and a palliative approach in the end stages of their lives?
- How do we construct economically viable models of care that do not water down the palliative approach that promises impeccable attention to the concerns of patients and families?

There is a pressing need for palliative care nursing research that informs practice, allowing palliative care nurses to use the best possible empirical evidence so they can attend impeccably and tirelessly to the relief of distress. This knowledge development must be accelerated in order to respond to the challenges of delivering palliative care to populations who are currently not being well served by a palliative approach. We cannot assume that the models of palliative care developed to date will be appropriate for the future broad range of patients who will be receiving care in a variety of settings. The extension of palliative care to other populations will require innovative research approaches, to ensure that the models of palliative nursing care being used are responsive to the unique needs of the growing numbers and types of patients and families requiring care.

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Résumé

**L'autodétermination :
analyse du concept et implications
sur la recherche dans le domaine
des soins palliatifs**

Marie A. Bakitas

Cet article analyse l'évolution, la définition, l'emploi courant et l'application du concept d'autodétermination dans le cadre de la recherche et de la pratique en soins palliatifs. L'analyse présentée vise à servir de base au développement du programme de recherche sur les soins palliatifs. L'auteure examine une littérature choisie portant sur les soins de santé aux adultes atteints d'une maladie chronique ou mortelle, notamment sur l'aspect historique, bioéthique, clinique, médical et infirmier. À partir d'une synthèse de la documentation, celle-ci propose une définition conceptuelle tout en identifiant des moyens d'intégrer le concept d'autodétermination dans la recherche portant sur les interventions palliatives.

Mots clés : autodétermination, soins palliatifs

Self-Determination: Analysis of the Concept and Implications for Research in Palliative Care

Marie A. Bakitas

This paper analyzes the evolution and the definition, current use, and application of the concept of self-determination in palliative care research and practice. Undertaken as a foundation for the development of a palliative care research program, the analysis considers selected historical, bioethical, legal, clinical, and relevant medical and nursing health-care literature on adults with chronic and terminal illness. Based on a synthesis of the literature, a conceptual definition is proposed and ways of integrating the concept of self-determination into palliative care intervention research are identified.

Keywords: self-determination, autonomy, concept analysis, integrative review, palliative care, Rodgers method

Introduction

The goal of palliative care is to improve the quality of living and dying of patients with life-limiting illness (World Health Organization, 1990). A tenet of palliative care philosophy is the determining, acknowledging, respecting, and honouring of patients' values and wishes as they approach the close of life (von Gunten, Ferris, Portenoy, & Glajchen, 2001). The concept of self-determination is embodied in this philosophy. Experts in palliative care see the enhancement or support of self-determination as one way of improving the quality of a patient's final days (American Geriatrics Society Ethics Committee, 1998; American Nurses Association [ANA], 2001; Ferris et al., 2002; National Hospice Organization, 1997). How can key aspects of self-determination best be integrated into palliative care practice and research? A concept with such a high degree of abstractness is not easily translated into everyday clinical practice. The task is further complicated if one attempts to identify, describe, measure, or design interventions that exemplify an amorphous concept to improve the care of persons with serious illness. A first step is to return to the literature in order to examine the evolution and current use of the concept (Rodgers, 2000). Self-determination has evolved from its societal origins as the right of a people to be free, independent, and protected

from oppression, to its application in health care through laws and bioethical principles. In 1991 the *Patient Self-Determination Act (PSDA)*, a milestone in the evolution of palliative care in the United States, decreed that health professionals have an obligation to recognize patient choice in health-care decision-making (*Omnibus Budget Reconciliation Act [OBRA] of 1990*, 1990). Since then, many attempts have been made to formally integrate principles of self-determination into palliative care practices, quality improvement activities, and research.

This paper analyzes the evolution and the definition, current use, and application of the concept of self-determination in palliative care research and practice. Undertaken as a foundation for the development of a palliative care research program, the analysis considers selected historical, bioethical, legal, clinical, and relevant medical and nursing health-care literature on adults with chronic and terminal illness. Based on a synthesis of the literature, a conceptual definition is proposed and suggestions for integrating the concept of self-determination into palliative care intervention research are identified.

Sample and Setting

A literature search was conducted to examine the concept of self-determination in palliative care using Rodgers's (2000) evolutionary method. The purpose of the search was to identify literature on the origin, definitions, attributes, antecedents, consequences, and exemplars of the concept. Computer searches for the years 1985 through 2003 using MEDLINE, the Cumulative Index to Nursing and Allied Health (CINAHL), and PsycINFO were conducted using the search terms self-determination, *Patient Self-Determination Act*, autonomy, advance care planning, and advance directives, which were then joined with the terms palliative care and terminal care. The original 516 cited titles and abstracts were then reviewed for relevance using the following criteria: historical background, focus on a cancer or palliative adult population, and use of the concept prior to and following the passage of the *PSDA*. Articles and reference lists were then reviewed for relevance. Pertinent articles from the reference lists were also examined.

One study (SUPPORT Principal Investigators, 1995) generated more than a hundred articles (some identified through the initial search and the remainder in reference lists). Only two of the most representative and relevant articles reporting study results (Covinsky et al., 2000; SUPPORT Principal Investigators, 1995) and three analyzing the meaning of the findings (Lynn et al., 2000; SUPPORT Principal Investigators, 1997; Teno, 1998) were included in the analysis.

A preponderance of the literature cited the *PSDA*, a US law; however, several international studies exploring the related concept of “family determination” were identified. This literature was retained and analyzed to assist in concept clarification.

Also reviewed were two Institute of Medicine reports on improving end-of-life care and palliative care in cancer (Field & Cassel, 1997; Foley & Gelband, 2001), literature on background ethics (e.g., *Code of Ethics for Nurses*) (ANA, 2001), historical and legal materials (including electronic sources), the National Hospice Organization’s (1997) *A Pathway for Patients and Families Facing Terminal Illness*, a chapter from a major palliative care text, and a study of the “concept analysis” of self-determination in a population of long-term psychiatric patients (Valimaki & Leino-Kilpi, 1998). A total of 65 references met the criteria for inclusion.

Concept Analysis Results

The results of the literature analysis are organized as follows: historical context, definitions and attributes, antecedents, consequences, and exemplars.

Historical Context

Self-determination has origins in societal, ethical, legal, and, more recently, health-care, contexts. Regardless of context, a pattern of protecting and promoting self-determined choice is seen most vividly in response to oppression of an individual or group. Historically, a period of oppression often resulted in the adoption of rules or laws protecting the rights of the oppressed group. An early example of self-determination in a societal context is the 1620 voyage of Separatist Puritans to North America aboard the *Mayflower* seeking freedom from religious oppression (Pilgrim.net, 2002). This concept essentially gave birth to the United States and is pervasive in common law, in the *Declaration of Independence* and the *US Constitution* (THOMAS Web-based historical documents, 2002).

The concept of self-determination in health care grew out of the need for individual (patients’) rights. Before the advent of medical discoveries related to the prevention or treatment of fatal diseases and conditions, patients with illnesses such as cancer experienced deterioration and death. The role of doctors and nurses was to provide comfort in the progression towards “natural death.” As more and more means of fighting disease or prolonging life became available (e.g., antibiotics, vaccines, chemotherapy, cardiopulmonary resuscitation), patients could no longer passively await death with a caring doctor or nurse standing by to offer comfort (Robinson & Mylott, 2001). Physicians employed the new tools

to postpone or prevent death. Death was the enemy, to be defeated at all costs.

Thus evolved the practice of medical care in which every possible therapy was used simply because it existed. This phase of health care was marked by a paternalistic approach whereby the physician determined which therapies would be applied (Gadow, 1989) based on anecdote, experience, and availability — there being a dearth of scientific evidence. Rarely were patients' treatment preferences considered (Gadow). Nurses and patients played a passive role. Nurses followed doctors' orders and provided care that was consistent with a "death-defeating" approach, while patients accepted the care and treatments provided without question. Patient self-determination or choice was in the background, if present at all.

A legal precedent in self-determination was set by a 1914 ruling by New York Supreme Court Justice Cordoza: "Every human being of adult years and sound mind has a right to determine what shall be done with his own body and cannot be subjected to medical treatment without his consent" (*Schloendorff v. Society of New York Hospital*, 1914). Throughout the 1960s and 1970s more obvious applications of the concept of self-determination emerged in biomedical ethics (Beauchamp & Childress, 2001) and health-care legislation (Bradley & Rizzo, 1999; Meisel, 1998), in response to violations against vulnerable populations such as prisoners and the seriously ill. In research, self-determination was clearly transgressed in the use of unwilling, uninformed subjects (e.g., Nazi prisoner experimentation and the Tuskegee syphilis study) (Bradley & Rizzo; Department of Health, Education and Welfare, 1979). In the early years, scientific inquiry with human subjects placed a higher value on the knowledge to be gained than on the lives of subjects, resulting in many human rights violations (Katz, 1992).

In response to these events, efforts to protect basic human rights and autonomy and self-determination in health research were widely supported (Bradley & Rizzo, 1999). The 1979 Belmont Report set out ethical principles and guidelines for the protection of human research subjects (Department of Health, Education and Welfare, 1979). It defined autonomous decision-making (informed consent) and outlined protections for persons at risk for diminished autonomy (e.g., subjects of biomedical research) based on ethical principles such as the bioethical principle of respect for autonomy embodied in the value of self-determination and its related clinical ethical practices of truth-telling, information disclosure, and informed consent (Fan, 1997). Protection for health-care consumers came somewhat later.

In clinical practice, paternalism and indiscriminate use of life-saving technologies in health care was viewed by some as oppression (Gadow,

1989; Robinson & Mylott, 2001; Salem, 1999). As a result, basic human rights in medical care began to dominate public and health-care discourse. Concerns about the inappropriate use of life-sustaining treatments and the absence of patient self-determination in medical decision-making culminated in the US Supreme Court case *Cruzan v. Director, Missouri Department of Health and Human Services* (cited in Bradley & Rizzo, 1999). The decision in this case of a 25-year-old woman left in a permanent vegetative state after a car accident affirmed the importance of formally documenting one's treatment wishes in advance of a medical crisis. In 1989, months after the Cruzan decision, a bill was proposed (and ultimately passed under the federal Medicare/Medicaid-related *OBRA of 1990*) according responsibilities to institutional health-care providers with respect to advance directives (*OBRA of 1990*, 1990). These provisions grew out of an earlier (1989) version of the *PSDA*.

The central patient right addressed by this legislation was that of autonomy. The Act accorded patients the right to access information pertaining to decision-making about their care, to accept or refuse treatment, and to issue advance directives. As interpreted by Meisel (1998), "the *PSDA* does not apply solely to information about advance directives but rather applies to a patient's medical decision-making rights in general" (p. 52). Medical decision-making was later defined as inclusive of "consent to treatment, informed consent, and end-of-life decision-making" (p. 52). Appendix 1 summarizes key aspects of the *PSDA*.

In nursing, self-determination is grounded in the *Ethical Code for Nurses* of the American Nurses Association (ANA). In Canada both the *Code of Ethics for Registered Nurses* and the *Joint Statement on Advance Directives* uphold the "client's right to self-determination" (Canadian Nurses Association, 1994, 2002). In the United States the ANA originally generated its code in 1950 and revised it in 1960, 1968, 1976, 1985, and 2001 (Daly, 2002). The 1985 version was heavily influenced by aspects of self-determination and concepts directly applicable to end-of-life nursing care (Scanlon, 1996). Specifically, it encouraged nurses to assess patients' ability to make decisions about end-of-life care; defend patients' care wishes and promote their freedom to make end-of-life decisions; prevent and/or relieve suffering associated with dying; evaluate the benefits and drawbacks of treatment to the patient; and support decisions on the withdrawal or withholding of treatments (including cardiopulmonary resuscitation, artificial nutrition, and hydration) (Scanlon). These interpretations and ANA position statements in the 1990s were an attempt to protect the vulnerable population of dying patients with regard to issues that could greatly affect the quality of their living/dying (e.g., assisted suicide, withholding of food and fluids, provision of adequate pain relief).

An additional historical trend in self-determination comes from social sciences research. Deci and Ryan (1985) propose a theory of intrinsic motivation and self-determination to explain human behaviour. According to this theory, human beings can be proactive and engaged or passive and alienated largely as a function of the social conditions under which they develop and survive. Autonomy, in addition to competence and relatedness, is postulated as an innate psychological need: when satisfied, it yields self-motivation and mental health; when unsatisfied, motivation and well-being are decreased. This theory has been applied to research in education, work, sport, religion, psychotherapy, and health care. In health care, self-determination theory has been applied to alcohol treatment, weight loss in morbidly obese patients, smoking cessation, glucose control, and medication adherence (Ryan & Deci, 2000; Williams, Rodin, Ryan, Grolnick, & Deci, 1998). No studies of self-determination theory in palliative or end-of-life care were found.

Definition and Attributes of Self-Determination

Self-determination is defined as “free choice of one’s own acts or states without external compulsion; determination by the people of a territorial unit of their own form of government, future political status, without coercion or outside influence” (Merriam-Webster OnLine, 2003). It generally refers to the rights of both a people and an individual and is broadly thought to include the principles of liberty, privacy, individual choice, free will, and being one’s own person (Beauchamp & Childress, 2001). Synonyms and related terms include autonomy, independence, choice, decision-making, empowerment, and freedom. The terms autonomy and self-determination are often used as surrogates (ANA, 2001). Autonomy comes from the Greek *autos*, or self, and *nomos*, rule or governance, whereas self-determination is the process of exercising one’s right to autonomy.

As concepts become more abstract, “their reality basis and their empiric indicators become less concrete and less directly measurable” (Chinn & Kramer, 1999, p. 55). Self-determination is relatively abstract as a concept, its definition broad and context-dependent. In Western bioethical principles, it is a “subjective conception of the good and promotes the value of individual independence” (Fan, 1997, p. 309). As a right of persons and patients, it is defined as a process related to expression of the ethical principle of respect for autonomy (Beauchamp & Childress, 2001). It is also defined as the opposite of paternalism (Gadow, 1989; Sutherland, Llewellyn-Thomas, Lockwood, Tritchler, & Till, 1989). In law, self-determination has a very specific definition. The *OBRA* regulations state that patients are entitled to be aware of and use advance directives when they enter a facility that accepts Medicare funding

(Meisel, 1998; *OBRA of 1990*, 1990). Additional aspects of the law are summarized in Appendix 1.

Nordgren and Fridlund (2001) interviewed 17 Swedish hospitalized medical and surgical patients in order to define self-determination from the patient's perspective. Responses to the question "How do you perceive that your right of self-determination finds expression in the context of care?" produced the themes of trust in the health-care team, acceptance of the care that is provided, and feelings of powerlessness. The patients did not feel empowered to participate in decision-making and lacked the information on treatment strategies necessary to do so. Hence, instead of supporting the attribute of self-determination, they identified characteristics of its absence.

Proponents of assisted suicide use the term "ultimate self-determination," defined as the patient's right to choose the time and place of death (Baginski, 1992; Folker et al., 1996; Swarte & Heintz, 1999). While assisted suicide is prohibited by law in most US states, some also question its ethical soundness and its consistency with the principles of self-determination, as it conflicts with the fundamental ethical principles of professional autonomy and non-maleficence (Burt, 2002; Low & Pang, 1999; Muller-Busch, 2001; Salem, 1999). Salem argues that instead of supporting autonomy, assisted suicide (which requires physician sanction and prescription of a lethal combination of medications) is actually an impediment to self-determination, its parameters returning "ultimate authority over this 'private and deeply personal' decision to medicine and society" (p. 30).

Four characteristics of self-determination were identified in the literature: personal (self-) appraisal, decision-making process, activities, and goals or outcomes (see Table 1). *Personal appraisal* requires the mental capacity, functional "strength," freedom, power, and information to evaluate one's values and preferences related to health-care decision-making. Koenig (1997) describes seven attributes of individual self-determination in Western culture (see Table 2). These can be summarized as the need for information, desire for control, freedom, openness, personal health beliefs about the future, religion, and family. They are quite specific and suggest that patients possess a relatively high level of sophistication, particularly with regard to Western cultural beliefs. Koenig challenges the notion that these attributes apply to patients of different cultural backgrounds and different value structures related to individual autonomy. Similarly, Fan (1997) proposes that an East Asian definition of autonomy requires family-determination, "an objective conception of good [that] upholds the value of harmonious dependence" (p. 309). Valimaki and Leino-Kilpi (1998) conducted a "concept analysis" of self-determination based on content analysis of qualitative interviews with 72 long-term

Table 1 *Attributes of Self-Determination in Various Sources*

Attribute	Ethical	Legal	Health Care
<p>Personal appraisal</p> <ul style="list-style-type: none"> • possessing physical and emotional strength • possessing power • possessing knowledge • possessing mental capacity • not controlled by others 	<p>ANA (1991); Department of Health, Education and Welfare (1979); Gadow (1989); Scanlon (1996); Sutherland et al. (1989)</p>	<p>Bradley & Rizzo (1999); Low & Pang (1999); Meisel (1998); Salem (1999)</p>	<p>Koenig (1997); Nordgren & Fridlund (2001); Valimaki & Leino-Kilpi (1998)</p>
<p>Decision-making process</p> <ul style="list-style-type: none"> • advance care planning for when capacity is diminished • refuse or accept care or treatment • rights of others not violated • continuity of providers 	<p>ANA (2001); Baginski (1992); Beauchamp & Childress (2001); Bradley & Rizzo (1999); Department of Health, Education and Welfare (1979); Fan (1997); Gadow (1989); Hern et al. (1998); Katz (1992); Koch et al. (1999); Koenig (1997); Quill (2002); Ruhnke et al. (2000); Scanlon (1996); Swarte & Heintz (1999)</p>	<p>Bradley & Rizzo (1999); Cerminara (1998); Engel et al. (1997); Haynor (1996); Meisel (1998); <i>OBRA of 1990</i> (1990); Ott (1999); Salem (1999)</p>	<p>Nordgren & Fridlund (2001); Valimaki & Leino-Kilpi (1998)</p>

<p>Activities</p> <ul style="list-style-type: none"> • completing values history • provider- or patient-initiated discussions; family conferences • making a living will or appointing a proxy (durable power of attorney for health care) • completing “do not resuscitate” order • choosing “comfort measures” • completing unfinished business (relationships, finances, funeral) 	<p>American Geriatrics Society Ethics Committee (1998); ANA (2001); Candib (2002); Cantor (1998); Cerminara (1998); Engel et al. (1997); Havens (2000); Haynor (1996); Johnston et al. (1995); Miller (1991); Murphy et al. (2000); Ott (1999); Ruhnke et al. (2000); Scanlon (1996)</p>	<p>Bradley & Rizzo (1999); Cerminara (1998); Engel et al. (1997); Haynor (1996); Meisel (1998); <i>OBRA of 1990</i> (1990); Ott (1999); Salem (1999)</p>	<p>Havens (2000); Haynor (1996); Robinson & Mylott (2001); SUPPORT Principal Investigators (1997)</p>
<p>Goal/outcome</p> <ul style="list-style-type: none"> • self-determined life closure • peaceful death 	<p>ANA (2001)</p>		<p>National Hospice Organization (1997)</p>

Table 2 *Attributes of a Self-Determined Patient:
The Western Perspective*

- a clear understanding of the illness, prognosis, and treatment options, which is shared with the members of the health-care team
- a temporal orientation to the future and a desire to maintain control into that future
- the perception of freedom of choice
- a willingness to openly discuss the prospect of death and dying
- a balance between fatalism and belief in human agency that favours the latter
- a religious orientation that minimizes the likelihood of divine intervention (or other “miracles”)
- an assumption that the individual, rather than the family or any other social group, is the appropriate decision-maker

Source: Koenig (1997).

psychiatric patients; the patients’ personal appraisal focused on the importance of freedom of choice, access to power, and having the active support of others in pursuing their goals.

The characteristic of *decision-making process* is central in the *PDSA*. It is clearly specified as well in the ANA’s (2001) *Ethical Code for Nurses*, which also speaks to the role of nurses in enhancing the patient’s right to self-determination in terms of accepting, declining, or terminating treatment without “deceit, undue influence, duress, coercion, or penalty” (Provision 1, Section 1.4, “The right to self-determination”). Nurses are obliged to provide support throughout the decision-making process. The *Ethical Code for Nurses* speaks specifically to the patient’s right to elicit the support and advice of family members, partners, and nurses and other health professionals (Valimaki and Leino-Kilpi, 1998). More recent sources identify the role of the patient-appointed proxy in decision-making when the patient no longer possesses the ability to make decisions (Sullivan, 2002). The proxy, whether informal (family) or formal (health professional), must possess sufficient knowledge of the patient’s values and preferences to determine what care the patient would choose or refuse (Meisel, 1998). The standard is one of “substituted judgement” (recreating the patient’s choice), in contrast to “best interest” (doing what the proxy’s believes to be in the patient’s best interest) (Sullivan).

The third attribute, *activities*, refers to the many manifestations of self-determination, most notably the issuing of advance directives (Cantor, 1998; Cerminara, 1998; Engel et al., 1997; Havens, 2000; Ott, 1999;

SUPPORT Principal Investigators, 1997) but also issuing “do not resuscitate” orders, requesting “comfort care,” and attending to unfinished business (National Hospice Organization, 1997; Robinson & Mylott, 2001). Fear of over-treatment and desire for control are characteristic of persons who engage in these activities (Eisemann & Richter, 1999), an important legal aspect of which is the fact that self-determination supersedes the patient’s ability to state treatment preferences and allows for the appointment of a proxy (durable power of attorney for health care).

Lastly, *goals or outcomes* refers to the wishes that a patient hopes to fulfil as a result of self-determination, primarily with regard to dying on his or her own terms (Fan, 1997; Nordgren & Fridlund, 2001; Silveira, DiPiero, Gerrity, & Feudtner, 2000; Tulsky, Fischer, Rose, & Arnold, 1998). The goal of hospice care, as identified by an expert panel of the National Hospice Organization, is “self-determined life closure”: “Anticipating death, mentally competent patients will have full autonomy to make decisions about how the remainder of their life is spent within the allowances of law” (National Hospice Organization, 1997, p. 5).

In summary, self-determination is defined in the palliative care literature as an ethical principle, a right, a law, a care process, and an outcome of expert palliative care (ANA, 2001; Beauchamp & Childress, 2001; Koenig, 1997; Meisel, 1998; National Hospice Organization, 1997; *OBRA of 1990*, 1990). Its attributes include personal appraisal of individual rights, power, freedom of choice, decision-making process, activities, and outcomes. Following passage of the *PDSA*, activities of self-determination became more formalized through the use of a living will and/or the appointment of a health-care proxy (Bradley & Rizzo, 1999; Eisemann & Richter, 1999; Havens, 2000; Meisel; Rodgers, 2000; SUPPORT Principal Investigators, 1995). Palliative care professionals have contributed “self-determined life closure” as an outcome of palliative care. These attributes suggest the following revised definition of self-determination in palliative care: a process of decision-making that includes personal appraisal, the support and advice of others (family, health-care professionals), and activities that result in successful life closure and peaceful death.

Contextual Basis of Self-Determination

According to Rodgers (2000), clarification of a concept involves exploration of the contextual aspects (temporal [antecedents and consequences], socio-cultural, and disciplinary contexts, and exemplars) to gain an understanding of the situations in which the concept is apparent.

Table 3 gives a temporal perspective of self-determination.

Table 3 *Temporal Context of Self-Determination*

Antecedents	Attributes	Consequences
<ul style="list-style-type: none"> • healthy person with awareness of mortality • “becoming ill”: diagnosed with serious illness; worsening of chronic illness; admission to hospital, ICU, nursing home • reasonable functional status • mental capacity (or DPOA-HC appointment) • cultural/religious orientation • age — frequently older • relationship with health-care provider — primary care, palliative care (assessment or provider-initiated discussion) • information about condition/prognosis • family discussions • education about PDSA 	<p>Personal appraisal</p> <ul style="list-style-type: none"> • possessing physical and emotional strength • possessing power • possessing knowledge • possessing mental capacity • not controlled by others <p>Decision-making process</p> <ul style="list-style-type: none"> • advance care planning for when capacity is diminished • refuse or accept care or treatment • rights of others not violated • continuity of providers <p>Activities</p> <ul style="list-style-type: none"> • completing values history • provider- or patient-initiated discussions; family conferences • making living will or appointing a proxy (durable power of attorney for health care) • completing “do not resuscitate” orders • choosing “comfort measures” • completing unfinished business (relationships, finances, funeral) <p>Goal/outcome</p> <ul style="list-style-type: none"> • self-determined life closure • peaceful death 	<p>Consequences</p> <ul style="list-style-type: none"> • discussions with family, physicians, social workers, lawyers • completion of AD • peaceful death • dying and death not consistent with patient’s wishes • less aggressive care at time of death than desired • family- or physician-determined circumstances around death <p>Organizational consequences</p> <ul style="list-style-type: none"> • increased ethics consultations and moral dilemmas • increased AD documentation compliance • increased patient requests for information • increased patient and professional education about AD • increased workload and role redundancy (MD, MSW, RN, APRN) • increased family conferences

Antecedents

The literature suggests various antecedents to the concept of self-determination. The first and most obvious one is becoming ill. This could occur in conjunction with the diagnosis or awareness of a life-threatening or terminal illness, a sudden worsening of a chronic illness, or admission to hospital or transfer to an intensive care unit (SUPPORT Principal Investigators, 1995). The latter was the context of the *PDSA* (Bradley & Rizzo, 1999; Haynor, 1996; *OBRA of 1990*, 1990). However, the expression of self-determined choices and values is not necessarily associated with illness. In fact, healthy people are often encouraged to complete advance directives (Havens, 2000; Johnston, Pfeifer, & McNutt, 1995; Silveira et al., 2000). This trend was evident following publication of results showing that patients' expressed wishes (as stated in advance directives in hospital medical charts) had not been incorporated into the plan of care at the time of death (Covinsky et al., 2000; Lynn et al., 2000; SUPPORT Principal Investigators, 1997).

Mental competency or capacity is an antecedent to self-determination in many contexts (Valimaki & Leino-Kilpi, 1998), but appointment of a proxy could ensure durability of preferences in the case of incapacity. Other antecedents are functional status, age (Johnston et al., 1995), and cultural or religious orientation (Koenig, 1997; Ruhnke et al., 2000). There are conflicting views between patients and providers regarding age and functional or health status. Patients generally say they prefer to have discussions with physicians when they are young and healthy, during preventative medical visits (Havens, 2000; Johnston et al., 1995; Silveira et al., 2000), whereas physicians tend to state that they initiate such conversations with older, sick, hospitalized patients (Hesse, 1995; Johnston et al.; Tulsky et al., 1998). One review cites the lack of physician payment for discussions about advance care planning as a barrier to its increased frequency in an office setting (Cerminara, 1998).

Other antecedents include the need for relevant information about a condition and about available therapies (Tulsky et al., 1998), family discussions and appointment of a proxy (Hesse, 1995; Tulsky et al.), knowledge about end-of-life legal issues (refusal/withdrawal of treatment, assisted suicide, euthanasia, double effect) (Silveira et al., 2000), and factors related to physicians and the health-care system. Physician factors include assessment of patients' knowledge about their prognosis in order to clear up misconceptions (Silveira et al.), patients' values (Tulsky et al.), patients' desired level of participation in decision-making (Barry & Henderson, 1996; Havens, 2000; Sutherland et al., 1989), and physicians' personal beliefs about futility or, based on prior conversations, about the patient's wishes (Haynor, 1996; Hesse). The main antecedent to self-

determination in the health-care system is passage of the *PDSA* (Bradley & Rizzo, 1999; Haynor; Meisel, 1998; *OBRA of 1990*, 1990). Although one intervention study found that knowledge about advance directives increased compliance (Murphy, Sweeney, & Chiriboga, 2000), this did not translate into self-determined choices (in the form of advance directives) regarding end-of-life care (Covinsky et al., 2000; SUPPORT Principal Investigators, 1995, 1997). Contact with clinicians experienced in palliative care has been identified as an antecedent to “self-determined life closure” and peaceful death (Ferris et al., 2002; Field & Cassel, 1997; Foley & Gelband, 2001; National Hospice Organization, 1997).

Consequences

The consequences of self-determination, for patients (including healthy individuals), organizations, and health-care providers, are evident. Those found in studies with healthy individuals include discussions with physicians and family member about treatment preferences in the event of terminal illness, and, for some, use of a living will and/or durable power of attorney for health care (Eisemann & Richter, 1999; Havens, 2000; Johnston et al., 1995; Murphy et al., 2000; Ruhnke et al., 2000). Despite attempts to educate patients in the use of advance directives, understanding and use of advance directives did not always increase (Havens; Hesse, 1995; Nordgren & Fridlund, 2001; Ott, 1999; Sutherland et al., 1989).

For ill patients, self-determination does not necessarily result in a death experience that is consistent with their values and preferences (Covinsky et al., 2000; Hesse, 1995; SUPPORT Principal Investigators, 1997). Various strategies consistent with a patient’s wish for limited life-sustaining treatment and for comfort care may be integrated — for example, advance directives, actions regarding life closure, use of comfort measures, “do not resuscitate” or “no code” orders, referral to hospice or palliative care, and symptom management, including pain relief — but this cannot be attributed directly to the presence of an advance directive. Some patients receive *less* aggressive care than they have expressed a desire for (Covinsky et al.; Hesse; Ott, 1999; SUPPORT Principal Investigators, 1995, 1997).

An unexpected finding of the analysis is patient reliance on or desire for more family or physician involvement in end-of-life decision-making, which is apparent in more recent studies and studies with patients from non-Western cultures (Candib, 2002; Covinsky et al., 2000; Fan, 1997; Hern, Koenig, Moore, & Marshall, 1998; Murphy et al., 2000; Ott, 1999; Quill, 2002; Ruhnke et al., 2000; Sutherland et al., 1989).

One study (Haynor, 1996) and one review (Ott, 1999) summarize organizational consequences following passage of the *PDSA*. Haynor describes an increase in the complexity and volume of ethics committee

cases, in professional moral dilemmas, in compliance with advance directives, in patient requests for information, and in patient and professional education. Professional consequences were increased workload (for social workers and advanced practice nurses) and role redundancy in clarification of patient preferences (for physicians, nurses, social workers, and admitting clerks). Professionals also reported increased responsibilities related to patient and family discussions, family conferences, and clarification of the term “no heroics” (Haynor). Ott describes inconsistent consequences related to utilization rates and discussion of advance directives with providers and family proxies, effectiveness of interventions to increase the use of advance directives, patients’ understanding of and ability to complete advance directives, choices and application of treatment in the event of an advance directive, and cost issues.

Exemplars

Two published palliative care cases, those of an anesthesiologist with pancreatic cancer (Whedon, 2001) and a patient with breast cancer (Groopman, 2002), are presented as exemplars of self-determination.

In the first case the patient makes choices from diagnosis to death. He chooses symptom-relief methods that are consistent with his own beliefs and preferences:

Fred was admitted for uncontrolled pain for the third time in a week. He signed himself out against medical advice the day before. From the outset Fred was plagued by abdominal pain, nausea, fatigue, and weight loss. He declined a recommended celiac plexus block for pain management, nausea strategies, and nutritional advice. Rather than continuous analgesics by oral, subcutaneous, or transdermal routes for chronic pain, he chose intermittent intravenous injections via peripheral intravenous catheters inserted for his weekly chemotherapy. (In locations carefully selected so they would not interfere with his golf swing.) He chose smoking pot over other antiemetic regimens. He chose a diet of calorie and protein rich gourmet meals accompanied by an appropriate bottle of wine from his cellar. He altered his treatment schedules and traditional oncology appointment times to undergo Reiki treatments through which he found comfort and strength. He accepted Hospice home care only to alleviate the financial consequences of the treatment and symptom management. He did his utmost to maintain the same lifestyle post-diagnosis as he had pre-diagnosis. As it became clear that he was dying a long-standing relationship with the palliative care team allowed for frank discussions. Reconciliation, family gathering, communication, and planning for his death marked his final days. In a quote from his wife’s letter after his death she said, “he respected your knowledge and experience regarding the pain meds he needed. Let me assure you how much of a coup this was for you. And to your credit, you were able to back off when necessary and let him do things his way.” (Whedon, 2001, p. 32)

In the second case a physician describes a conversation with a patient newly diagnosed with advanced-stage breast cancer in which he solicits (and documents) her choices in the event of progression of the disease:

“We talked about the best-case scenario. But we also have to acknowledge that there is a worst-case scenario.”

I had found that this part of the discussion was best completed rapidly, as if removing an adhesive bandage.

“The worst-case scenario is that ultimately the cancer becomes resistant to all the treatments we have, and even experimental therapies are no use. Most people say that if they reach a point in the illness when their brain is impaired, and there is no likelihood of improving their quality of life, then nothing should be done to keep them artificially alive, through machines like respirators. It’s essential, Maxine, that I know what you want done if we reach that point.”

“I — I don’t think I would want that,” she said, haltingly.

“You mean that you would want only comfort measures to alleviate pain, and nothing done to prolong your life, like a respirator or cardiac resuscitation?”

“Yes, I think so,” Maxine whispered.

I nodded. This was her “end-of-life directive.” I would put it in writing in her medical chart.

“We have a plan of therapy and an understanding. Now let’s look on the positive side,” I said, trying to spark some of the determination she would need in order to endure the months of chemotherapy ahead. “You are young, your organ function is excellent — despite the deposits of tumor, your liver is still working well, and your blood counts are fine — so there is every reason to think that you will tolerate the drugs and we will make real progress.” (Groopman, 2002, p. 62)

Both cases contain attributes (personal appraisal, decision-making process, activities, and outcomes) that help to clarify self-determination as it exists in expert palliative care situations. In both cases the health-care providers demonstrate respect for autonomy. They share information that will be of value to the patients in making self-determined choices consistent with their values and preferences throughout the dying process. Family is an integral part of the decision-making process. Both cases show evidence of preparation for future dependence, while the patient still has mental capacity, including documentation of wishes and provider continuity throughout the illness trajectory. Opportunities for other means of ensuring “self-determined life closure” are evident, given the preparation for the possibility of a future marked by continued deterioration and death. Both patients experience the desired consequences of a peaceful death.

Discussion

This literature review demonstrates that the concept of self-determination, a relatively abstract, complex idea, has been actualized in many different ways in various health-care settings. As described by Rodgers (2000), concepts are dynamic, constantly changing and evolving contextually and over time. This is certainly true for the concept of self-determination. Societal, legal, ethical, cultural, and palliative care practice and research influences have contributed to the evolution of definitions and attributes. Historically, in periods of oppression of vulnerable groups the focus of self-determination was freedom and self-governance. Bioethical, legal (specifically, the *PDSA*), and palliative care practice and research attempted to guarantee self-determined choice to vulnerable groups, such as hospital patients, through the documentation of treatment preferences and appointment of a proxy to ensure that the patient's plan of care was respected. Self-determination was often conceptualized as the completion of an advance directive, an attempt to reduce the entire process of decision-making on end-of-life care to a single act.

However, it became apparent that completion of a simple form could not ensure that complex patient choices, which are often situation-dependent, will be effectively captured and consistently applied within complex health-care systems. This view, which has been expressed by many health-care researchers, is summarized by Teno (1998) in a comment by Mencken: "For every human problem, there is a solution, which is simple, neat, and wrong" (p. 1170). Clarification of self-determination as a complex process is an important step in concept development.

Many studies focus on self-determination as a basic human right without considering the fact that an individual's personal appraisal of self-determination is shaped by a host of multidimensional individual factors (e.g., ethnicity, age, health status). The ethicist Renée Fox (1990) describes this lack of cultural perspective: "There is a sense in which bioethics has taken its American (Western) societal and cultural attributes for granted, ignoring them in ways that imply that its conception of ethics, its value systems, and its mode of reasoning transcend social and cultural particularities" (p. 207). Several recent studies eliciting the views of patients, especially those from non-Western cultures, on self-determination add to our understanding of self-determination in health-care decision-making. Despite the fundamental nature of self-determination, some patients do not feel empowered to make choices (Nordgren & Fridlund, 2001; Valimaki & Leino-Kilpi, 1998), while others prefer to turn decision-making functions over to family members or health-care providers because of underlying cultural beliefs (Baker, 2002; Candib, 2002;

Fan, 1997; Hern et al., 1998; Koch, Braun, & Pietsch, 1999; Koenig, 1997; Quill, 2002; Ruhnke et al., 2000; Shapiro & Bowles, 2002) or in times of serious illness (Barry & Henderson, 1996; Covinsky et al., 2000; Haynor, 1996; Prendergast, 2001; Tulsky et al., 1998).

Patients' views concerning their own level of involvement and that of others in the decisions about their care highlight the need for partnerships among patients, family members, and providers prior to serious illness. This approach is evident in the World Health Organization's (1990) definition of palliative care, which focuses on holistic care from the perspective of the patient and family. It places the patient's values and preferences at the foundation of care over the entire illness continuum, beginning with diagnosis (and emphasizing the importance of self-determination as a process).

Although health professionals have expressed a firm belief in self-determination, often affirming patients' rights in their professional codes and position statements (American Geriatrics Society Ethics Committee, 1998; ANA, 2001; Cain & Hammes, 1994; Cerminara, 1998; Department of Health, Education and Welfare, 1979; Engel et al., 1997; Ferris et al., 2002; Haynor, 1996; Scanlon, 1996; World Health Organization, 1990), they are still uncomfortable with advance care planning and lack the ability to manage it skilfully (Baker, 2002; Jezewski, Meeker, & Schrader, 2003; Prendergast, 2001; Shapiro & Bowles, 2002). Interventions to improve communication (Johnston et al., 1995; Murphy et al., 2000; Tulsky et al., 1998), increase the use of advance directives (Havens, 2000), and increase patient access to information (Barry & Henderson, 1996; Bradley & Rizzo, 1999; Eisemann & Richter, 1999; Silveira et al., 2000) often fall short of actualizing self-determined choices in end-of-life care (Covinsky et al., 2000; SUPPORT Principal Investigators, 1995, 1997). Improved provider understanding of individual patient factors to be assessed, including their desired level of involvement, fears, misconceptions, cultural beliefs, and values, might be more effective in matching providers' desires with patient outcomes.

The health-care system appears unprepared to consistently accommodate individual choices regarding end-of-life care. This is graphically illustrated in the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT), which found that thousands of patients in leading academic medical centres suffered needless pain and discomfort in an effort to prolong life rather than to provide comfort (SUPPORT Principal Investigators, 1995). The SUPPORT intervention, conducted by advanced practice nurses trained in communications and armed with state-of-the-art prognosis predictions, failed to achieve the desired outcomes. A vast literature has been generated in

attempting to identify the reasons for this failure (Bookbinder, Rutledge, Donaldson, & Pravikoff, 2001; Rutledge, Bookbinder, Donaldson, & Pravikoff, 2001; Rutledge & Donaldson, 2001; Rutledge, Donaldson, & Pravikoff, 2001). Canada has no corollary legislation to the *PDSA* and its focus is broader, with professional, institutional, and regional efforts being made to improve patient and family involvement in decision-making (Bowman & Richard, 2004; Canadian Nurses Association, 1994, 2002; Davidson & Degner, 1998; Singer et al., 2001; Singer, Martin, & Kelner, 1999).

Clarification of the concept of self-determination in the palliative care setting is hampered by three additional research issues. First, because of the many gaps in the scientific evidence on quality-of-life outcomes, it is difficult for health-care providers to determine what a patient can expect from different palliative therapies (Field & Cassel, 1997; Foley & Gelband, 2001), a key factor in patient self-determination. Second, the manner in which health-care providers communicate information to patients can influence the way in which patients receive and use that information (Johnston et al., 1995; SUPPORT Principal Investigators, 1997; Tulskey et al., 1998); patients can make self-determined choices reflecting their personal values and wishes only if they have access to the relevant information. Finally, informed patients and families who wish to take an active role in their health-care decisions — the essence of self-determination — cannot be accommodated without widespread changes to health-care systems.

Limitations of the Study

The choice of Rodgers's (2000) concept-analysis method seemed appropriate to the goal of identifying the evolution and current status of self-determination as a foundation for developing a program of palliative care research. However, this method has several limitations. Selection procedures for abstract ideas such as concept evolution, attributes, antecedents, consequences, and exemplars may exclude literature that examines conceptual meaning in other ways. As a literature-based form of inquiry, this method does not reflect the perspectives of patients, clinicians, or researchers, which could be captured through in-depth qualitative interviews. Further, instead of describing self-determination definitively, it provides a conceptual understanding based on a finite literature at a particular point in time (Rodgers). Interactive or participative methods, such as dimensional analysis, or critical methods may also be appropriate for a dynamic concept with this degree of abstractness (Rodgers & Knafelz, 2000).

Conclusion

The concept of self-determination requires clarification. It is an abstract, complex concept that is likely to change over time and within the multiple contexts in which it is actualized. Following passage of the *PDSA*, the lack of a clear definition of self-determination and its process hindered efforts to develop interventions to enhance it and hence to improve end-of-life care. This is illustrated in the negative results of the multimillion-dollar *SUPPORT* intervention, which failed to yield improved outcomes for thousands of seriously ill patients in five well-respected academic medical centres (*SUPPORT* Principal Investigators, 1995).

The implications of this concept analysis for palliative care research are summarized in Appendix 2. Future palliative care interventions should consider the complexity and evolutionary nature of self-determination. Research interventions and other strategies should consider the essential attributes of personal appraisal, decision-making process, activities, and outcomes. Such a comprehensive view takes into account the variety of patient (especially socio-cultural), provider, and health-system factors that might support or facilitate self-determination.

Fostering the broader idea of advance care planning rather than simply completing advance directives (Cantor, 1998), reimbursement of self-determination activities, especially in managed care environments (Cerminara, 1998), provider training in communication skills, and determining the influence of different cultural perspectives on views of self-determination are some of the areas of research suggested by the results of this analysis.

Future concept analysis could compare the actualization of self-determination research and policy in different countries. For instance, US research has been dominated by the *PDSA*, whereas Canada has favoured a non-legislative approach to self-determination, resulting in the development of policy and research focused on patient autonomy in decision-making (Bowman & Richard, 2004; Davidson & Degner, 1998; Singer et al., 2001). Comparison of the outcomes of these different approaches may serve to inform the development of best practices and palliative care research directions concerning self-determination.

The concept of self-determination has evolved from the notion of group self-governance to that of individual self-determination in health-care matters by means of advance directives. Another transition seems to be imminent: from the notion of self-determination as the completion of a form to that of a dynamic process of communicating health-care values and preferences among individuals, their families, and health-care providers (Agency for Healthcare Research and Quality, 2003; Brooks,

Hardy, Moseley, Myrick, & Jones, 2003; Lynn et al., 2000; Teno, 1998). The next step calls for health-care systems and health-care providers that are prepared to care for patients who exhibit all shades of self-determined decision-making.

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Appendix 1 *General Provisions of the PSDA*

- applicability: applies to hospitals, “skilled nursing facilities,” home-care agencies, hospices, and “prepaid” health-care organizations
- provision of written policies: describing patients’ right to make decisions concerning medical care, right to accept or refuse treatment, and right to issue advance directives
- provision of written information to adult patients at time of admission to medical facility
- documentation: must be provided in medical record on whether advance directive has been issued
- non-discrimination: health-care providers are forbidden to discriminate on the basis of whether a patient has issued an advance directive
- compliance with state law
- provider education about advance directives: staff and the community at large must be provided with education in advance directives
- conscientious objection: health-care providers need not implement the law if they object as “a matter of conscience”
- written description of state law: states must develop laws concerning advance directives (including medical decision-making — e.g., consent to treatment, informed consent, and end-of-life decision-making) that are distributed to patients by providers
- public education campaign: the Department of Health and Human Services is required to “develop and implement a national campaign to inform the public of the option to execute advance directives and of a patient’s right to participate and direct health care decisions”

Source: Adapted from Meisel (1998).

**Appendix 2 *Concept Analysis of Self-Determination:
Implications for Palliative Care Research***

- Consider the complexity and dynamic nature of self-determination in the development of palliative care interventions.
- Consider the nature of self-determination as a cultural, social, ethical, and legal construction.
- Recognize the importance of family; persons from non-Western cultures are more likely to view family and others as key participants in decision-making.
- Intervention research should consider opportunities for system change, as many health-care systems do not feature a patient-centred approach that encourages and supports individual choice in end-of-life decisions.
- A focus solely on increasing self-determination through the use of advance directives does not address the complexity of the process of communicating patients' values and preferences within complex health-care systems.
- Increasing the evidence base for palliative care practice (e.g., symptom control, communication skills) can serve to improve the quality of patient and family decision-making.
- Creative strategies and interventions are needed, to honour the wishes of those patients who tend to interact passively with clinicians and the health-care system.

Résumé

Questions méthodologiques en matière de recherche portant sur la pratique infirmière en soins palliatifs

Joan L. Bottorff, Mary Kelly et Jennifer Young

Cette étude intégrative a comme but de décrire les recherches dirigées par des infirmières et des infirmiers depuis le milieu des années 90 dans le domaine des soins palliatifs et des soins de fin de vie. Elle vise également à identifier les progrès et les défis méthodologiques tout en proposant des stratégies pour appuyer le développement de la recherche en sciences infirmières. Une étude des bases de données a révélé la publication de 121 rapports de recherche entre 1995 et 2003. Nous avons inclus des études dont l'auteur principal était une infirmière ou un infirmier, dont le centre d'intérêt était soit la pratique infirmière, soit les attitudes du personnel infirmier à l'égard des soins palliatifs et de fin de vie. Nous avons constaté qu'un nombre relativement réduit d'études ont inclus des patients, que les méthodes utilisées dans la collecte des données présentaient certaines lacunes et qu'il y avait peu d'études destinées à évaluer les soins infirmiers palliatifs. L'accent mis sur l'approche interdisciplinaire en soins palliatifs peut empêcher les infirmières et les infirmiers d'examiner l'efficacité des interventions infirmières. Cet aspect, ainsi que le rendement, doivent faire l'objet d'une plus grande attention afin de garantir les meilleurs résultats pour les patients et leurs familles.

Mots clés : soins infirmiers palliatifs, soins de fin de vie, étude intégrative, méthodes de recherche, recherche en sciences infirmières.

Methodological Issues in Researching Palliative Care Nursing Practice

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The purpose of this integrative review was to describe the research conducted by nurses since the mid-1990s on nursing practice in the context of palliative/end-of-life care, identify promising methodological developments as well as methodological challenges, and propose strategies to support the development of this field of nursing research. A search of databases resulted in 121 research reports published between 1995 and 2003. Studies were included if the lead author was a nurse and the focus was nursing practice or nurses' attitudes about providing palliative or end-of-life care. Relatively few studies included patients, there were limitations in the data-collection methods used, and there was a lack of studies evaluating palliative care nursing. An emphasis on the interdisciplinary nature of palliative care may be hindering nurses from examining the effectiveness of nursing interventions. Increased attention should be given to examining the efficiency and effectiveness of nursing interventions to ensure the best outcomes for patients and their families.

Keywords: palliative care nursing, end-of-life care, integrative review, research methods, nursing research

As the development of palliative care services has become a priority in Canada, the difference that nurses can make to palliative care patients and their families has taken on greater significance. It is therefore timely to review the research on nursing practice in the context of palliative care and the methodological issues in this field of research. There is growing acceptance of palliative care as an interdisciplinary health service with a role to play throughout the trajectory of life-threatening disease, albeit with increasing input towards the end of life. The definition of palliative care, therefore, emphasizes the mutual reliance among representatives of different disciplines, and is shifting from a clear focus on end-of-life care to a broader view of services needed throughout the disease-illness trajectory. These changes make it increasingly difficult to define a "palliative care patient" and appropriate contexts in which to develop and assess palliative care nursing interventions and programs. The focus of this paper is nursing research that addresses aspects of nursing care related to the terminally ill who, although perhaps still receiving treatments for symptom control, are in the last days, weeks, or months of their lives.

Background

Benoliel (1983) conducted one of the first reviews of nursing research and terminal illness, spanning the years 1969 to 1981. She concluded that the body of research was fragmented and comprised largely descriptive studies. Benoliel recommended that greater attention be given to the integration of sound conceptual frameworks within research designs. Although nurses had made a significant contribution to the knowledge base on nurses' experiences of death, patient and family adaptation to death, and environmental and social processes affecting responses to death and terminal illness, there was a dearth of research addressing nursing practice interventions (other than psychosocial).

In the 1990s several systematic reviews were undertaken to describe developments in palliative care research conducted by nurses, as well as methodological trends and issues (Bailey, Froggatt, Field, & Krishnasamy, 2002; Froggatt, Field, Bailey, & Krishnasamy, 2003; Richardson & Wilson-Barnett, 1995; Wilkes, Tracy, & White, 2000). An increase was observed in the number of palliative care studies conducted by nurses in the 1990s. Although the focus was descriptive research, both quantitative and qualitative methods were used. Concerns were raised about the quality of some of the research, such as the limited use of nursing theories or frameworks and the lack of rigour in some of the qualitative research. Important developments during this period included the use of mixed-method designs, an interest in practice-based research, evaluation and patient-focused research, and the use of qualitative methods to study patient outcomes where nurses have an effect on care.

Nurses have also been involved in comprehensive reviews of palliative care research conducted by nurses and others (Corner, 1996; Johnston & Abraham, 1995). Issues in palliative care research identified in these reviews included the development of palliative care research as a specialized field, the disparate focus of palliative care research due to its relevance for many areas of health care, and issues related to conducting research with the dying. The predominance of descriptive studies, the narrow scope of evaluations, the lack of consensus on standard measures, and slow development of appropriate measures for palliative care research, particularly outcomes measures, were highlighted as methodological issues in palliative care research. Recommendations for advancing this field of research included increased use of flexible, multi-method designs, consensus on standard measures, creation of databases, and increased collaboration through interdisciplinary research.

Nurses have been important contributors to discussions about the unique issues and challenges of conducting palliative care research with families and children (Davies, Chekryn Reimer, Brown, & Martens,

1995; Davies, Steele, Stajduhar, & Bruce, 2003; McClement & Woodgate, 1998). Nurses have also described issues related to conducting qualitative research in the context of palliative care (Beaver, Luker, & Woods, 1999; Davies et al., 1995) as well as the special considerations demanded by the vulnerability of palliative care patients and their families (Dean & McClement, 2002).

In summary, nurses have been active contributors to the field of palliative care research and to the development of research approaches and methods. Yet there is no recent review of nursing research focusing on palliative care nursing practice in order to describe progress and identify methodological issues and challenges. The purpose of this integrative review was to describe the research conducted by nurses since the mid-1990s specifically on palliative/end-of-life nursing care, to identify promising methodological developments and challenges, and to propose strategies for supporting the development of this field of nursing research.

Methods

We searched CINAHL, MEDLINE, Sociofile and Web of Science databases to retrieve all the available literature published on palliative care nursing. The following keywords were combined: hospice and palliative nursing or palliative care; end of life or terminal care or palliative care; hospice or hospices; and terminal care. We also requested documents mapped to nursing attitudes or nursing experience/practice in palliative care, eliminating all editorials and commentaries. The search was confined to English-language empirical studies published between 1995 and 2003. We also limited the search to studies whose lead author was a nurse. This search strategy returned 467 articles, which were then reviewed for inclusion/exclusion criteria. Excluded were articles that focused specifically on family experiences of caring for relatives with terminal illnesses, patient experiences at end of life, nursing education, and experiences of health-care providers other than nurses, as well as literature reviews and organization audits. Studies that considered diverse perspectives were included if findings directly related to nurses were clearly reported. A pool of 121 published research studies met these criteria.¹ A data-extraction form was developed to systematically capture information about each study. Data were entered into a data file to assist with the summarizing of findings.

The most frequent source of studies was nursing journals, the majority being published in the *International Journal of Palliative Nursing* ($n = 38$) and the remainder in 27 different publications, including the *Journal of*

¹ A complete list of studies included in this review is available from the authors.

Table 1 Characteristics of Studies Included in the Integrative Review

Design Characteristics	Research Category			
	Professional Nursing Roles and Issues (n = 70)	Nursing-Care and Health-Care Context (n = 16)	Descriptions of Nursing Practice (n = 20)	Evaluation of Nursing Practice/Interventions (n = 15)
Palliative care population				
• adult, general	45	4	13	4
• child/adolescent	4	0	0	0
• cancer	7	2	7	9
• HIV/AIDS	1	0	0	0
• other	3	0	0	2
Research design				
Qualitative (n = 71)				
• generic qualitative	19	8	10	2
• grounded theory	6	0	5	0
• phenomenology	10	1	0	0
• ethnography	2	3	0	0
• case study	4	0	0	1
Quantitative (n = 38)				
• descriptive/correlational	23	3	3	2
• comparative survey	2	0	0	0
• experimental/ quasi-experimental	0	0	0	5
• pilot study (n = 5)	0	1	0	4
• mixed method (n = 7)	4	0	1	2

<p>Sampling method</p> <ul style="list-style-type: none"> • purposive • theoretical • convenience • random • stratified • other (e.g., whole population, systematic sampling) 	<p>27 1 21 2 0 19</p>	<p>0 0 3 1 2 0</p>	<p>10 1 8 1 0 0</p>	<p>4 0 6 2 0 3</p>
<p>Data collection^a</p> <ul style="list-style-type: none"> • standardized measures, unmodified • standardized measures, modified • investigator-developed measures • interviews, face-to-face • focus groups • observation • physiological measures 	<p>4 4 61 42 6 6 0</p>	<p>0 0 15 7 6 3 0</p>	<p>1 3 16 13 1 2 1</p>	<p>10 1 4 7 1 0 3</p>
<p>^aMultiple data-collection methods were used in some studies.</p>				

Advanced Nursing ($n = 8$), the *Journal of Clinical Nursing* ($n = 4$), *Nursing Ethics* ($n = 4$), and *Cancer Nursing* ($n = 6$). Non-nursing journals included the *Journal of Palliative Care* ($n = 2$), the *European Journal of Cancer Care* ($n = 2$), the *American Journal of Critical Care* ($n = 4$), and *Hospice Journal* ($n = 2$). Most investigative teams were made up entirely of nurses ($n = 99$; 82%); 21 multidisciplinary research teams were identified, and these included investigators from medicine, the social sciences, and information studies. We were unable to determine the composition of the research team for one publication. Over half of the reviewed studies were conducted in the United States and the United Kingdom ($n = 75$, 62%); 20 (16%) were conducted in Australia and the remainder in Canada (5%), Europe (4%), and other countries (13%), including Japan. Eighty of the studies (66%) were published since 2000.

Findings

The studies included in the review were classified according to target study population and design characteristics (see Table 1). The majority of the studies (63%) focused on the provision of palliative/end-of-life care for adults, 30% focused specifically on cancer patients with advanced disease, and only four focused on nursing terminally ill children or youth. Generic qualitative methods were represented in the majority of the qualitative studies ($n = 39$), followed by grounded theory ($n = 11$), phenomenology ($n = 11$), ethnography ($n = 5$), and case-study methods ($n = 5$). Among the quantitative studies reviewed, the majority were descriptive/correlational ($n = 31$; 25%); the remainder included five experimental or quasi-experimental designs, two comparative surveys, and seven mixed-method designs. Among the quantitative studies reviewed, random or systematic sampling approaches were used in only 13 (out of 33). The use of relatively small convenience samples was evident in some studies. In the qualitative studies, the adequacy of the sampling strategy was rarely addressed. Underrepresented in this body of research were palliative care patients and families from ethnocultural groups, children and adolescents, and those dying from diseases other than cancer.

In the 38 quantitative studies reviewed, less than half ($n = 17$) used standardized measures for data collection. The majority of studies ($n = 21$) used investigator-developed surveys and measures. Psychometric evaluations were limited to assessing content validity using expert panels and estimating reliability coefficients.

The foci of the studies were classified according to four topics: descriptions of professional nursing roles and issues related to the care of the dying ($n = 70$), descriptions of nursing care of the dying as influ-

enced by health-care context ($n = 16$), descriptions of nursing interventions/practices ($n = 20$), and evaluations of nursing interventions/practices ($n = 15$). Examination of the study designs and methods used with each of the topics revealed some interesting patterns.

Professional Nursing Roles and Issues Related to Care of the Dying

This category comprised the majority of the studies conducted since 1995 by nurse researchers, and included primarily exploratory, descriptive studies ($n = 70$). Qualitative designs were used to describe nurses' suffering, stress, moral distress, and grief; nurses' responses to ethically challenging situations (e.g., requests for assisted suicide); and the ways in which nurses found meaning in their work. Studies describing nurses' perceptions of palliative care services, nursing roles and professional issues (e.g., related to ethical issues at end of life) included both qualitative and quantitative designs. In this group of studies, only four used mixed designs.

Given the focus of these studies, samples comprised mainly nurses (76%, $n = 53$); 41 of the 70 studies used semi-structured interviews; one phenomenological study used open, unstructured interviews; 28 used questionnaires (predominantly incorporating investigator-developed measures); and a few used observational methods ($n = 6$) and focus groups ($n = 6$) in combination with this primary method. Several studies used innovative approaches to enhance data collection. For example, Wilkes, Boxer, and White (2003) used faxed photographs of malignant wound cases as prompts in telephone interviews with nurses caring for patients with these types of wounds. In another interview study, poetry about death and dying was used to help nurses reflect on their experiences (Larkin, 1998). A fictional case study was used to elicit responses and facilitate the interview process in a study of nurses' opinions regarding assisting or hastening a patient's death (Pierce, 1999).

Descriptions of Nursing Care of the Dying as Influenced by Health-Care Context

This set of 16 studies provided descriptions of the management of nursing care for dying patients in a variety of settings while accounting for influencing factors (e.g., norms related to disclosure of information about death and dying, the involvement of relatives, clinical practice environments, and relationships among health-care providers). With the exception of three survey studies, this group of studies used generic qualitative research designs.

Among the qualitative interview-based studies, nine collected data from nurses only. All three ethnographies employed observational methods, whereas eight qualitative studies principally used interviews and

focus groups. Three studies used institutional records as a data source, one of which was based principally on analysis of nursing discharge summaries.

Descriptions of Nursing Interventions/Practices

Twenty studies focused on nursing interventions and practices, particularly those developed over time by clinicians to address clinical problems. The underlying objective of this research was to identify and describe interventions so they could be formally incorporated into practice and evaluated in a variety of contexts. This group of studies used qualitative methods, with four exceptions. Survey methods were used to describe the use of hope-engendering interventions by nurses (Herth, 1995) and nursing practices used to manage malignant wounds (Wilkes, White, Smeal, & Beale, 2001). A descriptive correlational design was employed in a secondary data analysis to identify patterns of nursing interventions used to care for dying patients (McCorkle, Hughes, Robinson, Levine, & Nuamah, 1998). Finally, one researcher combined nurses' diaries and hospital-record data in a mixed-method design to describe the provision of telephone support by nurses to bereaved relatives of palliative care patients (Kaunonen, Aalto, Tarkka, & Paunonen, 2000). This group of studies was characterized by diversity of the samples.

All but three of the qualitative studies relied exclusively on individual or group interview data to describe nursing interventions. Only two studies used observation. In one of these, an initial period of participant observation during home-care visits was used to identify questions for inclusion in interviews with nurses to collect rich descriptions of nursing practice (Morgan, 2001). In the second study, participant observation of nurse-patient interactions in two palliative care units was used in conjunction with interviews with nurses and patients to identify strategies used by nurses to support the involvement of patients in decisions about their care (Botorff et al., 2000). Brief, informal conversations with both patients and nurses were included to elicit additional data. In this way, some patients who were unable to participate in in-depth interviews were included in the study.

Worthy of mention is the interesting approach used by McCorkle et al. (1998) to identify patterns of nursing interventions. Her study entailed analysis of comprehensive narrative records of nursing interventions maintained by nurses as part of a larger study. This team used Grobe's Nursing Intervention Lexicon and Taxonomy, a seven-category classification scheme, to code all descriptions of nursing activities. This approach allowed them to identify and describe the types of nursing interventions used by advanced practice nurses in home-care settings for older cancer patients in the dying phase.

Evaluation of Nursing Interventions/Practices

There were relatively few evaluations of nursing interventions led by nurse researchers. This small group of studies ($n = 15$) included evaluations of specific nursing interventions such as the use of quality-of-life scores to prompt the planning of patient-centred care (Hill, 2002) and attempts to link the spectrum of services provided by specialized palliative care nurses to patient and family outcomes. Only five evaluations of palliative care nursing services using experimental designs were identified, in addition to two mixed-method designs. Other studies included an evaluation of the validity of nurses' assessment of the symptom experiences of hospice patients using correlational methods, a case study of the nurse practitioner's role in palliative care, an evaluation of an after-hours telephone-support program for hospice patients, and two qualitative studies. Pilot studies ($n = 4$) to evaluate protocols prior to conducting full-scale evaluations were also included. In the only two longitudinal studies, outcomes were assessed at various points following admission to palliative care, and with follow-up assessments up to 25 months after the patient's death in two studies (Corner et al., 2003; McCorkle et al., 1998).

Although determining and measuring the quality of end-of-life care is a complex undertaking, researchers attempted to identify and measure nurse-sensitive outcomes for palliative care (Corner et al., 2003; McCorkle et al., 1998; Williams & Sidani, 2001) using quality of life, spousal distress, anxiety, and depression, as well as nurse, patient, and family accounts of the care provided. A few studies used multiple sources of data to determine outcomes. For example, in addition to using standard quality-of-life measures, Corner et al. collected and analyzed data from patient and caregiver interviews, clinical information, and nurses' records. These data were compiled into a single narrative for each patient and subjected to thematic analysis. When outcomes of care were evident, they were identified and coded as positive, equivocal, or negative. This approach allowed for the description of multiple outcomes for each patient at different points in time, and served to avoid some of the problems associated with examining outcomes among individuals whose condition worsens. The evidence provided by patients was deemed to be the strongest, followed by that provided by caregivers, other health professionals, and finally nurses. Once instances of care were identified, the balance of outcomes identified for each case was calculated to gain an overall picture for each patient. Positive outcomes related to improvement in physical symptoms or emotional state, the receipt of information/advice, feeling supported by the Macmillan nurse intervention, explicit acknowledgement of the value and/or beneficial quality of the

nurse's care, and an expressed belief that the presence of the nurse improved the quality of care. Negative outcomes were related to the absence of any of the above or the absence of improvement following application of the Macmillan intervention. In instances where there was an absence of information on outcomes or where the complexity of the patient's condition precluded assessment of the nurse's contribution, the outcome was categorized as equivocal. This innovative approach to capturing nurse-sensitive patient outcomes offered new insights into the complex ways in which nurses benefit palliative care patients and points to the limitations of relying on single indices to capture such benefits.

Discussion

The findings of this review indicate that there is a small but growing body of research, by nurse researchers, investigating the practice of palliative care nursing. Although nursing studies describing patient and family experiences at the end of life may inform research on palliative care nursing practice, these studies were not included in the review. Furthermore, the body of research included in the review does not represent all of the studies evaluating palliative services provided by nurses. The increasing emphasis on the interdisciplinary nature of palliative care has led some nurses to focus on the contributions of the palliative care team rather than on nursing interventions or nurse-sensitive outcomes. Although disentangling the unique contributions of nursing care is a complex matter, the evidence-based practice movement and the demand for professional accountability have prompted the development of research approaches that may hold relevance for palliative care nursing (Doran, 2003).

Descriptive research is still the dominant design used by nurse researchers studying palliative care nursing practice. The importance of this research should not be underestimated, because descriptive, exploratory qualitative research has the potential to uncover new knowledge about various dimensions of palliative care nursing and provide the foundation for the development of measures and interventions that address the needs of palliative care patients and their families. Furthermore, it has been suggested that the preponderance of generic qualitative descriptive methods is not uncommon in practice disciplines and offers comprehensive summaries that focus on the *who*, *what*, and *where* of the phenomena of interest (Sandelowski, 2000). Nevertheless, very few of the qualitative studies covered in this review focused on developing explanatory theory or on linking inductively derived concepts to construct theories.

Previous methodological reviews have regarded the use of mixed methods as a promising development in nursing research on palliative care, because their flexibility and ability to capture a wider range of dimensions make these methods particularly suited to palliative care. It appears, however, that mixed-method studies remain under-utilized. Furthermore, there is a lack of critical perspective in evaluating the influence of social structures and processes on the provision of palliative nursing. The relatively small number of studies that included patients, the limitations associated with data-collection methods, and the lack of evaluation of palliative nursing interventions highlight the need for innovative research approaches. This field of research could benefit from enhanced sampling and recruitment strategies, enhanced data collection, and the evaluation of palliative care nursing practice.

Sampling and Recruitment

Few of the studies acknowledged recruitment as a limitation in their research, although this issue is implicit in the reports of other studies. Even with detailed planning as to the identification of potential cases, careful consideration of the relevance of eligibility criteria, and use of methods to keep refusal rates low, difficulties can arise in obtaining samples (McMillan & Weitzner, 2003). In order to enhance accrual in palliative care research, investigators are being encouraged to examine such topics as individuals' responses to invitations to participate in research, factors that influence their decision whether to participate as well as their experiences as participants, the best times to request consent, predictors of impaired decision-making capacity, and interventions to improve decision-making capacity (Addington-Hall, 2002; Casarett, 2003; Koenig, Back, & Crawley, 2003). The inclusion of assessments of the impact of the research on participants is also likely to be useful in informing the development of research designs that minimize the burden for participants. In his study, for example, Hudson (2003) incorporated a four-item questionnaire to assess the impact of research participation on family caregivers of dying cancer patients. Nurses with expertise in qualitative methods could make a significant contribution to the investigation of patients' and bereaved relatives' participation in research. In addition, some palliative care researchers are proposing innovative approaches to both recruitment and informed consent. Two promising approaches are the incorporation of screening questions into routine intake procedures, to identify patients who are willing to participate, and the use of advanced consent.

The use of screening questions to distinguish between individuals who may and may not be interested in research could be useful in palliative care settings, to ensure that researchers approach only those

who are receptive. Crowley and Casarett (2003) evaluated the usefulness of two screening questions (for symptom-related research and disease-modifying research) in the intake process of a palliative care clinic. Patients were presented with both questions and were asked to explain their answers. They were told that affirmative responses to either question could result in their medical file being reviewed to determine their eligibility for research participation. Because recruitment typically begins with an assessment of interest in general terms, the usefulness of screening questions merits further evaluation for nursing studies. Exploration of a wide range of factors that may influence interest in research participation could provide direction for recruiting specific groups as well as for modifying designs to address patient concerns about participation. This approach may also serve to make clinicians feel more at ease about recruitment and to reduce gatekeeping.

Advanced consent procedures have been proposed for palliative care research, to address problems with patient accrual associated with fluctuations in cognitive status and the rapid course of many terminal illnesses (Casarett, Knebel, & Helmers, 2003; Rees & Hardy, 2003). Rees and Hardy conducted a feasibility study of an advanced consent process to enable research with patients in the terminal phase. The process entailed the provision of information about the study to eligible patients upon admission and the provision of an information sheet to those who expressed interest in the study, after which, during a follow-up visit by a nurse, patients were asked to sign their informed consent. At each subsequent admission, patients were asked if they were still interested and re-signed the consent. If the patient was unable to sign and relatives indicated there was no reason why the patient would have changed his or her mind about participating, the previous consent was considered valid. If the patient subsequently developed the clinical problem to be addressed in the study (in this case noisy respiration), he or she was randomized. Although the ethics of advanced consent have been questioned by some, the authors conclude that the process was viable and that the refusal rate suggested patients did feel free to decline.

Data Collection

As noted in previous reviews, there is a continuing need for standard outcome measures across care settings as well as for flexibility in measurement approaches to accommodate deterioration in patient health (Davies et al., 1995; Johnston & Abraham, 1995). In particular, efforts to define and measure nurse-sensitive patient outcomes are critical. Some recent developments may provide useful approaches to evaluating the effectiveness of palliative care nursing interventions. For example, Rankin et al.'s (1998) concept of "dignified dying" and the development of new

tools such as the Abbey Pain Scale to measure severity of pain in individuals with late-stage dementia (Abbey et al., 2004) will likely enhance our ability to assess nurse-sensitive outcomes in palliative care. While acknowledging the methodological and ethical difficulties of assessing individuals prior to death, Johnston and Abraham suggest that in the final stages of life open-ended measures may be more appropriate and may facilitate participation.

In qualitative studies, the tendency to rely on interview data was identified in previous reviews of palliative care nursing research, and it appears that this situation has not changed significantly. Despite the value of interview data, the use of in-depth interviews with patients may be compromised by their level of fatigue, pain, or other illness effects and unpredictable changes in their cognitive status. Over-reliance on interview data can also limit the range of nursing practices that are identified. For example, in an unpublished pilot study to identify interventions that home-care nurses providing palliative services used to support family communication, Miller (2003) found that nurses were often unable to report details of the verbal and nonverbal behaviours that made up their approaches to caregiving; sometimes their explanations indicated a lack of awareness of their behaviours or the language to describe their actions. Morse (2000) argues that the chief mode of identifying nursing interventions is observation, particularly non-participant observation along with in-depth interviews. Observation of naturally occurring clinical practice and associated patient outcomes is lacking in the emerging body of research on nursing practice in palliative and end-of-life care. Although the collection of observational data in clinical settings is represented in the studies reviewed, no observations were carried out in home-care settings despite the shift in the delivery of palliative care from hospital to home settings. It has been illustrated that observational approaches that are sensitive and ethical and that produce rich data can be developed. Stajduhar (2001) conducted participant observations in homes where family members were providing palliative care as part of a study to describe caregiving experiences during the “dying period” and to explore the influence of health-care context on these experiences. These observations included the provision of home-care support services by a variety of health professionals. Sensitive to the burden that participation placed on families, Stajduhar offered them a choice between interviews only or observations, negotiated the number and length of observation periods, and continually renegotiated consent. The number of observations in each home varied from 3 to 10, with some patients dying soon after she became involved. Instead of positioning herself as a detached observer, Stajduhar became involved in “normal” family life by helping with household chores, conversing informally with caregivers over cups

of tea, and playing with grandchildren. Using this approach, she completed over 100 hours of participant observation with a core group of seven caregivers and an additional 30 hours with another six caregivers. Thirteen other active caregivers who did not wish to participate in home observations agreed to be interviewed.

Spiers (2002) conducted a study of home-care nursing to explore the interpersonal contexts of negotiation in 10 nurse-patient dyads, including four patients with terminal illness. To enhance comfort levels and reduce reactivity with the data-collection approach, she interviewed all patients prior to videotaping their interactions with nurses. The participant-observation role she found to be least intrusive during the data-collection visits was that of minimal participation. Spiers videotaped 31 nursing visits using a camcorder, then interviewed the nurses to elicit data on their perceptions of the visit, the main topics of conversation, nursing goals, and any communication difficulties. She returned to patients' homes to interview them about their experiences and their expectations with regard to home care. Spiers' analysis of moment-by-moment communication revealed six interpersonal contexts for negotiation, providing a framework for reconceptualizing the notion of resistance in nursing care.

Evaluating Nursing Practice

Although randomized controlled trials (RCTs) are the gold standard for linking interventions with outcomes, few were identified in this review. This may be a reflection of the well-known difficulties of conducting research with dying individuals, the resources required to conduct an RCT, and the challenges of determining and measuring outcomes of high-quality individualized palliative/end-of life nursing care. Notwithstanding the advice that nurse researchers are beginning to provide to others considering RCTs with palliative care patients and their families (Hudson, Aranda, & McMurray, 2001; McMillan & Weitzner, 2003), three additional approaches hold promise for determining the effectiveness of palliative care nursing interventions for patient outcomes. Firstly, flexible and diverse mixed-method studies need to be developed. For example, intervention studies could be enhanced by incorporating qualitative methods into the design. While maintaining the integrity of each method and ensuring a fit with the overall purpose of the research, qualitative data-collection and analysis methods can be used to describe and explain individual variation on outcome measures obtained from instruments, to ascertain the validity of outcome measures, and to clarify the nature and course of an intervention (e.g., how it is executed, the expertise and labour required to execute it, and the response to it) (Sandelowski, 1996). Nesting qualitative methods into

clinical trials cannot compensate for or salvage poorly designed or executed trials. However, as Sandelowski suggests, when physiological and psychological outcomes appear less sensitive to nursing, the use of qualitative methods in RCTs provides an opportunity to discern nurse-sensitive patient outcomes and to increase the visibility of nursing efforts.

Other approaches to RCTs could also be considered. One potentially useful approach is Qualitative Outcome Analysis (QOA), proposed by Morse, Penrod, and Hupcey (2000). This approach makes use of qualitative methods to evaluate the effect of an intervention on patient outcomes while describing the application of the intervention. What makes this approach potentially useful in the context of palliative nursing is the fact that it is premised on the dynamic and complex nature of clinical work. Multiple collection methods are used to gather data on shifts and refinements in the use of interventions as patient conditions change over time and to ensure the capture of different perspectives and aspects of the intervention's efficacy. Unlike qualitative evaluation (Patton, 1990), QOA not only provides opportunities for researchers to describe both process and outcomes, but also allows them to expand or augment interventions by including other strategies learned through the implementation process.

Finally, databases of outcomes for all recipients of nursing services in a given hospital, region, or system could be an invaluable source of information for studies on end-of-life care across all settings. Although there are complex issues entailed in establishing such databases, commitments have been made to do so in some jurisdictions. Work has also begun with regard to developing evidence-based understandings of patient outcomes that have demonstrated sensitivity to nursing care and evaluating associated measurement instruments (Doran, 2003). It is important that palliative care nurse researchers be part of these initiatives.

Conclusion

Nurses have the potential to make important contributions to the development of knowledge in the field of palliative care — knowledge that is needed to guide decisions with regard to both practice and policy. Nevertheless, nurses will likely continue to be part of interdisciplinary palliative care teams. Therefore, unless researchers identify designs and methods for capturing nurses' unique contributions to outcomes, the development of research devoted specifically to nursing interventions will be further compromised. Examining the appropriateness, efficiency, and effectiveness of nursing interventions should be a priority, in order to ensure that the best outcomes for patients and their families are achieved.

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Transformer l'espoir : L'espoir chez les personnes âgées en soins palliatifs

Wendy Duggleby et Karen Wright

L'espoir est important pour les patients en soins palliatifs; toutefois, le processus qui permet à ces patients de continuer à vivre et à espérer est inconnu. Cette étude théorique à base empirique décrit les processus qui permettent aux patients en soins palliatifs de continuer à espérer. Seize entrevues ont été menées auprès de 10 patients recevant des soins palliatifs à domicile (moyenne d'âge 75 ans) auxquels on a posé des questions ouvertes. Les participants définissent l'espoir comme les attentes qu'ils ont, par exemple, de ne pas souffrir d'avantage et de mourir paisiblement. Ils décrivent leur principale préoccupation comme étant de vouloir « vivre et continuer à espérer » et ils y arrivent grâce au processus social fondamental de la transformation de l'espoir, ce qui implique d'accepter la « vie comme elle est », chercher du sens et procéder à une réévaluation positive. Les résultats de cette étude serviront de fondement à des recherches futures et à l'élaboration d'interventions visant à susciter l'espoir chez les patients âgés en soins palliatifs.

Mots clés: soins palliatifs, personnes âgées, espoir

Transforming Hope: How Elderly Palliative Patients Live With Hope

Wendy Duggleby and Karen Wright

Hope is important to palliative patients; however, the process by which these patients live with hope is unknown. The purpose of this study was to describe, using a grounded theory approach, the processes by which palliative patients live with hope. Sixteen interviews were conducted with 10 home-care palliative patients (mean age 75 years) in their homes using open-ended questions. The participants defined their hope as expectations such as not suffering more and having a peaceful death. They described their main concern as wanting to “live with hope” and they achieved this through the basic social process of transforming hope. Transforming hope involved acknowledging “life the way it is,” searching for meaning, and positive reappraisal. The results of this study provide a foundation for future research and the development of interventions to engender hope in older palliative patients.

Keywords: palliative, elderly, hope, qualitative research

Introduction

The alleviation of suffering at the end of life is considered a realistic goal for all health-care professionals (Lindholm & Erickson, 1993). Palliative patients describe their suffering in terms of multiple physical, psychological, and social losses (Daneault et al., 2004). They describe hope as the ability to endure and cope with their suffering (Duggleby, 2000). For patients with incurable cancer, hope is important for a meaningful life and a peaceful death (Benzein, Norberg, & Saveman, 2001).

Several studies of hope in palliative care patients have found that it is very important to these individuals (Benzein et al., 2001; Buckley & Herth, 2004; Duggleby, 2000; Duggleby & Wright, 2004; Hall, 1990; Herth, 1990). However, we do not know how palliative patients maintain their hope in the context of multiple losses. A grounded theory qualitative approach to uncovering the processes by which older palliative care patients maintain their hope may lead to the development of strategies for fostering hope in this population. By increasing hope we may be able to contribute to patients' quality of life (Herth, 2000), which is a goal of end-of-life care (Carstairs & Beaudoin, 2002).

The purpose of this study was to describe the processes by which older palliative home-care patients with advanced cancer live with hope. Specific strategies used by the participants to foster the hope identified in this study are described elsewhere (Duggleby & Wright, 2004).

Background

Although several studies have been conducted on hope in patients with cancer and chronic diseases, very few have focused on the hope experience of terminally ill patients (Duggleby, 2001). Two studies examined nurses' perceptions of how they fostered hope in palliative patients (Cutcliffe, 1995; Herth, 1995), though it is unknown whether their perceived means of fostering hope were actually effective. Another study examined nurses' perceptions of the hope experience of palliative cancer patients (Benzein et al., 2001; Benzein & Saveman, 1998). Nurses' views of the patients' hope experience may not be accurate, however, as health-care professionals often view the hope of terminally ill patients as a form of denial or false reality (Perakyla, 1991).

Interviews conducted with palliative patients suggest that they define hope as an inner resource and as a coping mechanism essential for their quality of life (Benzein et al., 2001; Buckley & Herth, 2004; Flemming, 1997; Hall, 1990; Herth, 1990). The patients hoped for the avoidance of suffering, a peaceful death, and life after death. Some patients also hoped for a better life for their families. The focus of hope in palliative patients is different from that in other patient populations. Medical/surgical patients (Cameron, 1993; Perakyla, 1991), stroke patients (Bays, 2001), and patients with chronic pain (Howell, 1994) focus their hope on getting better and living longer. The fact that palliative patients define hope differently suggests that their processes of hope may also differ from those of other patient populations.

Research examining the focus of hope for palliative patients has identified strategies that foster hope for these individuals. Such strategies include good symptom control, the setting of short-term goals, faith/spirituality, positive outlook, and connectedness. However, it is not known when and how patients use these strategies. Moreover, the methodological approaches used to examine hope in the studies conducted so far have not allowed for the descriptions of the processes associated with hope. These limitations suggest the need for exploratory research into the processes of hope in the palliative population, in order to facilitate the development of theoretically based frameworks for future hope interventions.

Methods

A qualitative, grounded theory approach (Glaser, 1992, 2001) was used to identify the processes of the hope experience for older palliative home-care patients with advanced cancer. The greatest contribution of grounded theory is in areas in which little research has been done and few adequate theories exist to explain or predict a group's behaviour (Chenitz & Swanson, 1986). It is "a very useful method to understand what is going on in a substantive area and how to explain and interpret it" (Glaser, 1978, p. 3). Specific interventions are more likely to emerge from the data when grounded theory is used as a methodological approach to studying hope (Cutcliffe & Grant, 2001).

Procedure

The study was approved by an Institutional Ethical Review Board. The palliative care coordinator in the health region identified potential participants based on the following criteria: male or female over the age of 65; diagnosed with cancer; receiving palliative home-care services from a rural Canadian health region; English-speaking; Palliative Performance Scale score of at least 30% overall; PPS score of at least 60% for consciousness level; and consent to participate. The PPS was used as a screening tool in order to exclude those who were unable to physically or cognitively participate. It is a reliable and valid measure of functional performance, progressive decline, and confusion in palliative patients (Virik & Glare, 2002).

When potential participants agreed to take part in the study, the research assistant contacted them to describe the study and arrange to meet them in their homes at their convenience. The research assistant (RN-RA) was an experienced palliative home-care nurse trained in obtaining consent and in data collection. At the first visit before data collection, the RN-RA obtained written informed consent.

Data collection entailed a demographic form, face-to-face individual interviews, and information from the patient's chart. The participants also completed the Herth Hope Index (HHI) and the Edmonton Symptom Assessment Scale (ESAS) to describe levels of hope and symptom intensity, respectively. The HHI has been found to be a reliable measure of hope in terminally ill patients (Herth, 1992). It consists of a 12-item, four-point Likert scale with a summative score; higher summative scores denote greater hope. The ESAS consists of nine reliable and valid numerical rating scales of symptom intensity (Chang, Hwang, & Feureman, 2000); higher scores denote greater intensity.

Open-ended audiotaped interviews ranging from 15 to 60 minutes in duration were conducted in the homes of the participants. Questions

were asked that invited participants to: describe hope, identify the things that gave them hope, specify the things that increased or decreased hope, and describe what others could do to foster hope.

In addition, field notes were taken on the setting, the non-verbal behaviours of participants, and the interactions of participants with others such as family members and with the environment.

Data Analysis

Each interview was transcribed verbatim. The transcription was then checked for accuracy by the RN-RA who had conducted the interview. Consistent with grounded theory methods, data analysis was carried out concurrently with data collection. Interview data were examined line by line using the constant comparative approach of grounded theory. From the transcripts, codes were identified using the participant's language as much as possible. Then the codes were grouped together to identify processes and underlying patterns. Coding occurred at three levels using Glaser's (2001) approach: open, selective, and theoretical. Open coding was completed when the main concern and basic social process were identified. Selective coding was focused on the basic social process and sub-processes. In theoretical coding, the relationships between substantive codes were conceptualized. The researchers used selective sampling of the literature throughout the analysis to help them fill in the missing pieces in the emerging theory. They used memoing to preserve ideas that came up throughout the data analysis with regard to the emerging theory.

Scientific rigour in qualitative research is judged on the basis of credibility, auditability, fittingness, and confirmability (Marcus & Liehr, 1998). In this study the audiotapes were transcribed verbatim and the participant's language was used in coding, categorizing, and theory writing to establish credibility. Credibility of the findings was also established by confirming the results with the participants whenever possible. Auditability was achieved by keeping raw data, field notes, and memos, ensuring an audit trail. Fittingness of the data was ensured by grounding theoretical observations in the data, and through cross coding and categorization of data. As well, the principal investigator and the co-investigator independently coded selected transcripts throughout the study and then compared the results.

Results

Sample

Ten participants were interviewed in their homes, located in a rural prairie community in Canada. Purposive sampling was used to select par-

ticipants of different genders, various ages, and with different types of cancer. Unsuccessful attempts were made to recruit patients who had low hope scores and high symptom scores. Once data analysis revealed the basic social process (BSP) present in the data, theoretical sampling was used to select interviewees who would inform the facets and dimensions of the BSP.

Five (50%) of the participants were female and five (50%) male. The age of the participants ranged from 65 to 85 years with a mean age of 75 years. All participants were Caucasian and had been diagnosed with various types of cancer as well as secondary conditions such as kidney disease, arthritis, or heart conditions. The average number of years of education was 10.70 (range 8–16 years). The majority of participants were married (70%; 30% widowed) and lived with their spouse (70%; 30% lived alone). All participants identified a religious preference, with 80% being Protestant and 20% Catholic. Mean HHI scores were 42.7/48 (range: 34–48), indicating high levels of hope, and ESAS scores were low (mean: 2.21), indicating minimal levels of symptom intensity.

Whenever possible, participants were interviewed twice, in order to have them review their transcript and to explore the concepts highlighted in the first interview. A total of 16 interviews were completed. Six participants reviewed their transcript. Four could not be re-interviewed because of physical symptoms ($n = 3$) or death ($n = 1$).

Main Concern: Living With Hope

From the analysis of transcribed interview data a main concern and a core category were identified. Glaser (2001) describes the main concern as the main preoccupation of the participants. In the present study, participants described their main concern as wishing to “live with hope” in spite of multiple losses with respect to function, independence, relationships, goals, and a longer life. The participants said it was important for them to “live life,” “keep on going,” and “live day by day.” When asked what happens if one does not have hope, one participant said: “I guess if you don’t have any hope, I would say you just slowly wither away. I would almost think, if you don’t have any hope, then you have nothing for the future or even for the present.” Another said: “You can’t live without hope.”

Core Category: Transforming Hope

In grounded theory, the main concern is continually resolved through a core category, which “organizes and explains most of the variation in how the main concern is resolved” (Glaser, 2001, p. 199). In order to live with hope, the participants described the basic social process of transforming hope. Hope was dynamic: “Well, it changes, that’s for sure.” The

participants had made a conscious decision to change or transform their hope: "What you can do is you can make it tougher in your mind or you can make it easier in your mind."

Through the process of transforming hope, new patterns of hope emerged. These were apparent in the participants' ways of defining hope as a future expectation — "something you hope will happen." They defined their future in terms of minutes, hours, and days and also in terms of their families. For example, they described their hope in terms of "not suffering more," "living life to the fullest in the little time I have left," a peaceful death, life after death, and "hope for a better life in the future" for their family. This differed from their previous patterns of hope, which for some participants included being cured of cancer, living longer, and achieving long-term goals.

The process of transforming hope was facilitated by controlled symptoms, supportive relationships, and spirituality. For example, the participants said that uncontrolled symptoms made it difficult for them to think about the future: "If you feel really in pain and down in the dumps, it's pretty hard to think about how far you're going to go." Supportive relationships were those in which friends and family members provided comfort and hope: "It's comfort from friends, from relatives, and the hope they are giving me." Spirituality fostered hope by providing a framework for understanding what was happening to them and a source of strength in terms of hope: "I think without God I don't have any hope at all. He certainly does provide a spot, or a garden, for our thoughts."

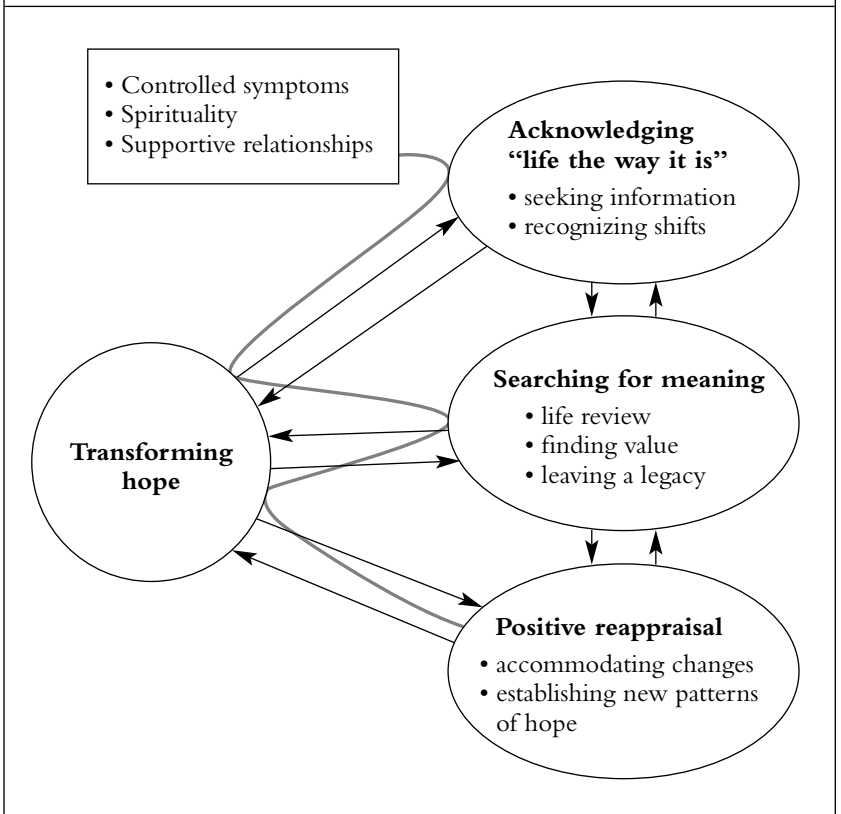
The participants described the sub-processes of transforming hope as acknowledging "life the way it is," searching for meaning, and positive reappraisal. Figure 1 illustrates the basic social process of transforming hope and its sub-processes. Although the figure appears to be linear, the processes are dynamic and interrelated.

Acknowledging "Life the Way It Is"

The participants began the process of transforming hope by acknowledging the changes that had occurred in their lives. Acknowledging "life the way it is" is the recognition that previous expectations and hopes are no longer viable. Two ways of acknowledging "life the way it is" were seeking information and recognizing the shift from what was to what is. One participant expressed the importance of seeking information: "If you don't know the good and the bad, or the pros and the cons, how can you decide on anything?" In this regard, the participants appreciated receiving honest information from nurses and doctors.

In order to accept the change from what was to what is, the participants had to come to terms with their losses, to acknowledge the impracticality of making holiday travel plans, for example, or the fact that they

Figure 1 *Transforming Hope*



would not be present for the birth of a grandchild. One participant said: "I had things I wanted to do, things that we haven't done yet that I am not going to get around to doing... We had our retirement hopes...it changes, that's for sure." For other participants the process entailed their acknowledging that they had incurable cancer: "You have to accept the fact that you've got it...and if you don't accept that, you're suffering more the way you feel and your own feelings than you are with the disease that's killing you... [You have to] make up your mind that this is the way it is and this is life the way it is."

Searching for Meaning

Participants described searching for meaning as reflecting on and finding value in their lives: "I think you stop then and take a look at yourself...what you have accomplished. I think it all helps us in life, at least

to keep hope.” Finding meaning and value in their lives was also related to leaving a legacy, something of value. Participants described a legacy as living on even when they were no longer alive: “It contributes to your hope to know that those will live on.” This legacy was described as letters, gifts, contributions related to their careers, and, for some, their children and grandchildren. By finding meaning in their lives, the participants were able to view what was happening to them in a positive way.

Positive Reappraisal

By acknowledging their current situation and finding meaning and value in their lives, the participants were able to engage in positive reappraisal, and through reappraisal of their situation, expectations, and goals they were able to change their hope. Positive reappraisal was a process of accommodating life changes and establishing new patterns of hope. One participant said: “I’ve had to change my outlook on that now. I’ll find something else to do, and when that happens I guess that’s the way you change your hope and you just have to keep on going.”

Discussion

The findings of this study are an emerging theory of hope within the context of the study participants. Glaser (1978, 1992) suggests that an emerging theory can contribute to the development of a formal grounded theory with broader scope and applicability. Elements of “transforming hope” may therefore contribute to the development of a hope theory for older palliative care patients.

The findings of this study are both similar to and different from those of other empirical work. The main concern of the participants, living with hope, was similar to that of the 11 palliative care patients in Benzein et al.’s (2001) study, who described “living in hope.” In that study, the concept was described as reconciliation between life and death, whereby the participants were prepared for death in both practical and emotional ways. The dynamic nature of hope and the transformed focus of hope identified in the present study are also consistent with the findings of other studies (Benzein et al.; Flemming, 1997; Hall, 1990; Herth, 1990). However, none of these studies addressed the transformative processes of hope.

Acknowledging “Life the Way It Is”

Acknowledging “life the way it is” was a process of transforming hope. Only one other study of hope reported palliative patients acknowledging or accepting their life situation. Benzein et al. (2001) describe acceptance as an aspect of reconciliation of life and death. However, they do not discuss how this acceptance influenced the hope of the participants.

Acknowledgement of “life the way it is” does not preclude the use of denial as a protective mechanism. Denial as a coping response may act as a self-protection mechanism for palliative care patients, enabling them to defend themselves from threats and therefore enhancing their perception of control and self-efficacy (Russell, 1993). Hope is situational (Rustoen, Wiklund, Hanestad, & Moum, 1998), so denial could be used as a coping mechanism in one aspect of the participants’ lives and acknowledging “life the way it is” in other aspects. The two concepts are not mutually exclusive.

The participants described hard facts as having helped them to acknowledge “life the way it is.” It is possible that in this sense the participants were playing the role of a monitor who seeks information and wishes to have a larger part in decision-making. Miller’s (1995) “blunters,” in contrast, coped by not seeking information. Fallowfield, Jenkins, and Beveridge (2002), in a study with 1,046 palliative care patients, also identified the importance of health-care professionals’ providing information; the majority of patients wished to receive as much data as possible, whether positive or negative. Benzein et al. (2001) found that lack of information contributed to uncertainty in palliative care patients. More research is needed to determine whether the method of information delivery has an influence on hope and how the concepts of monitors and blunters are related to the process of information delivery.

Searching for Meaning

The participants described searching for meaning as a sub-process of transforming hope, one aspect of which was life review. The concept of searching for meaning has been described in several hope studies with palliative patients (Benzein et al., 2001; Hall, 1990; Herth, 1990). An emergent theme in the Benzein et al. study was the patients’ description of their lived experience of hope as the will to find meaning; for them, life review fostered reconciliation between life and death. Life review has also been found to be a mechanism for fostering hope among elderly residents of long-term-care facilities (Gaskins & Forte, 1995).

The participants also described the importance of leaving a legacy. Life review is focused on the individual, while leaving a legacy is focused on others. This finding is not reported in other studies of hope in palliative care patients. However, in a study of spirituality among palliative patients, the participants over 71 years of age said it was important to them to have accomplished something, whereas those under 71 did not (Thomas & Retsas, 1999). Therefore, leaving a legacy may be an aspect of searching for meaning that is specific to older palliative care patients.

More research is needed to determine whether life review and leaving a legacy are linked to finding meaning and hope in other populations.

Positive Reappraisal

The participants' ability to interpret positively the changes in their lives was fostered by finding meaning in their lives. They described a process of reappraising their situation, expectations, and goals, the sub-processes of which were acknowledging "life the way it is" and finding meaning in life.

None of the published studies of hope among palliative patients describes the process of positive reappraisal. Benzein et al. (2001) describe envisioning a better future and Herth (1990) describes a positive outlook. However, these concepts are different from positive reappraisal, which is a cognitive change in perception of situation, expectations, and goals.

In a study with non-palliative, non-elderly breast cancer patients, Wonghongkul, Moore, Musil, Schneider, and Deimling (2000) found positive appraisal to be significantly associated with hope; with increased use of positive appraisal, hope increased. More research is needed to clarify the concept of positive reappraisal and its relationship to hope in palliative patients.

Transforming Hope

The participants in the present study described the sub-processes of transforming hope as interconnected. For example, without acknowledging their situation, they could not find meaning in their experience or use positive reappraisal of their experience in order to transform hope. All three of the sub-processes appeared to be important in transforming their hope. Transforming hope, as described by these participants, was more than the goal-setting and problem-solving that has been the focus of goal-setting theories of hope (Stotland, 1969; Synder, 2000). Nikolaichuk and Bruera (1998) suggest that multidimensional models of hope reflect the palliative experience of hope more accurately than current theories of hope. The emerging theory of transforming hope discussed here is not only multidimensional but also adds conceptualization of hope as a transformative process with the three sub-processes. As well, the interrelationship of all the sub-processes and the concepts of symptom control, spirituality, and supportive relationships are not discussed in the palliative care literature.

Limitations

The study had several limitations related to the sample and methodology. The sample was 10 older palliative home-care patients living in rural Canada, so it is possible that category saturation as outlined by Glaser

(2001) was not reached. The sample was relatively homogeneous. Palliative home-care patients in different geographic regions, of different ages and ethnicities, and with other religious or non-religious preferences, education levels, and incomes may describe their hope experience differently. As well, the participants had low symptom-intensity scores and high hope scores. The processes could differ for palliative patients with high symptom-intensity and/or low hope scores. Finally, given the increasing need to recognize the care requirements of patients with many end-stage illnesses, future research on hope should be conducted with individuals with diseases other than cancer.

Conclusion

It would be premature to generalize the findings of this study. However, the findings provide an empirical basis for informing our understanding of how palliative patients live with hope, and may serve as a basis from which to extend notions of hope captured in theories described in the literature. The sub-processes identified in the model provide a framework from which to conduct further research and to develop strategies for engendering hope in older palliative patients. The findings underscore the importance for nurses of symptom control and the fostering of spirituality and supportive relationships, as these measures are related to the process and sub-processes of hope. Nurses can also provide older palliative patients with information and can promote and facilitate life review, the leaving of legacies, and finding meaning in life. By actively engaging with older palliative care patients in these ways, nurses can foster hope that “enriches life and empowers individuals to live fully in greater aliveness, awareness and reason” (Fromm, 1968).

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Best Practices in Research Methods

Palliative Care Research in Practice

Julia Addington-Hall

Introduction

From an initial focus on the care of people in the last weeks or days of life, the principles and practice of palliative care have been increasingly recognized as beneficial for people earlier in their disease trajectory, from the point of diagnosis (Ahmedzai & Walsh, 2000; World Health Organization, 2005). Yet the reality is that the majority of patients receiving care from hospice and specialist palliative services are in the last months, weeks, or days of life (Eve, Smith, & Tebbit, 1997; Lamont & Christakis, 2002). In addition, although the relevance of palliative care to people who die from conditions other than cancer is increasingly recognized (Addington-Hall & Higginson, 2001), the majority of patients currently receiving care in most settings have cancer, with most of the remainder having AIDS or neurological conditions such as motor neurone disease. This article focuses on the challenges of working as a researcher with people with advanced, progressive disease who are coming to the end of their lives.

Our empathy with and compassion for our fellow human beings facing the end of their lives can cause us to find the idea of palliative care research rather unsettling, and to even question whether it is an appropriate pursuit. To address this satisfactorily we need, I think, a clear sense of the potential benefits of research in this area, the risks of not doing such research, and the ethical dimensions of such research.

Benefits of Palliative Care Research

One of the factors that differentiated the initial modern hospice services from the homes for the dying that had preceded them was their emphasis on research — ensuring that interventions were based on science rather than just on practice and tradition. Rapid improvements were made in pain control, for example, because hospice pioneers built on emerging scientific knowledge about pain mechanisms and opiate drugs. Medical and nursing research into the etiology, mechanisms, and treatment of symptoms such as pain, nausea and vomiting, dyspnea, and con-

stipitation have played a vital role in the progress in palliative care we have seen over the past four decades. There is still much to be done in order to address problems and to ensure that practice is evidence-based (Higginson, 2004).

Given the particular sensitivities (indeed, difficulties) entailed in conducting research in this area, it might be tempting to argue that the usual standards of evidence-based practice should be lowered, that the costs of collecting randomized controlled trial (RCT) evidence outweigh the benefits that will accrue from that evidence. As elsewhere in health care, this stance runs the risk of denying patients access to interventions shown by RCTs to be beneficial — including nursing interventions that might have been ignored or rejected without that evidence (Moore et al., 2002) — and of offering care that is ineffective (Todd, Rees, Gwilliam, & Davies, 2002). In the area of evidence-based practice, palliative care patients as a group may have more to lose by being excluded from research than they have to gain by being included.

Clinical research is not, of course, the only research being conducted in palliative care. Much of my research comes under the heading of health-services research: studies that seek to understand people's health-care needs, to determine whether and how these needs are being addressed, and to evaluate the appropriateness and effectiveness of service interventions. Some may dismiss the need for health-services research in the field of palliative care, arguing that such care is self-evidently "good" and therefore does not require empirical validation. This is an attractive argument in the United Kingdom, where hospices have largely developed outside of the National Health Service in response to local need and funded by local people rather than out of taxation: a clear demonstration of support for and, it can be supposed, the quality of hospice services. Health technology assessment is receiving increasing attention in the health-care systems of industrialized countries, however, creating the need for hospice and palliative services to show that they too are effective and efficient — in short, that they offer value for money. These services usually score high for user satisfaction, but that alone is not enough for them to score well in more formal health-care evaluations. Conducting high-quality service evaluations in palliative care is a challenging task. Such evaluations do not always come to the expected conclusions, sometimes leading to debate about whether the findings are "true" or whether the evaluation has misrepresented the services due to poor methods and/or the choice of inappropriate outcomes. Nevertheless, if we do not engage in health-services research we risk the future funding of palliative care and its integration within health and insurance systems.

My third argument in favour of palliative care research may be the most important one. In our desire to avoid causing patients any additional distress or burden, we risk acting in a paternalistic manner — doing what we think patients want or what we would want in their position. This is a paradox in palliative care, which has always strived to treat patients as individuals; indeed it sought to provide “patient-centred care” before the term was even invented. Research can be a powerful means of putting patients in a position to make their views known. In quantitative research, for example, patients’ accounts of pain in a drug trial influence judgements about the effectiveness of a new analgesic (in contrast with a sole reliance on the views of health-care providers), while qualitative research methods seek to understand the participant’s experience from his or her own perspective. Such research can produce findings that challenge accepted wisdom (Stajduhar & Davies, 2005) and serve to demonstrate that, however well intentioned and well informed, health professionals do not necessarily have the same views as users. Research that explores users’ perspectives and investigates their experiences of care is a requisite for any patient-centred health-care system. The field of palliative care is no exception. In addition, there is evidence that palliative care patients who choose to participate in research interviews are positive about their experiences (Emanuel, Fairclough, Wolfe, & Emanuel, 2004). Therefore, the advantages of palliative care research for society and for palliative care patients do not seem to come at a cost to the research participants — provided, of course, that their decision to participate is fully informed. It is to the ethics of palliative care research that we now turn.

Ethics of Palliative Care Research

It has been suggested that research in palliative care may be unethical because participants, given their limited life expectancy, cannot benefit from any changes resulting from the study (Janssens & Gordijn, 2000). Whilst an inability to benefit directly is particularly clear in palliative care, it is not restricted to this field. Other patients also participate in research knowing that any resultant changes are unlikely to benefit them (because, for example, they do not expect to have another knee replacement). Thus while palliative care is perhaps an extreme in this respect, it is not unique. It has also been argued that it is unethical to take up the limited time of palliative care patients with research matters. While patients clearly should be free to use their remaining time how they wish, non-palliative patients also have demands on their time. In both cases, patients need to weigh the advantages and disadvantages of allocating time to research and make an informed decision. Finally, some object

to enrolling palliative care patients in studies because they are a “captive audience” (Raudonis, 1992), dependent on various professionals for their care; the argument is that they may be reluctant to give honest evaluations or may feel coerced into participating. Again, this issue is not unique to palliative care.

Palliative care is therefore not a special case in terms of research ethics. The usual safeguards established to protect research participants and to ensure that they are making autonomous, informed decisions to participate therefore apply (Casarett & Karlawish, 2000). It can be difficult, however, to persuade ethical review boards that this is the case. Indeed, investigators are frequently uneasy about asking people to participate in research at the end of their lives, and it would be surprising if members of ethical review boards did not share this uneasiness. Given the inherent sensitivity of palliative care research, it is neither unexpected nor inappropriate for palliative care investigators to be asked repeatedly to revisit the ethical basis of their research.

The application of the principles of ethically sound research can present challenges in palliative care. The desire of health professionals to protect patients from unnecessary demands can conflict with the patient’s right to make an informed autonomous decision about research participation. Even very sick patients may wish to participate for altruistic reasons, to give something back to society, or even to make some sense of their situation. At the same time, these patients can be very vulnerable, particularly as they become sicker and more dependent on others for care, effective symptom control, and support. This can make it difficult for them to decline participation. Relationships between clinical staff and researchers around the ethics of palliative care research can be strained. Whilst clinical staff may feel strongly that “their” patients should not be burdened by taking part in a study, researchers may view this as gate-keeping behaviour — as denying the patients their autonomy and threatening the viability of the study.

Such issues are not easily addressed. Involvement of clinical staff and, where possible, the users themselves at an early stage in the research design will help to ensure that the type of participation expected is appropriate and that clinical staff understand the importance of the research. Partnership between investigators, clinicians, and users is an important step in ensuring an ethically sound, appropriate, and acceptable research design.

A related issue is whether it is necessary for researchers who collect data from palliative patients to have a clinical background. Those who do have a clinical background are more likely to be aware of the patient’s clinical condition and limitations, to be alert to signs of fatigue and distress, to seek consent appropriately, and to refrain from engaging in

excessively burdensome data-collection protocols. They are also more likely to be familiar with the physical manifestations of advanced disease. As a young social scientist with no clinical background, I often worried when interviewing dying patients that I would reveal my negative reactions to the sights and smells that result from very advanced cancer and thus distress the person. During discussions with my clinical colleagues, it became clear that they were no longer aware of these aspects of dying. However, clinicians do not have a monopoly on good empathic skills or research expertise. They can also experience tension between their role as carer — wishing to intervene on the patient's behalf — and that as researcher. While it may not be necessary for researchers working with palliative care patients to have a clinical background, those who supervise the investigators have a responsibility to provide good induction programs and continuing supervision so that the researcher behaves in a way that causes minimal harm to the patient and the researcher (Clark, Ingleton, & Seymour, 2000).

An under-recognized issue in palliative care research is that of capacity — the ability to understand the issues and give informed consent. This clearly lies at the heart of research ethics. Although reduced capacity has been the subject of much debate in the literature on research in dementia, it has received less attention in palliative care despite the growing evidence of high levels of cognitive impairment in palliative care populations (Jenkins, Taube, Turner, Hanson, & Bruera, 1998). This is an area that requires further research. In the meantime, palliative care researchers need to be alert to the possibility that a patient may lack the capacity to give consent (Casarett, 2003). Those conducting longitudinal studies should be aware that the patient's capacity may diminish as the disease progresses; in any case, the patient's changing condition may make it good practice to renegotiate consent at each contact in any palliative care study that follows patients over time.

In summary, palliative care is not a special case. The usual principles of research ethics apply. However, it is an area that requires particular care in the application of those principles (Jubb, 2002). Partnerships between researchers, clinicians, and users can be helpful, as can advice from experts in research ethics. Issues around patient recruitment and retention in palliative care research will now be examined.

Patient Recruitment and Retention

The most challenging aspect of palliative care research is the fact that the patients are very sick and then die. This has implications for participant recruitment and retention. As discussed above, although the average life expectancy of patients referred to palliative services varies among services

and settings, it is measured usually in weeks, sometimes in months, and rarely in years. By the time patients are referred they are likely to have a number of troublesome problems, which indeed may have been the trigger for referral (Walsh, Donnelly, & Rybicki, 2000). The proportion of patients who are well enough to be approached by an interviewer, are not too fatigued to absorb all the necessary information, and have sufficient mental capacity to give informed consent will vary between settings, but is not likely to be high, even at first contact with palliative services. This has particular implications for survey researchers seeking representative samples in order to draw inferences about the whole population. It may also limit the widespread applicability of trial data, and, if not carefully documented and described, the transferability of data from qualitative studies, where appropriate (Crowley & Casarett, 2003). It can also require patience, tenacity, and forbearance on the part of the researcher and generosity on the part of the funding agency, which in the ideal world (but all too often, alas, not in the real world) recognizes the specific recruitment challenges in palliative care and their implications for the time and funding needed.

As the disease progresses, the patient will become more fatigued and more functionally impaired. This has particular implications for longitudinal studies, including RCTs, where the researcher must follow patients over time in order to measure outcomes. Although a sufficient number of patients may have been recruited at baseline (usually after considerable effort), the number who are still alive and well enough to participate at time two will be significantly reduced, even with a short interval such as 2 weeks — and the situation will of course worsen as the study progresses. This is clearly beyond the researcher's control (as I would rather have liked to point out to the author of a systematic review of RCTs of palliative care services who marked her own trial down for quality because “too few” took part in follow-ups [Rinck et al., 1997]).

I have argued above that palliative care cannot afford to “opt out” of evidence-based health care and health technology assessment, and thus needs evidence from RCTs and other strong research designs (in addition to good qualitative data where appropriate to the research question). The question now is not whether RCTs are possible in palliative care, but how best to resolve the problems associated with them, at the heart of which lies the recruitment and retention of sufficient numbers. Expert statistical advice on sample size is an important first step, but in order to calculate a meaningful sample size one must make a judgement about what proportion of those recruited are likely to survive to the follow-up interview. The literature now contains enough data from palliative care trials for one to base this judgement on evidence from the real world. These data can also be used to help determine the optimal time between

baseline and follow-up interviews. Partnerships between researchers, clinicians, and users can help ensure that research studies address problems seen as important by clinicians and users, that the methods are not burdensome for patients, thus reducing gatekeeping, and that user advice is sought on recruitment methods. Research networks, such as those currently being established in the United Kingdom, can facilitate multi-centre studies and increase recruitment numbers, thus ensuring that effort is not wasted on studies that are underpowered statistically and therefore cannot answer the research question (and that are consequently ethically suspect). Patient recruitment and retention will remain a challenge in palliative care because of its very nature; good practice exists, however, and no study should be started without realistic plans for meeting the necessary sample size, based on experience in the “real world” and developed in consultation with clinical partners and users.

Conclusion

Despite the growing recognition that the principles and practice of palliative care are relevant from the point of diagnosis in cancer, and indeed throughout the course of other chronic diseases, most recipients of palliative care have cancer that is no longer responsive to treatment. For these people death is certain and not far off. They need the best possible physical, psychological, social, and spiritual care to enable them and their loved ones to live as fully as possible for as long as possible. Palliative care research has played a vital role in providing the evidence base that makes such care possible. There are still many unanswered questions, and we therefore continue to need high-quality palliative care research. The fact that most patients are very sick at the point when they begin to receive palliative care and then become sicker presents challenges related to both the ethics and the practicalities of research. Those who are uncomfortable with the very idea of asking people facing the end of life to participate in research force those of us who work in this field to question the importance of the studies we want to do, the methods we have chosen, and, in particular, the demands we will make on our participants: it is imperative that our work meets the highest possible ethical standards. Part of meeting these ethical standards is ensuring that our work is of the highest possible academic quality: despite the challenges entailed in palliative care research, there can be no excuse for poor research. If palliative care is to fulfil its potential, we will have to find creative, imaginative, and ethical ways of conducting high-quality quantitative and qualitative research into the problems encountered by people at the end of life. Partnerships between researchers, clinicians, and service users will have an important role to play in this process.

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Happenings

The Promise of Quality Care at the End of Life Takes a Leap Forward

Doris Howell

Serious quality-of-care problems in the delivery of palliative and end-of-life care continue to be documented across North America (Desbiens & Wu, 2004; Teno et al., 2004; Tolle, 2000). Consequently, improving the quality of palliative and end-of-life care has become a national priority and is considered an entitlement for all Canadians (Carstairs & Beaudoin, 2002). Widespread change has been slow, unfortunately, as palliative care populations are unable to demand the changes that are needed. As noted in testimony at the Senate Subcommittee hearings (Chochinov, 2000), there is no vocal constituency in end-of-life care since the deceased are no longer here to speak, the dying are often too ill to speak, and the bereaved are too overcome by their loss to speak. Reports of poor quality of care at the end of life will continue until we improve access to appropriate evidence-based care, evaluate the quality and effectiveness of care, and develop performance indicators to hold health organizations accountable for the quality of the care they deliver. In order to meet these priorities, we urgently need advancements in the scientific basis of palliative care interventions and health-service research focused on the evaluation of new and existing ways of delivering care at the end of life. Palliative and end-of-life research is one of the most promising avenues for improving the quality of care and will help to ensure that the voices of patients and families are heard regarding the quality of care they experience.

Until recently, limited access to funding specifically for palliative and end-of-life research has greatly hampered our ability to improve the scientific basis of palliative care and to evaluate the quality of care delivered. Since 1999, both the Canadian Strategy for Cancer Control and the Canadian Hospice Palliative Care Association have been advocating for dedicated funds to build research capacity and for funding of investigator-driven palliative care research. Strides have recently been made in terms of recognizing the need for excellence in palliative care research. In 2003, the Canadian Institutes of Health Research (CIHR) launched

its initiative to support innovative palliative and end-of-life research as its number-one priority through the Institute of Cancer Research. Funding from this initiative was announced in 2004, supporting nine teams of interdisciplinary researchers who will advance palliative care knowledge in the following areas (only team leaders are listed):

- Cancer Associated Cachexia/Anorexia Syndrome (Vickie Baracos, University of Alberta)
- End of Life Care and Vulnerable Populations (Harvey Chochinov and Deborah Steinstra, University of Manitoba)
- Palliative Care in a Cross-Cultural Context: A Net for Equitable and Quality Cancer Care for Ethnically Diverse Populations (Richard Doll and Araminee Kazanjian, University of British Columbia)
- Developing and Evaluating New Intervention in Palliative Care (Pierre Gagnon, Université Laval)
- A Multidisciplinary Cancer Pain Research Network to Improve the Classification, Assessment and Management of Difficult Cancer Pain Problems (Robin Fainsinger and Penelope Brasher, University of Calgary)
- Understanding and Improving Communication and Decision-Making at the End of Life (Daren K. Heyland, Queen's University)
- Overcoming Barriers to Communication Through End of Life and Palliative Transitions (Peter Kirk and Francis Lau, University of Victoria)
- Transitions in Pediatric Palliative and End-of-Life Care (Harold Siden, University of British Columbia)
- Family Caregiving in Palliative and End-of-Life Care: A New Emerging Team (Kelli Stajduhar and Robin Cohen, University of Victoria)

Palliative care as a health-research discipline in its own right was further acknowledged in 2005 with the establishment of a grants peer-review committee under the auspices of CIHR, which will evaluate all applications for operating grants in the area of palliative and end-of-life care. As noted by Dr. Phil Branton, scientific director of CIHR, this support will radically change the face of palliative care research across Canada. Increased funding in palliative and end-of-life research comes as welcome news to palliative care nurse researchers, who have been contributing greatly to empirical knowledge development in the field. Palliative care nurse researchers across Canada have been integral to the evolution of the science of palliative care, making a significant contribution to our knowledge in decision-making/communication (Hack et al., 2003), domains of quality end-of-life care (Howell & Brazil, in press),

symptom distress (Lobchuk & Degner, 2002; McClement, Woodgate, & Degner, 1997), symptom experience for children (Woodgate, Degner, & Yanosky, 2003), and the needs of family caregivers (Stadjahur, 2003). These are just some examples of palliative care nursing research endeavours in Canada. These nurse researchers will be further empowered with funding from the CIHR's Institute of Cancer Research in their quest to advance the scientific basis of care that is vital to practising nurses and health-care teams in improving the quality of palliative and end-of-life care.

Another important advancement in palliative care nursing research is the recent establishment of an endowed research chair position in cancer nursing. Early in 2004, a Chair in Oncology Nursing Education and Research was established at the University Health Network. Dr. Doris Howell assumed the Chair position, which is supported with funding from the Royal Bank of Canada Financial Group and established through a partnership between the University Health Network, the University of Toronto, the Canadian Cancer Society (Ontario Division), and Cancer Care Ontario. Dr. Howell is cross-appointed by the Faculty of Nursing at the University of Toronto and the comprehensive cancer centre at Princess Margaret Hospital, the oncology program site of the University Health Network. The Chair will be responsible for leading a program of oncology and palliative care nursing research and development of a specialty oncology stream in the Acute Care Nurse Practitioner Program as well as a clinical stream in the master's program of the Faculty of Nursing at the University of Toronto. The Chair position will become a fully endowed research chair in approximately 3 years. Dr. Howell is developing a patient-focused outcomes-research program that will have two foci: effectiveness of health-care delivery, and nursing intervention research in symptom assessment and management.

The research cluster around effectiveness of health-care delivery will examine integrated models of interdisciplinary care delivery specifically in palliative and end-of-life care, with an emphasis on the integral role of advanced practice nursing in the provision of care. The impact of advanced practice nursing and integrated delivery systems on symptom-relief outcomes, reduction in unmet needs, continuity of care, and quality of living and dying will be examined as part of the research focus on health-service effectiveness. A randomized trial and two demonstration evaluation studies are currently in progress to evaluate nursing roles, specifically as they relate to patient outcomes of care continuity, unmet needs, psychosocial distress, and quality of life. In addition, two models of integrated interdisciplinary palliative care delivery focused on building primary care capacity are being evaluated. Theory-based evaluation is

being used to evaluate these models using domains of quality end-of-life care developed from a metasynthesis of qualitative research on patient and family perceptions of what constitutes quality care (Howell & Brazil, in press).

The research cluster around nursing intervention symptom assessment and management will evaluate interventions based on an integrative biopsychosocial-spiritual approach to symptom assessment and management, one that emphasizes nursing's empirical and therapeutic contribution to symptom-relief outcomes. A patient-centred focus, in order to elicit patients' perceptions of their symptom experience and build this perspective into nursing interventions, will be an important aspect of the research. In addition, this area of research will seek to understand nurses' therapeutic roles and their influence on meaning of illness, suffering, symptom distress, and psychosocial distress. Integrative bio-psycho-social-spiritual interventions in symptom management are important for development and further evaluation, since it is known that symptoms are multidimensional experiences. In the multidimensional symptom-management model developed by Dodd and colleagues (2001), symptoms comprise both the biological basis of the symptom and the symptom experience, including the individual's perception of the symptom, evaluation of the meaning of the symptom, and response to the symptom. This theory of symptom experience calls for interventions that address the totality of patients' symptom and illness experience. Consequently, effective symptom control has an impact not only on the biological basis of symptom problems often reflected in symptom-intensity measures, but also on symptom experience, perception, and the meaning of symptoms to the individual often reflected in distress measures and in clinical observations of suffering. Earlier work on lung-cancer dyspnea by the author and colleagues using an intervention designed to address the totality of the illness experience, inclusive of the meaning of symptoms for individuals facing the end of life, demonstrated promising improvements in symptom distress and quality of life. This study replicated integrative breathlessness interventions in lung cancer found to be effective, in randomized trials in the United Kingdom, in reducing dyspnea severity and distress and in improving quality of life (Bredin et al., 1999). Finally, an underlying assumption in both of these research clusters is that the adoption of interventions is paramount to effectiveness. Pilot research is currently underway to examine strategies that support evidence-based practice in symptom management using innovative approaches such as reflection-on-practice and mindfulness-based education.

This evolving program of symptom intervention and health-service research by the RBC Financial Group Chair in Oncology Nursing

Education and Research is positioned to significantly improve the quality of palliative and end-of-life care, adding to the cadre of exemplar palliative care nursing scientists in Canada. The program will emphasize the preparation of nurse scientists in cancer care nursing research, an important aspect of building capacity in oncology and palliative care nursing research.

Canada has taken a leap forward with recent developments in the establishment of palliative care research as a health-research discipline in its own right with dedicated funding and focused peer-review activities. These developments and the establishment of a second Chair in Oncology Nursing Research in Canada will improve our ability to deliver quality care across the continuum of cancer, including palliative care, enabling us to ensure that quality end-of-life care is an entitlement for all Canadians.

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Happenings

The Manitoba Palliative Care Research Unit: Collaboration in Action

Susan McClement

The Scottish-born American inventor and educator Alexander Graham Bell asserted that “great discoveries and improvements invariably involve the cooperation of many minds.” He clearly knew something about the importance of collaboration! Palliative care’s greatest strength is its commitment to a rich multidisciplinary model. This can be a liability if one is unable to bring together individuals from the various disciplines into a cohesive research team.

With infrastructure funding from the Canadian Foundation for Innovation, Dr. Harvey Chochinov, who holds a Tier 1 Canada Research Chair in Palliative Care, recently formed a palliative care research laboratory, housed within CancerCare Manitoba’s newly expanded facilities. The Manitoba Palliative Care Research Unit (MPCRU) has a broad mandate to study a wide range of palliative care issues pertaining to both malignant and non-malignant conditions.

The unit houses six workstations, a secretary/reception area, and a common space for multidisciplinary meetings. It is occupied by Dr. Chochinov, a Research Associate (Dr. Susan McClement of the Faculty of Nursing at the University of Manitoba), a full-time palliative care research nurse, a data manager/biostatistical consultant, a post-doctoral fellow, and other trainees and itinerant experts (local and visiting faculty). A local area network of computers has been established for managing highly sensitive data/patient information, data analysis, and software packages. This network enables facets of the research program exploring information and communication technology and their application to end-of-life care. The system ensures that researchers at the MPCRU have optimal information technology to support their work

and will be supported by CancerCare Manitoba's Department of Information Services.

The laboratory also has video-conferencing capacity. This greatly facilitates multi-site collaboration and allows for the training of staff at sites outside of Winnipeg. The equipment will also allow observational studies of patients and their families in palliative care specialty units, non-palliative care hospital settings, hospice settings, long-term care facilities, and home-based care settings.

The laboratory serves other research needs, including the coordination of research studies, cross-disciplinary collaborations on determining appropriate research design and protocol development; the planning and implementation of various data-analytic strategies, preparation of papers, and conference presentations.

Embedded within the World Health Organization definition of palliative care is the fact that psychosocial sources of distress are indivisible from other domains of suffering. There is, however, a dearth of empirical research addressing these issues in patients nearing death. The program of research emanating from the MPCRU will directly contribute to the quality of life for dying patients and their families in a number of tangible ways. First, the MPCRU will examine large cohorts of dying patients, in order to better understand and document the various sources of their suffering. This kind of observational study is critical and will inform practice and policy around end-of-life care. Second, the MPCRU will examine e-health applications as they apply to end-of-life care. The Canadian Virtual Hospice (Chochinov & Stern, 2004), for example, offers an unprecedented opportunity to increase access to various aspects of palliative care for patients, families, and other key stakeholder groups with vested interests in end-of-life care. At the same time, this work will pilot a model of care that may have applications across various areas of health care where needs exceed available resources. Third, the MPCRU will develop and pilot new interventions, targeting various aspects of suffering encountered by the dying and their families. For example, psychotherapeutic applications as they pertain to the dying are currently being piloted, with multinational trials showing promising early results. Fourth, the unit will serve as a provincial hub of research and training activity for health-care professionals from various disciplines with an interest in psychosocial and behavioural issues in end-of-life care. As such, it will increase the capacity of skilled investigators to inform and shape the quality of care being provided to dying patients. Finally, the MPCRU will be engaged in international research initiatives. Such work will ensure that the knowledge upon which evidence-based palliative care is practised in Canada meets international standards.

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Translating Research

Knowledge Translation in Palliative Care: Can Theory Help?

Lesley F. Degner

In 1747, Lind, a Scottish Naval Surgeon, conducted the first practical medical research to find a cure. He recommended lemons, oranges, and their juice. Yet he was unable to penetrate the Admiralty high-mindedness, or to persuade them to enforce the fruits' universal application. Only in 1795, when court physician Gilbert Blane championed Lind's work were the Sea Lords persuaded to act. But by then, James Lind had been dead for a year and thousands had needlessly perished. (Harvie, 2002)

Few of us who are career researchers would want to suffer the fate of poor Dr. Lind. His attempts to establish definitive evidence about a cure for scurvy were relatively simple compared to what he went through trying to get that knowledge put into practice. Remember, this was the man who had to invent the randomized controlled trial in order to generate the evidence! Reading the short but detailed account of his experiment, one is impressed by the economy of his efforts (sample size equalled 12 sailors) to produce definitive evidence within a 6-day period. Such dramatic results today would certainly warrant publication in a very high-impact journal, no doubt on the "fast track" to ensure immediate dissemination. Surely Dr. Lind would have fared better in today's world, with such a strong focus on knowledge translation to improve health outcomes. Or would he have? Historical examples of attempts at knowledge translation provide cautionary notes for today's researchers and decision-makers who are promulgating new concepts and methods to move research results into practice more quickly for the benefit of the public.

Uptake of Practice Guidelines

Today, perhaps, Dr. Lind would have received funding to convene a conference of naval surgeons to consider his findings, and he might have been successful in having practice guidelines based on the findings disseminated throughout the fleet. However, the results of Grimshaw et al.'s

recent systematic review of the effectiveness and efficiency of guideline dissemination (Grimshaw et al., 2004) leads one to question whether such a process would have resolved the scurvy problem in the navy. This extensive review included 235 studies that had evaluated single interventions of reminders (38 comparisons), dissemination of educational materials (18 comparisons), and audit and feedback (12 comparisons), as well as 23 multifaceted interventions entailing educational outreach. The authors conclude that the overall quality of the studies was poor and that the majority of studies observed modest to moderate improvements in care. Specifically:

The median absolute improvement in performance across interventions was 14.1% in 14 cluster randomized trials of reminders, 8.1% in four cluster randomized comparisons of dissemination of educational materials, 7.0% in five cluster randomized comparisons of audit and feedback and 6.0% in 13 cluster randomized comparisons of multi-faceted interventions involving educational outreach. (p. x)

Grimshaw et al. conclude that the lack of a coherent theoretical basis for understanding professional and organizational behavioural change limits our ability to formulate hypotheses about which interventions are likely to be effective under different circumstances. They recommend testing educational, behavioural, social, and organizational theories to determine their applicability to the behaviour of health-care professionals and organizations. But how would one go about selecting these theories for testing? The systematic review leaves this question unanswered, as indeed it must. Although cluster randomized trials can produce a very high level of evidence, as Grimshaw et al. point out, it is not useful to proceed with such trials unless the theoretical underpinnings of the intervention are well thought out. I am grateful to Dr. Grimshaw for publishing this advice, as it is exactly what we are doing in the project described below.

The Health Sciences Centre Project

A process of theory selection took place over a period of 3 years (2001–04) at the Health Sciences Centre in Winnipeg, Manitoba, Canada, as a prelude to conducting a cluster randomized trial of an organizational intervention to help frontline nurses use evidence in their daily practice. The impetus for this research was the report of the Evidence-Based Ward Project (Newman & Papadopoulos, 2000). In that study, action research was used to explore ways in which the culture of nursing practice on a busy acute-care ward in England could be developed to make knowledge translation (KT) part of the “normal” approach to practice. A surprising finding was that the average sickness rate for all the

participating nurses on the unit was significantly lower (an average of 10 days per month, CI 5.3–14.3) during the study than during an equivalent period the previous year. The report stimulated the question of whether a KT intervention could achieve similar reductions in absenteeism in Canada. Given that professional nurses have the highest rates for absenteeism of any occupation in Canada (Lowe, 2002), equivalent to 10,800 full-time positions per annum, the results of the HSC research program could be of relevance throughout the Canadian health-care system.

Theory was actually the last thing on our minds at the outset, but as the idea for the intervention took shape — after participant observation on nursing units, repeated interactions with senior management, and strategic observation at meetings of key players in the nursing hierarchy — it became clear that any organizational intervention that was tested would need to have a strong theoretical basis or it would not be replicable in other institutions. The relatively high cost of the intervention proposed — at the Centre for Clinical Nursing Scholarship, where nurses would spend 3 to 4 paid hours per month gathering and processing evidence with respect to one key outcome they wanted to improve on their nursing unit — was also a strong impetus for the building of a sound theoretical base. If the proposed intervention was relatively inexpensive and did not produce the desired outcomes, little would have been lost.

Selection of the theories was a dynamic process entailing considerable interaction between the author and her decision-maker partner in practice, the Chief Nursing Officer, Ms. Helga Bryant, with input from the two co-investigators for the project, Dr. Carole Estabrooks of the University of Alberta and Dr. Heather Laschinger of the University of Western Ontario. Through an iterative process, the theoretical perspectives that seemed best suited to this project were eventually selected. It quickly became apparent that the theories had to function at different levels, from the level of the individual nurse up to the organizational level (as subsequently recommended by Dr. Grimshaw) and had to “make sense” in the world of the Chief Nursing Officer as well as that of the Directors of Patient Services. Because many of the patient outcomes that frontline nurses can be expected to focus on will be of a supportive or palliative nature, we shall now briefly describe the theories, as they may be useful for those initiating KT projects in palliative care settings. Nurses in acute-care hospitals still provide the vast majority of care for dying patients in Canada, and they need knowledge that will enable them to create a “haven for safe passage,” as described by Thompson, McClement, and Daeninck (in press).

Theory 1: Social Network Theory

As Elizabeth West and her colleagues at the Royal College of Nursing Institute note in their seminal 1999 article, interest in the social networks of clinicians has been revived through the recognition of their importance for the dissemination of information to clinicians as well as for processes that could have a constructive influence on clinician behaviour (West, Barron, Dowsett, & Newton, 1999). We might conceive of nurses working on a given unit as interacting primarily with their co-workers, who are engaged in caring for the same group of patients, on the same shift, on the same unit. By means of random rewiring of the interactions of nurses through involvement in a KT initiative, they would now be interacting with different nurses, potentially increasing the density of their social network. West et al. argue that a dense social network has advantages for KT: “The multiplicity of ties gives members the opportunity to persuade, cajole, and monitor the performance of others” (p. 635). This type of network is more reflective of those currently existing in clinical medicine than those in nursing. As West et al. note: “In a medical network, ties are so dense that even if the respondent were removed, information would still flow relatively well because so many alternative channels to communication exist” (p. 643).

At the same time, the existing hierarchical nature of nursing brings with it some distinct advantages:

Cascading information from the top down may work for the nursing profession, especially if your first point of contact is a director of nursing. They have access to information and their networks are far-reaching. Certain behaviors which are acceptable in a hierarchy, such as orders, would not be acceptable in the more egalitarian structure of medical communities. (West et al., 1999, p. 644)

This observation illustrates the importance of key decision-makers, such as the Chief Nursing Officer, to any KT project aimed at nurses. It also provides insight into why KT strategies that make assumptions based on the social networks of physicians may not be effective in a nursing context. An organizational intervention that could increase the density of the social networks of nurses, while at the same time harnessing the nursing hierarchy to provide for cascades of evidence to inform practice, may have the greatest probability of success given this theoretical perspective.

Theory 2: Royal College of Nursing Institute Framework, “Getting Evidence into Practice”

In 1998 Kitson and her colleagues at the Royal College of Nursing Institute published a conceptual framework representing the interplay of

many factors that influence the uptake of evidence into practice. They posit that KT can be described as a function of the relationship between *evidence* (research, clinical experience, and patient preferences), *context* (culture, leadership, and measurement), and *facilitation* (characteristics, role, and style), with these three elements having a dynamic, simultaneous relationship (Kitson, Harvey, & McCormack, 1998). They suggest that the most successful implementation occurs when evidence is robust, the context is receptive to change, and the change process is appropriately facilitated. In 2002 the RCN Institute group published two seminal papers elaborating, through two detailed concept analyses, the concepts of *context* and *facilitation*.

Context (McCormack, Kitson, Rycroft-Malone, Titchen, & Seers, 2002) is characterized as having three themes: culture, leadership, and measurement or evaluation. Culture is defined as “the way things are done around here” and includes “the forces at work which give the physical environment feel.” The authors argue that the culture of a practice context must be understood if meaningful and lasting change is to be achieved. They also provide figures defining the elements of both “strong” and “weak” context and culture that could explain why KT strategies are effective in one context within an organization but not in another. Similarly, they analyze strong and weak leadership and situations that characterize strong and weak evaluation. This concept analysis provides useful tools for both researchers and decision-makers and suggests that case studies of nursing programs using these dimensions of context could elucidate both the KT-promoting and KT-impeding factors that would have to be addressed as part of any organizational intervention.

Facilitation (Harvey et al., 2002) refers to the process of enabling (making easier) the implementation of evidence into practice. The concept analysis of facilitation led to a broad distinction between “doing for others” and “enabling others.” The authors distinguish between the role of facilitators and the skills and attributes of facilitators on a dimension with the polar extremes of “doing for others” and “enabling others.” They argue that in the context of KT the “enabling” may have a greater impact because practitioners need time to think about, translate, and particularize research findings. The authors’ summary of the characteristics of facilitation provides very specific guidance for structuring a KT intervention such that it could be replicated in multiple settings.

Theory 3: Contextualized Feedback Intervention Theory

Bickman and colleagues have developed a theory to study the uptake of empirically supported treatments in the field of mental health. Contextualized Feedback Intervention Theory (CFIT) (Riemer, Rosof-Williams, & Bickman, 2005) harnesses the power of systematic external

feedback to change clinician behaviour. It was developed through a synthesis of several research literatures, including dissonance, attribution, and self-regulation theories. Briefly, CFIT postulates that self-persuasion is much more powerful than motivational strategies based on external pressure, which tend to have short-lived effects and run the risk of generating resentment and resistance. It assumes that members of the target group are committed to a higher common goal (for example, to improve management of pain and other symptoms). If clinicians become committed to a goal, they are more likely to persist in pursuing it. They may or may not pay attention to any feedback they receive on their progress in achieving that goal, depending on several factors. First, the source of the feedback must be trustworthy and the method of data collection must be both reliable and valid. Second, if clinicians are held accountable for attending to the feedback, they are more likely to do so, but this could also create resentment. Third, individuals have different levels of “feedback propensity”; those with what Riemer et al. call a high level of internal feedback propensity prefer self-generated feedback and are unlikely to respond to external feedback. Riemer et al. describe a series of steps that facilitate the process of feedback intervention, so that it is provided in a way that is acceptable and relevant to clinicians in their real-world practice and that avoids the possible decrements in feelings of self-efficacy that can occur when feedback is negative.

Theory 4: Kanter’s Theory of Organizational Empowerment

Kanter (1993) posits that employees are empowered by work environments that provide access to information, resources, support, and the opportunity to learn and develop, and that support flexibility in job activities and strong interpersonal relationships across functional groups. Work-empowerment structures engender feelings of personal psychological empowerment — that is, role self-efficacy, job meaningfulness, and autonomy — and thus have an impact on organizational decisions. In such a work environment, employees are encouraged to make decisions based on their expertise and judgement and therefore work more efficiently and effectively; they are more committed to the organization, have more trust in management, are more accountable for their work, and are less likely to experience job strain. As noted by Laschinger, Finegan, Shamian, and Wilk (2001), there is considerable support for Kanter’s theory in nursing, with several studies having linked Kanter’s concept of empowerment to organizational outcomes such as job autonomy, perceived control over nursing practice, job satisfaction, and lower levels of job burnout. Laschinger et al. point to the links between empowerment, autonomy, and job satisfaction, noting that one of the reasons why nurses leave the field is working conditions that limit their

autonomy and their control over their practice. Kanter's theory was selected because of its fit with the proposed organizational intervention and because it provided the conceptual underpinnings for the nursing worklife measures to be used as endpoints in the HSC project. The recent results of Laschinger and Finegan (2005) further demonstrate the relevance of this theory for any intervention aimed at empowering nurses in their workplace.

Challenges for the Future

As many of us know from experience, it is all very well to start out with some theories, but will they still be relevant when it comes time to write up your results? As our esteemed peer reviewers at the Canadian Institutes for Health Research insightfully noted, we have failed to indicate how each of these theories relates to the others, a problem we hope to resolve over time as our project unfolds. If others studying KT in nursing were also to use these theories, it would be interesting to examine their usefulness in KT interventions with different groups of nurses in different parts of the country and given different endpoints for different types of interventions. Although our project is focused on an organization-wide intervention, the CFIT theory could, for example, prove useful in studying smaller groups of nurses within a specific program or unit such as a palliative care unit. In studies with smaller groups of nurses, it is difficult to imagine that the work of the RCN Institute and West's observations on social networks would not be relevant. If the combined work of many researchers and decision-makers were theoretically driven, it would certainly help to optimize interventions to promote KT in nursing, for the benefit of many specialty fields in our discipline.

And what of Dr. Lind? He, like many of us, came face to face with the reality that when new knowledge collides with pre-existing beliefs, the latter usually win. This is as much the case in nursing as it is in other disciplines, as Estabrooks (1999) found. In her structural equation modelling of predictors of knowledge utilization by nurses, "belief suspension" was one of only 3 out of 26 concepts that predicted knowledge utilization. Our challenge in nursing is to find ways to help practitioners suspend their beliefs and entertain the possibility that new evidence might actually improve patient outcomes.

Gabbay and le May (2004) describe a new perspective on knowledge uptake as a result of an ethnographic study with nurses and physicians in two general practices in England: "Clinicians rarely accessed and used specific evidence from research or other sources directly, but relied on 'mindlines' — collectively reinforced, internalized, tacit guidelines"

(p. 1015). Such mindlines were vividly exemplified when one of our students ingenuously stated, after completing a systematic review for our Evidence-Based Nursing Practice course, “But I don’t believe it [the evidence]!” Yes, new evidence based on statistical differences is “pallid” to practitioners and much less compelling than the evidence of their own eyes. So we need to attend to historical examples to constantly remind ourselves that what is obviously effective to us today may go the route of bleeding or indeed the radical mastectomy of not so long ago. Perhaps such historical examples need to be made more vivid to practitioners, to help them suspend their pre-existing beliefs and embrace new knowledge for the benefit of the public — so that people do not necessarily have to suffer and perish, as did those sailors with the deadly scurvy.

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Film Review

The Man Who Learned to Fall

Feature documentary by Garry Beitel
Montreal: Beitel/Lazar Productions, 2004. 77 min.

Reviewed by Annemarie K. Hoffmann

Without the façade of Hollywood drama, this documentary film vividly and realistically portrays a family dealing with terminal illness.

Philip Simmons was diagnosed with amyotrophic lateral sclerosis (ALS), or Lou Gehrig's disease, at the age of 35. He was a teacher, writer, husband, and father in the prime of his life. Nine years after being diagnosed, he published the book *Learning to Fall: The Blessings of an Imperfect Life* and sent a copy to Dr. Balfour Mount, a professor of palliative medicine at McGill University. Mount contacted Simmons and suggested that a portion of his challenging journey be preserved on film.

The resulting documentary captures the ordinary and unique moments of his family's life in Center Sandwich, New Hampshire, and the physical changes that Phil underwent in the last year of his life. At times, Phil and his wife, Kathryn Field, speak directly to the camera, describing their thoughts and experiences and reflecting on their journey. They do so with such eloquence, honesty, and humour that the viewer is simply left in awe.

Beitel's film opens with a folksy blues song playing in the background — music composed by Phil when he was still strong. As Phil and Kathryn, an artist, tell the story of how they met, we immediately get a sense of the humour, openness, and tenderness that characterize their relationship. We are introduced to their two children, Aaron and Amelia, through photographs and then also in footage of their daily lives, as they perform routine chores such as yard work. As we see Phil dictating to his computer, see Kathryn walking beside his electronic wheelchair along a forest road, and hear Kathryn's descriptions of Phil before the onset of ALS, we come to realize the many ways in which their lives have changed in the 9 years since Phil's diagnosis.

Several segments of the film capture Phil's talents as a public speaker. Although forced to cut short his teaching career, he continued to speak at various academic and church gatherings. (The DVD version of the documentary includes an address, "Reflections on Healing," delivered by Simmons at Harvard Medical School.) His ability to captivate an audi-

ence with wit, candour, and insight is obvious as he artfully incorporates his grasp of science with his passion for literature to examine and describe his experiences. He speaks, for instance, about discovering the value of religious language in “the business of rescuing joy from heart-break.”

In one scene we see Phil in his wheelchair playing basketball with Aaron while explaining that the most pressing issue for him at this stage in his journey is imagining the family’s future without him. Here, he introduces the paradox that will be a theme of *The Man Who Learned to Fall*: “My delight in watching them is inseparable from my sadness in knowing I will lose them...my happiness is more profound because of my knowledge of loss.”

Phil and Kathryn movingly describe the ways in which they have come to accept his illness and the impact of this acceptance on their lives. Their everyday activities have been radically altered. “In the midst of all that activity and normal life,” says Phil, “I’m aware that I am dying, I’m aware that I am losing everything, I’m aware that my children will lose me, that my wife will lose me, and I accept all that as the nature of things.” Each small failure or loss brings home to him the beauty of accepting help. Kathryn’s acceptance has grown out of seeing her husband’s courage and out of her own use of art as a means of release. We see the couple learning to live in spite of death, letting go of the “drama” and using each setback as an opportunity to practise letting go.

After Phil is hospitalized for 2 weeks with pneumonia, the couple decide that his future care will take place at home. Phil and Kathryn explain that this has created a sense of living in “end time.” The ordinary moments of daily life such as a walk outdoors, breakfast, homework, and piano practice take on special meaning and become precious for the entire family. In these moments of closeness the family members also face the reality of letting go. While in hospital, Phil realizes that “fashioning language” is so integral to him that letting go of that ability will be unimaginably difficult, awakening his desire to “embrace the paradox... continue to strive and live while letting go of everything.”

As Phil’s health visibly deteriorates, husband and wife continue to immerse themselves in their work: Phil reads and Kathryn becomes absorbed in her art. The solitude of these pursuits offers them release from daily life and also gives them the strength to keep supporting each other. In recognition of his work and his exemplary life, Phil’s alma mater, Amherst College, presents him with an honorary degree in May 2002, just months before his death. In a weakened voice, Phil speaks of engaging ever more intensely in the process of letting go, as he is forced to let go of his external working life. With a smile, he balances suffering with humour as he reflects on the truth of Bob Dylan’s lyrics. “Just when

you think you've lost everything," Phil says, "you find out you can lose a little more."

Phil's 46th birthday celebration is an occasion for many friends and relatives to gather round. Even in his weakened state, Phil proposes an eloquent toast to those who have supported him and his family. (More than 35 people had joined FOPAK — Friends Of Phil And Kathryn — a support network that allowed Phil to live at home throughout his illness.) *The Man Who Learned to Fall* closes gracefully with Phil narrating passages from his book, describing his perception of passing from one life into the next.

The individuals in this documentary exhibit an overwhelming sense of acceptance. While the film never shows the tearful and angry episodes they undoubtedly endured, Phil and Kathryn are honest about their long and difficult journey to acceptance. They articulate a new and challenging perspective of terminal illness as a time of healing and calm amid the most painful losses. The characters in *The Man Who Learned to Fall* verbalize the very experiences, emotions, and responses that nurses and nurse researchers find value in expressing.

Among my class of master's students who watched Beitel's film, there was an immediate sense that it captured the essence of themes we had been discussing in our nursing seminar throughout the semester. This family's sustained capacity to cope with the changes in Phil's abilities illustrates in a striking and moving way the notion of finding health in illness.

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Profil des sources de connaissance préférées par le personnel infirmier canadien dans le domaine de la pratique clinique

**Carole A. Estabrooks, Huey Chong,
Kristin Brigidear et Joanne Profetto-McGrath**

Des chercheurs et des chercheuses ont examiné les sources de connaissance utilisées par le personnel infirmier dans le contexte de l'utilisation de la recherche, mais les conclusions de l'étude sont ambiguës. Parmi les problèmes les plus communs, on retrouve le manque de reproduction, la présence de résultats contradictoires, la généralisabilité limitée des résultats et l'absence d'implications claires relativement à la pratique. Les objectifs de cette étude ont été : (a) de décrire les sources de connaissance et la fréquence de leur utilisation par le personnel infirmier de sept unités de chirurgie; (b) de comparer les tendances dans l'utilisation des sources par les sept unités; (c) de déterminer si la préférence pour certaines sources de connaissance a un lien avec le taux d'utilisation de la recherche; et (d) d'établir le profil historique des tendances quant à l'utilisation des sources par les infirmières et les infirmiers généraux. L'étude comprend un sondage autoadministré auquel ont participé 230 infirmières et infirmiers œuvrant dans cinq unités chirurgicales pour adultes et deux unités pour enfants dans quatre hôpitaux situés dans les provinces canadiennes de l'Alberta et de l'Ontario. En comparant les résultats de ce sondage à ceux des études antérieures, les auteurs ont constaté, dans les sept unités, une similarité en ce qui a trait aux préférences du personnel infirmier pour certaines sources de connaissance, sans égard à leur éducation, ni au taux d'utilisation de la recherche. Dans toutes les unités, les infirmières et les infirmiers préfèrent utiliser des connaissances acquises à travers des expériences personnelles et des interactions avec des collègues de travail et des patients, plutôt que d'avoir recours à des articles de revues ou à des manuels. Cette conclusion est compatible avec la comparaison longitudinale des deux études antérieures. À la différence du personnel infirmier clinicien, les chercheurs et les chercheuses ont tendance à attacher plus de valeur aux connaissances fondées sur la recherche que sur celles fondées sur l'expérience. Pour encourager l'utilisation de la recherche dans la pratique infirmière, les chercheurs, les chercheuses et autres interlocuteurs concernés doivent d'abord comprendre les raisons pour lesquelles les cliniciens et les cliniciennes préfèrent les connaissances acquises à travers l'expérience et l'interaction sociale. Ils doivent ensuite concevoir des stratégies de diffusion et de mise en œuvre de la recherche qui reflètent davantage les préférences des cliniciens et des cliniciennes.

Mots-clés : sources de connaissance, utilisation de la recherche, utilisation des connaissances, personnel infirmier clinicien

Profiling Canadian Nurses' Preferred Knowledge Sources for Clinical Practice

**Carole A. Estabrooks, Huey Chong,
Kristin Brigidear, and Joanne Profetto-McGrath**

Several researchers have examined nurses' knowledge sources within the context of research utilization, but conclusions are equivocal. Common problems include a lack of replication, conflicting results, poor generalizability of results, and unclear implications for practice. The objectives of this study were to: (a) describe sources of knowledge and their frequency of use among staff nurses across 7 surgical units, (b) compare knowledge-source patterns across the units, (c) determine whether knowledge-source preferences correlate to research utilization scores, and (d) profile staff nurses' knowledge-source patterns over time. A total of 230 nurses in 5 adult and 2 pediatric surgical units from 4 hospitals in the Canadian provinces of Alberta and Ontario completed a self-administered survey. The results were compared to the findings of previous studies. Nurses' knowledge-source preferences were consistent across the 7 units despite differences in education and in research utilization scores. Across all units, nurses preferred to use knowledge gained through personal experience and interactions with co-workers and with individual patients rather than journal articles or textbooks. These findings are consistent with the longitudinal comparison in the 2 earlier studies. In contrast to the knowledge privileged by nurse clinicians, researchers tend to place greater value on research-based knowledge than on experience-based knowledge. To increase research utilization in the practice setting, researchers and others need first to understand the reasons behind clinicians' valuing of experiential and social knowledge sources and then to consider research dissemination and implementation strategies that are more closely aligned with clinician preferences.

Keywords: sources of knowledge, research utilization, knowledge utilization, clinical practice nurses

Nurses work in complex environments where they inevitably draw on many different types of knowledge in their practice. Understanding the types and variety of knowledge resources used by nurses is critical to our understanding of research utilization and decision-making processes in clinical settings. In the absence of a clear understanding of the sources of knowledge selected by practising nurses, solutions targeting the seemingly persistent research-practice gap will be ineffective. In this context, researchers have conducted empirical studies of nurses' knowledge

sources over the past two decades, but findings are equivocal, hindering the development of strategies for the dissemination and implementation of research.

Discussions of the research-practice gap in nursing (e.g., Allmark, 1995; Bostrom & Wise, 1994; Landers, 2000; Rafferty, Allcock, & Lathlean, 1996; Rolfe, 1998; Upton, 1999) often assume that a problem exists on one or both sides of the "gap," frequently associated with clinicians. In addition, a disconnect is emerging between researchers' understanding of practice knowledge and their subsequent approaches to measuring research use and nurses' actual sources of practice knowledge. Investigators in the academic setting generally continue to promote more traditional dissemination strategies, such as journals and textbooks, despite evidence of their limited effectiveness (Grimshaw et al., 2001; Grol & Grimshaw, 1999, 2003; McCaughan, Thompson, Cullum, Sheldon, & Thompson, 2002; Michel & Sneed, 1995; Valente, 2003). Related work in the decision-making field (Baumann & Bourbonnais, 1982; Hamers, Abu-Saad, & Halfens, 1994; Laurir & Salantera, 1998; Thompson & Sutton, 1985) suggests that nursing practice is highly contextual and that interpersonal knowledge and experiential knowledge are critical. This work suggests that traditional interventions to increase research use in nursing practice, such as the promotion of critical appraisal skills, and concomitant library use, may be inadequate. Further, a number of studies report low frequencies of reading among staff nurses (Armstrong & Gessner, 1992; Barnett, 1981; Fisher & Strank, 1971; Kajermo, Nordström, Krusebrant, & Lützén, 2001), which suggests that current strategies to increase research use may need reconsideration. We argue that, in order to increase research use in the practice setting, we need to step back and more carefully consider the knowledge required for practice and the information sources currently used by nurses.

The need for basic work in this area is, in part, the result of difficulties in drawing consistent conclusions about nurses' preferred knowledge sources from studies completed to date. Few "sources of practice knowledge" studies build on previous work and most are one-time "snapshots" of nursing subgroups (Estabrooks, 2001; Estabrooks, Floyd, Scott-Findlay, O'Leary, & Gushta, 2003; Estabrooks, Scott-Findlay, & Winther, 2004). The lack of replication in the field and inconsistent examination of knowledge-source items across studies result in equivocal findings and lack of generalizability. Without the ability to generalize findings, the applicability of research conclusions is called into question and implications for practice are unclear. Hence, additional basic work in the field is needed before we can understand how and where nurses acquire essential practice knowledge.

The purpose of this paper is to report new empirical findings on staff nurses' sources of knowledge, with links to their research utilization behaviour. In light of the generalizability issues presented above, a *secondary purpose* is to build a longitudinal profile of how nurses use a set of defined knowledge sources over time. Our analyses draw on: (a) data from two research utilization studies (2002¹) reported in this paper, (b) findings from Baessler et al.'s (1994) study on knowledge sources, and (c) findings from Estabrooks' 1996 study on research utilization (Estabrooks, 1998), which included Baessler et al.'s questions on sources of knowledge. All studies targeted staff nurses and examined a comparable group of knowledge-source items.

The objectives of the paper are to: (a) describe the knowledge sources and their frequency of use among staff nurses across seven surgical units, (b) compare knowledge-source patterns across units, (c) determine whether patterns of knowledge preferences (and use) correlate to research utilization scores, and (d) profile knowledge-source patterns over time.

Methods

Sample

Data from the 2002 research utilization studies were collected using a survey administered during two ethnographic multiple case studies examining the use of research by Canadian nurses in the context of adult and pediatric pain management. Each participating hospital and its academic Ethics Review Committee approved the study protocol. The self-administered survey was completed on two adult and five pediatric surgical units located in four teaching hospitals in the Canadian provinces of Alberta and Ontario. Nurses from the seven units were similar demographically except for their educational credentials; Ontario nurses reported a higher percentage of university degrees (see Table 1).

In the 2002 studies, research associates distributed packages containing survey instruments, including the research utilization survey, to all

¹ The 2002 research utilization studies comprise two studies examining research utilization in the context of pain management. Data for the first study concerned adult pain management and were collected over the 6-month period April to September 2000. Data for the second study concerned pediatric pain management and were collected over the 6-month period April to September 2001. Estabrooks, C. A. (PI), Lander, J., Norris, J., Boschma, G., Lau, F., Watt-Watson, J., O'Brien-Pallas, L., Stevens, B., Donner, G., & Williams, J. I. (1999–2002), *The determinants of research utilization: Pain management in adults*, funded by Canadian Institute of Health Research, Grant #144765, and Alberta Heritage Foundation for Medical Research Grant #199800311; Estabrooks, C. A. (PI), Landry, J., Norris, J., Boschma, G., Watt-Watson, J., O'Brien-Pallas, L., Stevens, B., & Donner, G. (2000–2003), *The determinants of research utilization: Pain management in infants and children*, funded by Canadian Institute of Health Research, Grant #44649.

Table 1 Demographic Characteristics of the Samples Across Studies

Characteristics	2002 Studies (n = 228) ^a							Baessler et al. (1994) (n = 212)	Estabrooks (1998) (n = 600)
	Unit 1	Unit 2	Unit 3	Unit 4	Unit 5	Unit 6	Unit 7		
Mean Age (SD)	39.1 (10.6)	35.5 (8.8)	49.8 (7.7)	46.8 (6.2)	38.1 (9.6)	37.7 (8.3)	35.1 (7.8)	32.6 (8.3)	41.7 (9.9)
Sex (%)									
Female	91.9	88.9	10.0	93.8	89.5	98.7	95.5	90.1	97.5
Male	8.1	11.1	.0	6.3	10.5	1.3	4.5	6.6	2.5
No response	.0	.0	.0	.0	.0	.0	.0	3.3	.0
Highest Education (%)									
LPN	13.5	.0	15.4	12.5	5.3	.0	.0		
RN diploma	54.1	42.2	76.9	81.3	47.4	38.2	40.9	22.2	70.8
AD/AA								30.7	
BS/BA								7.5	
BSN/baccalaureate	27.0	51.1	7.7	6.3	47.4	51.3	5.0	31.6	25.2
MS/MSN ^b	.0	2.2	.0	.0	.0	9.2	9.1	3.3	.5
Other	.0	.0	.0	.0	.0	1.3	.0		2.7
No response	5.4	4.4	.0	.0	.0	.0	.0	4.7	.8
Mean hours worked per week (SD)	34.9 (9.6)	37.2 (10.8)	32.6 (8.8)	34.5 (6.5)	33.6 (10.6)	34.6 (8.5)	36.8 (5.9)		28.14 11.86

Note: Units 1 and 2 are adult surgical units and the rest are pediatric surgical units. Units 1, 3, 4, and 5 are Alberta sites and the rest are Ontario sites. LPN = licensed practical nurse; RN = registered nurse; AD/AA = associate degree/associate of arts; BS/BA = bachelor of science/bachelor of arts; BSN = bachelor of science in nursing; MS/MSN = master of science/master of science in nursing.
^a Only 228 of the 230 nurses who completed the survey are profiled demographically because these data were collected separately.
^b Only Baessler et al. (1994) included non-nursing education.

staff nurses on the units. Detailed instructions for completing the various surveys were included in the packages and nurses were asked to return the completed survey in a sealed envelope to a secure location on the unit. Research associates collected completed surveys from the designated location daily. The survey was administered twice during the 6-month data-collection period on each unit, once at the beginning and once close to the end. Interviews and focus groups with the nurses over the 6-month period, along with availability of project newsletters and other dissemination tools, were likely to have heightened awareness of research utilization. Therefore, the survey was administered twice, to investigate the study's impact on nurses' perception of their day-to-day research use. In the 2002 studies, 314 usable surveys were returned. Since 84 respondents were surveyed in both data-collection periods, the 314 returned surveys from the studies yielded a combined sample of 230 staff nurses.

In contrast, Estabrooks' 1996 survey (Estabrooks, 1998) was mailed out to a stratified random sample of 1,500 nurses selected from a total of 15,698 staff nurses registered with the Alberta Association of Registered Nurses in 1996. This survey yielded a sample of 600 using Dillman's (1978) methods.

Baessler et al. (1994) mailed questionnaires to 572 registered nurses in a large city in the northeastern United States working in medical-surgical clinical areas (excluding specialty areas such as emergency and critical care). Of the 572 nurses who received the questionnaire, 212 completed it.

Measures

The survey used in the 2002 studies was a condensed version of that used in Estabrooks' 1996 study (Estabrooks, 1998). However, data presented in this paper came from knowledge-source questions in the survey that were identical in the original and the condensed version of Estabrooks' survey. Questions on the frequency with which nurses used various sources of knowledge were scored on a five-point Likert scale, ranging from *never* to *always*. Responses to the overall research utilization question examined in our correlation analysis were also scored on a five-point Likert scale.

In the analysis, the knowledge-source data from the 2002 studies were compared to those from Baessler et al. (1994) and Estabrooks (1998). Twelve of the 16 knowledge-source questions in Estabrooks' 1996 and 2002 surveys were identical to those used by Baessler et al. The four items added are items j, n, o, and p listed in Tables 2 and 4. A detailed description of this survey's development is provided elsewhere (Estabrooks, 1998, 1999). Demographic characteristics of the various samples are reported in Table 1.

Analysis

SPSS 11.0 for Windows was used to perform all data transformation and analyses. Because the survey was administered twice in the 2002 studies, a paired-samples *t* test was used to determine whether sequence of data collection influenced nurses' responses to knowledge-source questions. The 84 nurses who completed the survey twice did not significantly differ in their responses over time at the specified .05 significance level, except on the in-service item. Based on these results, data from these nurses' first survey were included in the analyses. Although data from their second survey were equally representative, their first survey was chosen to parallel participants who were surveyed only once in this study and to parallel participants in the Baessler et al. (1994) and Estabrooks (1998) studies.

Descriptive statistics provided an overview of knowledge-source patterns and research utilization scores across the seven units in the 2002 studies. Nurses' knowledge-source preferences were *inferred* from their frequency of use of each item. In ongoing work, we have made the inference that reported frequencies equate reasonably well with preferences. Rank ordering of the sources in these studies, rank ordering of sources in other studies in the literature, and findings in our qualitative work reveal a consistent pattern of ranking and stated preference among those sources reported as used most often by nurses (Estabrooks, 2002²). We caution, however, that some assumptions must hold for this inference to be valid in isolation from other substantiation (e.g., that all or most sources of knowledge stated are available to nurses).

Items were ranked in ascending order based on mean frequency scores. Sources with tied means were assigned tied ranks. Ranks allowed for descriptive comparisons across the seven units, as well as across studies. In order to make more comprehensive comparisons across the seven units, one-way analysis of variance and, when applicable, nonparametric Kruskal-Wallis test were used to determine whether unit membership influenced knowledge sources. The null hypothesis tested was that nursing units do not differ in their frequency score on each item. Subsequent post-hoc multiple comparisons located differences among groups if the null hypothesis was rejected at the predetermined *p* value of .05 or less. Pearson's *r* correlation values were calculated between knowledge-source scores and overall research utilization scores to determine possible relationships.

²Estabrooks, C. A., Landry, R., Dickinson, H. D., & Golden-Biddle, K. (2002-2007). *Knowledge utilization and policy implementation*, funded by Canadian Institutes of Health Research, Grant #53107.

Results

Nurses' general patterns of knowledge-source use from the 2002 studies are presented in Table 2. Two items tied as the top source of knowledge: individual patient information³ and personal experience in nursing. The other items in the top five sources used were, in descending order of use: information from attending in-services, information learned in nursing school, a tie between discussions with physicians and information from fellow nurses, and intuition. In comparison, the five sources used least often were, in descending order of use: nursing journals, ways nurses have always done it, nursing research journals, medical journals, and the media. Nurses also used multiple sources.

The numbers of different knowledge-source items that are frequently or always used by nurses are reported in Table 3. Approximately half of the nurses sampled often used 6 to 10 sources in their practice, while approximately one quarter frequently or always used 11 to 15 sources.

Seven-Unit Comparisons

Few differences were seen when the seven units were compared descriptively on their ranked knowledge-source items. On average, nurses on all seven units ranked "my personal experience of nursing patients/clients over time" and "information that I learn about each patient/client as an individual" as their top two sources of knowledge. Nurses on these units also relied heavily on information learned in nursing school and in-services in the workplace. Another similarity among the seven units was infrequent use of journal articles. This observation is consistent with the findings reported by Baessler et al. (1994) and Estabrooks (1998). As with periodicals, textbooks were consistently ranked lower across the seven units.

Nonparametric Kruskal-Wallis single-factor analysis of variance by ranks indicated significant differences ($p < .05$) among units in nurses' use of specific sources of knowledge. These specific sources are, in order of decreasing importance: in-services in the workplace, nursing school, what has worked for years, nursing journals, nursing research journals, and medical journals. Post-hoc tests were then run to discover where the differences lay across the units. Dunn's (1964) multiple contrasts using ranked sums, which accounts for unequal group sizes, were able to detect only where these differences lay across units in their use of nursing school and nursing research journals. Even then, conclusions were ambiguous because the majority of units overlapped into different population subsets. This procedure failed to detect differences among units for the other knowl-

³Individual patient information refers to the information learned from each patient/client as an individual.

Table 2 *Distribution of Nurses' Sources of Knowledge in Daily Practice (2002 Studies)*

Item	Percentage (%)						Mean Score (SD)	Rank
	Never 1	Seldom 2	Sometimes 3	Frequently 4	Always 5	No Response		
a. Individual client / patient	0.4	0.0	12.2	52.6	30.4	4.3	4.18 (.68)	1.5
b. Intuition	1.3	7.0	29.6	45.7	13.0	3.5	3.64 (.85)	7
c. Personal experience	0.0	1.3	10.0	55.7	30.0	3.0	4.18 (.66)	1.5
d. Nursing school	1.7	5.7	23.9	46.5	18.3	3.9	3.77 (.89)	4
e. Physicians' discussions with nurse	0.4	4.3	29.1	48.3	13.9	3.9	3.74 (.78)	5.5
f. Physicians' orders	0.4	5.7	38.7	37.0	12.2	6.1	3.58 (.81)	9
g. Medical journals	10.0	31.7	33.5	19.1	1.7	3.9	2.70 (.97)	15
h. Nursing journals	1.7	15.7	40.9	33.5	4.3	3.9	3.24 (.84)	12
i. Nursing research journals	7.8	27.8	38.7	19.1	2.6	3.9	2.80 (.94)	14
j. Textbooks	1.3	14.3	37.4	34.3	7.8	95.2	3.35 (.88)	11
k. What has worked for years	2.2	10.0	24.3	48.7	9.1	5.7	3.56 (.89)	10
l. Ways nurse has always done it	3.0	20.9	45.7	23.9	1.7	4.8	3.00 (.82)	13
m. Fellow nurses	0.0	1.7	29.6	57.8	7.8	3.0	3.74 (.63)	5.5
n. In-services in workplace	0.9	3.0	27.0	49.6	16.5	3.0	3.80 (.79)	3
o. Policy and procedure manuals	2.2	10.4	27.4	37.0	18.7	4.3	3.62 (.99)	8
p. The media	14.8	38.3	31.3	9.6	1.3	4.8	2.42 (.92)	16

Note: Frequencies for each item total to 100%.

Table 3 *Variety of Sources of Knowledge Used by Nurses (2002 Studies)*

Number of Sources of Evidence Used	Number of Nurses	%
0	8	3
1 to 5	46	20
6 to 10	119	52
11 to 15	55	24
> 15	2	1
Total	230	100
Mean number of sources used: 8		
<i>Note:</i> Table reports the number of sources that were frequently or always used by the nurses in their daily practice.		

edge-source items queried using the Kruskal-Wallis test. This failure results partly because multiple comparison tests are underpowered in comparison to the analysis of variance tests and because type II errors are more likely to occur in multiple comparison tests (Zar, 1996). Despite a lack of detail, the possibility that units differ in their use of knowledge sources, especially in their use of highly ranked sources, have important implications for research utilization dissemination strategies.

Relationship Between Use of Knowledge Sources and Research Utilization

Pearson's correlation coefficients were calculated for each pairing of individual information items to overall research utilization. The items that were positively and significantly correlated ($p < .01$) with overall research utilization were: nursing journals, in-services in the workplace, discussions with physicians, nursing research journals, personal experience, and textbooks. However, only half of these items were ranked as top sources. Personal experience, in-services in the workplace, and discussions with physicians were ranked among the top five sources, while nursing research journals, nursing journals, and textbooks were ranked among the lowest five.

Longitudinal Cross-Study Comparison

Across the three studies (Baessler et al., 1994; Estabrooks, 1998; Estabrooks et al.¹) and over a period of 6 years, information learned about the patient and personal experience consistently ranked as the two most frequently used sources of knowledge (see Table 4). Other highly ranked

¹See note 1, page 121.

Table 4 Mean Frequency Scores of Knowledge-Source Items and Their Ascending Ranks Across Studies

Item	2002 Studies (n = 230) ^a							Baessler et al. (1994) (n = 212) ^b	Estabrooks (1998) (n = 600) ^a
	Unit 1	Unit 2	Unit 3	Unit 4	Unit 5	Unit 6	Unit 7		
a. Individual client / patient (SD) Rank	4.08 (.64) 3	4.22 (.88) 1	4.23 (.60) 1.5	4.25 (.56) 2	4.17 (.62) 2	4.23 (.61) 1	4.00 (.71) 2.5	2.30 (.56) 1	4.29 (.69) 1
b. Intuition (SD) Rank	3.46 (.90) 8	3.68 (1.01) 8	3.92 (.76) 4	3.94 (.77) 5	3.78 (.88) 8	3.51 (.75) 7	3.86 (.79) 4.5	1.70 (.74) 8	3.56 (.78) 9
c. Personal experience (SD) Rank	4.11 (.74) 1.5	4.18 (.82) 2	4.23 (.60) 1.5	4.31 (.60) 1	4.22 (.55) 1	4.18 (.63) 2	4.14 (.48) 1	2.19 (.55) 2	4.11 (.70) 2
d. Nursing school (SD) Rank	4.11 (.74) 1.5	3.93 (.89) 4	4.00 (.91) 3	4.13 (.72) 3	3.89 (.68) 6.5	3.42 (.97) 9	3.57 (.68) 8	2.17 (.53) 3	3.83 (.77) 3
e. Physicians' discussions with nurse (SD) Rank	3.38 (.98) 9	3.86 (.72) 5.5	3.69 (.86) 7	3.75 (.86) 7	3.89 (.68) 6.5	3.88 (.66) 3	3.52 (.68) 9	1.73 (.59) 6.5	3.61 (.81) 7
f. Physicians' orders (SD) Rank	3.62 (.92) 7	3.78 (.80) 7	3.54 (.88) 9.5	3.75 (.93) 7	3.72 (.83) 9.5	3.49 (.73) 8	3.24 (.63) 12.5	1.73 (.60) 6.5	3.61 (.83) 8
g. Medical journals (SD) Rank	2.30 (.91) 15	2.86 (.93) 15	2.23 (1.24) 16	2.81 (1.22) 14.5	2.17 (.93) 15	2.91 (.81) 14	3.00 (.89) 15	0.99 (.69) 12	2.67 (.94) 14
h. Nursing journals (SD) Rank	2.81 (.88) 13	3.36 (.93) 12	3.00 (1.08) 13	3.37 (.86) 11	3.06 (.94) 13	3.38 (.66) 10	3.48 (.68) 10	1.54 (.71) 10	3.25 (.95) 12

i. Nursing research journals (SD) Rank	2.46 (.93) 14	2.93 (.95) 13	2.77 (1.09) 14	2.56 (.89) 16	2.17 (.99) 15.5	2.95 (.81) 13	3.38 (.87) 11	1.17 (.67) 11	2.55 (.95) 15
j. Textbooks (SD) Rank	3.32 (.88) 11	3.62 (.87) 9	3.31 (1.11) 11	3.19 (1.05) 12.5	3.39 (.92) 11	3.31 (.84) 12	3.10 (.70) 14		3.26 (.81) 11
k. What has worked for years (SD) Rank	3.64 (.90) 6	3.44 (1.12) 11	3.69 (1.01) 7	3.75 (.68) 7	3.94 (.54) 4.5	3.34 (.82) 11	3.86 (.73) 4.5	1.97 (.55) 4	3.54 (.74) 10
l. Ways nurse has always done it (SD) Rank	3.19 (.91) 12	2.88 (.85) 14	3.15 (.56) 12	3.38 (.62) 10	3.22 (.65) 12	2.76 (.84) 15	3.24 (.70) 12.5	1.63 (.62) 9	3.04 (.73) 13
m. Fellow nurses (SD) Rank	3.68 (.63) 4.5	3.86 (.63) 5.5	3.69 (.86) 7	4.00 (.63) 4	4.00 (.59) 3	3.59 (.57) 6	3.71 (.56) 7	1.89 (.46) 5	3.64 (.58) 6
n. In-services in workplace (SD) Rank	3.68 (.67) 4.5	4.07 (.73) 3	3.77 (1.01) 5	3.19 (1.17) 12.5	3.94 (.80) 4.5	3.76 (.70) 5	4.00 (.63) 2.5		3.77 (.74) 4
o. Policy and procedure manuals (SD) Rank	3.35 (1.18) 10	3.54 (1.14) 10	3.54 (.88) 9.5	3.50 (.97) 9	3.72 (.96) 9.5	3.78 (.86) 4	3.76 (.83) 6		3.66 (.83) 5
p. The media (SD) Rank	2.24 (.90) 16	2.63 (1.06) 16	2.69 (1.25) 15	2.81 (.54) 14.5	2.17 (.92) 15.5	2.27 (.78) 16	2.57 (.98) 16		2.41 (.84) 16

^a Responses were based on a five-point Likert scale: 1 = never, 2 = seldom, 3 = sometimes, 4 = frequently, 5 = always.

^b Responses were based on a four-point Likert scale: 0 = never, 1 = seldom, 2 = frequently, 3 = always.

knowledge sources were information learned in nursing school, in-services, and information learned from other nurses and from physicians. Nurses not only found discussions with physicians to be valuable, but learned almost as much from physicians' patient-care orders. Although personal experience and co-workers were preferred sources of knowledge, intuition ranked relatively low. Nurses may rank intuition lower than personal experience and interpersonal relationships because following their intuition sounds less reliable than scientific sources of information. However, we believe this finding may question the assertion that intuition, as a result of personal experience and interpersonal relationships, plays a central role in nursing practice (Agan, 1987; Benner & Tanner, 1987; Berragan, 1998; Correnti, 1992; Rew & Barrow, 1987). At the very least, it questions the assertion that intuition plays a central role if identified as a source of practice knowledge.

Regardless of the type of journal (nursing, medical, or research), nurses consistently ranked journals among their least preferred sources. Only popular media, which included magazines, television, and the Internet, were used less frequently than journals. Another infrequently used source was textbooks, despite their availability on most units. Textbooks were ranked only slightly higher than journals in the 1998 and 2002 studies; these results suggest that nursing staff prefer socially driven and relational knowledge sources to print sources such as journals and textbooks.

“What has worked for years” and “ways nurses have always done it” rank inconsistently across the three studies. In Baessler et al.'s (1994) sample, these sources ranked 4th and 9th, respectively. However, in the other recent studies, they decrease in use to 10th and 13th. This decrease in use over time may indicate that nurses change their practices, or it may be a response to the active rhetoric of evidence-based practice over the last decade. In the latter case, the two information sources rooted in tradition are less credible than those rooted in research. Hence, decreasing scores for these items over time may be a reflection of social desirability rather than actual practice.

Discussion

The overall trend emerging from the cross-unit and cross-study comparisons is that nurses rely most often on individual patient information, personal experience, and interactions as primary information sources for practice. Palfreyman, Tod, and Doyle (2003) used the same knowledge-source survey questions with a group of staff nurses in the United Kingdom and found parallel results. That group of nurses ranked information from the client as their top source, followed by personal experi-

ence and information from fellow practitioners. Although we could locate no other empirical studies that directly measured personal experience as a knowledge source, numerous authors have discussed its importance in nursing practice (i.e., Baumann & Bourbonnais, 1982; Benner, 1984; Berragan, 1998; Burrows & McLeish, 1995; Goding & Cain, 1999; Kennedy, 1998; Luker & Kenrick, 1992; Palfreyman et al.; Will, 2001). Similarly, individual patient information (learned from each patient/client as an individual) as a knowledge source was not measured in most empirical studies. Logically, individual patient information should rank high because it defines situational context, which nurses cite as critical to the decision-making process in practice (Clarke & Wilcockson, 2002; Corcoran-Perry & Graves, 1990; Luker & Kenrick). Cardiovascular nurses surveyed in the Corcoran-Perry and Graves study most frequently sought patient-specific data when seeking supplemental information.

Despite limited comparability, various findings from previous empirical studies support the importance of interactions among colleagues, particularly other nurses. Several investigators identify nursing staff, peers, and colleagues as main sources of practice knowledge (Bunyan & Lutz, 1991; Corcoran-Perry & Graves, 1990; Lathey & Hodge, 2001; Lawton, Montgomery, & Farmer, 2001; Palfreyman et al., 2003; Salasin & Cedar, 1985; Stetler & DiMaggio, 1991; Urquhart & Davis, 1997). Also, in Barta's (1995) study, pediatric nurse educators frequently scored interpersonal communications in their top three choices of useful sources for updating their instruction of students.

The Use of Journals

Part of the overall trend observed is the relative under-use of journals, textbooks, and popular media, including the Internet. The findings of Thompson et al. (2001a, 2001b) support this trend. Their cross-case analysis of qualitative data from hospital nurses in the United Kingdom shows that human sources of information are considered most useful and accessible in nurses' daily decision-making. Nurses in the practice setting prefer oral to written sources, most likely as a result of the hands-on nature and structure of their work (Salasin & Cedar, 1985). In addition, oral sources of information may best suit their need for immediate solutions to patient care. However, few empirical studies specifically examining nurses' sources of practice information support this claim; most actually report the opposite and report journal use to be moderate or high. In these studies, occupational-health nurses (Lathey & Hodge, 2001), nurse practitioners (Rasch & Cogdill, 1999), and staff and community nurses (Winter, 1990) ranked journals midrange amongst their sources. Groups that rated journals as the top source or one of the top sources

include community nurses (Lawton et al., 2001; Urquhart & Davis, 1997), nurse teachers (Love, 1996), acute-care nurses (Spath, 1996; Urquhart & Davis), and clinical nurse specialists (Stetler & DiMaggio, 1991). Of these eight studies, five also measured the use of books/textbooks, and nurses in all but one ranked these in their top three sources of knowledge.

The greater use of print sources by certain subgroups compared to staff nurses in our cross-study comparison (Baessler et al., 1994; Estabrooks, 1999) may relate to their degree of specialization and/or the nature of their tasks. In their survey of health professionals, Stinson and Mueller (1980) found that information sources used were partly related to practice type and specialty. Similarly, Salasin and Cedar (1985) report significant relationships between the use or value of various knowledge sources and nurses' work roles and settings. The nature of some work may dictate greater reliance on information to support practice decisions. For example, researchers argue that specialized nursing roles in highly complex environments, such as critical care and public/occupational health, differ from those in other areas (Baumann & Bourbonnais, 1982; Blythe, Royle, Oolup, Potvin, & Smith, 1995; Bucknall, 2000; Bucknall & Thomas, 1996; Lathey & Hodge, 2001; Thompson & Sutton, 1985). Hence, differential use of journals and textbooks by various specialities may be a function of the different nursing tasks and practice environments.

Despite nurses' self-reported frequent use of journals in some studies, the evidence for this trend is ambiguous. Bostrum and Suter (1993) and Rizzuto, Bostrum, Newton Suter, and Chenitz (1994) report that in one survey of 1,200 nurses only 21% used research findings in practice over the previous 6 months. Generally, nurses are unaware of or make limited use of research findings disseminated through research literature (Brett, 1987; Corcoran-Perry & Graves, 1990; Coyle & Sokop, 1990). Corcoran-Perry and Graves report that written sources sought by nurses relate mainly to patient records or other documentation. Along the same theme, other researchers report that nurses do not frequently read, subscribe to, or have access to journals (e.g., Corcoran-Perry & Graves; Crane & Urquhart, 1994; Urquhart & Crane, 1994; Wright, Brown, & Sloman, 1996). Regardless of reading or access issues, nurses reportedly lack library search and retrieval skills and the other technological skills needed to tap available information resources (Blythe, 1993; Royle, Blythe, Potvin, Oolup, & Chan, 1995). When they do overcome these barriers and read journals, many nurses still lack the critical appraisal skills to evaluate research quality and applicability (Camiletti & Huffman, 1998; Royle et al.). Few nurse researchers have directly addressed this apparent contradiction between nurses' reported use of journals as an

important information source and their reported inadequate access and inadequate reading and appraisal skills. One explanation — on the reported use of journals side of this equation — is that social desirability may positively skew responses to self-report surveys (Thompson, 1999). As discussed by Thompson, studies that combine observation with self-report have found that respondents over-report the use of journals and under-report the use of colleagues as information sources (e.g., Covell, Uman, & Manning, 1985).

Methodological Issues

The contradiction between our findings around print sources and the findings in the literature serves to highlight a number of methodological limitations in this field. One limitation is the sampling bias that impedes the ability to generalize results. Except in a handful of studies, hospital staff nurses were not widely sampled. Stetler and DiMaggio (1991) point out that their sample was “small, non-random and comes from one institution and one geographical area.” Lathey and Hodge (2001) note that their modest response rate (28%) and the choice to sample a subgroup of occupational-health nurses limit interpretation. Lack of replication in the field and lack of longitudinal studies, along with difficulties comparing sources of knowledge across studies, all add to the problem.

Another limitation is that nurses' knowledge sources are frequently examined with little regard for the highly contextual and situated nature of their work, which is critical in defining working knowledge (Kennedy, 1983). As an example, Luker and Kenrick (1992) point out that nurses are studied in the hospital setting rather than in their natural work environment, which limits the types of implications that can be drawn for practice. Taking it further out of context, researchers often ask nurses to reflect on knowledge use over a long period (e.g., weeks, months, years), thus failing to account for the dynamic nature of their daily work. Most importantly, nurses' knowledge sources are studied in isolation from other influences that might drive their information-seeking behaviour. Information-resource use is rarely measured in conjunction with critical determinants such as resource accessibility (e.g., Champion & Leach, 1989), organizational support (e.g., Champion & Leach; Clarke & Wilcockson, 2002; Hicks, 1998), and available time (e.g., Regan, 1998; Rizzuto et al., 1994). All research-design issues discussed ultimately affect the generalizability of findings and the subsequent implications derived for practice.

We chose a longitudinal cross-study approach when looking at nurses' information sources in order to mitigate some of these methodological issues. Because the same survey questions pertaining to knowledge sources were repeated in three different studies with staff nurses

over 6 years, patterns emerging from the data have greater validity when generalized to the population. Examination across units and across studies yielded consistent results. Staff nurses repeatedly rely more on informal and interactive, relational sources such as their experience, colleagues, and patients than on formal sources such as journals and textbooks. Despite the consistent patterns seen over the three studies, our longitudinal approach only served to highlight ongoing issues around lack of replication and lack of standardization of survey questions in this field, which affects the validity of findings.

Although an improvement over those of “snapshot” studies, the findings from this study illustrate a fundamental problem with current research in this area. Nurses report their reliance on experiential knowledge, yet the majority of researchers leave out experience as a knowledge item in empirical studies. Also, current methods of measuring research utilization primarily tap formal research knowledge codified in journals and textbooks. We do not understand how or if research can be introduced through other knowledge sources. For example, researchers often separate non-research knowledge from research-based knowledge when discussing nursing knowledge (e.g., Estabrooks, 1999; Luker & Kenrick, 1992). However, if nurses prefer relational and interactive sources, as well as other informal sources not easily examined using current research methods, we are likely measuring research utilization inadequately.

Our cross-unit results show that nurses’ research use is not the “sum” of their information-seeking behaviour. Because nurses across the seven units differed in their research utilization scores but not in their selection of knowledge sources, we argue that research utilization is a more general phenomenon influenced by multiple factors. Consequently, nurses’ information-seeking preferences may be poor predictors of their research utilization behaviours. This finding illustrates one dimension of the complexity inherent in studying research utilization — determinants other than the frequency with which nurses rely on various knowledge sources may influence differences in research utilization scores.

At the same time, the types of information sources preferred by nurses have critical implications for how we disseminate research findings. Since practising nurses frequently favour experiential, relational, and interactive resources over formal resources, researchers need to strategize accordingly. Nurses are relatively consistent in their choice of knowledge sources, a factor that is likely driven by the overall structure of nursing work in contemporary settings. Since the fundamental structures of nursing work are unlikely to change in the foreseeable future, we must reconsider traditional dissemination and implementation strategies.

Conclusion

We propose that our findings and those of others in this area lend support to the following assertions. First, the research-practice gap is poorly understood. Second, current attempts to measure research use are inadequate. Third, improved conceptualization and measurement of research use will be predicated on an improved understanding of research use within the broader context of practice knowledge.

The gap between what nurses report and what researchers measure may represent the major threat to validity of investigations in the field of research utilization. Luker and Kenrick (1992) and Salasin and Cedar (1985) found the distinction between practice-based knowledge and research-based knowledge to be more artificial than real. They argue that nurses are being exposed to research findings but may not be able to report the extent to which research informs their practice because it has been reclassified as general nursing knowledge. We argue that nurse researchers need to better understand how both research and practice knowledge are conceptualized and subsequently measured, and grapple with the impact of researchers' academically oriented value systems in a field centrally concerned with the use of *practice-relevant knowledge*. The motivation for this study was to add to our understanding of the factors that influence nurses' use of research. We conclude that, as researchers, we need to better understand how nurses gain and sustain knowledge for everyday practice in order to more meaningfully advance the use of research in practice.

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Résumé

Étude qualitative sur le point de vue des personnes âgées et des aidants naturels quant à l'évaluation et au traitement de la douleur

Ronald Martin, Jaime Williams, Thomas Hadjistavropoulos, Heather D. Hadjistavropoulos et Michael MacLean

La documentation disponible donne à penser que la douleur chez les personnes âgées, en particulier celles atteintes de démence, est sous-évaluée et sous-traitée. Dans le cadre de cette étude qualitative, des personnes âgées, du personnel infirmier de première ligne, des administrateurs de résidences pour personnes âgées et des aidants naturels de personnes âgées souffrant de démence donnent leur point de vue sur la manière dont on évalue et on traite actuellement la douleur. L'opinion des participants complète les résultats de recherche cités dans la documentation. Même si certaines explications et solutions possibles concernant le sous-traitement de la douleur chez les personnes âgées font écho aux points de vue exprimés dans la documentation, les participants ont également mentionné des facteurs et des solutions qui ont été pris en compte de manière moins formelle, comme les obstacles systémiques à une évaluation et un traitement efficaces de la douleur. Ils ont également souligné la nécessité d'avoir d'autres stratégies en plus de la médication pour contrôler la douleur. Cette étude examine l'impact de ces résultats.

Mots clés : douleur, personnes âgées, démence, évaluation de la douleur, traitement de la douleur

A Qualitative Investigation of Seniors' and Caregivers' Views on Pain Assessment and Management

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The literature suggests that pain in the elderly, especially among seniors with dementia, is under-assessed and under-treated. This qualitative study solicited the perspectives of seniors, front-line nursing staff, nursing-home administrators, and informal caregivers of seniors with dementia on the current status of pain assessment and management. The views of these participants complement the research findings reported in the literature. While some of their explanations and potential solutions concerning under-treatment of pain in seniors echo views that have been presented in the literature, the participants also pointed to factors and avenues that have been given less formal consideration (e.g., systemic barriers to effective assessment and treatment of pain). They also highlighted the need for pain-control strategies beyond medication. The implications of these findings are discussed.

Keywords: pain, elderly, seniors, dementia, pain assessment, pain management

Most chronic health problems that are associated with aging, such as arthritis and osteoporosis, carry a substantial burden of pain. As a result, pain is a common preoccupation among older adults (Parmelee, Smith, & Katz, 1993; Roy & Thomas, 1986). In their survey, Cook and Thomas (1994) found that 50% of older Canadians reported experiencing daily pain and another 28% reported experiencing pain at least once during the previous week. In a study with elders living in the community, 86% reported experiencing significant pain during the previous year, with close to 60% reporting multiple pain complaints (Mobily, Herr, Clark, & Wallace, 1994). Pain is also a pressing concern for seniors who live in institutions (Chiou & Buschmann, 1999). Proctor and Hirdes (2001) conducted a large-scale study with seniors living in nursing homes and found that overall pain prevalence was 49.7%, with 23.7% of the residents experiencing daily pain. Marzinski (1991) examined patients' charts in an Alzheimer unit and, consistent with the idea that dementia does not spare a person from the many sources of pain that might afflict others, found that 43% of the patients had painful conditions. Proctor and Hirdes (2001) conclude that the association of pain with conditions that typically cause pain is comparable for seniors with and without dementia.

This finding complements those from several other studies, involving a wide variety of methodologies, and suggests that seniors with and without dementia react similarly to painful stimulation (e.g., Gibson, Voukelatos, Ames, Flicker, & Helme, 2001; Hadjistavropoulos, LaChapelle, MacLeod, Snider, & Craig, 2000; Porter et al., 1996).

Despite its high prevalence, pain is largely under-treated among seniors. This was recognized in a recent large-scale survey of the membership of the American Pain Society and the American Academy of Pain Medicine. Specifically, Ferrell et al. (2001) found that the under-treatment of pain among seniors represents one of the most pressing ethical concerns for pain clinicians. For example, although findings suggest that psychosocial interventions for pain in seniors are effective (e.g., Ferrell, Rhiner, & Ferrell, 1994), only rarely do seniors receive psychosocial treatment. The under-treatment of pain is especially pervasive among seniors with cognitive impairments. For example, Marzinski (1991) found that, although 26 of 60 patients with Alzheimer disease had painful conditions, only three patients were routinely given analgesics. Further, Kaasalainen et al. (1998) found that almost half of cognitively intact patients were receiving scheduled pain medications, compared to only 25% of those with cognitive impairments. Other investigators have reached similar conclusions (e.g., Horgas & Tsai, 1998).

Numerous reasons have been offered for the under-management of pain among older adults. Sengstaken and King (1993) found that physicians often fail to detect pain problems among seniors with neurological problems. Kapp (2003) argues that the under-treatment of older patients is a function of the fear of litigation and concern about the high cost of medication, particularly in the case of for-profit Health Management Organizations, in the United States. Other reasons that have been cited include a possible reluctance on the part of seniors to discuss their pain (believing that pain must simply be endured), fear of addiction to opioids, and the belief that pain is a natural part of aging (Hadjistavropoulos & Craig, 2004).

The various explanations that have been provided for the under-management of pain among older adults are largely based on the opinions of researchers in the field. We decided to take a novel approach and seek the perspectives of seniors and front-line nursing staff on the current status of pain assessment and management. We also chose to solicit the opinions of nursing-home administrators and informal caregivers of seniors with dementia. We believed that the view from the grass roots would represent a fresh perspective and complement the views of experts in the area. We anticipated that, while some of these explanations and potential solutions concerning the under-treatment of pain in seniors would echo those found in the literature, they would also point to factors

and avenues that have not been given formal consideration. It was our hope that our findings would pave the way for the development and implementation of more effective ways of assessing and managing pain in this population. To achieve our objectives we chose to explore both pain assessment and management separately for seniors with and without dementia.

Method

Focus groups consisting of up to nine participants were used to study concerns about pain assessment and treatment among seniors. We sought the perspectives of care recipients (i.e., seniors experiencing pain), informal caregivers of seniors with dementia, and health professionals. Focus-group discussions are a commonly used method in qualitative research. This method allows for the spontaneity of group interaction while maintaining the structure of an individual interview through the use of a moderator (Krueger, 1994). The dynamic interactions of the group allow for depth and insight into an issue (Seal, Bogart, & Ehrhardt, 1998).

Focus-Group Participants

Indices of saturation (i.e., repetition of material, confirmation of material across the groups) signified that we had a sufficient number (six) and variety of focus groups (Morse, 1994); that is, during analysis of the data, the themes would be repeated among the six groups and new material would not be uncovered towards the end of the analysis. Separate focus groups were formed for seniors, informal caregivers, and health professionals. There were two groups of seniors, one comprising those living independently in the community ($n = 8$) and the other comprising cognitively intact nursing-home residents ($n = 4$). There was one group of informal caregivers (persons providing care in their homes for relatives diagnosed with dementia) ($n = 8$). Finally, three groups of health professionals were formed; two of these ($n = 9$, $n = 10$) included roughly equal numbers of registered and practical nurses (11–31 years' experience), while the third comprised nursing-home supervisors and administrators ($n = 6$).

The group of community-dwelling seniors was recruited through advertisements at a seniors' centre inviting the participation of those with past or current pain problems. The group of nursing-home residents was formed via contacts (i.e., nominations) provided by the facility's administrator; the administrator identified residents with pain problems who would be well enough to participate in a focus-group discussion. The informal caregivers were recruited through the provincial Alzheimer society. Both groups of nursing staff were recruited through local nursing

homes via nomination (as it is often the case in focus-group research — see Patton, 1990); that is, nursing-home administrators were asked to nominate experienced staff members who had worked with seniors experiencing pain. The nursing-home administrators themselves were recruited through an announcement made during a meeting of administrators of long-term-care facilities in a mid-sized metropolitan area. The voluntary nature of participation was stressed in all cases.

Procedure

The researchers developed moderator guides (i.e., predetermined sets of open-ended questions regarding the assessment and treatment of pain) for each of the focus groups.¹ The majority of the questions were similar for all of the groups as they dealt with core topic areas in the assessment and treatment of pain (e.g., “How is pain assessed?”; “What concerns do you have about the way pain is assessed?”). However, some questions were specifically included to gather data pertinent to seniors with dementia.

Following approval by the Research Ethics Board of the university and that of the local health region, verbal and written informed consent (including consent to audiotape) was obtained from all participants. The participants were assured of the confidentiality of the focus-group discussions and were informed that only anonymous quotations would be included in written reports. Finally, they were told that all materials derived from the investigation would be kept securely in keeping with professional standards. A member of the research team acted as the moderator for the focus groups. The moderator encouraged participation from all group members and used scripted probes to stimulate further discussion. In the event that a discussion became tangential, the moderator refocused the dialogue on the question being addressed. The moderator also asked participants to clarify any vague or ambiguous responses. Each 90-minute focus-group session was audiotaped and transcribed verbatim.

Analytic Techniques

Given the open-ended nature of the focus-group method, we chose a data-analysis technique (i.e., thematic content analysis) that facilitates the identification of central themes from the data by determining the presence of common words or concepts. Specifically, we sought to identify and categorize commonalities (as well as differences) in views on pain assessment/management in seniors. This approach also allows for the classification of words and phrases into more than one category. Prior to

¹ The complete moderator guides are available from the authors on request.

analyzing the transcripts, we identified meaning units as the most basic component of our analysis. The meaning unit was selected because it is the smallest component of text that conveys a unitary, cohesive idea (e.g., "Medications don't help") (Frontman & Kunkel, 1994). Meaning units varied in length from a phrase to a paragraph.

The qualitative software package NVivo was used to facilitate the analysis (NVivo qualitative data analysis program, Version 1.3, 2000). NVivo was deemed suitable for this investigation because it allows for flexibility in coding the data and allows for searching and assessing relationships in terms of text and coding (Richards, 1999). Moreover, the internal graphical modeller was useful for exploring the relationships between the parts of the framework.

Using thematic content analysis (e.g., Lincoln & Guba, 1985), data analysis proceeded in the following way. First, the data were categorized into broad topics derived from the moderator guides (*pain-assessment issues, pain-treatment issues, impact of pain on quality of life, and issues specific to seniors with dementia*). The data were categorized separately for each focus group. Then, more specific sub-units (domains) were identified within the broad topics. To identify the domains, three members of the research team examined the moderator guides and identified the general areas of inquiry. Moreover, one researcher examined the transcripts to ensure that the focus groups proceeded as indicated by the moderator guides. The data were then categorized into the domains (separately for each focus group). The implications, criteria, and nuances of each topic and domain were discussed among the researchers and guidelines for categorization were developed to ensure trustworthy classification of the meaning units.

The meaning units, coded into the domains, were examined thoroughly for repetition of words, ideas, examples, and key phrases. This allowed for the identification of themes from the initial coding structure. It should be noted that even at this advanced stage of analysis, the data from each focus group were examined separately. This allowed the researchers to continuously clarify unique themes that were emerging from the different focus groups as well as common themes. The last stage of analysis was examination of the themes across the focus groups. To determine whether the themes were common, repetition of words, ideas, examples, and key phrases were considered. The labels associated with each theme were selected through discussion among three of the researchers. To enhance the trustworthiness of the coding process, members of the research team met regularly to resolve any discrepancies in the emerging framework. Throughout the coding process, following the constant comparative method, the framework was continuously revised to reflect the views of the team.

Trustworthiness of the Data

As an index of trustworthiness (e.g., Curtis et al., 2001), a second researcher independently coded a randomly selected portion of meaning units (15% across all transcripts) into the established domains. Initial agreement between coders was reached 84% of the time. All discrepancies in coding were discussed and complete agreement was achieved. As a second index of trustworthiness, member checking was carried out using a procedure adapted from Lark and Croteau (1998). The member checking confirmed the trustworthiness of our analysis.

Results and Discussion

The purpose of our study was to gather information on the assessment and treatment of pain among older adults. Four general topics were identified: *pain assessment among seniors*, *pain treatment among seniors*, *effects of pain on seniors' quality of life*, and *concerns specific to seniors with dementia*. Within each of these topics several domains were coded. The domains were then differentiated into themes (where applicable) and, in some cases, sub-themes. Table 1 illustrates the overall structure of the coding. Two of the topics (i.e., *pain assessment among seniors* and *pain treatment among seniors*) were elaborately coded into domains and themes (and two sub-themes). The other two topics (i.e., *effects of pain on seniors' quality of life* and *concerns specific to seniors with dementia*) were coded only into domains, because the data did not lend themselves to further elaboration (i.e., coding into themes).

Pain Assessment Among Seniors

Analyses of the focus-group discussions on pain assessment among seniors were organized into four domains (*assessment methods*, *ways of improving assessment*, *assessment challenges and concerns*, and *positive aspects of assessment*), 27 themes, and two sub-themes.

Domain: assessment methods. Self-report was the most commonly identified means of assessing pain, especially among cognitively intact seniors. Participants reported using self-report to assess pain (in the case of caregivers and health professionals) or to make their pain known to others (in the case of seniors). This finding is not surprising given that most professional assessments of pain entail verbal input from the patient. For example, an informal caregiver stated, "They [the physicians] ask questions: How does it feel? Where does it hurt? What kind of pain is it? When did it start? When do you feel it?" However, most participants did not advocate the use of self-reported information in the assessment of pain among seniors with severe dementia. The participants frequently expressed concern regarding the ability of seniors with dementia to

understand questions about pain and to provide accurate and reliable information. However, nursing staff reported using self-report with both dementia and cognitively intact patients. With regard to assessing pain in seniors with dementia, nurses discussed the importance of asking simple, direct questions that require a "yes" or "no" response. They further indicated that this line of questioning provides a foundation for the remainder of the assessment. This suggests that nurses are aware that seniors with mild to moderate dementia may be able to provide reliable information about their pain (e.g., Hadjistavropoulos, von Baeyer, & Craig, 2001; Huffman & Kunik, 2000).

Other ways of assessing pain that were frequently mentioned (especially in reference to seniors with dementia) included observation of behaviours that signal the presence of pain (e.g., grimacing, frowning of the brow, guarding, rubbing the affected area, physical withdrawal from touch) and changes in mood (e.g., irritability, impatience, frustration, depression) or behaviour (e.g., sleep patterns, eating patterns). Both self-report and behavioural observation were discussed in all of the focus groups. Even the community-dwelling seniors stated that their friends and family members often identified their pain by observing how they performed tasks. Physical examination and medical testing were mentioned less frequently as methods of pain assessment. Informal caregivers and health professionals said that they often served as an important source of information regarding pain. Caregivers, especially those who are very familiar with the older care recipient such as spouses or children, may be particularly adept at recognizing the more subtle signs and symptoms of pain. The following meaning units illustrate the use of behavioural assessment:

Health professional: *...the change could be shown in any number of ways, from not wanting to get up walking, or there's a change in behaviour, or resistance to care...a change...a cue.*

Health professional: *...body language, facial expressions.*

Domain: ways of improving assessment. Improved education of health-care providers was the most frequently identified theme in this domain, especially among health professionals and informal caregivers. Specific suggestions by professionals included continuing education (e.g., increased in-service presentations and satellite training events) and formal academic and supervised training. This theme was not identified within the seniors' groups.

All of the focus-group discussions indicated that a subset of health professionals may embrace myths about aging (e.g., believe that pain is a natural part of aging) that can hamper efforts to carefully assess pain.

Table 1 Coding Structure of Topics, Domains, and Themes

Topic: Pain Assessment Among Seniors

Domain: assessment methods

- Themes*
- pain behaviours
 - emotional and mood changes
 - facial expressions
 - self-report
 - caregiver report
 - medical examination or medical testing
 - change in behaviour

Domain: ways of improving assessment

- Themes*
- increased documentation and staff communication
 - improved assessment tools
 - more education
 - shorter waiting lists
 - greater accessibility to services
 - increased patient assistance
 - increased familiarity with person doing the assessment

Domain: assessment challenges and concerns

Themes and sub-themes

- lack of education
- long waiting lists
- inferior assessment tools
- lack of/inconsistency of staff
- assessments not thorough enough
- physician issues: lack of communication with patient; lack of/inefficiency of referrals
- subjectivity and individual differences in experiencing pain
- problems with self-report: limited communication; underreporting pain; reasons for underreporting pain
- limited documentation

Domain: positive aspects of assessment

- Themes*
- good physician-patient relationship facilitates assessment
 - assessment is thorough and fast
 - increased focus on assessment
 - assessment is facilitated by communication and a team environment

Topic: Effects of Pain on Seniors' Quality of Life

Domain: limitation in social activity

Domain: limitation in basic life-sustaining activity

Domain: loss of independence

Domain: mood changes

Topic: Pain Treatment Among Seniors

Domain: management methods

- Themes*
- rest and relaxation
 - holistic alternatives
 - information on pain
 - social and recreational activities
 - teamwork
 - exercise
 - attention from family, friends, and caregivers
 - medication
 - not telling others about the pain
 - distraction
 - talking about the pain
 - physical aids/manipulating the environment
 - living despite the pain

Domain: treatment challenges and concerns

- Themes*
- treating multiple problems
 - lack of treatment/undermedication
 - inefficiency of medication
 - medication side effects
 - medication options not explored
 - self-medication
 - lack of alternatives to medications

Domain: positive aspects of treatment/ways of improving treatment

- Themes*
- education
 - alternative/holistic treatments
 - interdisciplinary team approach
 - nursing staff teamwork/competency
 - medication options
 - willingness to prescribe medications
 - appropriate/specific prescriptions
 - active participation of the patient in treatment
 - positive physician-patient relationships
 - immediacy of treatment

Topic: Concerns Specific to Seniors With Dementia

Domain: communication problems

Domain: difficulties in making physical adjustments

Domain: behavioural problems and concerns

Domain: misattribution of pain behaviours

Although most medical schools and nursing programs provide some training in special populations, more emphasis may be required to address the specific concerns of seniors and to reduce the prevalence of erroneous beliefs about pain in old age.

Nurses were more likely than other focus-group participants to discuss the need for improvements in the documentation and communication of pain-related information in health-care settings. If the results of a pain assessment are not communicated to other staff members (e.g., documented in the older patient's medical chart), valuable information on pain in seniors may be lost (e.g., the timing, intensity, and correlates of pain). A health-care provider stated the following:

I do believe that...there is sometimes lack of communication among the staff, because if there is a change...why not pass it on to the other nurses and make them aware? Or put a note that states, "Please continue doing this," and then the assessment can be more accurate.

Less frequently identified themes (primarily arising in the community-dwelling seniors and informal caregiver groups) in this domain that could be beneficial for assessment included improved access to services (e.g., for assessment of dental pain), shorter waiting lists, and improved patient-physician communication (e.g., informing the physician of all potentially relevant information). Health professionals and informal caregivers expressed a need for better and more accessible assessment tools, especially those suitable for seniors with severe dementia.

Domain: assessment challenges and concerns. The most frequently identified theme in this domain was related to self-report. Closer inspection revealed that the meaning units within this theme diverged to form two distinct sub-themes regarding barriers to self-reporting information during pain assessment: difficulty communicating and underreporting pain. All of the groups noted that pain can be underreported by older adults for various reasons (e.g., stoicism, not wanting to bother others). In addition, the health professionals discussed a reluctance on the part of many patients to report pain for fear of being prescribed excessive amounts of medication and having restrictions imposed upon them. Further, all of the focus groups except the group of nursing-home residents noted that seniors may have difficulty describing the intensity and quality of their pain to health professionals.

Other themes included concerns that pain assessments are insufficiently thorough and that subjectivity and individual differences in the experience and expression of pain (e.g., gender differences in reporting pain) make assessment difficult. Participants also expressed the concern that health-care providers may not be receiving adequate education regarding the assessment of pain among seniors.

The following are representative meaning units from this domain:

Moderator: *Do you feel that pain is more likely to be ignored in seniors?*

Senior A: *...because we're grey and wrinkly and over the hill...*

Senior B: *Because you're getting older —*

Senior A: *— they don't —*

Senior B: *— you just get aches and pains when you're older, right?*

Senior A: *Definitely.*

Health professional: *If you talk to them [physicians] about someone with pain, well, "She's old, she's saggy, she's going to die, what can you do for her?" Instead of really looking at what the problem is and giving something that might help, whatever the situation is at the time. But they seem to think, "Oh, she doesn't have much longer to live, she's 80-something or 90-something; she's bound to have pain."*

Themes that emerged less frequently in this domain included long waiting lists for medical appointments to discuss pain-related problems, staff shortages, and the inconsistency of health-care staff in conducting pain assessments. These themes were identified primarily among the health professionals. These larger, contextual issues within the health-care system may result in either the neglect of pain assessments (in the face of more pressing medical issues) or assessments that are conducted quickly and in a cursory fashion. Nursing staff also mentioned staff shortages as a concern, saying they had a limited amount of time to conduct pain assessments. This is problematic given that seniors often need more time than younger people to convey information about their pain. The following statement by a health professional illustrates the time restrictions placed on front-line workers:

There's not even extra time to talk to that person while you're getting them up in the morning...we don't have enough to give them an extra 5 minutes in the morning per resident so...you could find out that something is sore today. ...they may be telling you but you're not listening because you're so busy doing.

Poor communication between physicians and patients, limited documentation of pain in medical charts, and the lack of adequate pain-assessment tools for seniors with cognitive impairments were also mentioned as obstacles to accurate pain assessment. For example, although the value of behavioural indicators of pain was discussed frequently, participants (especially nurses) were quick to point to a paucity of formal assessment tools that actually employ this method of pain evaluation.

Domain: positive aspects of assessment. Themes within this domain indicated that the pain assessments of many health-care providers are fairly frequent and thorough. Moreover, the participants acknowledged

that inroads have been made in terms of revising the curriculum of medical schools and nursing programs to cover the unique characteristics of older populations. All groups of participants noted that effective pain assessments are facilitated by good patient-physician relationships and a multidisciplinary or team approach. The health professionals discussed the value of having assessments conducted by nurses, physicians, aides, physical therapists and others, who then communicate their conclusions to one another.

Pain Treatment Among Seniors

The analysis of discussions on this topic revealed three domains (*management methods, treatment challenges and concerns, and positive aspects of treatment/improving treatment*) and 30 themes. In the original structure of this topic, *positive aspects of treatment/improving treatment* was treated as two domains. However, because further coding revealed significant overlap of content (i.e., participants reported that the positive aspects of treatment could often be used to improve the treatment), it was decided to merge the two.

Domain: management methods. The theme that emerged most often across all focus groups was the use of medications. The participants acknowledged that physicians have an array of pharmacological interventions at their disposal, including non-opioid analgesics, non-steroidal anti-inflammatory medications, and opioids. For example, one senior commented on the use of medication for chronic pain:

...that's why I think I look so healthy, but people don't realize that I'm on long-acting medication and I couldn't go without it for...if I missed a dose...I would be in quite severe pain.

Community-dwelling seniors frequently mentioned the use of assistive devices (e.g., canes) and physical accommodations (e.g., propping up an injured limb) in managing pain, noting that these forms of pain management are easy to implement and cost-effective. Nursing staff said that these methods were useful in managing pain among cognitively impaired and cognitively intact seniors. Alternatives (e.g., massage, acupuncture) to pain medications were discussed in all of the focus groups. This suggests a willingness to explore and incorporate alternative approaches into pain management and may reflect shifts in health-care training and societal attitudes towards pain interventions. Health professionals stated that measures such as massage and music therapy are sometimes implemented. An informal caregiver commented:

I think that doctors are becoming more willing to refer, too, to some of the more holistic things, like chiropractors and massage therapists, than what they used to be.

Participants also expressed the view that lifestyle choices may affect pain. This theme was particularly robust among seniors living in the community. For example, appropriate physical activity was seen as beneficial in managing chronic pain. Exercise, in addition to enhancing cardiovascular and musculoskeletal health, was viewed as helpful in maintaining and improving mobility and managing other aspects of chronic pain such as stiffness. Participants also acknowledged that regular physical activity (e.g., gardening, participating in social or recreational pursuits) may be helpful in managing chronic pain indirectly, by maintaining everyday functioning, building self-esteem and self-efficacy, and enhancing mood.

The participants agreed that physical activity should be balanced with rest and relaxation. This reflects an awareness of the value of pacing (i.e., scheduling rest periods before the onset or exacerbation of symptoms) as a coping strategy in chronic pain. Another coping strategy mentioned in all of the focus groups was the use of distraction; for some older adults, focusing on a task can be helpful in shifting their attention and awareness away from their pain. A few participants also noted the value of information on pain, carrying on with one's daily life despite the pain, talking about the pain in order to share the burden, and receiving attention from family, friends, and caregivers.

Domain: treatment challenges and concerns. The most commonly identified themes in this domain were untreated pain and under-medicated pain. These themes emerged primarily among the health professionals. The participants spoke of difficulties with "as needed" medications, including inconsistency of administration and lack of systematic protocol. In addition, they were troubled by the reluctance of many physicians to prescribe stronger analgesics (i.e., opioids) when more conventional analgesics cease to be effective. Concerns about under-medication of pain were especially prevalent during discussions of cancer pain in older adults. Nurses discussed the need for an effective dose and type of medication in order to make patients as comfortable as possible:

We have a resident who has chronic back pain and her family physician told me specifically...we wanted something stronger for her pain...and her family physician told me that the neurologist said that she can't have any, and this lady has a brain tumour and she is dying and she is not very old and I am thinking...why are we worried...isn't it better to give her some quality to make her comfortable?

Another common theme — identified in all of the groups — was concern about the side effects of pain medications (e.g., drowsiness, sedation). The participants indicated that seniors are more likely than younger adults to be taking other medications, as a result of the increased number of chronic health problems that occur with advancing age, thus

compounding the problems associated with adverse side effects. One senior commented on his difficulties with side effects:

Give me stronger and stronger medication, making me stupider. The pain is still there. I can go to sleep, sleep for 5 minutes, and it's lucky if I get 5 minutes a night... I can't sleep with the pain... Those guys are so smart, they...kill you, make you sicker...stupid half the time.

Nurses discussed the need for availability of different medication options. For example, without the option of using an analgesic patch nursing staff may be required to use pain medications in pill form, which could lead to problems with patient compliance, especially among patients with dementia. Themes that emerged less frequently in this domain included the ineffectiveness of many medications, patient self-medication, difficulties associated with treating multiple conditions, and the dearth of non-pharmacological alternatives.

Domain: positive aspects of treatment/improving treatment. The most frequently identified theme in this domain was the willingness of a subset of physicians to prescribe potent pain medications, especially stronger narcotics, for the management of severe cancer pain. The participants also noted that pain medications are often available in different forms (e.g., pills, analgesic patches), which enhances their flexibility and utility. These points were stressed primarily by health professionals:

The doctors seem to be getting more at treating the pain and allowing the treatment to be done. Whereas it was really hard to get a narcotic order for someone who was really ill and...their final stages of life when I first started, but now...most of the doctors are...whatever they need to keep them comfortable.

We do have a range of options available to us now. Even in the area of just giving analgesic. At one time it was just oral or IM, but now we've got patches and we've got subcutaneous deliveries... We've got different delivery options as well. So I think that, too, is a positive in pain management.

Seniors living in the community, informal caregivers, and nursing-home residents made the point that a positive patient-physician relationship is vital for effective pain management. Health professionals mentioned increasing education in pain management. Less commonly identified themes in this domain were the availability of alternative approaches to treatment, the immediacy of treatment, teamwork and competency among nursing staff, interdisciplinary approaches, and the active participation of the patient in treatment.

The Effects of Pain on Seniors' Quality of Life

During discussions about the effects of pain on quality of life, four domains emerged: *limitation in social activity, limitation in basic life-sustaining activity, loss of independence, and mood changes*. The most commonly discussed of these domains was *limitation in social activity*. All of the focus groups noted that seniors may be discouraged or prevented from engaging in social activities because of their pain. The participants also expressed a concern that older adults may become more reclusive and isolated over time. Common side effects of pain medications such as drowsiness and sedation were also noted as impairing social functioning. Limitation in everyday activities was seen as central. Hobbies (e.g., gardening, woodworking, card-playing) and other enjoyable pursuits (shopping, volunteering) were reported as being negatively affected by pain, as expressed by a senior participant:

I could sit and play cards and all at once my thumbs, they get stiff. I can't move them... Or the fingers. They just stiffen up and you got to work on them, to loosen them up a bit. It's the golden years, right? Isn't that what it is?

The participants said that even the most basic activities of daily living such as washing, dressing, and cleaning become difficult when pain is present. Further, they acknowledged that poor quality of life is most evident when functions that are necessary for survival such as sleeping, eating, and breathing become difficult due to chronic pain. The health professionals noted that difficulty sleeping, in particular, creates a cycle that exacerbates pain. One nursing-home resident said, "I can't walk, can't do exercise, can't do anything, so what do you do?" Such concerns were not mentioned by the community-dwelling seniors, likely because they are more prevalent among frail seniors residing in institutions. It was noted in all of the focus groups except the group of informal caregivers that chronic pain forces many seniors to seek support and assistance with everyday tasks. Some seniors perceived having to relinquish such tasks as losing their independence or becoming a burden to friends or family members. The impact of pain on quality of life was also said to cause negative mood shifts and a loss of independence. This was discussed in all of the focus groups. One senior commented:

My biggest concern was that I was a trouble to my family. That's one thing. And...just why did I have to get this pain. ...I'm a great one in silence. I suffered in silence, I guess I'll put it that way.

Concerns Specific to Seniors With Dementia

Discussions on this topic yielded four domains: *communication problems*, *difficulty making physical adjustments to manage pain*, *behavioural problems*, and *misattribution of pain behaviours*. The most common of these domains was *communication problems* (i.e., limited ability of seniors with dementia to accurately convey pain-related information), which was prominent within the groups of formal and informal caregivers. The participants said that, because of communication difficulties, pain conditions are more likely to go unrecognized and untreated among seniors with dementia than among other seniors. As a result, seniors with dementia may be at increased risk for escalating symptoms and aggressive behaviours. The literature also suggests that pain problems tend to go undetected in people with limited ability to communicate (Biersdorff, 1991; Sengstaken & King, 1993).

Another prominent domain was *misattribution of pain behaviours* — a concern that overt signs of pain (e.g., behavioural disturbances, mood changes) are being incorrectly attributed to a dementing process, resulting in interventions that are misdirected. For example, several participants commented that seniors with dementia are sometimes given a neuroleptic medication when the underlying cause of their behavioural disturbances is pain. In such cases, the underlying pain may go unrecognized and untreated for long periods, resulting in prolonged and unnecessary suffering.

Less prominent domains were the concern, raised by health professionals, that pain may lead to more severe behavioural reactions among those with dementia, and the related concern that these individuals will have particular difficulty managing their pain (by, for instance, elevating a limb). This point is illustrated in the comments of three health professionals:

I think the cognitively intact people get treated quicker, because they can tell you what they want and they can ask and the staff are more likely to respond to that, whereas people with dementia, it makes it much more difficult.

Well, with the dementia, it is usually the behaviour problems...people saying so and so is being difficult and we have to do something because they are going into everybody's room...no one thinks it is really pain first, because when we are told we think, oh, it's their dementia.

Or they might not even know how to compensate or to do something to reduce the pain. A person that has dementia that maybe has a bad knee and is still walking on that knee although they are obviously limping and showing pain, but can't put the process together to sit down, take the pressure off, and reduce the pain, can't say, "I will no longer do this 'cause it hurts."

Conclusions: Towards a Multidimensional Approach to the Assessment and Treatment of Pain in Seniors

When we cross-referenced our findings with the pain-assessment and pain-management literature, it was evident that the views of front-line workers and seniors themselves are, in many ways, consistent with what has been suggested by authorities in the area. First, there was recognition of both the frequent use of self-report and its limitations (Turk & Melzack, 2001). Moreover, there was recognition by the health professionals that self-report should be attempted with seniors who have mild to moderate dementia although this needs to be supplemented by observational approaches and caregiver reports (e.g., Hadjistavropoulos et al., 2001; Huffman & Kunik, 2000). There was recognition of the paucity of pain-assessment methodologies for seniors with limited ability to communicate but also lack of familiarity with suitable assessment procedures that have been developed recently (Feld, 2000; Fuchs-Lacelle & Hadjistavropoulos, 2004; Hadjistavropoulos et al., 2001). This lack of familiarity underscores the need for continuing staff education. It is incumbent upon health-care facilities to provide staff with adequate release time for such education in order to ensure that quality of care is maximized.

Some of our participants' explanations for the under-treatment of pain in seniors, such as fear of addiction to opioids and myths and beliefs about pain and aging, are frequently cited in the literature (Balfour & O'Rourke, 2003; Craig & Hadjistavropoulos, 2004; Malloy & Hadjistavropoulos, 2004). The seniors in particular discussed societal bias with respect to the expression of pain. The consensus among the group of community-dwelling seniors was that society views pain as a natural part of aging and that they are expected to "put up with it." The seniors said that discussing their pain and asking for relief was analogous to whining: "Just don't tell anyone; that's the way to do it." It is worth noting that some of the explanations for the under-treatment of pain in this population are not cited frequently in the literature; these include, for example, inadequate communication among nursing staff about the assessment and treatment of pain and systemic barriers such as staff shortages and waiting lists.

The participants reported that health-care providers often hesitate to use certain effective medications to control pain. This finding is consistent with those reported in the literature (Gloth, 2000). However, although the participants were concerned about under-medication, they also worried about side effects. Concerns about side effects, as well as frequently unjustified fears about addiction, are often cited in the literature as barriers to pain treatment (Gloth). The participants also pointed to the availability and effectiveness of non-pharmaceutical alternatives, echoing

researchers in the field who increasingly acknowledge the use of alternative medications and other means of pain management (Craig & Hadjistavropoulos, 2004).

The findings of this study give weight to the frequent assertions of pain researchers and clinicians about barriers to pain assessment and management. They also underscore the need for immediate intervention when seniors experience pain. Our professional curricula should conform to the guidelines of such organizations as the International Association for the Study of Pain (IASP), the American Geriatrics Society, and the Canadian Pain Society. Our interventions also need to incorporate development and adaptation of treatment and assessment procedures suited for seniors and especially for those with severe limitations in ability to communicate. The urgent need for coordinated care was clear in the comments of our participants regarding the level of communication among health-care providers. In addition, greater attention should be paid to alternative methods of pain management such as cognitive and behavioural approaches, including self-management strategies. A list of recommendations, based on our focus-group data, is presented in Appendix 1.

Although the focus groups of health professionals discussed more systemic and technical issues such as staff shortages and the availability of analgesic patches than our other participants, generally the views expressed were consistent across groups. Our group of nursing-home residents consisted of only four participants. It is possible that a larger group would have produced richer material. Moreover, the concerns and experiences of our sample of caregivers, recruited with the aid of the provincial Alzheimer society, could differ somewhat from those of caregivers not connected to such an organization. It would be useful for future research to assess for the presence of such differences.

We are humbled by the task ahead but remain optimistic in light of recent developments in our field. These developments include changes in the conceptualization of pain to better accommodate the needs of persons with communication difficulties (see, for example, the note that has been added to the IASP's conceptualization of pain: <http://www.iasp-pain.org/terms-p.html#Pain>) and attempts to incorporate specific relevant guidelines into the current revision of the IASP's curriculum for professional pain education. Moreover, longitudinal studies with seniors are beginning to systematically incorporate the study of pain concerns (Canadian Longitudinal Study of Aging) and the literature is increasingly focusing on clinical issues affecting these populations. Our next challenge is to integrate all of the latest developments into practice in a way that will have a strong impact on both seniors and front-line caregivers.

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Appendix 1 *Recommendations for Pain Assessment and Management*

- Pain assessment should include both self-report and observational procedures.
- Self-report approaches to pain assessment should be attempted with patients with mild to moderate dementia, because many of these patients are likely to provide useful information; in this population, self-report should be used in conjunction with patient history, the results of physical examinations, caregiver reports, and observational assessment procedures.
- Training programs for health professionals should cover more pain assessment and management of seniors, including seniors with dementia.
- Health-care providers should keep more systematic records of pain complaints and concerns in order to enhance continuity of care.
- Additional staffing can enhance pain assessment and management.
- Multidisciplinary approaches to pain management should be used where possible.
- Communication between patients and health-care providers should be improved in order to enhance pain assessment and management.
- Continuing education for health professionals should put more emphasis on pain management, including issues related to effective use of opioids and medication side effects.
- Non-pharmaceutical alternatives to pain management should be included in routine patient care as much as possible.
- Seniors should be encouraged to discuss their pain complaints with health-care providers and to not assume that pain is a natural consequence of growing old.
- Research in pain assessment and management among seniors should be encouraged; one area that warrants special attention is pain assessment and management in those with severe dementia and communication difficulties.

Élargir le dialogue sur la démence: (Re)positionner le diagnostic et le récit

JoAnn Perry

Le modèle biomédical qui oriente les processus d'évaluation et de diagnostic de la démence est fondé sur des hypothèses et des approches qui, bien qu'essentielles sur le plan médical, peuvent diminuer l'importance de ces processus pour les soins infirmiers. Même si la recherche du personnel infirmier en gérontologie sur la démence utilise fréquemment le diagnostic comme critère d'inclusion pour les projets et bien que les outils de dépistage soient souvent utilisés pour évaluer l'impact des interventions, il serait peut-être bon de penser à élargir nos points de vue sur les évaluations pour y inclure le récit du patient. Ce document prend position en faveur de cet élargissement du dialogue et propose que le personnel infirmier repositionne le diagnostic médical pour tenir compte du récit du patient. Dans cette optique, le document examine et critique les limites du processus de diagnostic et met en doute sa pertinence pour les soins infirmiers. Les autres facteurs qui sont abordés sont notamment les approches constructionniste et interprétiviste, l'exploration des hypothèses et une approche relationnelle pour soutenir l'identité individuelle.

Mots clés: démence, recherche du personnel infirmier, récit, diagnostic

Expanding the Dialogue on Dementia: (Re)Positioning Diagnosis and Narrative

JoAnn Perry

The biomedical model that guides the processes of assessment and diagnosis of dementia is based on assumptions and approaches which, while critical to medicine, may render them less consequential for nursing. Although gerontological nurses' research concerning dementia frequently uses the diagnosis as an inclusion criterion for projects, and screening tools are often employed to evaluate the impact of interventions, we may wish to consider expanding our views of assessment and evaluation to include the person's narrative. The purpose of this paper is to argue for this expanded dialogue and to suggest that nurses reposition the medical diagnosis behind the narrative of the individual patient. To that end, this paper explores and critiques the limitations of the diagnostic process and questions its relevance to nursing. The alternative considerations that are discussed include constructionist and interpretivist approaches, the exploration of assumptions, and a relational approach to supporting personhood.

Keywords: dementia, nursing research, narrative, diagnosis

The consequences of being diagnosed with dementia are not trivial. For an individual they include loss of autonomy and rights, stigma, possible institutionalization (Askham, 1991; Austrom & Hendrie, 1990), and, according to some, loss of personhood. For the family they include changes in family roles and relationships (Perry, 2002), increasing responsibility, increasing stress and burden (Connell & Gallant, 1996), and significant out-of-pocket expenses (Fast, Williamson, & Keating, 1999). Once dementia is diagnosed, it is all but inevitable that the person with dementia as well as family members will have some contact with nurses in various settings, ranging from clinics to long-term-care facilities. In addition, gerontological nurse researchers often address the lives and concerns of persons with dementia and their kin. Therefore, since the diagnosis of dementia is likely to bring nurses together with persons who have dementia and their families, it seems timely to consider the benefits of expanding the discussion of dementia. The purpose of this paper is to consider some of the limitations and consequences associated with the medical diagnosis of dementia, and to discuss the implications of nurses' using this diagnosis when working with persons who have dementia. It has been suggested that, for nursing, the medical diagnosis of dementia

be repositioned in the background so that the person and the person's narrative can be kept in the foreground of both nursing research and nursing practice.

The medical diagnosis of dementia is based on positivist approaches and is narrow in focus. It may serve the physician and those researchers who work at the cellular level as they seek to identify the particular "cause" and "cure." However, an approach that fails to consider social contexts and discourses omits an orientation to the person, which is central to nursing. The social contexts and discourses that shape the everyday world of persons with dementia and their kin must be explored if we are to more appropriately locate nursing's research, theorizing, and clinical care of persons with dementia and their kin. To adequately conceptualize dementia we need to use approaches that embrace the dialogic nature of the exchanges between the person with dementia, the family caregiver(s), and the researcher.

The Diagnosis of Dementia

Dementia is inconsistently defined and conceptualized; some of the inconsistency relates to the ambiguities in the relationships between dementia and cognitive impairment and between dementia and aging. As if to illustrate the consequences of such ambiguities, Erkinjuntti, Ostbye, Steenhuis, and Hachinski (1997) found that the frequency of dementia varied dramatically when different systems of diagnostic classification were used. Although there was substantial overlap among the groups of participants identified by the various systems as having dementia, many individual participants identified as having dementia by one classification system were not so identified by another; the problem is not simply that some systems are more restrictive than others but, rather, that they identify different individual participants as having dementia (pp. 1671–1672).

The *Diagnostic and Statistical Manual*, 4th edition (American Psychiatric Association, 1996), presents the general criteria for dementia as "the development of multiple cognitive deficits manifested by both memory impairment and one or more of the following cognitive disturbances: aphasia, apraxia, agnosia, disturbance in executive functioning (planning, organizing, sequencing and abstracting)" (p. 275). A workgroup drawn from members of the National Institute of Neurological and Communicative Disorders and Stroke and the Alzheimer's Disease and Related Disorders Association developed the most comprehensive set of diagnostic criteria for Alzheimer's disease, taking behaviour as the basis for the diagnosis (McKhann et al., 1984). In order to diagnose Alzheimer's disease, the physician must rule out other possible causes of a slow-onset progressive dementia, such as brain tumour, manic-depressive disorder,

Parkinson's disease, multi-infarct dementia, and drug side effects. The diagnostic criteria are for possible, probable, or definite Alzheimer's disease and include a medical history, neurologic examination, psychiatric examination, and clinical examinations, as well as laboratory and neuropsychological tests (Corey-Bloom et al., 1995; McKhann et al.). Clearly, the diagnosis must be made over time, because the criteria include evidence of identified plateaus and progressive worsening of memory and other cognitive functioning (Corey-Bloom et al.; McKhann et al.). More recently, the Canadian Consensus Conference on Dementia (Patterson et al., 1999) stated that dementia is diagnosed "when acquired cognitive deficits are sufficient to interfere with social or occupational functioning in a person without depression or clouding of consciousness" (p. S3); this group supports estimates that Alzheimer's-type and vascular dementia, occurring separately or overlapping, constitute approximately 80% of occurrences of dementia.

A slightly different view of dementia emerges when the disease is considered as one of behavioural problems. While all authors recognize that behaviour changes are part of the trajectory, some see these changes as the defining aspect. The behaviours in question include getting lost in a familiar place and being unable to perform activities of daily living, such as bathing and dressing, and instrumental activities of daily living, such as shopping and keeping appointments (Davies, 1991; Morris & Rubin, 1991). Other behaviours, referred to as "behaviour disturbances" or "problems," may include agitation, screaming, depression, aggression, and wandering (Geldmacher & Whitehouse, 1996; Morris & Rubin; Teri et al., 1992). Geldmacher and Whitehouse refer to these as "noncognitive symptoms." Efforts to correlate cognitive decline with specific behaviour changes or behaviour problems yield contradictory results (Cohen et al., 1993; Colerick & George, 1986; Lowenstein et al., 1989; Teri et al., 1992; Teri, Borson, Kiyak, & Yamagishi, 1989). The focus on problem behaviours is understandable given that, according to Patterson et al. (1999), estimates of the likelihood of problem behaviours occurring at some point are now as high as 90%.

Assessment and Screening of Cognitive Function

If we examine the tools that are presented as integral to assessment, we notice that the conceptualization of dementia is problematic, particularly in terms of the relationship between dementia and cognitive impairment; furthermore, the process of assessment is itself problematic. Tests of cognitive function range from simple screening to complex neuropsychological tests. The most effective diagnostic approach seems to be clinics that draw on the array of neuro-psychological tests and assessment of speech and language proficiency. However, in some situations a brief

screening test may be sufficient for the diagnosis of dementia to be affixed to a patient, and such tests are a major concern. Ritchie (1988) noted that more than 50 screening tests for cognitive function had been published in the 20 years preceding 1988, and since that time the number has increased. These instruments evaluate some combination of memory, orientation, attention, constructional ability, judgement, speech comprehension, and calculation ability (Applegate, Blass, & Williams, 1992; Berg, Edwards, Danzinger, & Berg, 1987; Davies, 1991; Gurland, 1980; Kane & Kane, 1981). They have been identified as having the following flaws: (1) often, no adequate conceptual framework or even definition of cognitive impairment to guide item construction (Folstein, Anthony, Parhad, Duffy, & Gruenberg, 1985; Ritchie); (2) the scoring system tends to be pass/fail, suggesting that cognitive impairment is an all-or-nothing phenomenon (Perry & Murphy, 1993; Ritchie); (3) poor testing methods based on a lack of understanding of validity testing, confounding the interpretation of results (Ritchie); (4) recognition of the impact of demographic variables (including education, race, and income) on cognitive performance (Inouye, Albert, Mohs, Sun, & Berkman, 1993).

Questioning the Implications of the Medical Diagnosis for Nursing Practice and Research

The complexity of dementia and the difficulty in diagnosing it suggest that an exploration of practices and beliefs associated with diagnosis is highly relevant to nursing. Consider, for example, that nursing activities are initiated because of a person's diagnosis of dementia, that many persons and their kin are asked to participate in nursing research because of the diagnosis of dementia, and that some placements in facilities and day programs are reserved for persons who have a diagnosis of dementia. It is important that, as reflective researchers and practitioners, we scrutinize the assumptions about and approaches to the diagnosis of dementia, not with a view to criticism but rather in order to consider the fit between our own understandings and those of others. There are several possible approaches to reflective exploration; the two that are addressed here are the philosophical orientation of medicine and many health sciences and the diagnostic interview.

Philosophical Orientation

Medical diagnostic assessments are located in the positivist tradition, according to which observers can be neutral and objective and thus can pursue the "truth" of the pure data. Data, it is assumed, will be unambiguous, observable, and measurable; the investigator is positioned as an independent entity, as is the "object" being investigated. As long as the

prescribed strategies are followed, values and bias will not influence the outcomes (Guba & Lincoln, 1994). In this tradition one seeks the direct relationship between cause and effect and identifies relationships between the independent and dependent variables; prediction and control are the goals. Positivism is viewed as essential to the natural sciences, and many consider it central to the health sciences as well. "For positivism the standard list of differences between the sciences and other forms of inquiry had derived from a view of the natural sciences that turned on the supposed neutrality of observation, the 'givenness' of experience, the independence of empirical data from theoretical frameworks, the idea of a univocal language, and belief in the rational progress of science" (Bohman, Hiley, & Shusterman, 1991, p. 3).

One must question the premise of neutrality of the observer and the nature and source of data when a clinician or researcher gathers data from, or about, a person who may have dementia. For example, the literature directs clinicians who are assessing a patient for dementia to seek family input regarding behaviours, suggesting that family input is needed to substantiate information from patients (Patterson, 1999). While clinicians and researchers may consider themselves unbiased observers, they are not always the ones doing the observing, since they are getting information from family members. This, in turn, raises the question of whether the principle of objectivity can be respected, for when kin are reporting on observed behaviours the reporting is likely to be influenced by the context of the behaviours and the meaning and significance ascribed to them by the family member. It is not surprising that there is often a lack of fit between diagnostic criteria, definitions of behaviour problems, and family reports. Family caregivers and health-care professionals do not always see behaviours the same way. For example, a caregiver may not report a particular behaviour as a problem because he or she does not see it or experience it as a problem; a behaviour that health-care professionals define as a problem, such as aggression or, sometimes, passivity, may in fact be consistent with the person's long-time behaviour. Conversely, reports of behaviours identified as problems have been shown to be related to the degree of stress and distress they cause in the caregiver (Zanetti, Geroldi, Frisoni, Bianchetti, & Trabucchi, 1999). Family caregiver data often amount to a report on the caregiver's experience, rather than an objective observation of the person's behaviour. We know from nursing research that family caregivers differ, in their views of persons with dementia, not only from health-care professionals but also from other members of the family (Lindgren & Murphy, 2002; Perry & Olshansky, 1996). When behaviour is reported and described to others, it is difficult to argue that it is objective and detached.

The Diagnostic Interview

Finally, there is a consideration that is generated not by positivism but by the traditional diagnostic interview, which may systematically disadvantage the person with dementia. Mishler (1986) suggests that an assumption about the interview is that it is a behavioural rather than a linguistic event: the discourse between two people, which under most circumstances is rich and requires interpretation, becomes (as a behavioural unit) a mere fragment that relates to other fragments by “a history of past associations and reinforcements that varies from person to person” (p. 11). For people with dementia, the interview is problematic because communication is a part of the problem being experienced — for example, the use of vague terms and incomplete sentences, repetition, circumlocutions, and long, vague responses. Orange and Purves (1996) examined the most systematic studies of communication and dementia and found that three substantiated problems were difficulties with turn taking, topic management, and conversational repair. Difficulty with topic management, also identified by Mentis, Briggs-Whittaker, and Gramigna (1995), is a particular problem because of the frequent topic shifts that are characteristic of the diagnostic interview. In addition, an increasingly compelling dimension of communication in dementia is the person’s reliance on nonverbal communication to convey meaning (Hubbard, Cook, Tester, & Downs, 2002; Perry, Galloway, Bottorff, & Nixon, 2005).

These concerns, taken together, suggest that the medical diagnosis and selected diagnostic tools may be increasingly less relevant for nurses, and that we need a different way of gathering knowledge and information, one that expands the dialogue on persons with dementia and their lives, at home and in care facilities, and that advantages the affected person.

Expanding the Dialogue

To identify the considerations for nursing that arise from the diagnostic process is not to disregard or ignore the pathological process of dementia or to question the existence of dementia as a complex syndrome. Asking questions and raising issues serve simply to remind us of the potential benefit to patients and research participants of nurses extending our views of and approaches to dementia. Recent research shows a continuous move away from positivism based on epistemological arguments (Bernstein, 1991; Good, 1994) and changing research traditions (Lather, 1991). “Constructivists and interpretivists in general focus on the processes by which meanings are created, negotiated, sustained and modified within a specific context of human action” (Schwandt, 1994, p. 120). Critical theory holds many of the same perspectives but aims at

the “critique and transformation of the social, political, cultural, economic, ethnic and gender structures that constrain and exploit humankind” (Guba & Lincoln, 1994, p. 113). Given the nature of dementia, it is easy to see the consequences of using an interpretivist approach. Indeed, using this approach, scholars have deftly described the extent to which macro-level social contexts have shaped constructions of dementia (Fox, 1989; Gubrium, 1987; Holstein, 1997; Lyman, 1989; Robertson, 1990), making clear that there have been no revelations of definite pathological determinants and that what we are calling diagnostic criteria may only be points in the social history of the disease — that is, “the features that characterize the disease at a given time in a given community” (Eisenberg, 1988).

Increasingly, nursing research methods have drawn on interpretivist and critical social philosophies, thus contributing to our understanding of the ways in which language, social processes, and the taken-for-granted in everyday life have influenced the experiences of our clients. But in dementia research and care, where difficulties with language, interaction, and communication are part of the disease process, we must consider the impact of *how* we get to know the patient as well as *what* we get to know about the patient. In nursing we rely heavily on our knowledge of the person, for, as Jenny and Logan (1992) suggest, getting to know the patient as a person is what shapes caring activities. Others assert that skilled clinical judgement must be based on knowledge of the patient, and that this knowledge is richer and more inclusive than the data gathered “in formal assessments of physical systems” (Tanner, Benner, Chesla, & Gordon, 1993, p. 277). Hill (1999) undertook a deconstruction of dementia in an effort to “give voice to the further possibilities in understanding the lives of all people affected by dementia” (p. 76); this is a striking comment given the longstanding assumption that persons with dementia cannot communicate meaningfully.

Our knowledge of our patients or research participants generally comes from them and the stories they tell. Narrative plays multiple roles in our lives, offering us a way to make sense of the world and what happens to us in it. Narrative represents how we see ourselves as well as how we wish others to see us. It also represents our actions and our agency (Becker, 1997; Gergen, 1999). It seems clear that in reflecting on the ways in which we tell our own stories, we regard one another as essentially self-interpreting. When working with persons who have dementia or are being assessed for dementia, clinicians and researchers make decisions about whether the person is able to self-reflect — that is, we make decisions, consciously or not, about the “reality” of what we see in the patient and what we hear from family members. Perhaps we should reconsider how we view this knowledge. If we accept the fact that

we are culturally bound, embedded in our own set of personal and professional codes, fears, and beliefs, we must recognize that the self-interpreted narrative of the person with dementia is also being interpreted by us. When we listen to an account by family members, we are hearing their version of the event, their experience of it. This makes the information about the person with dementia triply interpretive, for one must somehow account for one's own beliefs and assumptions about the illness, the family member's beliefs and assumptions about the person and the illness, and the actual experience of the person with dementia. The question of whether we can become "comfortable with the blurring of lines between the science and art of interpretation" (Schwandt, 1994, p. 132) is critical to expanding our understanding of dementia.

Considering Alternatives

Once nurses expand the dialogue on dementia they must address the question of what this may mean for research and for practice. Though the present discussion is far from exhaustive, it suggests some possible alternatives. In the spirit of advocating for an interpretivist approach, the most compelling alternative is to consider narratives by the person with dementia and by the family. A growing body of research affirms that people with dementia retain a sense of self despite cognitive impairment (Downs, 1997; Sabat & Harre, 1993; Saunders, 1998; Small, Geldart, Gutman, & Clarke Scott, 1998). Interpretivist and constructivist perspectives have developed an understanding that the person's selfhood or personhood is relationally developed and maintained. This view suggests that dementia sufferers' loss of sense of self or personhood results primarily from how they are seen and treated by others (Golander & Raz, 1996; Hanson, 1997; Harding & Palfrey, 1997; Kitwood, 1997; Kitwood & Bredin, 1992; Perry, 2002; Perry & O'Connor, 2002; Vittoria, 1998).

Hence the need for nurses to increasingly consider our interactions and conversations with the person who has dementia. Orange, Ryan, Meredith, and MacLean (1995) found that careful analysis of the conversations of people with dementia revealed "islands of retained abilities" (p. 26). These researchers and others have demonstrated that successful interactions can occur when persons with dementia are supported by their conversational partners (Mayhew, Acton, Yauk, & Hopkins, 2001; Norman, Norberg, & Asplund, 2002; Small et al., 1998). An alternative is to consider it part of the nurse's role to manage the coherence of exchanges with persons who have dementia. Where the nurse clinician or researcher locates himself or herself with regard to understanding and interpreting the patient has consequences for that person; the researcher's

level of commitment to grasping the patient's motivation, awareness, or meanings determines his or her likelihood of finding what can be constructed as the patient's coherence. Ripich and Terrell (1988) remind us that coherence is related to the *listener's* ability to derive meaning from what he or she hears, and that incoherence is partly related to an inability to assume the speaker's perspective. Researchers can pursue this idea by examining effective communication and by developing and testing interventions that support interactions, self-care, and connectedness with staff, family, self, or other patients. Clinicians can continue to relate to the person with dementia using knowledge gained from family, or can attempt to relate by creating an experience with the person or relating what they see in the embodied person. The history that is found in a person's wrinkles, hands, or eyes can be related as what the nurse sees. There is no truth claim here; rather, it is an effort to connect through the person's story in whatever way we can. In addition, fragments that the person with dementia can share should be treated with respect, and efforts made to find a point of connection in *any* utterance — the assumption being that we are more than our memories.

Some consider interpretivist and social constructionist views too laden with overtones of the Cartesian mind/body split and find that "embodiment" has been overlooked. Benner (2000), while stressing embodiment, also suggests that nurses' ability to interpret or read another's emotional state can be learned and enriched over time through openness and attentiveness. Outside of nursing, Kontos (2003) argues that developing a deep awareness of embodiment for persons with dementia challenges the very notion that agency is lost to the person who has dementia. Her framework presents a view of the person as extending far beyond the boundaries of cognition. In the nursing research on dementia, little attention has been paid to the experiences of the individual. Phinney, however, has successfully addressed the need for nurses to attend to the person's experience and his or her awareness of this experience (Phinney, 2002; Phinney, Wallhagen, & Sands, 2002).

Moving to a more specific orientation to practice, Dawson, Wells, and Kline (1993) have long advocated for an abilities-focused approach when working with persons who have dementia. Their approach serves as a reminder to suggest caution in using some of medicine's tools for the evaluation of nursing interventions, both bedside and research. Given the difficulties with these tools, as described above, it is somewhat uncharacteristic of nursing, as an art and as a science, to rely on them instead of either developing new approaches or developing measurement instruments that are more explicitly linked to our particular conceptualizations of work, such as by addressing a patient's abilities.

Conclusion

While no one denies the reality of dementia, the difficulties identified in the literature leave the nurse researcher and the clinician concerned about the ways in which dementia is conceptualized, defined, and diagnosed; reluctant to accept the score of a screening test; sceptical about the data reported by caregivers; and aware of the need to address the individual.

Dementia in all its forms is a complex phenomenon. Part of that complexity is the fact that the very difficulty that persons with dementia have in relating their experiences can be examined to reveal new understandings of the experience. The “voice” heard by researchers has mainly been that of family members or friends as they explain and describe their experience. This perspective is invaluable, yet it must not be mistaken for the experience of the person with dementia. The positivist approach is ambiguous in its treatment of family data and neglects the social dimensions that influence family caregivers, health-care professionals, and researchers. These issues are of concern for all health-care professionals who participate in diagnosing, monitoring, and conducting research concerning persons with dementia. Nurses are in a position to make a substantial contribution to the dialogue on dementia by considering diagnosis and research as social processes. Their failure to do so will leave us with inadequate knowledge and tools for designing appropriate care and respectfully studying the experience of the person who has dementia.

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