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McGill University School of Nursing

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GUEST EDITORIAL

Palliative and End-of-Life Nursing Research Now and in the Future

Wendy Duggleby

The face of palliative and end-of-life care is changing (Grant, Elk, Ferrell, Morrison, & von Gunten, 2009), and so is nursing research in this critical area. *CJNR* published its first focus issue on palliative and end-of-life care in 2005 (Vol. 37 N° 2). The guest editors were Susan McClement and Lesley F. Degner. That focus issue included one research study — I was first author (Duggleby & Wright, 2005). It also included many wonderful articles on methodological and conceptual research issues and translating evidence to inform palliative and end-of-life nursing practice. I have the privilege of being the guest editor for this current issue, and it was exciting to see both the number of research studies submitted and the quality of those studies. It was very difficult to select the five articles that would be part of this issue. Without a doubt, there has been an increase in nurse researchers leading multidisciplinary teams conducting and publishing research in palliative and end-of-life care since 2005. Whatever the reasons for this change, it has been inspiring to see where palliative and end-of-life nursing research has been and where it is now and to contemplate where it might be in another 5 years.

In the 2005 focus issue, Linda Kristjanson (2005) was invited to write the Discourse. Kristjanson made several recommendations for future research. She suggested that research to inform nursing practice should focus on increasing our understanding of the unique needs of diverse palliative populations and that investigators would need to utilize innovative research approaches to reach this goal. In this current focus issue, several of the articles reflect innovative research with diverse populations. For example, Brenda L. Cameron and her colleagues use participatory action research to study palliative care health professionals in Chile and Canada. A mixed-methods approach is used by Genevieve N. Thompson and her colleagues to ask family caregivers of persons in nursing homes, the majority with dementia, about respect and kindness. Parents of pediatric palliative care patients and their relationships with nurses are the focus of a phenomenological study by Judy Rashotte and her colleagues. Kelli I. Stajduhar and her colleagues look at the relationship of nursing home care professionals and family members using interpretive description. The processes of care of persons with heart failure at the end of life are the focus of a qualitative study by Sharon Kaasalainen and her colleagues. Mary Hampton and her colleagues have worked for 7 years in Saskatchewan to increase awareness of appropriate Aboriginal end-of-life health care among non-Aboriginal health-care providers; in the Happenings contribution they describe unique research approaches and partnerships they have formed with this population. All of these articles not only increase our understanding of diverse populations at the end of life, but also mirror the diversity of palliative and end-of-life nursing practice.

The articles also reflect some of the essential aspects of palliative nursing practice. In her Discourse contribution, Stadjuhar quotes Cicely Saunders (2006) as saying that nurses enable people to find relief, support, and meaning at the end of their lives. Kassalainen and her colleagues describe how persons with heart disease, their families, and health professionals strive together to find relief and reduce suffering from symptoms. Both Cameron and her colleagues and Stadjuhar and her colleagues describe how palliative nurses empower others through engagement and the sharing of knowledge. Rashotte and her colleagues describe the importance of receptivity and attentiveness as moral considerations in clinical judgement and decision-making that support the preferences of parents. As well, the importance of respecting and valuing persons at the end of life is described by Thompson and her colleagues.

Nurses providing palliative and end-of-life care bear witness to the deepest issues of humanity, suffering, and mortality. Their moral ethic demands that they have the knowledge and skills necessary to provide comfort and care at a very important time of life. Palliative nurses use specialized knowledge from all fields of inquiry, such as physiology, psychology, and sociology, and work with multidisciplinary teams to improve the quality of life of the persons they care for. However, only through nursing research, examples of which are presented in this focus issue, can we begin to understand that palliative nurses also require knowledge and skills to deal with the complex moral dilemmas associated with empowering persons who are suffering.

Where Will We Be 5 Years From Now?

In the next 5 years, nurse researchers will be working within networks of palliative care researchers to develop innovative and flexible research designs and approaches that are specific to palliative populations. Research designs are typically determined by the research question being asked. However, in choosing a research design it is important to also consider the population that is the focus of study. For example, Hampton and her colleagues clearly demonstrate, in their Happenings contribution, the importance of their research approach in working with Aboriginal populations. In the next 5 years, palliative and end-of-life research will have to focus on other diverse populations, such as people who are homeless and those with disabilities. As a result, there will be an escalating need for even more innovative approaches to research.

As suggested by Stadjuhar in her Discourse, innovative models and systems of palliative and end-of-life care should also be a research focus over the next 5 years. It is imperative, however, with research focused on improving systems of care, that the ultimate goal of providing care not be forgotten. The goal of palliative care as defined by the World Health Organization (2011) is to improve quality of life for persons with life-threatening illnesses and their families. Enhancing quality of life is an essential goal of palliative and end-of-life nursing research and should not be lost in our focus on systems of care. I was recently asked by the Oncology Nursing Society to develop, with my colleague Pat Berry (University of Utah), research priorities for palliative and end-of-life care. Through an extensive literature review and discussion with nurses, it was evident that there is a great need for research on all aspects of quality of life (psychosocial, spiritual, physical, mental, and environmental) (Oncology Nursing Society, 2011). This research needs to focus on diverse populations in terms of ethnicity, language, and culture, as well as specific age groups, such as older adults and children.

The research articles in this focus issue also remind us that future research should focus on the essence of palliative and end-of-life nursing practice, as this is at the heart of improving quality of life for persons with life-threatening illnesses. Examples of future research questions might be the following: How can we best ensure that nursing care is provided respectfully and with kindness in complex, impersonal organizational environments? How can we enhance quality of life where suffering and loss are part of the person's experience? How can nurses reach those who may not have access to palliative and end-of-life care?

It has been a great pleasure to be the guest editor of *CJNR*'s 2011 focus issue on palliative and end-of-life care. I am looking forward to the next focus issue 5 years from now. At that time, I hope, we will see the number of nurse researchers in the field continuing to grow, along with the development of knowledge that will inform palliative and end-of-life nursing practice.

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Discourse

Chronic Illness, Palliative Care, and the Problematic Nature of Dying

Kelli I. Stajduhar

Nurses encounter people with life-limiting illness in virtually every sector of the health-care system. In the care of the dying, the role of nurses is central, as the goal typically moves from one of cure to one of care (Coluzzi & Rhiner, 1996). Nurses spend more time with people who are dying than any other health professional (Baggs, 1993; Fakhoury, 1998; Murray Frommelt, 1991) and are, therefore, perfectly positioned to influence the care that dying people and their family members receive. Palliative care nurses pride themselves on adopting a "whole person" approach to care, an approach that promotes quality of life along the illness trajectory, across the lifespan, and with a focus on both the dying person and those who are significant to him or her (Beckstrand & Kirchhoff, 2005; Coyle, 2006). Key concepts associated with palliative nursing have been defined. They include dignity, hope, comfort, quality of life, knowing the patient, teamwork, suffering, and care and caring (Seymour, 2004). Palliative care nursing has emerged as a specialty alongside other nursing specialties such as critical care nursing, perinatal nursing, emergency nursing, and gerontological nursing (Canadian Nurses Association, 2011).

As palliative care nursing practice has developed, palliative care research undertaken by nurses has also emerged. By the early 1960s some of the first studies conducted by nurses were published, providing evidence pertaining to the social and clinical aspects of dying in contemporary society (Clark, 2004). Nurses' contributions to research in palliative care have included studies on the prevalence of symptoms, the needs and experiences of patients and family caregivers, bereavement care, health-service needs, communication skills, and, to a lesser extent, nursing interventions (Bottorff, Kelly, & Young, 2005; Ingleton & Davies, 2004). Research in palliative care, including that conducted by nurses, has focused on people with cancer and their families. Nursing and other research has informed care and resulted in vast improvements in symptom management and psychosocial and spiritual care. And yet a story recently told by a woman who participated in a study I led

(Stajduhar et al., 2010; Stajduhar et al., in press) poignantly illustrates the problems that persist for dying people and their families within our health-care system:

> Catherine is the bereaved daughter of Sarah, an 89-year-old woman brought in to the ER with progressive weakness, confusion, and diarrhea. After 5 days in the ER, Sarah was admitted to a private room on an acute-care medical ward where she required isolation after being diagnosed with hospital-acquired diarrhea. Twenty-four hours later, Sarah was moved to a four-bed room, as another priority patient required the private room. Catherine came to the hospital to help her mother move, and when she arrived she found an unsettling scene: Sarah was sitting on a commode in the hallway of the medical ward, with a nurse draping a blanket around her. As in many busy hospitals, visitors and staff were walking by, noise levels were high, and the nurse needed to attend to another patient. As Catherine approached her mother, she saw that Sarah was visibly upset, crying and pleading to be moved into her room. Sarah, while waiting in the hallway for her room to be cleaned, urgently needed to go to the bathroom. The nurse placed Sarah on a commode in the hallway; Sarah was expected to defecate with all the sounds and smells that go along with this made public. The nurse apologized, saying that in her 25 years of nursing she had never done anything like this. Four days later Sarah died. Catherine recalls this incident as one that haunts her today; deeply stitched in her memory is a vision of her mother sitting on the commode in full public view and pleading to simply have some privacy.

Disturbing though it is, this is a story I have heard frequently in my research. While other types of health care are typically rated as highly satisfactory, patients and families report that there is much room for improvement in the quality of care at the end of life (Heyland et al., 2005; Stajduhar, 2003; Stajduhar & Davies, 2005; Stajduhar et al., 2010).

Why Does Care of the Dying Continue to Be Problematic?

The hospice/palliative care movement has, without question, irreversibly improved the standards of care for the dying. So successful has this model been that specialized palliative care programs have proliferated worldwide. Initially focused on those with terminal cancer, these programs have recently expanded to include people with other terminal diagnoses (Zimmerman, Riechelmann, Krzyzanowski, Rodin, & Tannock, 2008). With palliative care programs becoming increasingly part of mainstream health care, at least in the Western world, and with specialty services such as palliative consultation teams, inpatient units, and bereavement and spiritual care programs offered in many settings, it is surprising to learn that quality end-of-life care is not always accessible. Even in Canada, with its well-established palliative care programs, only 16% to 30% of the population has access to palliative services (Canadian Institute for Health Information, 2007). Many reasons have been cited for the persistence of care-quality issues. Our health-care system continues to operate within an acute, cure-focused ideology (Thorne, 2008), with minimal value placed on and attention given to the needs of dying people and their families. Coordination of care and the integration of care-delivery systems to support dying people continue to be problematic (Stajduhar, 2003). Many hospice programs are underfunded or funded by donor dollars and lack the resources needed to support the ever-increasing numbers of people requiring palliative care (Higginson & Foley, 2009). Finally, many health-care providers are ill-equipped and/or unprepared to care for people who are dying, do not know how best to support the family members of those people, or simply do not realize that their patients could benefit from application of the principles of palliative care (Addington-Hall, 2002; Chang & Daly, 1998; Chung, Lyckholm, & Smith, 2009).

In teaching an undergraduate palliative care elective to (mostly) post-RN students, I was struck by how many believed that palliative care is a *place,* an inpatient unit where people go to die and where they are cared for by nurses, physicians, and counsellors specializing in palliative care. These students, mostly nurses working in critical care, acute medicine, emergency, or long-term care, did not know that they could provide quality palliative care *where they were,* or that their many patients with chronic life-limiting conditions could benefit from application of palliative care principles. Palliative care is for people with cancer, they believed — people who are best cared for by those who specialize in this form of care, in places (hospices, palliative care units, home) where dying people *should* be cared for. These notions are reflected in interviews with acute-care nurses participating in a knowledge translation study currently being carried out by our research team. These nurses believe that where they work is the "last best place" for people to die — even though most Canadians, in fact, die in inpatient health-care settings. The moral distress felt by these nurses when they are not able to access specialized palliative services on behalf of their patients is palpable. Reliance on specialized services is partly responsible for the nurses believing that they are not equipped to care for the dying or that care of the dying is not within their remit.

Who Is in Need of Palliative Care?

Specialized models of palliative care have historically been developed for cancer patients. It is now recognized, however, that individuals with chronic conditions such as heart disease, stroke, chronic respiratory illness, diabetes, dementia, and renal disease could greatly benefit from application of the principles of palliative care (Kristjanson, 2005). Chronic conditions account for 46% of the global burden of disease (World Health Organization [WHO], 2002) and are by far the leading cause of mortality worldwide, representing 60% of all deaths (WHO, n.d.). The rising number of people facing old age makes it likely that serious chronic and life-limiting illness will be a dominant challenge for health-care delivery in the next half century. By 2026, one in five Canadians will be a senior (Williams, 2005), and planning for end-of-life care for these and other individuals living with life-limiting chronic illness is vital to a well-managed and person-focused health-care system.

Current models of palliative care — primarily specialist models — are not necessarily appropriate to meet the needs of the expanding population of people who could benefit from application of the principles of palliative care. A "palliative approach" has been recommended as one way of applying specialized knowledge in the field of palliative care to a wider range of patients, with a variety of diagnoses, cared for in a variety of settings, at earlier stages in the illness trajectory (Kristjanson, 2005). A palliative *approach* takes the principles of palliative *care* and applies them to the care of any sick person, regardless of their illness (Katz & Peace, 2003). A palliative approach does not closely link the provision of care with prognosis, but focuses on conversations with patients/families about their needs and wishes; comfort measures; support for psychosocial, spiritual, and cultural issues; information requirements; and provisions for death and for care after death (Coventry, Grande, Richards, & Todd, 2005; Jackson, Mooney, & Campbell, 2009). A palliative approach recognizes that, although not all people with life-limiting illness require specialized palliative services, they do require care that is aimed at improving quality of life by preventing and relieving suffering through early identification, assessment, and treatment of physical, psychosocial, and spiritual concerns (Krisjanson, Toye, & Dawson, 2003). In short, a palliative approach differs little from respectful, compassionate, knowledgeable nursing care for patients and their families at any point in the health–illness trajectory.

Will a Palliative Approach Fix the Problems?

The adoption and integration of a palliative approach may be a welcome direction for nurses and others who have struggled to care for the dying outside of or without the support of specialist models. Nurses working in rural settings, for example, where access to specialist services is limited or non-existent, have been practising for many years using what is now defined as a palliative approach. But will such an approach work in all settings? It is clear that something must be done to address poor-quality care and under-recognition of those people who could benefit from a palliative approach. However, the evidence base for a palliative approach is limited, and it cannot be assumed that models of specialist palliative care are directly applicable to the large and expanding chronically ill population.

To address this issue, a team of nurses in British Columbia was recently funded by the Michael Smith Foundation for Health Research to examine if, how, and in which contexts a palliative approach might better meet the needs of people with chronic life-limiting conditions and guide the development of innovations in health-care delivery to better support nursing care of the dying. Our team, iPANEL (Initiative for a Palliative Approach in Nursing: Evidence and Leadership; www.ipanel.ca), is pursuing this line of inquiry through a survey of nursing-care providers across the province (registered nurses, licensed practical nurses, care aides, and community support workers) and through three substantive research strands, each co-led by a university-based nurse researcher and a clinical practice leader.

We are synthesizing the existing research in this area, grappling with the complex definitional issues in our field (Bennett, Davies, & Higginson, 2010), studying nurses' perceived competency in palliative care, and examining the staffing and skill-mix models required to integrate a palliative approach. In the process, we are developing methodologies relevant to the conduct of applied nursing health-services research. We are focusing on three areas — acute care, long-term care, and home and community care — that traditionally have not been a focus of research at the end of life. And, despite the increasing interdisciplinarity of research in palliative care (Desa et al., 2009), our team is composed entirely of nurses, because we believe that nursing scholars and nursing administrative and clinical leaders ought to be at the forefront in the study of care-delivery models that are germane to nursing practice. We are not ignoring the crucial contributions of our non-nursing colleagues, but, rather, positioning research that is essential for nursing practice within nursing scholarship.

We are embarking on our research with a critical eye, seeking to both problematize and examine the opportunities that a palliative approach can bring to the care of people with life-limiting chronic conditions. Our ultimate aim is to contribute to the evidence base on health-system reforms that will enhance nursing practice and, ultimately, result in improvements in the care of the dying.

Is a Palliative Approach Enough?

It would be naïve to think that integration of a palliative approach alone will "fix" the problems that dying people and their families face in seeking support from the health-care system. Developing models of care that will serve dying people in a range of settings, in different circumstances, and with a variety of diseases and prognoses will require well-designed research that capitalizes on the skills and abilities of researchers concerned with the dying and that also addresses research shortfalls in our field. In those areas of study where we know a lot, we need to move beyond small-scale descriptive studies, synthesize what we know, identify the gaps, and move forward with the development and testing of interventions. In those areas where we know little, we need to engage in research examining subjective experience, in order to understand the "human" dimensions of the illness process. We must also examine what we have learned from the cancer experience and determine the applicability of this evidence to the population of people with chronic life-limiting illness. And we need to consider approaches to the care of vulnerable people who are dying, such as the marginalized and homeless, Aboriginal peoples, people with disabilities, and people from a variety of cultural and ethnic groups.

Nurses are poised to contribute to the creation of an evidence base that informs health-system developments and reforms. Nurses' knowledge of the inner workings of health care affords a unique angle of vision from which to identify questions that have relevance — those that inform both health-system developments and nursing practice at the bedside. Identifying relevant questions and undertaking research that will inform the "real life" world of decision-making and practice is something that nursing scholars have always done well. But relevant knowledge is useful only when placed in the hands of those who need it most. Much attention has been given to generating knowledge to improve the experience of those who are dying. There has been less focus on understanding how to best translate that knowledge and the contexts in which knowledge translation occurs. Knowledge translation is, by definition, designed to influence health-care practice, policy, and program development. Its primary goals are to help knowledge users to become aware of new knowledge and to actively facilitate use of that knowledge to improve health, health services, and health-care systems, narrow the gap between what we know and what we do, and move knowledge into action (Graham & Tetroe, 2010). It is the moving knowledge into action that ought to become the focus of our inquiries, particularly as it influences nursing practice directly. It is becoming obvious that transferring knowledge to nurses in traditional ways — through peer-reviewed publications, conference presentations, and the like — is not producing the kind of sustainable change that we would hope to see relative to end-of-life care. We need to better understand the contextual realities of nursing practice and the facilitators of and barriers to the clinical uptake of knowledge. This could be a step towards the achievement of quality end-of-life care for all.

Conclusion

In her reflections in the *Textbook of Palliative Nursing,* Cicely Saunders (2006), who is widely recognized as the founder of the modern hospice movement (and who trained as a nurse and social worker prior to becoming a physician), asserts that nurses remain "the core of the personal and professional drive to enable people to find relief, support, and meaning at the end of their lives" (p. v). Virginia Henderson (1961) writes that hospice nursing is the "essence of nursing" (p. 42). The primary goal of palliative care is to improve the quality of life and quality of dying and death for individuals facing life-limiting illness and to support them and their families through the provision of excellent care. Such care is enhanced when supported by a strong evidence base, including an understanding of the strategies needed to translate findings into clinical practice and health-care policy and decision-making. Nurses are perfectly positioned to become leaders in forging new research initiatives and partnerships to maximize the uptake of knowledge. This will ultimately move us towards the development of clinical practices and a care-delivery system that better supports people with chronic life-limiting conditions who face the end of life.

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Résumé

Échange de savoir participatif en faveur des soins palliatifs au Chili : leçons tirées de la recherche en santé mondiale

Brenda L. Cameron, Anna Santos Salas,
Donna deMoissac

Les auteurs ont conçu une étude de recherche qualitative avec participation active afin de développer un partenariat de collaboration entre praticiens en soins palliatifs au Canada et au Chili. Le but de la recherche était de défendre le recours aux soins palliatifs dans des milieux vulnérables par un processus d'échange de savoir participatif grâce à des méthodes qualitatives et de participation active. L'étude faisait appel à une équipe interprofessionnelle en soins palliatifs d'un centre de santé primaire au Chili ainsi que cinq adultes recevant des soins palliatifs et leur famille. Des infirmières et des professionnels de la santé apparentés appartenant à une équipe de soins palliatifs à domicile au Canada participaient également à l'étude. Les activités d'échange de savoir participatif comprenaient un travail conjoint avec l'équipe de soins primaires au Chili et un processus d'échange de savoir participatif avec des cliniciens en soins palliatifs au Chili et au Canada. L'étude a engendré des données qualitatives sur l'efficacité d'un processus d'échange de savoir participatif avec des praticiens en soins palliatifs provenant de deux milieux différents.

Mots clés : soins palliatifs, santé mondiale, recherche qualitative, échange de savoir

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Participatory Knowledge Exchange to Support Palliative Care in Chile: Lessons Learned Through Global Health Research

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The authors designed a participatory qualitative research study to develop a collaborative partnership between palliative care practitioners in Canada and in Chile. The research goal was to support the provision of palliative care in vulnerable settings through a participatory knowledge exchange process using qualitative and participatory methodologies. The study involved an interprofessional palliative care team from a primary health care centre in Chile and 5 adults receiving palliative care and their relatives. It also involved the participation of registered nurses and allied health professionals from a palliative home care team in Canada. Participatory knowledge exchange activities included teamwork with the primary health care team in Chile and a process of participatory knowledge exchange with palliative care clinicians in Chile and Canada. The study produced qualitative evidence on the efficacy of a process of participatory knowledge exchange with palliative care practitioners from 2 diverse settings.

Keywords: palliative care, global health, qualitative research, knowledge exchange, developing countries

Palliative care is a comprehensive approach intended to enhance the well-being of persons living with life-threatening illnesses and their families. Over the past few decades, the World Health Organization (WHO) has shown a marked commitment to the development of palliative care globally (Sepúlveda, Marlin, Yoshida, & Ulrich, 2002; WHO, 2000, 2004, 2007). The WHO defines palliative care as a comprehensive approach that provides relief to "patients and their families facing the problems associated with life-threatening illness" (Sepúlveda et al., 2002, p. 94). In 1998 the Pan American Health Organisation (PAHO) declared palliative care one of the main components of its cancer-control initiative for the Americas (WHO, 2002). Globally, too many people continue to be diagnosed at a late stage due to late cancer detection and limited access to health services and oncology treatments (Sepúlveda et al., 2002). Considering this scenario, palliative care may be the only available treatment choice in many countries (WHO, 1990, 1996, 2000).

Palliative care advocates have pointed to the need for justice and equity in the provision of palliative services throughout the world. In 2008 access to pain relief and palliative care was declared a basic human right (Human Rights Watch, 2009). Yet too many individuals remain far from obtaining basic pain relief and palliative care (Human Rights Watch, 2009; Sepúlveda et al., 2002; Webster, Lacey, & Quine, 2007). Wide gaps in opioid consumption within and among countries are one of the most salient indicators of inequitable access to palliative care (International Narcotics Control Board [INCB], 2009a, 2009b). Insufficient health-care coverage, poor housing conditions, low socio-economic status, lack of food, limited drug availability, selective access to palliative care training for health professionals, the high cost of drugs, restrictive legislation, and limited advocacy for under-privileged populations act as constraints against access to palliative care in many regions of the world (De Lima, 2001; De Lima & Hamzah, 2004; Human Rights Watch, 2009; INCB, 2009a, 2009b). In line with the 1978 Alma Ata declaration on primary health care (PHC) (WHO, 1978) and recent WHO recommendations (Sepúlveda et al., 2002; WHO, 2007), developing countries are following a community-health approach in the provision of palliative services. Community and home-based care has been shown to be a low-cost, effective means of increasing access to palliative care among the very poor (Olweny et al., 2003; Sepúlveda, 2003).

We designed a participatory qualitative research study with a view to developing a collaborative partnership between palliative care practitioners in Canada and PHC professionals in Chile delivering palliative care in the community. The overall research goal was to support the provision of palliative care in vulnerable settings through a process of participatory knowledge exchange. A related goal was to further investigate the experiences of individuals with late-stage cancer and the experiences of PHC professionals delivering palliative care in the community in Chile.

This global health research study built on a doctoral study with palliative home care nurses and recipients of home palliative care in Canada (Santos Salas, 2006) and a qualitative pilot study with PHC professionals and recipients of palliative care in Chile (Cameron & Santos Salas, 2009). The palliative home care study in Canada facilitated the partnership with Canadian palliative home care practitioners. The qualitative pilot study in Chile generated evidence on the delivery of palliative care through PHC and helped us to initiate a partnership with Chilean clinicians. Our team comprised investigators and clinicians in both countries with interdisciplinary clinical and research expertise in palliative care. The study received institutional ethics approval in both Canada and Chile and ethical procedures were strictly followed throughout the study.

Three underlying premises found in the hermeneutic philosophical tradition provided the basis for the research study and the knowledge exchange process. The first was recognition of experiential knowledge as a specific type of knowledge relevant to clinical practice (Gadamer, 1996). The second was the acknowledgement that health professionals employ a variety of types of knowledge in their practice (Bergum, 1994). The third was the understanding that dialogue among practitioners facilitates the uptake of knowledge in practice.

In this article, we describe our participatory knowledge exchange process with clinicians and researchers in Chile and Canada. We first present the background to the study and an overview of the philosophical framework for the knowledge exchange process. We then outline the research methodology and research activities and provide a detailed description of the knowledge exchange process. We conclude with an outline of the lessons we learned and some final remarks.

Knowledge Exchange

Knowledge exchange is a practical approach that facilitates the sharing of experiential knowledge among practitioners. The WHO Knowledge Management Office has expressed the need to mobilize knowledge through a variety of approaches in order to reduce health inequities and the global burden of disease. The sharing and re-application of experiential knowledge has been identified as one of the key strategies for achieving this goal (Pablos-Mendez & Shademani, 2006).

Our knowledge exchange process sought to integrate practitioners' own knowledge about their local context of practice. Previous research (Cameron & Santos Salas, 2009) has revealed practitioners' interest in increasing their palliative care knowledge as well as a commitment to further developing palliative care practice and a desire to share practice developments and discuss clinical issues and barriers to delivering care with other practitioners. Participatory knowledge exchange was a means for practitioners to assess their own knowledge and understanding of their practice situations through respectful dialogue.

The word "exchange" has several meanings. The purpose of this study is reflected in two of the *Canadian Oxford Dictionary*'s definitions of exchange: "the act or an instance of giving one thing and receiving another in its place" and "a reciprocal visit between two people or groups from different regions or countries" (Barber, 2004, p. 510). We defined knowledge exchange as a reciprocal act of sharing knowledge and experience among clinicians from two distinct settings and countries through a process of visiting both settings and engaging in a continual dialogue about practice.

Pablos-Mendez and Shademani (2006) identify the lack of needs-driven research, particularly in developing countries, and the lack of knowledge created through practice as factors in the "know-do gap" — the gap between available knowledge and its application. The know-do gap is particularly wide in low- and middle-income countries, where resources are scarce (Santesso & Tugwell, 2006). Knowledge exchange can help to bridge this gap and mobilize knowledge to improve health among the world's peoples.

Knowledge Exchange and the Limitations of the Expert

In his essay "The Limitations of the Expert," Hans-Georg Gadamer (1992), one of the great scholars of the hermeneutic philosophical tradition, ponders the place of the expert in the age of science and technology. Gadamer points to the "intermediate position" of the expert (p. 181), someone who stands between science and the social and political context of life, within which decisions are made. Gadamer remarks that, in a world increasingly governed by science and technology, a final and direct answer is expected from the expert.

Gadamer's (1992) essay invites us to be aware of the limits of science and of the expert. Gadamer draws our attention to the fact that the expert cannot be given sole responsibility for decisions that affect us all. Nor, he points out, should experts assign this task to themselves. He alludes to two types of knowledge. One has to do with *how* to do a particular task — that is, the knowledge of the means (or the *how*) to achieve a particular end; he points out that this is the knowledge of the specialist, the researcher, the expert. The other has to do with *choosing* the means by which to achieve an end — the knowledge of *what* to do; this is the knowledge that pertains to the decision-maker, the person who understands the specific context of the decision. "One cannot just speak as a researcher and scientist when practical consequences, following from one's judgment, need to be considered" (Gadamer, 1992, p. 186). According to Gadamer, we need to assume self-responsibility in making decisions and choices. This requires us to recognize the limits of our knowledge and the fact that decisions are made within these limits.

A knowledge exchange process takes into consideration the limitations of the "expert" and sees all individuals as knowledgeable in their own life situations. It provides a means for continuous dialogue, where participants' needs are expressed and addressed in an atmosphere of trust and confidence. Knowledge exchange promotes the articulation of other types of knowledge and the sharing and replication of experience. It starts with the premise that "new knowledge can be created when learning takes place in practice from people's interaction" (Pablos-Mendez &

Shademani, 2006, p. 85). The process seeks to elicit both the specialist's knowledge about *how* to do something and the local practitioner's knowledge about *choosing* the means to do it. This is relevant for working with practitioners in developing countries, where choice is limited by accessibility to resources. Clinicians often work with incomplete knowledge: They act and treat, learn more, and try to make practice decisions that fit a particular moment (Cameron, 2004; Santos Salas & Cameron, 2010). The task of knowledge exchange is to bring these types of knowledge to the table.

Palliative Care in Chile

Chile is a middle-income country of 17 million people located on the southern Pacific seaboard of South America. Its health-care system is a composite of public and private. Approximately two thirds of Chile's population — the majority of low socio-economic status — are served by the public system. According to the Chilean National Statistics Institute (Instituto Nacional de Estadísticas Chile [INE], 2010), life expectancy in 2007 was 74.95 years for men and 80.66 years for women. The average life expectancy for 2005–10 was estimated at 78.45 years (Ministerio de Salud Chile, 2010). Cardiovascular diseases are the leading cause of death, followed by cancer (Medina & Kaempffer, 2007; Ministerio de Salud Chile, 2002; Ministerio de Salud Departamento de Estadísticas e Información de Salud, 2010). These two causes alone account for more than half of all deaths in Chile (Medina & Kaempffer, 2000, 2007). Chilean economic indicators reveal sustained growth and a reduction in poverty. Yet there persist wide income inequalities (Vega, Bedregal, Jadue, & Delgado, 2003), which limit access to basic services and result in poor health outcomes for individuals in the lowest socio-economic strata (Dachs et al., 2002; Vega et al., 2001, 2003).

In the past decade Chile has made good progress with palliative care (Derio, 2007), due in part to the inclusion of palliative care (since 2003) in the Chilean Explicit Health Guarantees Plan (Garantías Explícitas de Salud, or GES) and the development of palliative care training programs. In line with the country's 2000–10 health goals and its health-care reform in place since 2002, the GES plan (Ministerio de Salud Chile, 2002, n.d.) seeks to ensure universal access to timely, affordable, quality care for common health conditions. GES guarantees access to palliative care for Chileans with a confirmed diagnosis of late-stage cancer. The package includes interprofessional care, drug coverage, and nursing supplies throughout levels of care, with an emphasis on PHC. The provision of palliative care through PHC addresses the WHO/PAHO recommendation that palliative care and pain relief be approached from a public health perspective (Sepúlveda et al., 2002). Palliative care delivered through PHC results in improved access for individuals in their homes (Cameron & Santos Salas, 2009; Fernández & Acuña, 1996). Palliative care through PHC remains heterogeneous in Chile, with some areas showing positive development and other areas where it is incipient. These inequities illustrate the need for initiatives to ensure timelier and fairer access to palliative care in the community.

Research Approach

The past few years have seen growing recognition of the global research gap in palliative care and the need to support the conduct of research and the building of a robust evidence base to enhance the delivery of palliative care in developing countries (International Association for Hospice and Palliative Care [IAHPC], 2007). There has been limited research on local experiences of palliative care practice in developing countries (Bertolino & Heller, 2001; Cameron & Santos Salas, 2009; Grant, Murray, Grant, & Brown, 2003; Kikule, 2003; Olweny et al., 2003; Uys, 2002; Wenk & Bertolino, 2002), due in part to a lack of research resources in the developing world, where financial support for health research is scarce (Global Forum for Health Research, 2004; Wenk, de Lima, & Eisenchlas, 2008). The WHO (2007) points to the need for reports from poorly served regions of the world describing local experiences with the delivery of palliative care. This knowledge would broaden our understanding of palliative care practice in these regions and help local practitioners and researchers to develop interventions to serve their populations.

Health research scholars have highlighted the need to integrate participatory and emancipatory research methodologies when working with vulnerable and marginalized populations (Hall, 1999; Israel, Schulz, Parker, & Becker, 2001; Israel et al., 2006; Meleis, 1996). Such approaches promote participation, critique, and emancipation. Participatory studies are attentive to participants' knowledge as well as their ability to analyze and give voice to their situation and then take action. Participants' perspectives can produce rich subjective data that can be used to improve palliative care practices (Canadian Senate, 2000). The need to acknowledge the importance of qualitative methodologies in palliative care research is stated in the 2006 *Declaration of Venice* (IAHPC, 2007).

Our study followed a combination of qualitative and participatory research methodologies. The qualitative approach was hermeneutic phenomenology (Gadamer, 1989; Van Manen, 1997). Hermeneutics and phenomenology are philosophies concerned with the understanding and interpretation of human experience. These approaches are well delineated in the work of scholars of the Human Science philosophical tradition (Gadamer, Heidegger). The aim of hermeneutic phenomenology is to provide a profound understanding of the elements that make up human experience (Cameron, 2004; Santos Salas & Cameron, 2010). Phenomenology is concerned with the description and hermeneutics with the interpretation of experience. In practice, description and interpretation are intertwined, as elements of one are always contained in the other (Van Manen, 1997). Hermeneutic phenomenology examines experience in a specific context — in this case, the patient's experience of living with a terminal illness and the health professional's experience of providing palliative care in a low-resource setting.

Participatory research calls for the active involvement of those taking part in the study. Its hallmark is the creation of an environment for reciprocal learning that builds capacity with community members (Couzos, Lea, Murria, & Culbong, 2005; Minore, Boone, Katt, Kinch, & Birch, 2004). A participatory approach includes ethical reflection on action (Carson & Sumara, 1997). Participatory research supports individuals who undertake actions that can have a significant impact on their community (Hyrkas, 1997). It also assists health professionals in formulating health-care policies and practices that are pertinent to the local setting (Stringer & Genat, 2004). Participation promotes equity, mutuality, and capacity-building and generates knowledge that fits the needs of the community (Dickson & Green, 2001; Gibson, Gibson, & Macaulay, 2001; Stringer & Genat, 2004). Participants are able to discuss the tensions inherent in theory and principles — that is, the principles and guidelines of palliative care — while at the same time acknowledging the realities of practice issues — that is, the delivery of palliative care in low-resource areas.

Settings and Community Involvement

The study took place at a PHC centre (referred to as *consultorio*) in the Chiguayante district (*comuna*) in Concepción, Chile. It also entailed the participation of nurses and allied health professionals from a palliative home care team in Edmonton, Canada. In addition, community members in Chiguayante collaborated on the study through a group of volunteers affiliated with the *consultorio* who visited palliative care patients on a regular basis. The study received support from managers, practitioners, and local authorities in both countries. Research participants included an interprofessional palliative care team from the participating *consultorio* in Chile and a small sample of five adults receiving palliative care through this centre and their relatives. A knowledge exchange workshop in Concepción was attended by 22 palliative care teams from all the

PHC centres under the Concepción province health authority, hospital palliative care teams, and palliative care guests from Edmonton. In Edmonton, palliative care practitioners from palliative home care and tertiary settings engaged with and mentored the Chilean guests. In Chile, PHC professionals providing palliative care shared their time and clinical expertise with the Canadian guests. This enabled participants to better understand the scope and context of practice in both countries and to learn about developments and initiatives in local practice.

Research Activities

Participatory knowledge exchange activities involved participatory teamwork with a PHC team in Chile over a 1-year period and a participatory knowledge exchange process with palliative care clinicians from Chile and Canada. This exchange process included clinicians' visits to Chile and Canada as well as knowledge exchange workshops. These activities are described below. The study also entailed individual in-depth interviews with patients and family members in Chile, participant observation of clinical practice in Chile, field notes, and monthly meetings of the research team.

The research project was launched in Chile. Following ethics approval, we respectfully approached the Chiguayante PHC centre to request its support for and approval of the study. An outline of the study was presented to the director, nursing supervisor, and palliative care team, and was met with enthusiastic support. We then began research activities entailing participatory work with the interprofessional team and visits to patients and families. To undertake this work, we hired a physician and a clinical psychologist. Both had solid training and clinical experience in palliative care. They had worked in palliative care in the Concepción area and had actively participated, with one of the co-investigators, in the initial palliative care training of *consultorios* in that city. Our understanding of the setting and our relationship with the team established during the qualitative pilot study (Cameron & Santos Salas, 2009) facilitated the development of the study. Health professionals, patients, and family members provided written consent to participate in the study. Research activities in Chile were conducted in Spanish. The presence of Spanish-speaking and bilingual research team members facilitated the research process and the North-South dialogue.

Analysis and Interpretation of Findings

In line with the hermeneutic stance of the study, analysis and interpretation took place in a conversational manner whereby previous understandings are revised and new ones emerge until a common understanding is reached on a particular subject (Gadamer, 1989; Smith, 1994). According to Gadamer, "to reach an understanding in a dialogue is not merely a matter of putting oneself forward and successfully asserting one's own point of view" (1989, p. 379). Rather, in a dialogue our horizons of understanding shift until we reach a new understanding that is deeper, richer, and more evocative than previous ones. Hermeneutically speaking, dialogue moves us beyond our own truths towards a shared truth that evokes further meaningfulness (Smith, 1994).

In our analysis process, investigators, research personnel, and clinicians met in person and via teleconference to talk about their experiences with the delivery of palliative care in Chile. Research personnel were directly involved in on-site activities and conversed frequently with practitioners. Often, the conversations took place after a period of participant observation, to allow for reflection on what had transpired during the home visit. Field notes were also taken and informed follow-up discussions with participants. In Chile, dialogue with local clinicians informed participatory work throughout the study. Conversations within the research team about fieldwork data were continuous and served to address questions and concerns and to shape the direction of research activities. Analysis and interpretation were carried out mostly in Spanish. Discussions and interpretations of data within the research team were conducted in English throughout the study. Data collection, analysis, and interpretation took place in parallel and sequentially.

Findings

Below we present the findings according to each of the knowledge exchange activities. Findings related to the experience of individuals in palliative care and their families are not included in this article.

Participatory Teamwork and Team/Program Growth

One of the main research activities was participatory teamwork with a PHC team that delivered palliative care at the Chiguayante PHC centre. This work took place over 1 year. The team comprised health professionals from nursing, medicine, nutrition, pharmacy, psychology, midwifery, and social work. The registered nurse was the program coordinator who oversaw the development of the program. The physician carried out the medical development of the program. Both the nurse and the physician were team leaders and the main frontline health-care providers for the program. Team members also provided services in other clinical programs in the *consultorio,* This resulted in only part-time commitment to the palliative care program.

Participatory work consisted of accompanying team members on their visits to patients' homes, attending team meetings, engaging in individual and team dialogue, and taking field notes. This work took place two or three times per week, depending on the practitioner's schedule. The team met on a monthly basis. At the team's request, our research staff provided guest lectures on clinical issues pertaining to palliative care practice.

Participatory teamwork provided an opportunity for continual dialogue with clinicians about practice concerns, clinical issues, teamwork, and ethical dilemmas. Our research personnel established a relationship with the team, who opened their space to them. The team created an atmosphere of learning that facilitated mutual growth and development. Team members felt motivated to further develop the program, initiate new activities, and advance their palliative care learning. While in the past team meetings had been held irregularly, they were now held every month. Each member took responsibility for an in-service, where they reviewed topical practice issues. They improved clinical records to facilitate patient follow-up, produced written educational materials for families, and raised awareness about palliative care among *consultorio* staff. This served to improve the quality of navigation for patients and families, as they were given priority for medical appointments and prescription drop-off and pick-up. The formation of a group of volunteers, under the leadership of the physician with the support of team members, also contributed to program consolidation and better patient follow-up within the home.

Following the example of the Regional Palliative Care Program in Edmonton, the team in Chile instituted family conferences, where team members met with the family to discuss critical issues concerning patient care. The Chilean team were proud to have this initiative in place and saw it as producing positive results. They also created a sympathy card for bereaved family members. Overall, the team provided comprehensive care through periodic home visits, interprofessional care, family conferences, patient and family education, and bereavement support. An increase in the number of services was one of the strongest indicators of team development. The additional services included enhanced treatment of pain and other symptoms. The team members were more confident about morphine in terms of prescriptions, breakthrough use, and dose increases; they used a wider range of available opioids in oral, subcutaneous, and patch preparations and adjuvants to prevent and treat symptoms; and they implemented strict patient follow-up, with other team members acting as collaborators to monitor patient status in the home.

Towards the end of the study the Chiguayante PHC team was more cohesive and enjoyed the recognition of peers and administrators. The team identified several elements as contributing to their positive development. These included their commitment to the program; the existence of the Ministerial Palliative Care Program in the country; national funding through the GES plan; availability of medications and nursing supplies; access to palliative care training; and the support of administrators. They also indicated that this participatory research initiative was an important catalyst in the development of their program.

Participatory Knowledge Exchange

The participatory knowledge exchange process, which began with the participatory teamwork, was complemented by a brief visit to the palliative care program of the partner country; two knowledge exchange workshops; and regular teleconferences, where participants discussed their practice and learned about the experiences of their clinical partners.

Visits to Local Programs

Two participants from Canada and two from Chile visited the palliative care program in the partner country, where they interacted with local practitioners, patients, and families. The visits lasted 2 weeks and included participation in the daily activities of the team as well as visits to other clinical teams. First, a physician and a registered nurse from the Chiguayante team in Chile visited the palliative care program in Edmonton. Then two palliative home care nurses and a palliative nurse practitioner (a member of our research team) from Edmonton visited the program in Chiguayante. Our guests from Canada and Chile had the support of their health-care authorities in taking part in the exchange. In both countries, translation assistance was provided to facilitate communication with clinicians.

In Edmonton, our guests engaged with the palliative home care team participating in the study. They accompanied team members on their home visits with patients and participated in team meetings. They also followed practitioners in tertiary settings (hospital support teams and regional consultants). Clinicians gave our guests a warm welcome and made their visit a fruitful learning experience. They shared their knowledge and vast clinical experience in an informative and respectful manner. They encouraged the Chilean visitors to ask questions and to share their own understanding and knowledge. We presented an overview of the study at regional palliative care rounds, where our guests described their program to a wide and interested audience of clinicians. The Chileans stated that their visit to Edmonton was a remarkable learning experience that had transformed their careers. Language was at times a challenge, but translation support and everybody's willingness to communicate facilitated the exchange.

In Chile, the Chiguayante *consultorio* held a welcome reception that included greetings from the mayor and the health director, dances and folk songs by the staff choir, and of course food. Guests engaged daily with the palliative care team. They accompanied team members on their home visits, participated in team meetings, and met with volunteers. The team met frequently during the 2-week visit to dialogue about a variety of clinical issues. Case reviews were an excellent means for practitioners to exchange knowledge and clinical experience. These exchanges provided an opportunity for team members to ask questions, raise concerns, learn from one another, and collaboratively seek solutions to pressing issues. Notwithstanding language difficulties, the dialogue that took place during reviews reflected practitioners' genuine interest in practice developments. Participants viewed these exchanges as key to achieving an understanding of how the context of practice shapes the delivery of care.

Our Canadian guests also visited other PHC teams providing palliative care in the city and surrounding area. Teams offered hospitality to our Canadian visitors and were eager and proud to show how they cared for their palliative population despite resource and time limitations. They shared success stories and challenges in working with highly vulnerable communities. One team told of a family physician and her children surprising patients in their homes with music and Christmas carols and recalled how cheerful this had been for everyone. Our guests also witnessed a PHC pharmacist make opioid preparations with morphine or codeine powder. They visited a primary care hospital and saw how the entire hospital staff took care of palliative patients. They also engaged with academics and clinicians in the Concepción area. Our nurse practitioner gave a well-attended keynote presentation on palliative care for people with non-malignant conditions and a lecture on opioid rotation addressing clinicians and academics in the city.

Knowledge Exchange Workshops

Knowledge exchange workshops with palliative care clinicians were held in Edmonton and Concepción. The workshop in Edmonton was attended by a palliative home care team that covered approximately half of the city's population, two clinicians from Chile, and the research team. It focused on the global situation in palliative care and generated a discussion about world inequities. Global morphine consumption and its uneven world distribution was a subject of concern and keen interest. Reported data led practitioners to raise the question of an overreliance on morphine (or related opioids) for the treatment of pain in high-income countries. The Chilean visitors related their experiences and understandings on the topic. The striking difference in morphine consumption between Canada (2.3 tons per year) and Chile (55 kilograms per year) (INCB, 2009) was examined from many viewpoints and led practitioners to think beyond resource availability as the sole basis of the inequities. Our Chilean guests presented information relative to their clinical program and its evolution since its inception in PHC in 1998. Their stories sparked interest in learning about practice developments in developing countries and in contributing to the advancement of palliative care globally.

The workshop in Concepción was attended by representatives of twenty-two PHC teams, delegates from two PHC hospitals (Santa Juana and Lirquén), a hospital palliative team from the city of Talcahuano, the team from the Chiguayante PHC centre, two volunteers, our Canadian guests, members of the research team, and professors and graduate students from the University of Concepción. The workshop included an overview of the research study and the global context of palliative care, a presentation by the Chiguayante team on their program followed by a case review, an overview of the Edmonton palliative care program and the palliative home care program presented by our Canadian guests, and a question and answer session.

The afternoon consisted of small group discussions around several questions: *Can you tell us about a successful experience in palliative care practice, no matter how small? What else do we need to learn about partnership, skills for collaboration, and how to network with others? What are the steps to a better life for patients and families? What are the steps to a better life for yourself? From what you have heard today, can you name four things you want to learn more about? What are two things you would like to develop?* The questions were meant as a guide only, and they elicited rich dialogue.

Participants identified several factors that facilitated their practice as well as gaps to be addressed. While there were differences among the teams, there were many commonalities. The latter included a commitment to caring for people with a terminal diagnosis, support for the involvement of an interdisciplinary team, the infrastructure necessary to undertake program activities, a sharing of patient load, and an interest in continuing to develop programs. The involvement of many team members contributed to the dissemination of information about the program among allied health-care staff. Team members explained that their involvement in palliative care helped them to better understand the experience of dying and the need to offer timely relief to patients and families. One team shared their story of grief and bereavement after losing a dear nursing colleague and how their palliative care practice had helped them to come to terms with the loss. The home visit was described as an excellent resource for supporting people in extreme poverty and for providing assistance during their last moments. Some teams identified the value of having undergraduate students as volunteers.

Among the limitations, participants identified the need for further training, as many acknowledged that they were learning on the job. Their needs included additional resources, including computers, better coordination with other levels of the network, and improved teamwork. They voiced a need to provide "after-hours care" and to broaden the scope of care to people with other conditions. They expressed concern about family members and the need to involve more than one carer in order to prevent burnout. One group identified several topics they wished to learn more about, including additional approaches to the treatment of pain, bereavement support, complementary therapies, ethical decision-making, and communication. Visits to clinical centres of excellence were cited as a means by which to strengthen their practice. All of the teams expressed a need to know other people within the network, to keep in touch, and to find opportunities to present their local experiences and learn from their own developments.

Our Canadian guests reported positive experiences and were proud of their ability to preserve "the person" as the patient approached death. They acknowledged the need to become better at listening and at sharing the patient's experience. They also identified a need to remain positive and open about work and to not take things for granted. They expressed a need to take steps to a better life, such as by getting adequate sleep and maintaining a proper diet. They acknowledged a need to practise flexibility with colleagues, to learn to accept not always having an answer, to promote normality with families, acknowledging that they cannot take families' grief away, and to accept that sometimes there is no right or wrong way. They also said they would like to further examine the differences between Canada and Chile in terms of opioid consumption.

In sum, workshop participants actively contributed to the discussions, generously shared their experiences, asked questions of presenters, and commented on the realities of their practice. They showed great enthusiasm for and commitment to the delivery of palliative care in the community and did not shy away from expressing their infectious love for what they do.

Lessons Learned

Overall, the study provided participants with an opportunity to learn from one another with regard to the delivery of palliative care in two distinct settings. They shared their treasured palliative moments and sought to broaden their understanding of how palliative care practice comes about in a particular practice context. While there were important contextual differences, the way in which the practitioners engaged around matters of clinical concern was impressive and surpassed our research expectations. Conversations during case reviews turned into a dynamic exchange of knowledge, experience, and wisdom. The patient's story would trigger a critical dialogue that revealed clinicians' inquiring minds. This rich dialogue around human suffering was one of the most remarkable aspects of our knowledge exchange process.

In the context of critical pedagogy, the Brazilian educator Paulo Freire (2001) writes that teaching cannot be understood as the transfer of knowledge: "To know how to teach is to create possibilities for the construction and production of knowledge rather than to be engaged simply in a game of transferring knowledge" (p. 49). Freire underlines the need to enact this view of teaching in education, particularly when working with vulnerable communities that have been abandoned by society. Practising teaching as the creation and production of knowledge prevents us from imposing our own "truth" on others. It demands that we become acquainted with the "knowledge of the skills and crafts, even the astuteness, with which human groups produce their own survival" (Freire, 2001, p. 76). The survival of the Chilean miners trapped underground in 2010 is a prime example of how human beings can survive hostile circumstances through the skills and knowledge they develop working in adverse conditions. The particular set of skills and knowledge that groups acquire in their milieus also helps us to put into perspective the role of the expert when working with these groups. We need to remain attentive to this knowledge when applying an expert's perspective to a particular context of practice.

In this study, the implementation of a knowledge exchange process helped us to learn about the knowledge and skills that practitioners develop in their local areas, especially in areas of limited resources. The participatory process provided a means for us to produce knowledge together as the research progressed. This was not without challenges, as the application of our foreknowledge seemed at times the obvious course of action, yet the imposition of our knowledge would have resulted in a knowledge transfer process. Knowledge exchange caused us to listen to how practitioners creatively and knowledgeably craft local interventions that, in the long run, have positive effects on their patient population.

In sum, knowledge exchange provided a dialogical means of interacting with and learning from one another. At the end of the study, participants voiced an interest in establishing a virtual exchange site where they could discuss clinical cases and continue to learn. We believe this would be an important step in supporting practitioners in developing settings and in engaging at a global level. In our view, there is a need to continue to build two-, three-, and multiple-way exchanges where participants enter into a dialogue as equal partners and bring their own, local knowledge to the fore.

Final Remarks

This study produced qualitative evidence on the efficacy of a participatory knowledge exchange process with palliative care practitioners from two diverse settings. This evidence speaks to the parameters of development during the course of the study, as described in this article. Further research is needed to examine how and the extent to which each of these parameters develops. The findings indicate a need for continued investigation of the development and efficacy of local interventions, particularly in developing settings where resources are very limited. Globally, there is an urgent need for research evidence on accessible and affordable interventions that benefit low-income populations.

In the case of Chile, the proximity of the *consultorio* to people's homes facilitated access to care and the provision of care in the home. In the past, PHC professionals in Concepción voiced concerns about taking on the care of terminally ill individuals. However, the findings of the present study and our earlier pilot study in the area point to the effectiveness of palliative care delivered through PHC. At the same time, the findings suggest a need to ensure access to continued palliative care training for PHC teams. In their day-to-day practice, PHC professionals think creatively to make the best use of their limited resources. The end result is patients settled at home with their families and able to engage in life until their final moments.

One important lesson from a Canadian perspective has to do with our frustrations when resources that we consider necessary are not readily available. Seeing what the Chilean group were able to accomplish with sheer determination was viewed as a call for Canadian practitioners to dig deeper into their own creativity to circumvent resource shortfalls. "Do the best with what you have" took on new meaning: If they can provide caring and comfort with what little they have in Chile, we can certainly make an impact on the lives of patients and families with what we have in Canada.

To end, we present a summary of our lessons learned, recommendations, and future research steps:

- We need to pay attention to relevant sources of knowledge such as health professionals' and patients' experiences, collective and cultural understandings of health, and practitioners' day-to-day interactions.
- We need to work with practitioners in developing settings to locate knowledge in their own context of practice.
- Participatory knowledge exchange is an excellent way to facilitate the creation, production, and transformation of knowledge in practice improvements.

- Knowledge and practice modalities developed by practitioners in developing countries need to be recognized and integrated into international practice guidelines.
- Further research is needed to examine specific changes in practice parameters through participatory research interventions. Examples include symptom control, opioid and non-opioid consumption, and access to education, medications, treatments, interprofessional care, and volunteer support.
- Team, patient, family, and community perspectives should be integral components of research studies in palliative care.
- The provision of palliative care to low-income populations evokes the political and societal need to pay attention to the experience of those with a terminal illness who live on the margins of society.
- Palliative care offers justice to the poor and marginalized when access to health resources is limited.
- There is much to be learned from the poor and marginalized about what it is to be human.

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Résumé

La gestion des soins palliatifs prodigués aux adultes atteints d'insuffisance cardiaque à un stade avancé

**Sharon Kaasalainen, Patricia H. Strachan, Kevin Brazil,
Denise Marshall, Kathleen Willison, Lisa Dolovich,
Alan Taniguchi, Catherine Demers**

Notre étude visait à étudier le déroulement de la prestation des soins prodigués à des adultes résidant dans la communauté, mourant d'insuffisance cardiaque à un stade avancé, à la lumière de l'expérience des patients, des proches aidants et des prestataires de soins. Un plan d'analyse descriptive et qualitative a servi à guider la collecte, l'analyse et l'interprétation des données. L'échantillon comportait 8 patients, 10 proches aidants, 11 infirmières, 3 médecins et 3 pharmaciens. L'analyse des données révèle que certains facteurs contextuels particuliers influent sur la prestation des soins palliatifs (soit le modèle de soins palliatifs en matière de cancer, l'accès limité aux ressources et les difficultés relatives à la pronostication). Les patients ont décrit le choix des interventions et le fait de composer avec la fatigue, la douleur, la dyspnée et la perte d'autonomie. Les proches aidants ont parlé de surmonter le fardeau de la prestation des soins et de la foi qui les soutenait. Les professionnels de la santé ont décrit leur rôle relativement à la coordination des soins, au transfert de compétences, à la gestion des médicaments et à l'optimisation de la collaboration interprofessionnelle. Les participants aspiraient à atteindre trois résultats : la gestion efficace des symptômes; la satisfaction à l'égard des soins; et une mort paisible.

Mots clés : soins palliatifs

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Managing Palliative Care for Adults With Advanced Heart Failure

Sharon Kaasalainen, Patricia H. Strachan, Kevin Brazil, Denise Marshall, Kathleen Willison, Lisa Dolovich, Alan Taniguchi, Catherine Demers

The purpose of this study was to explore the care processes experienced by community-dwelling adults dying from advanced heart failure, their family caregivers, and their health-care providers. A descriptive qualitative design was used to guide data collection, analysis, and interpretation. The sample comprised 8 patients, 10 informal caregivers, 11 nurses, 3 physicians, and 3 pharmacists. Data analysis revealed that palliative care was influenced by unique contextual factors (i.e., cancer model of palliative care, limited access to resources, prognostication challenges). Patients described choosing interventions and living with fatigue, pain, shortness of breath, and functional decline. Family caregivers described surviving caregiver burden and drawing on their faith. Health professionals described their role as trying to coordinate care, building expertise, managing medications, and optimizing interprofessional collaboration. Participants strove towards 3 outcomes: effective symptom management, satisfaction with care, and a peaceful death.

Keywords: access to care, cardiovascular disease, community health nursing, palliative care

Background

Heart failure (HF) is a leading cause of hospitalization in older Canadians and it is predicted that the aging of the population will result in increasing numbers of those affected (Johansen, Strauss, Arnold, Moe, & Liu, 2003; Tsuyuki, Shibata, Nilsson, & Hervas-Malo, 2003). Surprisingly, HF is associated with mortality rates higher than those for some cancers (Naylor, 1999). Despite treatment, patients with advanced HF continue to report a heavy daily symptom burden (Janssen, Spruit, Wouters, & Schols, 2008). The high prevalence of distressing symptoms includes fatigue (42–82%), dyspnea (18–88%), pain (20–78%), insomnia (36–48%), anxiety (2–49%), constipation (12–42%), anorexia (11–43%), edema (33–44%), and depression (6–59%) (Janssen et al., 2008; Solano, Gomes, & Higginson, 2006). The prognosis for HF patients with advanced disease is poor. The 5-year mortality rate following a first hospitalization for HF has been reported as 68.7% with a median survival of 2.4 years (Ko et al., 2008). A 1-year mortality rate of 40% to 50% has been reported for those who are symptomatic at rest (Pantilat & Steimle, 2004).

Patients living with advanced HF are particularly underserved in relation to end-of-life care, since the palliative care paradigm as we know it is based on a cancer model. This model bases transitions to end-of-life care and services on somewhat predictable illness trajectories, leaving individuals with advanced HF often ineligible and devoid of explicit end-of-life care (Goodlin et al., 2004; Horne & Payne, 2004).

Managing palliative care issues can be challenging for adults who live in the community, especially those who have advanced HF (Murray et al., 2002). The care of patients with advanced HF usually falls to community-based caregivers such as nurses, physicians, and pharmacists. Many community-dwelling adults with advanced HF have the additional support of informal caregivers (e.g., family members, friends, neighbours), who assist them with daily responsibilities such as activities of daily living and management of medications. However, these informal caregivers, as well as health professionals, are often faced with the daunting task of trying to care for adults with advanced HF with little support from the health-care system. Exploring the experiences of these individuals and the issues they regard as important could lead to efforts directed at improving quality of care at all levels (i.e., individual, health professional, system).

Recent research conducted in the United Kingdom has highlighted several barriers and supports related to optimal palliative care for patients who have advanced HF (Selman et al., 2007). In Canada, however, little research has been conducted in this area, particularly from the perspectives of patients with advanced HF, their family caregivers, and their health professionals. Such rich, subjective information provides early evidence that is critical to the planning of end-of-life care and to the development of care that is identified as a national health priority in the 2009 Canadian Heart Health Strategy and Action Plan (www.chhs.ca).

The purpose of this study was to explore the processes of care and the inherent challenges that are experienced by community-dwelling adults dying from advanced HF, their family caregivers, and their health-care providers. The findings could offer solutions and future directions for research aimed at improving the management of palliative care for patients with HF in Canada.

Methods

A descriptive qualitative design was used to guide data collection, analysis, and interpretation (Patton, 2002; Sandelowski, 2000). This qualitative design was appropriate for the study because it facilitated the gathering of rich, contextual data that reflected the experiences of adults dying from HF and their caregivers. The study was approved by the McMaster University Research Ethics Board. Confidentiality agreements were obtained from those who collected, transcribed, and analyzed the data. Written informed consent was obtained from all participants prior to interview.

Semi-structured interviews were conducted with patients, informal (family) caregivers, and various health professionals (physicians, including geriatricians and palliative care specialists, nurses, and pharmacists) involved in the palliative care of patients with advanced HF in Hamilton, Ontario. Purposive and theoretical sampling were used to guide data collection and maximize those perspectives that would most clearly illuminate the process of palliative care. We collected data from multiple sources by recruiting participants with different roles in the palliative care experience (i.e., patients, caregivers, physicians, nurses, pharmacists). Purposive and snowball sampling were used to recruit participants. First, physicians and pharmacists who were members of a clinician and researcher network aimed at improving drug prescribing and use among seniors (Team for Individualizing Pharmacotherapy in Primary Care for Seniors; www.tippsnetwork.ca) were contacted via telephone and invited to participate in the study. In addition, physicians were recruited through the Division of Palliative Care at McMaster University. Physicians and pharmacists were asked to identify any patient in their practice who (a) had advanced HF (New York Heart Association class 4 and ACC/AHA task force stage D), and (b) lived in the community. Any physician or pharmacist who had not had at least five patients with advanced HF in the previous 3 years was excluded from the study. The selected patients or their caregivers were approached by a participating physician or pharmacist and asked for permission to have their name and phone number given to the research assistant. Staff from a local Heart Function Clinic identified potential participants and contacted them for permission to have their name and phone number released to the research assistant. These potential participants were also sampled purposively and were considered eligible to participate in the study if they were diagnosed as having advanced HF (New York Heart Association class 4 and ACC/AHA task force stage D), English-speaking, and deemed, by their health professional, capable of taking part in a one-to-one interview.

The interviews were held at a location most convenient for the participants: for patients and family caregivers, either at home or at the Heart Function Clinic; for health professionals, at their place of work. A trained interviewer conducted face-to-face interviews with each of the participants using a semi-structured interview guide. Although the patients and caregivers were from the same dyad, they were interviewed separately, one after the other. For two of the dyads, the caregiver was present during the patient interview for support in case the patient became fatigued and needed help. These interviewees were asked to relate their experiences living with HF, the patients' medical symptoms and symptom management, the roles of the various health professionals involved in care, and the supports and difficulties they experienced related to those areas. Similarly, health professionals were asked to identify their experiences of managing HF in the community, the predominant issues encountered, and barriers to and facilitators of optimal care provision. Two interviewers conducted 35 interviews that ranged from 20 to 70 minutes in length. Interview guides were adjusted to focus on various thematic areas that arose as the interviews progressed.

Data Management and Analysis

All interviews were audiorecorded, transcribed verbatim, and imported into NVivo 7 for thematic content analysis. All transcripts were read and coded by two members of the research team (PS and SK) and the interviewer. Concepts that were identified as important and/or recurring were labelled, categorized, and coded (Boyatzis, 1998). Consistency checks were completed between investigators (PS and SK). Memos and reflective journals were used extensively to ensure credibility and dependability (Crabtree & Miller, 1999). Any discrepancies were reviewed by the investigators and discussed until consensus was reached. After 35 participants were interviewed, consensus was reached on the suspension of recruitment.

Findings

Description of Sample

A total of 35 persons were interviewed. They included 8 patients (NYHA class 4), 10 family caregivers (7 spouses, 3 adult children), 11 nurses, 3 pharmacists, and 3 physicians from the Hamilton area. Of the 8 patients interviewed, 6 were male (75%). Patients ranged in age from 61 to 87 years (mean age = 76 ± 7.9). Eight of the 10 family caregivers were female and ranged in age from 35 to 85 years (mean age = 65 ± 16.1). Most participants (83%) were married. Family caregiving experience ranged from 2 to 18 years with an average of 7.6 years. Many patients and family caregivers reported co-morbid conditions such as diabetes, depression, and chronic lung disease. At least 50% of patients had implantable cardioverter defibrillator (ICD) and pacemaker combinations. Of the 17 clinicians interviewed, 11 were nurses (6 palliative care specialists, 3 cardiology specialists, and 1 community nursing consultant), 3 were physicians (2 palliative care specialists and 1 geriatrician), and 3 were pharmacists in private practice.

Overview of Findings

Participants described a number of activities related to the provision of palliative care for individuals with advanced HF. These care activities were influenced by contextual factors, including adoption of the cancer model of palliative care by the health-care team, limited access to resources, and prognostication challenges (see Figure 1). They were described differently by patients, family caregivers, and health professionals, and they included many challenges. Patients were challenged to choose treatment interventions and live with increasing and debilitating functional decline. Family caregivers were challenged to manage their caregiver role and to draw on their personal resources. Health professionals were challenged to coordinate care; develop HF-specific palliative care expertise; manage HF-specific medications; and optimize interprofessional collaboration between cardiac, palliative, community, and hospital care providers. All participant groups strove to achieve optimal symptom management, patient and family satisfaction with care, effective transition to palliative care, and a peaceful death.

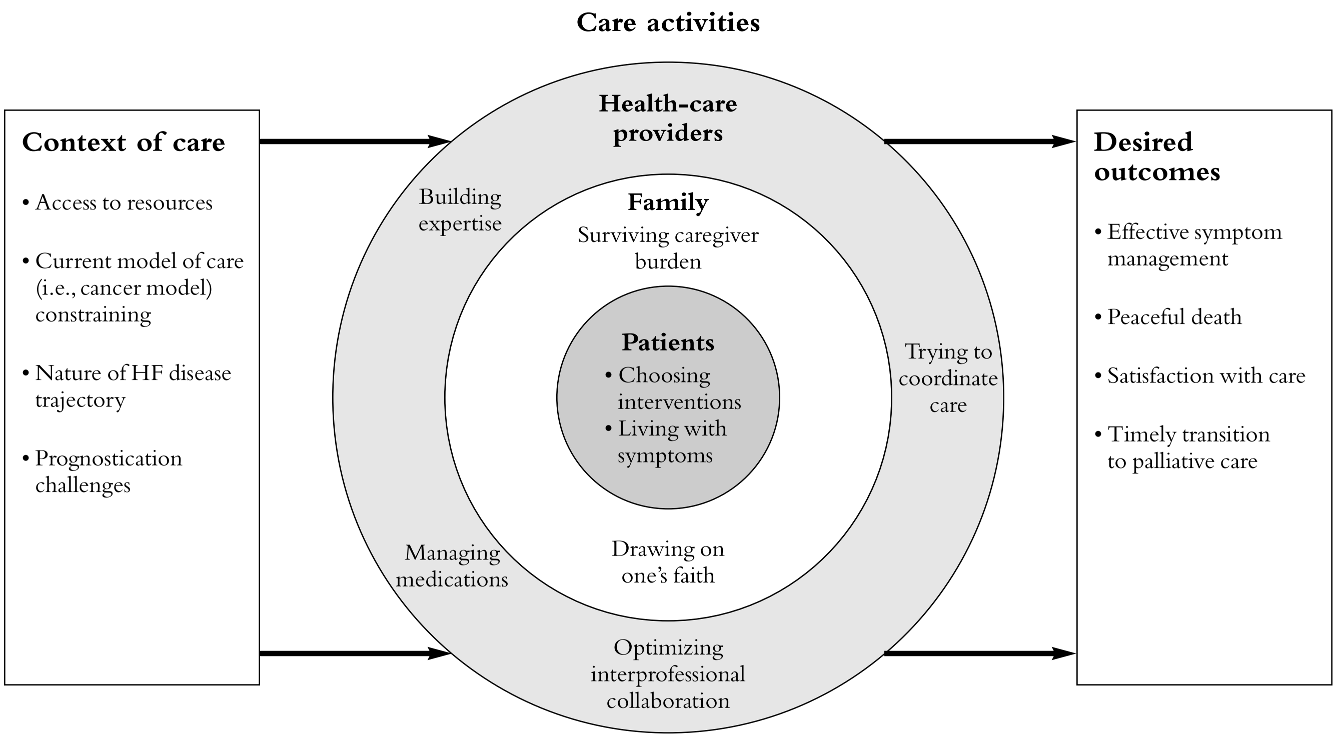
Context of Care

Several factors influenced the care activities of patients with advanced HF. A major constraint was that the cancer model of palliative care is the only predominant model in use to manage an end-stage, non-cancer disease (HF). Participants drew contrasts between what they regarded as two types of palliative care patients (cancer and non-cancer). Individuals with HF and their family members said they were ineligible for subsidized equipment and community services, such as hospice or transportation programs that accommodate only patients with cancer. A physician concurred:

> *The cancer patients have volunteer drivers, but there's a lot less access for the heart failure patients . . . there's less support groups. And the caregiver needs are very different than the caregiver needs of cancer patients.*

Health professionals delivering palliative services struggled to deal with the unpredictable nature of the HF disease trajectory. This unpredictability was dramatically illustrated in cases where patients appeared to be on their deathbed and then, after a short period, rebounded to a higher level of functioning. For example, one nurse stated, "We had one fellow who left CCU to die last January — well, he's riding his bicycle now." Due to such uncertainty, practitioners were often reluctant to transition their HF patients to palliative care, as they believed this would

Figure 1 *The Management of Palliative Care for Adults With Advanced Heart Failure*



involve changing the treatment regimen from an aggressive approach that appeared to make a difference to a "comfort measures only" approach. Additionally, even if practitioners felt that palliative care was appropriate for an HF patient, they encountered challenges in gauging the temporal criteria established by many palliative services, such as a projected survival time of 6 months.

In other cases, delayed referral to palliative care resulted in the palliative care team having too little time with patients and families or patients dying prior to being seen by the palliative care team. The decision to transition patients with HF to palliative care was further complicated when patients resisted the transfer. This was partially attributed to patients failing to understand or acknowledge the need for or relevance of the transfer of care or not wanting to give up their primary care team. A nurse elaborated:

> *Some of the patients don't see themselves as palliative, so when we [the primary care team] bring up issues and talk about their referral to the palliative care team, they see that as a death sentence. If they don't perceive that they are dying, they don't feel the need for that referral. So we're trying to sell the palliative care team to them. And if they don't feel they need it, they're not going to take it.*

The conflict between trying to maintain a sense of hope and adopting the "palliative" designation was expressed by all participant groups. There was an overriding perception that for patients with HF there is always "one more thing [pharmaceutical or technological intervention] to try." This belief was perceived as at odds with the commitment to a palliative approach to care.

Family members could impede the transition to palliative care, often due to their own fears and a reluctance to face the imminent death of their family member. This could make it difficult for health professionals to manage care in the most appropriate manner. One nurse illustrated this point:

> *It can be the family that doesn't want to hear the conversation. There was a gentleman that was deemed palliative a year and a half ago but has been moved out of that picture a bit because his wife doesn't want to discuss that. And that's really frustrating, because we had to re-admit this gentleman a week ago and the cardiac staff are saying, "Well, what's the goal?" . . . he's still functioning in daily life, he's not bedridden, he's still able to get around and enjoy sitting on his deck and visiting with his family. The family is not to the point where they can say, "Let's just have a little bit of morphine for the dyspnea and discomfort and let's just start calling it a day" . . . And it's harder to get them to that point because you can't give*

> *them a prognosis like you can with end-stage pancreatic cancer, where you've got weeks to live. We can't do that. We really don't have a clue exactly how long they'll live.*

All participant groups expressed concern about the perceived lack of continuity in care when patients were transitioning from the cardiac "community" to a palliative care service. The following comment by a family member illustrates the concern expressed by all participant groups about the transfer from cardiac to palliative care ending the patient's relationship with cardiac care providers that had developed over time:

> *There isn't a lot of continuity in your care. I don't know how it works with cancer . . . but when you read death notices it says, "Thank you very much to Dr. so and so" who treated this patient for a long time. And that's a good thing. . . . it's hard to get accustomed to a doctor and have them walk out and leave you alone. It's really difficult when you're so ill and you rely on that doctor.*

Care Activities of Health-Care Providers

The majority of the health professionals interviewed identified the need to build expertise in managing palliative care for patients with advanced HF. Specifically, they expressed a lack of confidence in their knowledge about the technologies used in treating HF (e.g., ICDs) and the pharmacological and non-pharmacological treatments available to manage symptoms in this group of patients. A nurse experienced in the care of patients with cancer outlined several concerns:

> *I don't have the same expertise. I don't feel as confident as I do in oncology, because I know what I'm doing [with oncology] and I know what to expect there because I've been doing this for a long time. But with heart failure I don't know the drugs as well. I know the blood work but I don't know how that prognosticates. And I don't have the same comfort with the drugs, so when I'm called in I'm thinking, is there something more we can do with the cardiac drugs? I can tell . . . with the cancer patients generally, or we send them to the cancer centre and get a blessing one way or another. So I feel a bit more hesitant . . . it feels a little outside my comfort zone.*

Nurses and physicians expressed many concerns about safety issues considering the large number of medications that patients with HF tend to be prescribed, particularly when opioids commonly used for patients terminally ill with cancer are added to the regimen of cardiac medications. A physician cited the importance of consulting the pharmacist in such a case:

> *I think it's more pronounced in cardiology patients. Many end-of-life patients tend to be on a lot of medications, but cardiology patients have by far the most medications, more than cancer patients. So I think they can benefit from information and a relationship with their pharmacist and having that person or that team involved in the care, to make sure (a) that the patient is taking the medications that are prescribed, (b) that they are appropriate, and (c) that there are no interactions. There's so much greater potential for medication errors for these patients.*

Health-care providers also spoke about their attempts to coordinate care for patients with advanced HF and their family members in the midst of addressing challenges arising from changes in patients' health status. It was not uncommon for patients with advanced HF to make repeated visits to the hospital for help with their symptoms during exacerbations. Nurses often assumed a case manager role even though they were not always assigned this role, to address gaps they perceived as resulting from patients being treated by different cardiologists who rotated through the Heart Function Clinic.

Most participants described the importance of optimizing interprofessional collaboration to meet patients' needs within a holistic perspective. The interprofessional care culture was familiar to those who were members of a palliative care team. A nurse made the following comment:

> *Certainly in palliative care we try to optimize quality of life for heart failure . . . they need a good multidisciplinary team that looks at things like function, things in the home, energy-conserving techniques . . . somebody they can talk to about their fears, because sudden death is such a big issue for people with heart failure. Maybe they don't need palliative care right away if they start seeing the cardiac nurse or cardiologist at the Heart Function Clinic . . . but in time we [the palliative care team], with interdisciplinary rounds, we go over cases once a month . . . then the OT says, "Well, I think I could do this with him at home," and the palliative nurse says, "Well, have you thought about this at home?" . . . maybe that kind of thing would work.*

Communication issues within the health-care system often precluded effective collaboration in the management of care for patients with advanced HF. One pharmacist provided an example:

> *We're trying to encourage the physician to communicate with the pharmacist via the prescription . . . what their intentions are in terms of changing doses and stopping medications . . . I've had patients try to re-order medications that the doctors had intended to stop. I've had a family doctor try*

> *to re-order medication that the cardiologist had changed. I've had a cardiologist try to increase the dose of a medication that the family doctor had changed. So I really think the pharmacist is the one that tries to communicate . . . with all of the health-care providers through the medication profile, to make sure that information is as accurate as possible.*

Care Activities of Family Caregivers

Family members described the toll that their caregiving took on their physical and mental health and the challenges related to managing medications and personal care for the patient. Some of the caregivers were also struggling with the demands of managing their own chronic illnesses. They described how roles in their marriage inevitably changed as their spouse's HF worsened, leaving them to assume more responsibility for maintaining the home and family life. As a result, they became more housebound and socially isolated, with progressively fewer opportunities to engage in activities outside of the home. One caregiver described her desperate state:

> *I was like a mother . . . I don't feel nothing like a wife . . . I have to support, I have to take care of everything . . . everything about the pills and how I have to look after him — it's just like a little baby and I was like a mother . . . make me so uncomfortable.*

Other caregivers described a more positive experience where they coped by mobilizing personal resources to maintain a positive outlook. Caregivers told stories of enduring commitment and dedication to their marriage despite the daily burden that they faced. One caregiver drew on her faith to meet challenges arising from her role:

> *It's just become part of our life that has to be done. If he needs something and I'm reading, then that's fine. If it can wait for a few minutes then it does, but if it has to be done then it has to be done. Like, right now I have to help him shower and I make up his needles and I help him take his needles . . . and he doesn't do much walking on his own so he takes my arm, even in the house. He's got extra dizziness right now because of the added medication, but even if we go out from the car he's always got my arm. But really, when you think of what some other people have to deal with [in] caregiving, my load is light . . . we just take it day by day and have a lot of faith. I have strong faith and that helps me. And as a friend of ours said — because they're going [through] the same type of thing — he said, "Well, we got married 50-some years ago and this was our commitment and that's it." And I say, "That's how I feel too."*

Care Activities of Patients With Advanced HF

The challenges for patients with advanced HF included choosing medical interventions (medications, surgical procedures, and technological interventions such as an ICD) and living with symptoms (fatigue, shortness of breath, pain, and functional decline). Most patients intended to "fight to the bitter end," with the primary goal of extending their life for as long as possible. One nurse provided an example of this approach:

> *One gentleman who is on morphine . . . we just brought up the discussion about when do you want your defibrillator turned off and he was really offended by this . . . so we just try to touch on issues . . . Another lady was young but her defibrillator kept going off over and over again, to the point where she wore out the battery in 8 months and it's supposed to last for 8 to 10 years . . . We asked her if we should put in a new one and she didn't even think twice. She said, "Of course, if I don't have it I'm going to die. Every time it [the ICD] goes off it brings me back, so it's doing its job." So they spent $25,000 and put in a new one and she lived only 2 months after that . . . she just assumed she would see her grandchildren one day.*

A challenge of working with cardiac patients was the nature of their symptoms, in particular "the acuteness of the shortness of breath, which sometimes can be much more unbearable than actual pain . . . shortness of breath and a feeling of suffocation." One nurse explained that "you have to treat pain differently [from] what you're accustomed to, because it's not a persistent pain like you'd see in cancer patients." Fatigue was viewed as most troubling in the home setting due to the limitations of known effective treatments. A patient described his challenge of managing prevailing symptoms:

> *I've had everything — you name it. I've had lots of angina, lots of bloating — that's one of the reasons that I'm on dialysis . . . I've been in the hospital at least 10 times . . . I've had 3 heart attacks, I have a pacemaker, defibrillator, and now I have kidney failure. I'm a diabetic . . . so I've had every symptom you can think of . . . I take [nitro spray] to bed with me because during the night I get so flustered . . . I was thinking about it last night and I thought, when I get this weak feeling I know that this side of me isn't right [points to left side of chest] . . . so I get this out and I lie with it in my hand and I elevate my bed and take [cardiac medication] and it saves me going all the way to the bathroom, but of course I have to get up and down to the bathroom all night anyway because I'm getting rid of the fluid.*

Desired Outcomes

A number of key desired outcomes of palliative care were identified by participants — specifically, effective symptom management, satisfaction with care, and a peaceful death. All of the participant groups stated that their primary goal was to achieve effective symptom management, with pain and dyspnea as the two most common foci. One nurse elaborated:

> *I think the goal at that point is to keep them at home and [let them] die comfortably . . . The biggest concern is the feeling of dyspnea — that really unpleasant feeling of shortness of breath that gets worse and worse. So if we're in a true palliative care mode, we're trying to keep the fluid balance a little more in check, but it's more the symptoms . . . you're trying to keep them comfortable.*

In addition, health professionals hoped that patients and family members were satisfied with the care being provided to them and that their needs were being met. However, they often faced many challenges in trying to achieve these outcomes — challenges that stemmed from the environment and the system as a whole.

Health professionals and patients also described a desire for a timely and smooth transition to palliative care. In most cases, patients and their caregivers stated that they had hoped to be better prepared for the discussions about transitioning to palliative care. One man described some of his experiences and wishes during the transition:

> *I guess the doctors were telling me there wasn't much they could do for me any more. I guess that's when it really hit me that the old heart could stop any time now . . . But I think just sitting down — when you're feeling good and when you don't have any pain and that kind of stuff, if they sat down and slowly brought the subject to a head. I think that would have been better than just coming right out with it, especially when you weren't feeling well. But just the other day I was at the heart clinic and they said there were still things they could do for me . . . that's what they're saying now, that there's still something that they can do.*

Discussion

The findings from this study highlight the vulnerability of those adults who are dying from advanced HF and their family caregivers, and the misalignment of current end-of-life services in a Canadian community and the needs of palliative patients with HF. Notably, the strongest influence related to the inadequacy of the current model of care for those individuals who are dying from advanced HF is that most palliative services are based on the traditional, cancer model of care provision.

A number of contextual factors predisposed HF patients to suboptimal or even non-existent palliative care (see Figure 1). The desired outcomes common to all three participant groups provide a consensual, positive, and client-centred basis for changes to the health-care system.

The findings indicate that challenges to achieving these desired outcomes of care were related to coordination of services within the health-care system. The traditional cancer model of care does not meet the needs of those individuals who are dying from a disease other than cancer — in this case advanced HF. Under this model, patients with advanced HF often find themselves ineligible for community supports and services, such as hospice care and assistance with transportation, when these are dependent upon a prognosis of 3 to 6 months. Of particular concern are those patients with HF who are no longer able to attend outpatient clinics for monitoring due to their declining functional status but are not eligible for palliative care in the home. There is a clear need for a new model of palliative care tailored to the needs of those with advanced HF. It has been argued that care models with a primary focus on symptom management, quality of life, and psychosocial support for patients and their families would routinely integrate a "palliative approach" to care without the need for the patient to be diagnosed as "palliative" per se (Boyd et al., 2004; Thompson, 2007; Ward, 2002).

The findings indicate that the transition from active cardiac care to palliative care is poor and disjointed. The findings are consistent with recent reports by seriously ill Canadians hospitalized with HF who identified wide gaps in their care in relation to advance care planning, symptom relief, and reduction of the emotional and physical toll on their family caregivers (Strachan, Ross, Rocker, Dodek, & Heyland, 2009). The transition to palliative care is complicated by the fact that there is often "one more thing to try" with respect to prolonging life, as opposed to focusing on optimizing the quality of the patient's remaining weeks or months (Hauptman & Havranek, 2005). When palliative services are not available and aggressive cardiac care continues, serious issues may occur. For example, the opportunity to achieve symptom relief and a meaningful closure of life may be missed (Jaarsma & Levanthal, 2002). Interestingly, Heyland et al. (2006) found that seriously ill patients and their family members felt it was extremely important that they be able to "complete things and prepare for life's end — life review, resolving conflicts, saying goodbye" (p. 4). Patients with advanced HF are unlikely to have this opportunity given their unpredictable disease trajectory and the constraints of the current model of care.

Most of the health professionals interviewed for the study commented on the need to introduce palliative care earlier in the disease process so that patients can be prepared well in advance, thus alleviating the pressure to "find the right time" to talk about death and dying. This kind of discussion should be ongoing so that patients and their families will have access to palliative services when needed to promote continuity of care and will have time to develop a trusting relationship with their care providers. Murray et al. (2002) propose a dual approach to care for patients with HF, with active management being continued but the possibility of death being acknowledged and discussed. This would call for an interprofessional approach and a focus on symptom management. However, Hauptman and Havranek (2005) state that "an interdisciplinary approach has been relatively slow to reach the care of advanced HF, because there has been little tradition and experience with this approach among cardiologists" (p. 375). Thompson (2007) argues that models of care should "take account of strategic planning across primary and secondary care sectors, involve healthcare and social care services and specialist palliative care providers, and be informed by the needs, experiences and preferences of patients, carers and health professionals" (p. 901). Thus continuity of care may be better facilitated within a more coordinated approach.

Participants also spoke of the need for adequate case management for the HF population. In this study community, nurses often assumed such a role in the hospital, particularly in the Heart Function Clinic. In addition, pharmacists played an important role in medication management, as the transition from aggressive therapy to palliative care is complicated by the need to manage side effects with a combination of medications that many health professionals are unaccustomed to and uncomfortable with. Pharmacists are also well positioned to help manage and oversee the transition from hospital to community and from one physician to another. Finally, given the fatigue, functional impairment, and caregiver burden that accompany advanced HF, pharmacists may be able to assist with transportation issues around having prescriptions filled. Such services ought to be not only available but also communicated to patients dying from HF and their family caregivers, to prevent unnecessary stress and fatigue.

There is a clear need for a model of care that is responsive to the health contexts of cardiac patients. The importance of a coordinated approach to care for these individuals cannot be overstated. Murray et al. (2002) propose that the deployment of cardiac nurse specialists might reduce the number of hospital admissions and improve the coordination of care. Advanced practice nurses with specialties in both HF and palliative care could help to bridge gaps in care, particularly for patients living in the community. Advanced practice nurses have been shown to be effective in care coordination and consultation within the palliative care community, since they have the skills necessary to meet the unique and diverse needs of these individuals (Froggat & Hoult, 2002; Weggel & Hamric, 1997). Innovative models that incorporate both of these specialties show positive results and indicate promising trends for the future (Daley, Matthews, & Williams, 2006; Johnson & Houghton, 2006).

Not surprisingly, patients with advanced HF and their families valued a trusting, supportive relationship with their health-care providers. This relationship was often challenged when the move away from active cardiac care meant leaving one "camp" (acute cardiac care) and being placed in another (palliative care). This transition was troubling for the patients, as it meant that they were introduced to a new set of health professionals at a time when they felt the worst and had the least amount of energy to develop new relationships. Heyland et al. (2006) found that what mattered most to seriously ill patients and their family members was that they have trust and confidence in the physicians looking after them. When HF patients are eventually deemed "palliative," they are left feeling alone and abandoned at a time when they most need familiar, trusting relationships with health-care providers. Murray et al. (2002) found that patients dying from HF and their family members felt neither involved in the decision-making about their care nor empowered to work in partnership with professionals and that the prognosis was rarely discussed with them. Similarly, Aldred, Gott, and Gariballa (2005) found that, due to fragmented care provision, HF patients and their caregivers understood little of their condition, had inadequate discussions with health professionals, and felt that they had "no-one to talk to" (p. 119). There is a danger that the widespread promotion of self-care for HF patients will fuel this fragmentation if supports for patients and families are not in place when self-care begins to deteriorate. There is a paucity of research to support patients and families through the transitions (Riegel et al., 2009). Additionally, there is no consensus on whether a general palliative model that incorporates the needs of patients with advanced HF is better than an HF-specific model (O'Leary, Murphy, O'Loughlin, Tiernan, & McDonald, 2009).

This situation is particularly troubling given the many demands on those caring for a family member with advanced HF, which can leave one feeling emotionally and physically exhausted, as described in vivid detail by the participants in the present study. Brannstrom, Ekman, Bowman, and Strandberg (2007) found that caregivers were constantly worried and that caregiving was a 24-hour commitment with many life-threatening moments and many "ups and downs." In fact, Weller Moore (2002) describes caring for a family member with advanced HF as "surviving chaos." Caregivers not only are responsible for performing household tasks and providing physical care that keeps them indoors most of the time, but many are struggling with declining health and serious health problems themselves (Aldred et al., 2005). Despite these caregiver challenges, there are no published research interventions designed to alleviate caregiver burden in the HF population (Lorenz et al., 2008).

This study has its limitations, including a voluntary sample based in one particular region. Therefore, the findings may not be transferable to other settings or populations. Research using a more rigorous design, such as grounded theory, could further explicate the themes and/or validate the model. Also, the sample of health professionals was limited in scope. Future research should include other important members of the health-care team, such as social workers, rehabilitation therapists, and chaplains.

In summary, the findings from this study highlight the inadequacies of the health-care system in meeting the needs of community-dwelling adults dying from end-stage heart failure and their family caregivers. In addition to increased continuity of care and a focus on symptom control and family support, patients with advanced HF and their family members would greatly benefit from an interprofessional approach to care, which is another hallmark of palliative care (Higginson & Addington-Hall, 2001; Murray et al., 2002). A profound understanding of these issues is critical to meeting the palliative care needs of community-dwelling patients with advanced HF and their caregivers. The findings suggest that a coordinated interprofessional approach that bridges hospital and community care, cardiac subspecialties (including HF), and palliative care expertise is required to meet the needs of patients with advanced HF living in the community and their caregivers. This information could inform the design and implementation of supportive networks and interventions for adults with advanced HF and is consistent with national recommendations (www.chhs-scsc.ca). In turn, undesirable outcomes such as morbidity, caregiver stress, and hospitalizations can be minimized.

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Résumé

Le dilemme moral des infirmières concernant l'administration d'anticonvulsivants au besoin dans le cadre des soins palliatifs pédiatriques

Judy Rashotte, Judy King, Margot Thomas, Betty Cragg

Le présent article étudie le processus de décision des infirmières concernant l'administration d'anticonvulsivants au besoin à des enfants souffrant de troubles convulsifs de longue durée dans le cadre des soins palliatifs. À cet effet, on a utilisé l'étude phénoménologique herméneutique suivant la démarche méthodologique de van Manen. Six infirmières ont participé aux entretiens. L'analyse des données a révélé que la réaction globale des infirmières étaient qu'elles ne veulent pas que cela se produise quand elles sont de garde, puisqu'elles sont les témoins de ce qui se passe, elles sont à l'écoute des patients, créent des liens avec eux et savent ce qu'il faut faire. Quatre thèmes sont ressortis de l'étude : savoir ce qui se passe — ce qu'il faut savoir et les façons de savoir; prendre en note ce qui se passe au bon moment — attendre et minuter; trouver un certain réconfort personnel — développer un sentiment de réconfort, être confronté à la détresse et y répondre; et prendre la décision — reconnaître une crise convulsive, déterminer les options, peser le pour et le contre et repenser la décision. Cette étude révèle qu'en prenant ce genre de décisions, les infirmières peuvent se retrouver face à des cas de conscience engendrant une détresse morale. Elle nous permet aussi de mieux comprendre les tensions et les récompenses qui s'y rattachent.

Mots clés : processus de décision, soins palliatifs pédiatriques

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Nurses' Moral Experience of Administering PRN Anti-seizure Medications in Pediatric Palliative Care

Judy Rashotte, Judy King, Margot Thomas, Betty Cragg

This article explores nurses' decision-making related to the administration of PRN anti-seizure medications to children with long-term seizure disorders in palliative care. Hermeneutic phenomenological inquiry guided by van Manen's approach was the method used. Six nurses participated in interviews. Data analysis revealed that *not on my watch* was the overarching theme in which nurses engaged in bearing witness, being attentive, creating connectedness, and finding the right thing to do. Four themes emerged: being in the know — what to know and ways of knowing; marking time — waiting and timekeeping; seeking a sense of personal comfort — developing a sense of comfort, experiencing distress, and responding to distress; and making the decision — recognizing a seizure, identifying options, weighing the options, and rethinking the decision. This study reveals the moral dilemmas and resulting moral distress that may be experienced in making this type of decision and advances our thinking about the corresponding tensions and rewards.

Keywords: chronic illness, decision-making, ethics, pediatric nursing, palliative care

Over the past several decades, palliative care in the home and in hospices has become an alternative to hospital care for children living with an incurable illness. Hospice nursing is unique because parents have spent the most time living with and managing their child's care, such as assessing their child's need for and responses to PRN (as the need arises) anti-seizure medications. As a result, nurses' and parents' decisions about the best course of action may not always be congruent and tensions may arise. There is no literature describing tensions between nurses' and parents' decisions. However, the impetus for this study was nurses' concern that they might be administering PRN anti-seizure medications more frequently than parents, indicating that their decision-making is somehow different from that of parents and could be upsetting for parents.

Since the early 1960s nurses have been examining the closely related phenomena of clinical judgement (Benner, Tanner, & Chesla, 1996), critical thinking (Brunt, 2005), diagnostic reasoning (Carnevali, 1984), and clinical decision-making (Rashotte & Carnevale, 2004). Despite the large body of research in this area, the process of clinical decision-making is still not well understood. In contrast to the substantial literature pertaining to the decision-making process in general, there is little systematic research addressing nurses' decision-making related to PRN medication administration. Several studies have examined mental health nurses' practices regarding administration of PRN psychotropic medications (Craven, Voore, & Voineskos, 1987; Usher, Lindsay, & Sellen, 2001), but these are adult-focused. Of those studies addressing PRN medication administration in pediatric nursing, most have focused on nurses' decisions related to pain medication (Hudson-Barr, Duffey, Holditch-Davis, Funk, & Frauman, 1998; Ross, Bush, & Crummette, 1991). Both groups of studies have focused either on actual administration as documented in patients' charts or on the identification of factors influencing the administration of PRN medications. We found no studies related to nurses' decision-making associated with PRN anti-seizure medications in the pediatric acute-care or palliative-care populations.

Research on the cognitive processes of nurses administering PRN medications is even more limited and is centred on the decision-making of nurses in adult acute-care settings (Eisenhauer, Hurley, & Dolan, 2007; Manias, Aitken, & Dunning, 2005). Nurses' complex process of critical thinking has been found to include all of the following: direct patient observation, interpretation of pertinent data before and after medication administration, application of knowledge related to specific patient situations, anticipatory problem-solving in relation to a patient's clinical trajectory, communication with physicians for verification of data interpretation, patient advocacy, and prevention of adverse drug events.

While research has made valuable contributions in the area of clinical decision-making, little is known about decision-making related specifically to nursing interventions in pediatric palliative care. This article reports the results of a qualitative study conducted in part to understand nurses' decision-making related to the administration of PRN anti-seizure medications to children living with a long-term seizure disorder in a palliative care program.

Method

We sought a methodological approach that would disclose the meaning of making this type of decision from the perspective of those who have lived the experience. Hermeneutic phenomenology as outlined by van Manen (1997), an approach in the human science tradition, employs interpretive (hermeneutic) and descriptive (phenomenological) elements. This approach, which "aims at gaining a deeper understanding of the nature of the meaning of our everyday lived experiences" (p. 9), can lead to a more sensitive understanding of the phenomenon.

The methodological structure we employed was a dynamic interplay among six research activities (van Manen, 1997): (1) turning to a phenomenon that seriously interests us and commits us to the work, (2) investigating experience as it is lived rather than as it is conceptualized, (3) reflecting on the essential themes that characterize the phenomenon, (4) describing the phenomenon through the art of writing and rewriting, (5) maintaining a strong and oriented relation to the phenomenon, and (6) balancing the research context by considering the parts and the whole (pp. 30–31).

Participants and Setting

A sample of six registered nurses and registered practical nurses, all women, who self-identified as having made a decision about administration of PRN medications at least three times for this group of children at the participating centre willingly participated in the inquiry. We purposely sought nurses with three experiences in order to "maximize opportunities to obtain the most insightful data possible" (Morse, 1986, p. 183). Their years of nursing experience ranged from 2 to 30. With the exception of one nurse, who had been there for just under a year, all had worked at the centre since it opened, 3½ years earlier. Three participants had administered PRNs in pediatric acute-care settings before working at this centre.

The participants were recruited from an eight-bed pediatric residential hospice in the Canadian province of Ontario. The hospice provides temporary respite. It welcomes families with children who have a life-limiting illness that results in increased pain and symptoms and a progressive decline in health. Once approval was obtained from the appropriate research ethics boards, recruitment letters were left at the reception desk and distributed via internal mail by the clinical manager. The study was discussed at a staff meeting and recruitment posters were placed in several prime locations throughout the centre. Interested participants contacted the research assistant directly. Formal consent was obtained at the time of interview.

Data Collection

The nurses participated in one in-depth audiorecorded interview — the traditional data-collection strategy in this research approach — with the second author in a private, quiet setting of their choosing. The interviews lasted an average of 90 minutes. Each interview began with the prompt *Share with me an experience where you made a decision about giving a PRN anti-seizure medication in this setting.* The goals of decision-making in this context, accounts of satisfaction and dissatisfaction with their decisions, and factors influencing time and method of PRN administration were explored using a flexible guide with open-ended questions.

Data Analysis

The thematic analysis of the textual data (i.e., the de-identified interview transcripts) was guided by three approaches suggested by van Manen (1997): the sententious or holistic approach, the selective or highlighting approach, and the detailed line-by-line approach. An initial analysis was independently conducted by the authors for each transcribed interview. The resulting aggregate of formulated meanings was organized into clusters of themes. Through the processes of reflection, writing, and rewriting, we transformed these themes into "more phenomenological sensitive paragraphs" (p. 95) using the technique of varying the examples to demonstrate the invariant aspects of the phenomenon as it came into view.

Van Manen (1997) considers an interpretive-descriptive text to be valid when it provides an "adequate explication of some aspect of the lifeworld — [when] it resonates with our sense of lived life" (p. 27), "something that others can nod to, recognizing it as an experience that one has or could have had" (p. 27). We discussed the evolving text with the participants and considered our text trustworthy when they responded with such statements as "That's exactly how I feel" and "I didn't realize others felt the way I did."

Findings

The overarching theme *not on my watch* captures the meaning of nurses' decision-making experiences in this context, which involved finding the right thing to do in each seizure event in such a way that "in the absence of parents, parental care happen[ed]." Nurses' decision-making was a balancing act of finding the right decision for each child and family in the context of the centre's philosophy of enhancing their quality of life. In order to know when to administer a PRN medication, they needed to know the child and parents and be willing to engage in situations of uncertainty, as decision-making often took place in the context of a child's changing seizure patterns.

Bearing Witness

An essential aspect of *not on my watch* was bearing witness, but this was not easy to endure. Nurses described watching a child seize with such statements as "it breaks my heart" and "it really, really hurts." Bearing witness was particularly "distressing" for nurses who were less experienced. It was more difficult when seizures were prolonged or were perceived as causing the child distress, such as when the child had tearing, cried out, made whimpering sounds, or showed signs of physiological compromise. Yet bearing witness was different from nurses' responsibility to be objective observers for the purposes of intervention and documentation. The nurses wanted to ensure that the child was not alone in his or her suffering; they engaged in caring acts, such as patting, stroking, holding and rocking, and giving gentle reassurances.

Being Attentive

Of necessity, *not on my watch* meant being attentive, which meant being on constant alert for any changes in the child's behaviour. It was also an essential strategy for learning to know *this* child. The nurses paid attention to the small but significant details of the child's movements that were indicative of a seizure, such as the "star formation that [one child's] arms and legs go in" or "this child leans to one side and the eyes flutter." Being attentive to *this* child enabled them to recognize the need to engage in decision-making and to verify parental reports when seizures had not yet been captured on an electroencephalogram.

Creating Connectedness

Nurses embraced parental partnerships, and creating connectedness became an essential aspect of *not on my watch* if they were to provide parental care in the parents' absence:

> *With kids with chronic conditions, you feel like you're on a team with them [the parents]; it really is a dialogue. If they're there, you talk to them about the seizures, and if the child is having a seizure when you're both there, you ask them, "What do you think about this one?" They even make the decision and explain why they made it. You develop a relationship with the child and parents so that you feel more comfortable when it comes to making a decision on their behalf.*

The nurses believed that parents were experts in their child's care and regularly sought opportunities for parents to teach them how to identify their child's seizures and about seizure management. Engagement in this type of dialogue facilitated the creation of trust, which influenced nurses' decisions: "I felt like I should have given [Ativan] earlier but I deferred to the parents. Even though she wasn't there, I knew she really knew her child. I trusted her." Nurses were transparent with parents about the seizure events, their decision-making process, and even their uncertainty.

They asked parents if they had done the right thing or if there was another choice the parents would have made.

Doing What Is Right

"I just wanted to do it right. I wanted to treat the ones that should be treated and not treat the ones that [shouldn't be]." The right thing to do during a seizure event was not always easy to determine. Many children lived with extremely complex and unpredictable seizures, ranging from "very quiet, with just an eye roll, a little grimace" to drop seizures, full upper body twitching with head back, to prolonged grand mal seizures with bradycardia, cyanosis, and apnea. Some children also lived with infantile spasms that could easily be confused with seizure activity. Others experienced multiple types of seizures that could occur separately or in combination during the same seizure event, each requiring different medications. Seizure patterns could suddenly change, rendering a child non-responsive to his or her PRN medication. Medications could unexpectedly become ineffective for a type of seizure. One nurse said, "For each of these children there's an evolution in what their seizures look like over time," so that what nurses may have known about a child's seizures on one visit would not necessarily hold true on the next.

Nurses indicated a number of goals for their nursing care. These included stopping the seizure, reducing the number and length of seizures, making the child comfortable, preventing over-sedation, reducing body stress, preventing harm — especially "not hav[ing] the seizure kill the child" — and meeting parental goals for seizure care. The nurses worried about making a decision that would cause parents to lose trust in them. On the one hand, doing the right thing involved seeking a balance between giving children "enough anti-seizure medication so that they're not seizing all the time but not giving them [so] much that they're sleeping all the time"; on the other hand, it involved finding a balance between keeping the child safe until the parents' return and providing seizure care as the parents would have done, sometimes in a context of uncertainty about the parents' wishes, particularly if the child was new to the palliative care program or to the centre. *Not on my watch* is best summarized by the adage "better safe than sorry," an expression the nurses used when alluding to the hidden complexities of their decision-making.

The overarching theme *not on my watch* is supported by four themes simultaneously at play: *being in the know, marking time, seeking a sense of personal comfort,* and *making the decision.* These themes speak to how nurses struggled to create strong connectedness with each child and parent to better enable them to make the right decision.

Being in the Know

Being in the know was not always easy, as some children visited the centre for respite care only once or twice a year. Nurses used the word "knowing" to describe the knowledge they required to make a decision. What to know and ways of knowing constitute this theme.

What to know. Nurses indicated that what to know included seizure disorders as a medical entity: the different types of seizures, seizure presentations, and the consequences of repeated, prolonged seizures, as well as seizure care in general, such as how to monitor a seizure, types and dosages of seizure medications, management of adverse effects of seizures and medications, and administration techniques for specific drugs. It also involved knowing *this* child's seizure story: "It's more who knows the child better than who knows seizures." Knowledge about *this* child's seizure pattern, including frequency, duration, body involvement, intensity, and triggers, helped nurses to discern an important change in the child's condition and to make sense of the event. Knowing who *this* child was in terms of his or her normal behaviour, level of interaction, and mood was essential knowledge for identifying a seizure.

What to know also included parental expectations for *this* child's seizure care — such information as how long to wait before giving a PRN if it was different from the protocol, if and when to call the parents about a seizure and PRN administration, and when to notify the physician. Knowing the parents' comfort level with their child's seizure behaviour was critical to nurses' decision-making, but "sometimes it's a couple of visits before you really get to understand that this PRN has been given a bit more often or not as much at home, and you find out that they tend to just ignore those [particular seizures] because they don't want [the child] too sedated all the time."

Ways of knowing. An essential way of knowing was nurses' dialogue with parents on their arrival at and departure from the centre, during visits, and over the phone during specific seizure events. This knowledge was so crucial that a "getting to know you" form was developed within the first year of the centre's operation. The information gathered from the parents by the admissions coordinator prior to every scheduled admission was translated into a care plan in a standardized format "so that nurses always know where to look for the information." Other written resources that facilitated ways of knowing included the centre's records of the child's previous stays, seizure logs, and seizure protocol. The seizure protocol, provided by parents upon the child's arrival, was a formal letter from the child's neurologist akin to physician orders, detailing the dosage, route, and timing parameters for each PRN. Nurses also frequently turned to their nursing colleagues, the centre's interprofessional palliative care team, and other care providers, such as those at the child's school or rehabilitation centre, to better know the child and family. Knowing the child and parents grew out of the connectedness that developed over time. Nurses gradually learned the child's rhythms and idiosyncrasies as a result of experience with the child as well as from hearing and reading stories about the child: "After they've been to see us maybe two, three, or four times, we know the child better; we know what to expect; we can say, 'He's behaving differently than usual.' You just get a feel for the child because you're more familiar with them."

Marking Time

There was an uncomfortable sensory awareness of time during or surrounding the seizure event, which, nurses admitted, affected their judgement. Time moved too slowly — "It just seemed like forever." Waiting and timekeeping constituted this theme.

Waiting. Waiting was associated with the seizure itself — waiting for it to start, stop, change pattern, and turn into a nurse's worst fear, such as a respiratory or cardiac arrest, or even death. Waiting was also associated with the treatment — waiting to initiate the seizure protocol, repeat the PRN, or administer a new PRN, as well as waiting for the PRN to take effect or for its side effects to wear off. Finally, waiting was sometimes associated with waiting for the other: waiting to connect with parents, physicians, or other health-care providers to help the nurse better know the child and the parents' expectations or to help the nurse make a decision. This experience of waiting and living with mounting worry was described by one nurse, who "prayed, 'Please, please, please don't arrest — don't let this seizure kill you'."

> *That seizure went on for about 5 minutes . . . So we give him the Ativan, but it takes him a little while to respond to it, so we waited a while. But his seizures . . . were getting worse and his [oxygen desaturations] were more prolonged . . . So once the 10-minute mark passed . . . we gave him the second dose . . . Then he started to have decreases in his heart rate . . . so we started getting out the Paraldehyde but . . . it was too soon after the last Ativan and we were supposed to wait a certain time period, like we would have to wait another 10 minutes, which I wasn't comfortable with. So we called the doc and mom and . . . waited for them to come.*

Timekeeping. In the more traditional sense, nurses learned to watch the clock — "a kind of reflex" — as part of routine seizure care; consequently time was experienced objectively when it was being chronologically measured. Ironically, watching the clock helped nurses to control their feelings of distress as they watched the child seize. As one nurse noted, looking at the clock "is a comfort too. You look to it and then you're, like, okay, it's only been this long — because often it feels longer than it is." Watching the clock involved monitoring the start and stop times of the seizure and specific seizure movements, the time of change in the pattern of movement, and the time between each seizure event. It also involved noting the time when adverse physiological events became manifest. Timekeeping was an essential part of the decision-making process, as seizure protocols were framed within specific periods: "For some, if they're having a tonic-clonic seizure for 5 minutes, we treat it, whereas they'll have to have 10 to 15 startle seizures over 10 minutes [before a PRN is given] . . . Others, if they have 10 seizures in 24 hours, you treat at the moment of the 10th seizure."

Timekeeping also consisted of writing it down, which meant documenting the seizure event in a variety of records. One essential informal record was the seizure log, a record of the child's seizure activities that belonged to the parents and travelled with the child. The log was a place where nurses "tried to write as much detail about the timing, just to get the pattern down" and other aspects of the seizure event, such as how it was treated and the child's response to the PRN. Writing it down communicated the child's seizure story and became an essential component of knowing *this* child. Nurses shared the story with the parents, who then shared it with other care providers. In this way, the nurse contributed towards helping others to know the right thing to do. Unexpectedly, writing it down enhanced nurse-parent connectedness and the building of trust. Nurses' written accounts indicated that they had borne witness; demonstrated that what the parents had observed had now been observed by others, making the parents feel less alone; and enhanced parents' credibility when they shared the log in health-care settings where they and their child were not yet known.

Seeking a Sense of Personal Comfort

The nurses experienced a sense of comfort when they perceived that they would be able to do the right thing, specifically to meet the goals and expectations of the child, the parents, the centre, and oneself. Being comfortable with one's decision-making was individual and personal; it was not static; it had a threshold — the point at which distress was experienced. Distress informed nurses that their comfort level had been breached and thus served as a moral compass for their decision-making.

Developing a sense of comfort. Developing a sense of personal comfort with making a decision about PRN administration was intricately and dynamically intertwined with nurses' development of competence and confidence about the various components of seizure care. Experience was the best tool: The greater their exposure to seizure events, the more comfortable they felt. The recognition and trust of parents and colleagues also increased their confidence in their critical thinking abilities and culminated in a "comforting feeling that I didn't do anything wrong."

Being comfortable meant developing a trusting relationship with parents. Nurses described a need to feel secure with the parents' rationale for their decisions about seizure care before feeling comfortable proceeding in a similar fashion. One nurse described her comfort with the decision to bear witness to a child's seizure for 45 minutes without administering a PRN, based on her trust in the parents' decision-making: "I had talked to the family. They knew exactly what they were doing and how they were doing it and what their approach was. And they gave good, intelligent answers [with respect] to their decision. So then I said, 'Okay — we're willing to give this a try with you and see how it works'."

Comfort was also enhanced when nurses' personal values and beliefs about nursing care were or became congruent with the centre's philosophy of care. For example, nurses who had moved from acute-care settings acknowledged that they had initially experienced distress waiting to administer a PRN in a palliative care context. In acute care, stopping a seizure was the primary goal, and, as a result of immediately administering a PRN anti-seizure medication, bearing witness to the seizure event became less frightening: "What the one great thing about the medications is, as a nurse you didn't have to feel totally helpless: 'Good, I can actually do something here'." An indication that nurses had undergone a philosophical transformation was their concern that they might "jump the gun" and needed to learn patience. "When I first started, seizures scared me more, and I think I was less patient with them. Whereas now I'm more patient. I'll watch them for a bit longer before I treat them, because sometimes they will settle out on their own . . . and it's what the parents would have wanted and is a better quality of life for the child if he's not over-sedated." Embracing the centre's philosophy fostered a sense of comfort because it supported the decision to follow parents' wishes, which meant that bearing witness to a seizure with the intention of withholding a PRN (whenever possible) was a legitimate nursing action.

Experiencing distress. Distress regarding the decision-making process was experienced as being scared, frightened, worried, anxious, stressed, and distressed, and it was the antithesis of being in the know. "The first time a child is here and he has a seizure," said one nurse, "you're questioning a lot more about when you should be giving it to him and how often he has seizures and whether this is a norm for them, that kind of thing. Those all have to go through your head." They experienced distress if they began to second-guess themselves or if they perceived an incongruity in the answers to a series of questions they asked themselves during the decision-making process: When should I act? Whose call should I respond to — the child's or the parents'? What is the right thing to do?

Responding to distress. Nurses were never alone. They turned to others for advice or reassurance, particularly if they did not know the child and parents well. Answers to questions such as Is this a bad seizure for him? or Have you seen him do this before? from nurses who knew *this* child well calmed and reassured them about their assessments or helped them readjust their perception of the situation. Physicians offered direction based on what they knew about the child's medical condition and the parents' wishes, although they reiterated that responsibility for the decision remained with the nurse in the parents' absence. One nurse recounted a conversation with a medical colleague: "Ultimately, it's your decision to treat it. You're the one who's there and seeing it." Whenever possible, nurses contacted parents during the seizure event if they were uncertain as to the right course of action; they wanted to ensure that parental goals were met. It was not uncommon for parents to reassure the team with their "calm demeanour" and to choose to be with their child at this time, when they would make decisions together.

Nurses also turned to internal reflection to work through their feelings of distress. Thoughts such as "if only I'd known the parents' expectations for this type of situation" and "if only I'd known this child better" filled their minds for days after an event if they felt they had not "hit the mark." However, each event was a learning opportunity, as expressed in the reflections of one nurse: "I should have figured that one out, but now I know and . . . I'll do better next time." Engagement with others and an internal dialectic brought comfort. A personal transformation in making this type of decision was evident in statements such as "Just because the parents don't affirm the nurse's decision doesn't necessarily mean the nurse made the wrong decision."

Making the Decision

Making the decision about PRN administration in this setting entailed a series of complex cognitive processes. It comprised four elements.

Recognizing a seizure. Nurses were attentive to visual and auditory signs that alerted them to the possibility of a seizure. These cues could be either overt or subtle and were often unique to the particular child, such as the release of a moan, tearing, screaming, and yelling; agitation and irritability; evidence of pain; or inability to interact with or pay attention to the caregiver. Cues could also include changes in the child's colour, breathing pattern, facial features, posture, muscle tension, and physiological responses — anything suggestive of a change in the child's normal behaviour.

Following recognition of a behavioural change, nurses decided whether the behaviour indicated an actual seizure event. They first considered whether it fit with the parents' description of a normal seizure for their child; if it did not, their decision-making increased in complexity. They also considered whether the seizure warranted an intervention. Because some children experienced many seizures in their day-to-day lives, nurses interpreted the event in light of the normal character and frequency of seizures for *this* child. The seizure was also interpreted in relation to its possible threat to the child's well-being: "This one looked like it was bothering him . . . his whole body was involved, so I decided to give the PRN med."

Identifying options. Decision-making involved the identification of intervention options. This included whether to administer a medication, wait and watch, consult with others, administer supportive care, or send the child to the emergency department. If nurses chose to administer a PRN, they identified another set of options, including whether to administer the PRN as per the protocol or earlier than instructed and whether to administer a maintenance medication earlier than scheduled.

Weighing the options. "It's a lot of different things to balance out." Nurses next weighed the options in a complex series of cognitive processes activated in the form of a list of questions rapidly asked and answered, consciously or subconsciously, throughout the seizure event. If an option was congruent with the various goals of seizure care and the seizure protocol, it was usually chosen with confidence and comfort. However, when nurses' experienced feelings of distress, weighing the options became more difficult.

Rethinking the decision. Rethinking decisions was common practice. Nurses debriefed the event with their colleagues at shift report and later with members of the palliative care team. Days later, they often sought out others who had cared for the child during a seizure. They discussed and shared their experience with the parents, looking for cues as to their level of satisfaction. One nurse stated, "After talking to the parents, it has changed how I give medication to some children." Nurses frequently ruminated over having "jumped the gun," wondering whether the seizure would have ended on its own if only they had waited another 2 minutes. Yet they also wondered if they should have acted sooner: "You try and treat the seizure before it gets so bad . . . Maybe [I] waited a little too long to treat that seizure." They struggled with the fact that their decision-making was not always ideal. Rethinking helped nurses to eventually come to terms with the choice made when a sense of comfort had not been achieved at the time of the seizure:

> *We have a child who will seize for an hour and you just sit at his bedside and watch him, and with all your heart you just want it to stop, because it's hard to witness that, but you know that at home this is how they handle it. And you feel like maybe you should be treating it a bit more often. But then, if he's happy, he's having a good quality of life, although he's having a lot of seizures, why am I treating them? He's functioning and the seizures don't seem to be causing any further damage . . . So it may break my heart to watch and I worry that he might be in pain, but the parents want this and he's not lethargic and drowsy and sleeping for 24 hours, so I know the reason behind it and it makes it easier. I can live with the decision.*

Discussion

The findings of this study begin to uncover the complex, largely invisible, nature of nurses' decision-making with regard to the administration of PRNs to children with long-term seizure disorders in a palliative care setting. The findings demonstrate that nurses in this situation can experience tremendous decision-making tension as they struggle to find the right thing to do in each seizure event. Much of the reported tension arose from a desire to make the decision that the parents would make while ensuring that the child not suffer or come to harm on the nurse's watch. Meeting these goals was not always easy, because a child's seizure pattern could unexpectedly change, the seizure protocol did not necessarily fit with what was being witnessed, and sometimes parents' expectations for the imminent situation were unknown.

Some of our findings are similar to those of other researchers. For example, in this study the use of cues emerged as part of nurses' decision-making. This has two interrelated and interconnected core components: cue recognition and weighing of the options. Cue recognition is the sensing of cues that nurses see, hear, feel, or know about the child and the situation. It is an in-the-moment perceptual awareness of visual and auditory cues, combined with the nurse's general knowledge of seizures and specific knowledge of *this* child's story. The finding that clinical decision-making requires attention to specific information, or cue pattern matching, as part of the initial phase in decision-making is supported in the literature (Thomas & Fothergill-Bourbonnais, 2005).

Other salient contextual information that nurses considered included the parents' perspective and the centre's culture and norms. Contextual factors rendered decision-making even more complex and multidimensional. Some of these factors are identified in the literature (Bucknall, 2003). For example, nurses explained that knowing parents and their goals and expectations for PRN administration is often revealed over time through the development of a trusting relationship with them, which enables nurses to individualize decision-making to meet the specific needs of both the child and the parents. As part of deciding how and when to treat a seizure, nurses question whether their decisions are congruent with parental, personal, and the centre's goals for seizure care, as well as the seizure protocol. Nurses carefully determine the significance of their perceptions and corroborate their impressions with those of others in a process of weighing the options, which has been previously reported (Benner et al., 1996).

Decision-making on PRN administration in this context is also revealed as a moral experience. Nurses experience distress if they feel that their decisions might cause parental distress or negatively impact the nurse-parent relationship. They worry that the choices they make might mean that the child will receive less than the best care possible. They worry that they have not done or will not do the right thing on their watch. When nurses express worry or make comments such as "It breaks my heart," they reveal a state of moral distress, defined here as uneasiness about not doing everything one can to fulfil one's moral obligations (Wilkinson, 1987/88). It occurs when there is conflict between a nurse's belief system and the elements of the situation. Concerning the decision about PRN administration in this context, moral distress is often experienced as a result of a moral dilemma: What is the right thing to do in *this* situation? How am I to balance the multiple goals that I wish to achieve during this seizure event? In response to the question What am I to do? — what Frank (2004) describes as a microethical moment — the nurses in this study chose to "hold to the difficult" (Frank, 2004) in the interpersonal, locally contextualized, moment-to-moment. They committed to receptivity and attentiveness to the actual and potential suffering of the child and parents and to meet with parents in an attitude of respect and attention. This required that they engage in bearing witness.

To bear witness is "to dwell" with the child during a seizure event in the sense meant by Heidegger (1971): "to cherish and protect, to preserve and to care for" (p. 347). Bearing witness is the means through which the nurse and child remain engaged even though the child shows a level of absence during the seizure. It allows nurses to be ready to choose another course of action if necessary. It is also a means for nurses to demonstrate their commitment to parents and to ensure that they will not fail them. But as bearing witness is a human experience, nurses suffer when they watch and wait.

Ricoeur (1992) writes of bearing witness: "Because someone is counting on me, I am accountable to another" (p. 165). Levinas (1996) teaches that the meaning of suffering lies in the opportunity for the other to respond to it, to embrace the sufferer and, in so doing, fulfil their humanity and find existential meaning in life. For Levinas, the face is a means through which the vulnerable Other is revealed. As vulnerability is revealed, we realize that we have been summoned to assume responsibility. "The Other becomes my neighbour precisely through the way the face summons me, calls for me, begs for me, and in so doing recalls my responsibility, and calls me into question" (p. 131). The nurses in this study experienced intense feelings of vulnerability embedded in feelings of culpability about their decision-making when they realized that they had the potential to inflict harm on the child and the parents. The distress they experienced during and after some seizure events reveals their awareness of and commitment to the Other.

Decision-making around PRN administration sometimes requires that the nurse choose among the face of a seizing child, the face of a sedated child, and the face of a potentially distraught parent. In the act of administering a PRN, they have a sense of being helpful, of potentially diminishing the harm caused by the seizure. Stopping the seizure also reduces the nurses' suffering. Yet they quickly learn that administering a PRN is not always the best choice. The face of the sleeping child may indicate that the child's quality of life has been compromised because of the loss of connection with their world.

Initially, nurses may be unsure as to how to help the child and are left with doubts and heartbreak as they watch and wait for the seizure to stop or to give them some cue that a PRN is indicated. However, the parent's face also summons them. They feel a responsibility to make the decision that the parents would have made. A sense of comfort with decision-making is most evident when they can respond to both summonses. As this is not always possible, they have to find a way to live with their nursing practice, which includes PRN decision-making.

Kafka (1993), in his short story *At Night,* helps us understand the creation of new meaning. It is the story of a "flock" of people asleep in the open air under a cold sky on cold earth in a deserted region. They are being tended by watchmen, who keep a fire burning as they are attentive to the dangers that lurk nearby:

> And you are watching, are one of the watchmen, you find the next [danger] by brandishing a burning stick from the brushwood pile beside you. Why are you watching? Someone must watch, it is said. Someone must be there. (p. 404)

The watchers remind us of the perils of bearing responsibility; but there is something else in this story — firelight in their hands. Nurses in this setting make choices in relation to others, holding to their values (e.g., parental partnerships, respect and consideration for the parents' needs and for the child's quality of life), and that "holding" leads to a kind of illumination. It is their face-to-face relationship with the child and the parents that reveals the possibilities for their nursing practice.

We suggest that when nurses realize that the goals of seizure care cannot always be met, they find new meaning with respect to the outcomes of the choices they have and the decisions they make. They learn from their own reflecting and parents' feedback that bearing witness is valued. They seek reassurance, particularly from parents, that they have done the right thing in each event, and they learn to live with the heartache entailed in bearing witness. They learn that part of bearing witness is the quality of quietly *being with* the child during the seizure. Bearing witness, in the form of watching and waiting, becomes as dominant a nursing action in this setting as administering a PRN in the acute-care setting. The new meaning that the nurses ascribe to the event results in a reprioritization of nursing actions during other seizure events. Apparently the goal is not to relieve the tension but to develop gratifying relations with the parents. It is conceivable, then, that the experience of moral distress in this type of situation is, as posited by Austin, Lemermeyer, Goldberg, Bergum, and Johnson (2005), desirable insofar as it suggests an ethical sensitivity on the part of the nurse and is a function of moral sensitivity.

Knowing the child and parents is required, so that nurses can provide safe passage during the child's stay at the centre. "Knowing" refers to understanding the child, grasping the meaning of the seizure situation for the parents, and recognizing the need for a particular intervention. Moral distress arises when nurses do not know. However, building connectedness and developing a "responsive interdependence" with parents in order to engage in a relational ethic of care facilitate this knowing. Bergum and Dosseter (2005) teach us that it is in the relationship that possibilities for the right action for a particular situation can be discovered and grasped through discussion and reflection. The relationship with the child and parents provides the nurse an opportunity to consider not only the medical facts about the seizures, but also other components of the child's lived reality — the mind-body-spirit wholeness of the individual as a unique, autonomous person, while each individual is also part of a whole family and a whole community. Certainly, nurses purposely created a relational space for relational ethics to emerge. Decisions were negotiated and renegotiated with the parents as partners in the child's care, in order to create shared meanings about what needed to be done.

How do nurses make the connection that leads to decision-making within a framework of relational ethics? The findings reveal that *how* we enter into conversations and *how* we create the relational space are vital to decision-making. The "getting to know you" form and the pre-admission interviews are examples of how we can set the stage and begin to see each other. Connecting with parents at the time of the seizure event and discussing the decision with them after the event also help to create and maintain this space. Questions such as the following suggest how we might create relational space: What are the most important outcomes for you and your child? Given what is happening, what do you think is the fitting thing to do? Did we do the right thing? Such questions also show us that engaging in decision-making that embraces a relational ethic "requires deliberation, self-questioning, uncertainty, and contemplation" (Bergum & Dosseter, 2005, p. 59). Although ethical questioning and a degree of distress are part of each decision as a result of a relational ethics approach, they can also lead to self-understanding.

Concluding Remarks

We have not reported parents' decision-making, thus limiting the reader's appreciation of the similarities and differences in nurses' and parents' decision-making. The homogeneity of the population is a limitation of this study, and the findings cannot be generalized. However, the findings reveal that a nurse's decision whether to treat a seizure in the pediatric palliative care context can entail intense involvement with the child, parents, and the seizure event. Nurses showed a commitment to relational ethics and to the creation of a legitimate space where parents' voices are welcome, and heard, in the decision-making process. They demonstrated this commitment by creating opportunities to know the child and parents, inviting parents to take part in the decision-making process, and being transparent about their decisions. The findings of this study reveal the moral dilemmas and resulting moral distress that may be experienced in this type of decision, and they advance our thinking about the corresponding tensions and rewards.

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Résumé

Principaux aspects de l'autonomie des aidants d'après les chefs de file en matière de soins à domicile : soins palliatifs et maladie chronique

**Kelli I. Stajduhar, Laura Funk, Faye Wolse,
Valorie Crooks, Della Roberts, Allison M. Williams,
Denise Cloutier-Fisher, Barbara McLeod**

Les personnes qui s'occupent d'un membre de la famille à domicile reçoivent souvent l'assistance d'un service de soins, dont le but est de promouvoir la santé en renforçant l'autonomie des individus. Pour cette étude, les auteurs ont choisi une approche interprétative et une série d'entretiens qualitatifs approfondis. Ils ont examiné la façon dont les chefs de file et les gérants dans le domaine des soins à domicile décrivaient comment ils renforçaient l'autonomie des aidants dans la province de la Colombie-Britannique (Canada). Dans un contexte de restrictions budgétaires où les individus préfèrent se soigner eux-mêmes et mourir à domicile, les participants à l'étude ont décrit comment les infirmières à domicile les aidaient à devenir autonomes. Elles éduquent et informent les aidants, les font participer à la planification et à la prise de décision et les rassurent en leur disant que leur rôle est gérable et appréciable. Si certains participants considéraient que leur autonomie était renforcée (en temps de crise, p. ex.), d'autres pensaient le contraire (l'aide qu'ils recevaient encourageait leur dépendance). On considérait qu'un aidant était autonome quand il était capable de fournir des soins à domicile, avait confiance en ses capacités et pensait que son travail était positif et utile. À long terme, le renforcement de l'autonomie se traduisait par des clients qui étaient capables de se soigner eux-mêmes ou de s'occuper d'un membre de leur famille et qui étaient beaucoup moins dépendants des services officiels.

Mots clés : renforcement de l'autonomie, infirmières à domicile, aidants d'un membre de la famille

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Core Aspects of "Empowering" Caregivers as Articulated by Leaders in Home Health Care: Palliative and Chronic Illness Contexts

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Home-based family caregivers are often assisted by home care services founded upon principles of health promotion, such as empowerment. Using an interpretive approach and in-depth qualitative interviews, the authors examine descriptions of family empowerment by leaders and managers in the field of home health care in the province of British Columbia, Canada. In a culture of fiscal restraint, dying at home, and self-care, participants described how home care nurses empower family caregivers to meet these objectives. This involves educating and informing caregivers, engaging them in planning and decision-making, and reassuring them that their role is manageable and worthwhile. Though some participants viewed providing supports as empowering (e.g., during times of crisis), others viewed them as disempowering (by promoting dependence). Empowered caregivers were characterized as able to provide home care, confident of their capabilities, and believing that their work is positive and beneficial. The long-term goal of empowerment was characterized as client self-care and/or family care and decreased dependence on formal services.

Keywords: empowerment, home health services, home care nursing, family caregivers

In Canada, family caregivers (FCGs) play a critical role in supporting chronically ill and dying persons in the home. FCGs perform their work in the context of home care services founded upon health promoting models of delivery that strengthen one's capabilities to take control of one's health and health care. It has been suggested, for instance, that a health promoting approach to palliative care helps to foster a sense of control in terminally ill patients (Kellehear, 1999). Patient and family empowerment is viewed as promoting physical and mental health, enhancing the quality of care, promoting autonomy, and containing service-delivery costs (Ashworth, Longmate, & Morrison, 1992; Langer & Rodin, 1976; Tulloch, 1995). The concepts of choice, autonomy, and participation are emphasized in definitions of empowerment; however, how "family empowerment" is enacted in clinical practice, within organizations, and by practitioners is not always clear. It could mean, for example, involving FCGs as "co-workers" in a partnership model (Ward-Griffin & McKeever, 2000) or involving them in decision-making (Drought & Koenig, 2002).

Implicit in many empowering approaches is an assumption that all individuals desire and benefit from active involvement in all aspects of care and decision-making. Yet research with acute-care patients, residents of long-term-care facilities, and, to a lesser extent, FCGs suggests that not everyone desires such involvement (Benbassat, Pilpel, & Tidhar, 1998; Catalan et al., 1994; Funk, 2004; Ward-Griffin & McKeever, 2000). Promoting empowerment of FCGs who do not desire it may cause stress, anxiety, fear, discomfort, and dissatisfaction; may be interpreted as a lack of care; and may even be unethical (Ashworth et al., 1992; Guberman, Lavoie, Pépin, Lauzon, & Montejo, 2006; Ward-Griffin & McKeever, 2000; Waterworth & Luker, 1990).

Understanding the potential benefits and risks of empowerment requires knowledge of how empowering approaches are implemented in both chronic and terminal illness situations. If we do not know how "family empowerment" is understood by decision-makers and clinical leaders, we will not be able to develop policies and services that effectively promote FCG well-being.

The purpose of this article is to examine the interpretation of empowerment among home health care leaders and managers in the province of British Columbia, Canada.

Literature Review

Empowerment, defined broadly as the ability to control and/or participate in one's life and environment (Robertson & Minkler, 1994), has been increasingly emphasized in health-services policy and practice. Most definitions focus on the psychological outcomes of empowerment, such as self-efficacy and locus of control, or on behavioural outcomes, such as self-management. Some, however, place the emphasis on self-determination (e.g., "the right and ability to choose by and for themselves"; Aujoulat, d'Hoore, & Deccache, 2007, p. 15) or, more broadly, on structural changes and power relations (Anderson, 1990). Yet others treat empowerment as a professional intervention or process of "providing the proper tools, resources and environment to build, develop and increase the ability and effectiveness of others to set and reach goals" (Hawks, 1992, p. 609). Though there has been less explicit discussion of family empowerment, its definitions are similarly varied. These include a sense of control and self-efficacy in providing care (Che, Yeh, & Wu, 2006;

Hulme, 1999; Magill, 2009; Wilkes, White, & O'Riordan, 2000); perceived positive benefits of care provision (Jones, Winslow, Lee, Burns, & Zhang, 2011); "experiences of inner strength and power and of participation in care" (Wahlin, Ek, & Idvall, 2009, p. 333); and "balance of knowledge, status, authority, and hence, power" (McWilliam, Ward-Griffin, Sweetland, Sutherland, & O'Halloran, 2001, p. 50).

Many authors have critiqued the application of empowerment approaches, suggesting that they ignore power differentials between professionals and individuals, minimize structural barriers and determinants of behaviour, and may be "mis-used" by policy-makers to justify cutbacks in formal services or by nurses as a control strategy (Anderson, 1996; Falk-Rafael, 1995; Robertson & Minkler, 1994). Others argue that true empowerment rarely occurs in practice because of a focus on compliance with health-service objectives (Aujoulat et al., 2007).

Empowerment tends to be interpreted at the level of health-service policy and management, imposed on families in the form of health-care interventions and delivery approaches. To understand the potential benefits and drawbacks of empowerment approaches, we need knowledge about how such approaches are understood by health professionals. Empowerment is an abstract ideal, and there is little clarity around what strategies are empowering, "what actually is covered by the term 'enabling role' and what kinds of skills are required to perform such a role" (Andrews, 1999, p. 280). For instance, empowerment has been operationalized within various types of interventions, from health education designed to enhance self-care, to the promotion of power-sharing in health-care interactions (Johnston Roberts, 1999), to the involvement of families in decision-making and/or the direct provision of care (Li et al., 2003). Empowerment equated with the downloading of responsibilities to families to contain costs may differ from strategies to increase choice in terms of services or care provider. In one study (Funk, Stajduhar, & Purkis, 2011), home care nurses (HCNs) conceptualized family empowerment as respecting and accepting decisions and promoting choice and independence, yet differing and sometimes conflicting interpretations of these ideals were noted, particularly with respect to palliative and chronic illness situations. Other research suggests that HCNs might misinterpret empowerment (McWilliam et al., 2003) as meaning that clients have to "survive the health care system on their own" (Brown, McWilliam, & Ward-Griffin, 2006, p. 164). HCNs may also receive conflicting messages about empowerment in service delivery.

Given the lack of consensus on the definition and operationalization of empowerment (particularly family empowerment), the definitional vagueness that creates space for wide-ranging interpretations, and the risks and potential benefits of empowerment approaches, this study was guided by a single question: *How is family empowerment interpreted and implemented at the management and leadership levels of home care nursing?*

Methods

To address our research question, we applied an interpretive approach, which is well suited to examining participant accounts as constructions of reality and meaning. However, we were also influenced by a critical lens in interpreting participant responses within our knowledge of the political and economic context of home health care in Canada.

We recruited 13 volunteers (3 males, 10 females) from three health-care agencies similar in size. Purposive sampling was used to select participants in a variety of leadership roles: four managers, four directors, one executive director, one social worker, one community resource nurse, one senior home care nurse, and one physician. The participants ranged in age from 42 to 62 years (average = 51) and had, on average, 25 years' experience in the field of health care. Inclusion criteria were that the person (a) hold a management or clinical leadership position at one of the three selected health-care agencies, and (b) be able to comment on the conceptualization and/or implementation of health promoting policies or practices within their organization.

In-depth, qualitative interviews were conducted with the participants by phone. With their consent, the interviews were audiorecorded and transcribed verbatim. The interviews were semi-structured, guided by "trigger questions" designed to elicit data that would help us to understand the philosophy and implementation of empowerment at the organizational level. Questions included the following: What does family empowerment mean to you? How is the notion of family empowerment meaningful to your organization and home care nursing practice? Participants were asked to consider care for both chronically and terminally ill clients in their responses and to focus on family caregiver (rather than client) empowerment.

Guided by an interpretive descriptive approach (Thorne, Reimer Kirkham, & MacDonald-Emes, 1997), members of the research team read the transcripts several times to identify recurring, converging, and opposing themes and patterns of empowerment, illustrative examples, and linkages to theory and the literature. Analytic questions focused on how the concept of empowerment, and its goals or outcomes, were described; whether the concept was adopted by managers; the kinds of HCN work that are described as empowering; and identified facilitators of and barriers to empowerment. Initial transcript review and analytic reflection informed preliminary coding categories applied to the data set in NVivo 8. Pieces of data within each code or theme were reviewed, compared, linked, and contrasted within and across transcripts, the purpose being to develop new codes, refine existing codes and conceptual frameworks, and identify areas for further exploration.

The following strategies were used to enhance the rigour of the study: ensuring that the participants could speak freely by phone at a secure location and transcribing their accounts verbatim; using a trained and experienced interviewer, who also recorded her own "debriefing" field notes for each interview; involving three team members in data analysis; and providing the draft findings to all team members (including those with extensive clinical backgrounds), to inform the development and identification of interpretations and implications.

Findings

The Context: Self-Care and Family Care

Participants' accounts were firmly rooted in a philosophy of home-based self-care and independence: "My job is to try to ensure that you can remain as independent as possible, to live at home for as long as possible." This philosophy extended to the importance of family care, particularly for terminally ill clients wishing to die at home. One participant said that, though the agency supported families, "we try to empower them to . . . manage as much as possible on their own until they're no longer able to." A general imperative of self-care and family care was linked by some to pressure to discharge patients from hospital, "tighten up" home support resources, and reduce home support hours. One participant elaborated: "Where resources are much more scarce . . . the expectation becomes quite high that the . . . loved one and family . . . need to take a large component of this on and/or will have to think of another plan of care." Another noted that in the current resource context HCNs are "being told, 'You've got to pull in the reins, you've got to make sure these people aren't abusing the home support; we've got way too big a home support budget so we need to start cutting back'." Other participants believed that self-care and family care should be promoted as part of a home health care philosophy, regardless of available resources.

The Work of "Empowering"

In the context of a culture of fiscal restraint, dying at home, and self-care, participants described several ways in which HCNs empower both clients and families. In speaking of HCN empowerment work, they frequently described how HCNs educate FCGs, providing them with information about the disease (expected illness progression), care (potential problems and solutions), and resources (negotiating the health-care system; available resources). One participant cited the need to educate the public about the limits of health-care resources. In addition, they explained that nurses teach and "upload" skills to clients and FCGs, mentoring, demonstrating, and modelling care tasks. However, one participant added that it is important not to "overload" FCGs with information and thereby overwhelm or frighten them.

Preparing FCGs by engaging them in planning and decision-making was characterized as an important aspect of empowering. In this respect, participants spoke of developing relationships; assessing preparedness, wishes, and needs; helping families to draw up a care plan; "prompting" families to prepare; and "planting the seed" for future independent decision-making and active problem-solving. FCGs are encouraged to contribute input and express their wishes. HCNs encourage the family to make informed long-term decisions about care challenges and to identify potential problems and solutions. The approach is subtle, with the nurse presenting options and discussing risks, perhaps describing possible scenarios, and encouraging the family to reflect and make choices. This may also involve negotiating with families to match their wishes to, in the words of one participant, "what we can actually provide." Other participants placed greater emphasis on, for example, "discussion with the family members around what their level of involvement is or what they want it to be: listening to them."

Reassuring FCGs was another frequently cited component of empowerment. This included quelling their fears about making mistakes, handling crises, or the quality of their care. Nurses' empowering work involves promoting the idea that family care at home is manageable and beneficial and can be a positive experience. For instance, one participant spoke of indicating to "the family that they are providing really good care, as good [as] if not even better in many ways than an institution could provide for them." Participants said it was important to reassure FCGs that experienced professionals are available to assist them in managing situations, "to let them know that we do have a plethora of other professionals, other clinical support behind us, to draw upon." For one participant, offering reassurance was more than telling families "they can do this"; it was also letting them know that options are available and "it's okay to change their mind." Nurses also reassured FCGs that "it's okay to be worried, it's okay to be concerned" — for example, in instances where clients choose to live at risk.

Other aspects of empowerment work were described to a lesser extent. These included advocating for families' wishes within the health agency; providing formal supports to let the family provide care at home for as long as possible (e.g., in times of crisis); and encouraging FCGs to seek other sources of support if needed and to care for themselves. Some participants referred in a more abstract way to promoting self-care, independence from formal services, and family provision of care. For example, one participant referred to teaching as "you're kind of weaning them into different tasks" such that the family will be able to take over:

> *Whenever there's something that can be handed off, you try to do that. So, as much as possible . . . while you're doing the tasks, if you happen to be the one having to preload all the medications, or you're doing a dressing or you're addressing issues, you try . . . to provide the education that's necessary, so they can do this when you're not there — and be confident doing it.*

Facilitators of and Barriers to Empowerment

Participants' perceptions regarding facilitators of and barriers to empowerment depended in part on their definitions of empowerment. Some perceived client health as influencing empowerment, since illness, and terminal illness in particular, can generate feelings of loss of control and strong emotions within the family. In some cases the empowerment process takes longer. For example, an FCG may need to be instructed about medications multiple times before absorbing the information. The client's wish to remain at home can facilitate empowerment. One participant said that strong client wishes in this regard lead to firmer team attempts to empower the family. Further, to empower families, HCNs need to be able to talk with them about the client; this requires (and is facilitated by) the client's permission.

Participants indicated that a nurse's ability to empower families is affected by FGC capacity: availability, involvement, willingness, health, stress level, prior knowledge, and external resources. With respect to palliative situations, however, one participant noted a potential barrier: "In our culture we've tended to isolate ourselves from the dying process, so there aren't a lot of people that feel overly empowered when it comes to palliative care." Nurses try to work with those family members who are the "most receptive, most able to absorb and process, and [most available]." When the FCG's capacity is low, the nurse faces more challenges and needs more time to empower, or must use different strategies (e.g., encouraging the FCG to seek outside help).

Empowerment work was also characterized as dependent on HCN skill and experience. As one participant stated, highly skilled and experienced HCNs can promote a "sense of power" in families. Personal qualities are also potential influences. For example, it was explained that some HCNs may avoid discussing death with families facing terminal illness because of their own discomfort. Emotional familiarity between the family and the nurse was identified as a barrier to empowerment, as the nurse can become "overly involved in things that really aren't her role."

The clinical tools available to HCNs are important; one participant referred to the lack of "best practice" guidelines for empowering families and the lack of tools for assessing family coping. Lastly, those in management positions referred to their role in hiring nurses with teaching skills and in providing leadership and mentorship for nurses, with a view to an empowerment nursing approach.

The overarching culture (reflected in individual values) was also an influence, particularly for those who perceived empowerment as self/family care and reduced dependence on formal services. Participants referred to the cultural shift away from "dependence on the system" and towards self-management and "supporting their own community" as facilitating empowerment. Home care nursing culture was another factor cited, as it is manifested in HCN role expectations. HCNs who view their role as supporting and teaching facilitate empowerment; barriers include HCNs who adopt a paternalistic "doing for" role (reflective of a traditional, paternalistic service-delivery culture and a medical-bureaucratic, acute-care model) and parallel public expectations "that we . . . do more for people rather than empowering people to do for themselves."

Some participants viewed formal services, including "too much" support or "over-servicing," as potentially disempowering (promoting dependence and discouraging self-care). In contrast, for those who defined empowerment as involving the receipt of formal services (such as intensive in-home nursing care during crisis periods) and the investment of HCNs' time, constraints on such services (e.g., limited financial resources) were viewed as a barrier. For instance, one participant referred to the health-care agency's elimination of the shift-care nursing option (continuous 8- or 12-hour in-home care by a registered nurse for up to 3 consecutive days). This type of intensive support during times of crisis was said to empower FCGs by helping them to cope, thus facilitating caregiving on their own or with minimal support.

Other ways that formal services can facilitate or impede empowerment were also described. Two participants, defining empowerment as decision-making and choice, cited a provincial government program that empowers some clients by allowing them to make service decisions and to directly pay their formal caregivers from designated monies. Another participant, who defined empowerment as having choice, acknowledged that not all families want to be "empowered" to perform care tasks; from this perspective, limited choice within the health-care system is a barrier to real empowerment. Finally, one participant, when asked about health-care policies that support empowerment, cited the Chronic Disease Self-Management Model, explaining that "it affects your care even around palliative patients . . . that approach starts to permeate your practice."

A lack of time was a commonly cited barrier to family empowerment: "In order to empower family members, they need to be given a lot more time with the patient to establish those relationships, to deal with the family to start planning and preparing and educating and modelling." Even in palliative situations, participants noted the importance of having enough time "to work with [family members], and gradually, as there's decline, they're able to take over." The lack of time was linked in part to resource constraints (e.g., on nursing hours and length of visits). One participant suggested that the empowering work of HCNs requires substantial resources (e.g., hours) but viewed this as a barrier in the current context: "I don't think [the health agency] wants to put any extra resources into empowering families . . . with the current budget restraints." In palliative situations, a lack of time also results from the added complexity, the illness trajectory, and late referrals that allow little time for the gradual process of teaching family members. One participant suggested that empowering families takes up more hours in palliative situations due to the intense emotions involved. Late referrals for palliative clients (even though these clients may receive more visits) can impede empowerment, as noted by another participant: "We are under the gun . . . a really short timeline to weave our education and help the family learn at the family's pace." In these situations HCNs may adopt a "doing for" approach, whereas in chronic illness situations they can "be proactive in the teaching, pace ourselves around what the family can manage." Consistency of HCN time with a family can also facilitate empowerment; one participant emphasized this for families that are under stress or that require more direction or connection to one HCN who is familiar with their situation.

The "Empowered" Caregiver

Participants viewed the ideal outcome of the empowerment process as an empowered family caregiver. In this respect, the emphasis was on two goals, capability and confidence, and to a lesser extent on feeling supported and having choice.

One identified goal of empowerment was to enhance FCGs' ability to deliver care. An empowered person was seen as possessing the knowledge, "ability, [and] skills to . . . manage, not just [think] about being able to do something." This included being able to access information, make informed decisions, ask the right questions, and know when to ask for help; perform care tasks (e.g., administer medication, change bandages); care for oneself; cope with often uncertain situations; negotiate the health-care system; and communicate with providers. A few participants said that some individuals, especially those with socio-economic resources, already possessed such capabilities. Most, however, spoke of empowerment as something to be generated rather than as existing qualities.

Participants also indicated that an empowered FCG is aware of and feels confident in and comfortable with his or her capabilities. Possessing information (including information about available resources), for instance, "helps people feel that they can do it, that it's a possibility." One participant's comment illustrates the outcome of confidence:

> *Often, when you get to the end of your involvement, you have family members [who] kind of jokingly say, "I could be a nurse now." They would never have imagined that at the start of the process. But over time, as the need is required and the nurse walks them through, they gain confidence.*

Without confidence, the question of actual capability is moot, because FCGs will not have faith in their abilities, will be frightened or worried, and may refuse to provide care or may call for help more often. Having confidence, in contrast, can facilitate family care and make the experience more positive, comfortable, powerful, and manageable and less frightening and stressful.

Some participants described an empowered FCG as an FCG who accepts the client's choice to live at risk and is able to cope with the attendant worry. Participants also described empowered FCGs as believing that providing care is a positive, beneficial, and satisfying experience: "They can feel good about the care that they have been enabled to provide."

Fewer participants expressed the view that an empowered FCG feels supported by the home care system; receiving support from home care nursing, for instance, empowers families "to make it through the next day and then the next day and then the next day." Others spoke about the confidence that comes from knowing that help is available if needed. Though empowered FCGs were characterized as actively seeking information, input, and/or involvement, behaviours such as seeking out additional resources and support from the health-care agency tended to be described as negative, challenging, or reflecting unrealistic expectations. Some participants explicitly stated that such behaviours reflect a sense of entitlement and thus contraindicate empowerment. One participant suggested that empowerment means understanding the limits of health-care resources and the importance of maintaining a healthy lifestyle in order to avoid inappropriate use of the system.

Some participants referred to family control and choice as outcomes of empowerment. An empowered individual might, for example, perceive that care options exist (such as hospice care as "plan B") and have a sense of "control to make decisions about what you can and can't do or . . . do not feel comfortable doing." An empowered FCG makes choices and has them respected. However, the concepts of choice and control were not frequently characterized by participants as family empowerment goals, with perhaps the exception of the need to support the client's choice to stay at home. In addition, wanting too much control was characterized by some as negative or as "over-empowerment."

The longer-term goal of family empowerment was described by many participants as reduced dependence on formal services and increased self-care or family care in the home environment. Participants suggested that, ultimately, empowered FCGs provide care for a longer period (e.g., they assume responsibility and "do whatever they are able to do"). As a result, clients remain at home and die there. One participant, in describing how HCNs are guided in part by the client's wishes with respect to remaining at home, further implied that empowerment can take the family beyond its comfort level: "If you have a patient who kind of goes with the flow either way, then you may not have that same need to . . . change or empower the family to go beyond what they feel comfortable with." For another participant, empowerment was "embedded in a chronic disease self-management approach" in which empowered FCGs and clients are perceived as managing "as much as possible on their own," with reduced dependence on health services.

Other participants added caveats in their talk about empowerment. One, for example, said that, though empowering families "in terms of being caregivers" is a goal, "we need to let them off the hook when they've reached their limit and allow them to resume their role as the wife or husband or daughter, and not the caregiver." Another cautioned against using empowerment language to enact "power over":

> *. . . using language like "we're empowering you to do this," when in fact the family has no willingness or ability to take that on, but, because there's no other way that it's going to get done, we're "empowering" you to do it. It's an abuse of the term. . . . when we run up against care needs that the system can't provide and we're looking to the family to do it . . . the risk is that we could use that empowerment language to steamroll patients and families.*

Discussion and Conclusions

This study concerned one geographic region with one particular home care delivery structure. It is possible that participants focused on "official messaging" in their accounts, with less emphasis on what actually occurs in practice. Also, we did not systematically question participants about differences between the contexts of palliative and chronic illness, asking them only to consider both contexts together in their responses. However, we found no other study that examines how "family empowerment" is interpreted by those who guide and manage home care. This study therefore represents a valuable and unique contribution to both the research literature, which has focused on empowerment as understood by frontline practitioners, and the practice literature.

Though implicit and explicit definitions of empowerment were highly variable (as in the research literature), there were common emphases. There were few alternative definitions. Particularly rare were definitions highlighting FCG choice and control (such as in care options or level of involvement) and those focused on the provision of formal supports to FCGs (or on the advocacy of families in this regard).

It is important that health agencies, before determining how family empowerment should be implemented in home care, critically reflect on different definitions (including those reported in the literature and those reflected in families' perceptions) and how they might be interpreted. A definition emphasizing reduced dependence on formal services might imply strategies (e.g., in home care guides and public documents) for educating the public about the importance of self-care and family care as well as about realistic expectations of home care roles and responsibilities. In contrast, a definition centring on the role of formal services in empowering families might give more attention to constraints faced in this regard due to budget concerns and home care policies (and strategies for addressing these areas). By discussing and negotiating a standard definition, health-care agencies will be well poised to develop guidelines and best practices for its enactment; this could include considering differences in empowerment approaches and challenges in terminal versus chronic illness situations. In formulating a definition, health-care agencies could (and should) engage in a dialogue with the public.

Participants' comments about family empowerment should be understood alongside their emphasis on independence (including reduced dependence on formal services) and on the client's remaining (and dying) at home by virtue of self-care and family care. Participants focused on HCN work to empower families with respect to these ultimate ends. This includes teaching, training, and promoting the benefits of family care. It also involves reassuring FCGs about their abilities while also reassuring them that help is available if needed. However, as one participant noted, an emphasis on empowerment in the context of independence at home can lead to misuse of the concept ("to steamroll patients and families") in a political and economic climate where families are increasingly expected to provide care. Other studies have also identified the risk of misinterpreting empowerment as compliance (Anderson & Funnell, 2010) or as "power over" (Brown et al., 2006).

Empowerment was seen as facilitated by HCN skills, experience, personal characteristics, and role perceptions. The findings point to the importance of HCN training and communication as well as reflexivity, to promote awareness of how HCNs' own assumptions and comfort levels might influence their approach to family empowerment. Critical thinking must also be encouraged, such that HCNs assess a family's specific wants and needs instead of imposing an empowerment approach on all families.

Successfully empowered FCGs were described as capable of delivering care at home (skilled and knowledgeable; knowing when to ask for help) and confident about (e.g., believing in) their abilities. Equally important, we would argue, are strategies to enhance FCG capabilities and confidence. Failure to focus on both capabilities and confidence could lead to an over-inflated sense of competence in FCGs; those who believe they can manage may not see the need for assistance — which, if they make mistakes or cannot manage, could ultimately result in feelings or defeat or guilt.

Empowered FCGs were described as comfortable with care provision and as experiencing it positively, relatively free of fear and anxiety. The emotional dimension of empowerment was highlighted, with some emotions (e.g., fear and anxiety) described as barriers to empowerment and others (e.g., comfort, satisfaction) as successful outcomes. HCNs need to be skilled in identifying and addressing FCG emotions, as well as in addressing affective (attitudinal) learning outcomes. The deployment of such skills will ensure that reassurance and encouragement do not inadvertently convince FCGs to become "empowered" or coerce them into accepting this role.

Though participants indicated that FCGs should feel supported during crises, they tended to describe advocacy for the support of the health-care agency as challenging and even disempowering. To some extent, empowerment work was seen as inclusive of ensuring that FCG expectations for support match what the system can provide — which has particular implications in the context of health-system reforms that can constrain the availability of resources and services.

FCG capacity (e.g., health, stress level, prior knowledge and ability) was characterized both as an outcome of empowerment and as a baseline factor influencing empowerment. Higher-capacity FCGs (described by some as those with more socio-economic resources) may be successfully empowered more quickly. Therefore, clients in already empowered, higher-capacity families may be more likely to remain at home and die there. Increasing the constraints on HCN time may serve to increase the inequities between higher- and lower-capacity families. One way to reduce such inequities is to assess FCG capacity in a formal and ongoing way throughout the trajectory and devote more time to working with lower-capacity FCGs.

Participants implicitly and explicitly identified the potential benefits of family empowerment for clients (e.g., remaining at home longer), FCGs (e.g., comfort, confidence, a more positive care experience), HCNs (e.g., less time spent on support), and home care administrators and the health-care system (e.g., less reliance on services, cost savings). Fewer participants acknowledged potential risks or negative outcomes for FCGs in particular (e.g., inadvertently coercing or overwhelming FCGs; contributing to feelings of guilt). Awareness of both risks and benefits is essential, to preserve the autonomy and ensure the well-being of those who provide care to family members at home.

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Résumé

Comment les résidents en fin de vie perçoivent-ils le respect et la bienveillance dans les centres d'accueil pour personnes âgées

**Genevieve N. Thompson, Susan E. McClement,
Harvey M. Chochinov**

Bien que le respect et la bienveillance soient les principes de base de la pratique infirmière, on ne sait pas très bien comment les résidents en fin de vie perçoivent ces marques d'attention dans les centres d'accueil pour personnes âgées. Le but de la présente étude est d'examiner si les familles ont le sentiment que la personne qui leur est chère a été traitée avec respect et bienveillance dans le dernier mois de sa vie en centre d'accueil. Une enquête rétrospective a été menée auprès de 208 personnes ayant perdu un proche dans 21 centres d'accueil situés dans une ville du centre du Canada. La majorité des participants a indiqué que le résident avait toujours été traité avec respect ou bienveillance. Toutefois, des différences significatives sont apparues, et toutes les familles ne croyaient pas que leur être cher avait toujours été traité avec respect ou bienveillance. Les écarts de pratique apparents dans les soins sont inquiétants et indiquent que l'on doit prendre des mesures pour y remédier.

Mots clés : respect, bienveillance, centre d'accueil pour personnes âgées, fin de vie

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How Respect and Kindness Are Experienced at the End of Life by Nursing Home Residents

Genevieve N. Thompson, Susan E. McClement, Harvey M. Chochinov

Respect and kindness are core principles of nursing practice, yet little is known about how they are experienced by nursing home (NH) residents at the end of life. The aim of this study was to examine the factors associated with being treated with respect and kindness in the last month of life as an NH resident. A retrospective survey of 208 bereaved family members was conducted in 21 NHs located in a city in central Canada. The majority of participants indicated that the resident had always been treated with respect or kindness. However, significant differences emerged, with not all family members believing that their loved one had always been treated with respect or kindness. The apparent lapses in care practices are troubling and indicate that steps must be taken to address them.

Keywords: respect, kindness, nursing home, end-of-life, older adults

Introduction

Treating nursing home (NH) residents with respect and kindness is a fundamental principle of nursing practice. Respect is a moral obligation to others, and it guides all nursing actions (Browne, 1993). Respect acknowledges the uniqueness of each individual NH resident encountered by nurses in their daily practice. Similarly, kindness derives from knowing the resident first as a person and through expressions of interest and concern (Green, 1995). Both respect and kindness develop through bonding with another human being and are demonstrated by approaching a resident as an equal and by listening to and "being there" for the resident (McGee, 1994; Rousseau, 2001). Considering the vulnerability that is experienced as one approaches the end of life, the provision of care based on the values of respect and kindness is more important than ever at this time. Indeed, research demonstrates that older adults and family caregivers view being treated with respect and kindness by health-care providers as a vital component of end-of-life care (Chochinov et al., 2002; Gardner & Kramer, 2009). Even though treating patients with respect is a primary ethical value (Canadian Nurses Association, 2008) and a critical marker of excellence in nursing practice, little is known about how the concepts of respect and kindness are experienced by those living in an NH at the end of life and by their families.

Literature Review

Excellent care at the end of life presupposes impeccable assessment and treatment of pain and other distressing symptoms; attention to emotional, spiritual, and existential distress; and incorporation of resident and family preferences into the plan of care. For most individuals facing the end of life, having control over their final days, dying in a place of their choosing, and being treated with dignity and respect are central concerns (Chochinov et al., 2002; Steinhauser et al., 2000; Vig, Davenport, & Pearlman, 2002). However, research suggests that quality end-of-life care is often lacking in NHs, resulting in residents dying with their symptoms poorly managed, their psychological or spiritual needs neglected, and their families feeling dissatisfied with the care provided (Teno, Kabumoto, Wetle, Roy, & Mor, 2004; Thompson, Menec, Chochinov, & McClement, 2008; Wetle, Shield, Teno, Miller, & Welch, 2005). It is not clear whether or not the failure to adequately meet these care needs translates into a feeling that one is not being respected or treated with kindness. The literature exploring the concept of dignity indicates that the care tenor (e.g., how a health-care provider interacts with the patient), the continuity of self (e.g., a health-care provider's knowing who the patient is as a person), and symptom distress significantly affect the sense of dignity in those with a life-limiting illness (Chochinov et al., 2002). Respect and kindness are behaviours that are intimately related to the experience of dignity. Therefore, failure to meet the dignity-related needs of residents nearing the end of life may compromise their integrity and cause them to feel disrespected.

To provide high-quality care at the end of life, nurses must be attuned to the needs of residents and families and possess the competence and interpersonal skills needed to proficiently deliver holistic care. Research examining expert palliative nursing care indicates that qualities such as kindness, warmth, compassion, and genuineness are key characteristics of an expert palliative care nurse as identified by patients and by nurses themselves (Johnston & Smith, 2006). These characteristics are echoed in the literature examining caring behaviours demonstrated by nurses. Expressive behaviours and interpersonal processes such as establishing trust, listening to the patient, treating patients with respect, and showing patients compassion and kindness, in addition to demonstrating technical competence, are consistently identified by patients and nurses as central to caring (Papastavrou, Efstathiou, & Charalambous, 2011; Radwin, Farquhar, Knowles, & Virchick, 2005; Smith & Sullivan, 1997).

Few studies have examined how family members assess nurses' demonstrations of caring in the NH environment and the corresponding nursing behaviours associated with caring. However, studies examining family members' assessments of a good death in long-term care have consistently identified the importance of staff empathy, a positive attitude towards caring for those who are dying, promotion of dignity and respect, and collaborative relationships in the delivery of high-quality care, all of which correspond to key caring behaviours (Gardner & Kramer, 2009; Munn & Zimmerman, 2006; Vohra, Brazil, Hanna, & Abelson, 2004). Little information is available on the impact of patient or family demographic variables such as age, gender, or patient diagnosis on the assessment of the perception of caring. The dearth of research in this area and the empirical knowledge required to better understand and predict family members' perceptions and reactions suggest a need to determine whether these perceptions are influenced by variables such as participant gender. The literature certainly indicates that gender, religious belief, frequency of visitation, and family functioning influence satisfaction assessments (Fakhoury, McCarthy, & Addington-Hall, 1996; Howell & Brazil, 2005; Kristjanson, Sloan, Dudgeon, & Adaskin, 1996). Thus it is reasonable to suggest that these factors also operate when kindness and respect are being evaluated. In order to redress this gap, the current study explored the impact of both resident and family member characteristics on perceptions of respect and kindness.

With an increase in the illness acuity, level of cognitive impairment, and frailty of older adults being admitted to NHs, these facilities cannot escape the responsibility of providing end-of-life care to a growing cohort of residents with highly complex care needs. Understanding who is most vulnerable to receiving poor-quality care at the end of life and, more specifically, who is not being treated with respect and kindness, may be one way to uncover patterns of care amenable to improvement. The overarching purpose of this study was to examine the factors associated with NH residents being treated with respect and kindness in the last month of life, as perceived by family informants. For the study, a family informant was defined as the individual self-identified as most involved in the care of the resident in the last month of life. The project was driven by three questions: *How prevalent is treatment with respect and kindness in the NH? How do resident, family, facility, and process of care variables correlate to being shown respect or kindness? Which factors are the most helpful in explaining variation in respect and kindness at the end of life in NH residents?*

Methods and Procedures

This article reports findings from a secondary analysis of data collected as part of a mixed-methods study with bereaved family members examining satisfaction with end-of-life care provided in an NH. Part of the study has been published previously (Thompson et al., 2008). Family participants, identified as the primary contact of residents who either died in an NH or had been transferred to hospital and subsequently died there, were recruited from 21 NHs located in a city in central Canada between May 2006 and December 2008. Family members were eligible to participate if they were 18 years of age or older, were conversant in English, and had been involved in the care of an NH resident who died within the preceding 12 months. Although the research literature suggests that bereaved individuals suffer no distress participating in surveys as soon as 2 weeks after a death (Casarett, Crowley, & Hirschman, 2003), the study solicited persons whose relative had died within the preceding 12 months in order to cause the least possible distress and to minimize recall bias. All potential participants who met these eligibility criteria were mailed a letter from the NH facility on behalf of the researchers. The letter invited those wishing to participate in the study to phone a research nurse and indicate their interest in taking part. Participant eligibility was confirmed during this initial contact. Approval by the University of Manitoba research ethics board and access to the individual NHs were secured prior to commencement of the study.

Measures

The module developed for evaluating NH care in the After-Death Bereaved Family Member Interview (Teno, 2004) was the main instrument used to collect data for the study. The After-Death Interview measures whether the care provided met the needs and expectations of family members and also provides a measure of family members' overall satisfaction with care. Developed on the conceptual model of patient-focused, family-centred medical care, this tool assesses quality of care in seven domains: attending to the family's information needs, advance care planning, individualized care, coordinated care, attending to the emotional and spiritual needs of the family, ensuring the physical comfort and emotional support of the resident, and an overall measure of the quality of end-of-life care. The tool has been validated through retrospective telephone surveys of family members of patients who died in hospice, NH, and hospital settings (Teno, Clarridge, Casey, Edgman-Levitan, & Fowler, 2001). Due to the use of skip patterns in the questionnaire, the questions in several of the domains are answered by a very small number of respondents. This affected the Cronbach's alphas in the current sample: inform and promote shared decision-making (0.69), encourage advance care planning (0.62), focus on the individual (0.79), support self-efficacy of the family (0.68), provide coordinated care (0.38), and attend to the emotional and spiritual needs of the family (0.37). As the After-Death Interview has little content regarding contact and communication with nurses and nursing assistants, respondents were asked additional questions exploring the communication of information by nurses and nursing assistants. The Cronbach's alpha for this domain was 0.70.

Five questions from the Nursing Facility Family Satisfaction Questionnaire, developed by Castle (2004), were added to evaluate the NH environment. This series of questions, comprised of 10-point Likert scales, ask respondents to rate how "home like" the facility was, how clean it was, the temperature of the resident's room, if they were able to make the resident's room "home like," and how private the room was. The reliability and validity of the instrument has been established, with Cronbach's alphas for the domains ranging from 0.77 to 0.86 (Castle, 2004).

The responses to the After-Death Interview questions are measured through a variety of response categories, including (a) ratings on a scale of 0 to 10; (b) four-point scales ranging from *always* to *never*; (c) three-point scales (e.g., receiving *less than was needed, more than was needed,* or *just the right amount* of care); and *yes/no* response options. For the purposes of our analysis, all were dichotomized to describe quality care (e.g., the right amount) versus less-than-desirable care.

The main outcomes of interest, respect and kindness, were assessed using two questions: *In that last month, how often was [the resident] treated with respect by those who were taking care of [him/her]? In that last month, how often was [the resident] treated with kindness by those who were taking care of [him/her]?* Responses to these questions were coded on a four-point scale (*always, usually, sometimes, never*).

The survey also gathered resident and family demographic information such as age, gender, medical diagnosis of the resident, presence of Alzheimer's disease or dementia, religious affiliation, length of time in NH, visitation patterns, and participant's relationship to resident.

Procedures

As the After-Death Interview is personalized (e.g., the name of the resident is inserted into the questions), it is read to participants rather than being self-administered. Thus the survey was conducted by a research nurse either by phone or face-to-face, as arranged with the family informant at a mutually convenient time and location. The majority of the interviews were conducted by telephone (n = 182) rather than face-to-face in the participant's home (n = 26). The average interview lasted 52 minutes (range = 20–120 minutes; *SD* = 18 minutes) and took place 7 months after the death of the resident (range = 2–16 months). Verbal consent was obtained from participants interviewed by telephone and written consent from those seen in person.

Data Analysis

Participants who reported that the resident was *sometimes, usually,* or *never* treated with respect or kindness were compared to those who reported that the resident was *always* treated with respect or kindness. Descriptive statistics were used to describe the demographic characteristics of the sample. Chi-square tests were calculated to compare those participants reporting positive experiences (i.e., *always* treated with respect or kindness) to those reporting less desirable experiences. To examine the dimensions that were uniquely associated with reports of being treated with respect or kindness, we performed multivariate regression analyses, using a stepped approach, entering those variables found to be significantly associated at $p < .05$ in bivariate analyses into the model. In this approach, the first phase of model-building consisted of entering significant resident and family demographic variables, including diagnoses and gender. A stepwise procedure was used to select model variables, with $p < .05$ considered statistically significant. In the second phase, those variables related to the resident's death, such as place of death, hospital transfers, and expectations of care, were added into the resulting model from step one. Statistically significant variables were retained in the model. In the final phase of analysis, variables related to the process of care, such as communication, and provision of emotional support were entered into the previous model. Analyses were performed using SPSS version 18.

Results

Sample Characteristics – Decedents and Respondents

A total of 922 letters were mailed to potential respondents. Of those who were mailed a letter, 208 contacted the researchers and were interviewed, for a response rate of 22.6%. Reminder letters were sent during the first year of data collection, but this failed to improve the response rate. Thus a decision was made to discontinue this practice during subsequent recruitment. Provincial privacy laws precluded the collection of specific information regarding non-responders. However, the profile of the respondents is comparable in terms of age, gender, length of stay, and prevalence of dementia to those of samples used in a number of studies examining family satisfaction with NH care (Teno et al., 2004; Vohra et al., 2004; Wetle et al., 2005) in addition to information available on the

NH population in the province of Manitoba (Doupe et al., 2006; Menec, Nowicki, Blandford, & Veselyuk, 2009).

A post-hoc power analysis was conducted using GPower statistical software (Faul & Erdfelder, 1992), to ensure that the sample size was sufficient to permit both precise estimation of predictive strength and a substantial degree of power in determining significance in multiple regression analyses. A sample size of 208 would permit the use of 10 predictor variables in the model and would result in an 88% power of detecting a significant model, assuming a type 1 error rate of 0.05.

Exploring the characteristics of the residents who died, nearly 60% (*n* = 124) were female and the mean age was 87.5 years. A total of 121 (58.5%) were reported to have had either dementia or Alzheimer's disease. The residents were diagnosed with an average of 4.8 medical conditions (range = 0–13). The average length of stay in the NH was 31.9 months (range = 2 weeks–180 months). The majority of residents died in the NH (*n* = 188; 90.4%), the remainder in hospital (*n* = 20; 9.6%). Of the 208 decedents, 64 (40.8%) had been transferred to hospital in the last month of life.

The participating family members had a mean age of 62.5 years and 146 (70.2%) were female; 157 (75.5%) were the adult children of residents; 92 (44.5%) reported having visited the resident two to five times per week, with 73 (35.3%) reporting daily visits and 42 (20.3%) other visitation patterns.

Table 1 shows the distribution of scores on the respect and kindness items. No participants indicated that the resident had *never* been treated with respect or kindness. Of those reporting less-than-desirable care, 33 (16.1%) reported that the resident had *sometimes* or *usually* been treated with respect and 43 (17.4%) that the resident had *sometimes* or *usually* been treated with kindness. The majority of respondents reported that the resident had *always* been treated with respect (82.7%) or kindness (78.8%) in the last month of life. Though respect and kindness are highly correlated (*r* = .78, *p* = .01), the decision was made to examine them as unique variables in order to explore their conceptual overlap and distinctiveness.

Table 1 ***Distribution of Respect and Kindness Scores***

	Always		**Usually**		**Sometimes**		**Never**	
	n	**%**	***n***	**%**	***n***	**%**	***n***	**%**
Respect (*N* = 205)	172	82.7	27	13.0	6	2.9	0	0.0
Kindness (*N* = 207)	164	78.8	36	17.3	7	3.4	0	0.0

Table 2 *Univariate Analysis of Respect and Kindness*

Variable	Respect				Kindness			
	Always %	**Not Always %**	X^2	p	**Always %**	**Not Always %**	X^2	p
Death in NH	86.5	13.5	9.40	.006**	81.8	18.2	7.90	.009**
Died in place wanted to	88.9	11.1	4.40	.04*	85.0	15.0	4.60	.03*
Not transferred to hospital in last month of life	86.8	13.2	3.17	.11	85.2	14.8	4.40	.03*
Death a surprise to family member	86.4	13.6	2.75	.14	71.9	28.1	2.39	.13
Palliative care program involved	84.6	15.4	.019	1.00	84.6	15.4	0.28	.74
NH not-for-profit	84.5	15.5	0.18	.66	80.8	19.2	0.91	.33
NH not religiously affiliated	84.7	15.3	0.19	.69	79.4	20.6	0.006	1.00
Nurse never provided confusing information	89.9	11.0	17.68	.00***	84.8	15.2	15.70	.00***
Nurse provided right amount of information	89.4	10.6	19.70	.00***	85.9	14.1	22.40	.00***
Nurse listened to concerns about care of resident	86.5	13.5	19.10	.00***	82.9	17.1	26.50	.00***
Nurse responded to concerns about care of resident	88.8	11.2	34.30	.00***	84.5	15.5	29.50	.00***

Family was kept informed about resident	93.8	6.3	33.60	.00***	88.9	11.1	26.16	.00***
Staff knew medical history of resident	88.7	11.3	25.80	.00***	83.2	16.8	16.00	.00***
Family/resident input in decision-making	87.2	12.8	25.88	.00***	81.1	18.9	2.29	.16
Resident had specific wishes for end-of-life care	83.7	16.3	.045	.83	79.6	20.4	0.009	1.00
Discussed end-of-life wishes with staff	81.8	18.2	.28	.67	80.5	19.5	0.46	.57
Care provided consistent with wishes	84.9	15.1	.39	.67	84.9	15.1	3.07	.08
Resident had advance care plan	82.9	17.1	.41	.61	77.7	22.3	1.57	.24
NH respected advance care plan	84.4	15.6	.84	.31	79.3	20.7	0.25	.64
Personal care needs addressed	95.6	4.4	41.13	.00***	91.4	8.6	37.25	.00***
Enough staff to help with activities of daily living	95.2	4.8	50.18	.00***	87.8	12.2	27.94	.00***
Enough staff to help with medications	90.3	9.7	44.31	.00***	84.7	15.3	27.04	.00***
No concerns about care when family not present	92.0	8.0	7.91	.005**	86.9	13.5	4.74	.03*
NH staff talked about how it might feel after death of loved one	97.3	2.7	6.08	.01**	94.6	5.4	6.35	.01**
Providing right amount of support with feelings about resident's death	90.5	9.5	21.78	.00***	85.3	14.7	15.6	.00***

(continued)

Table 2 *(cont'd)*

Variable	Respect				Kindness			
	Always %	Not Always %	X^2	p	Always %	Not Always %	X^2	p
Expectations of end-of-life care met	90.1	9.9	24.90	.00***	84.8	15.2	12.1	.001***
Staff talked to family about their spiritual needs	90.0	10.0	3.47	.07*	82.9	17.1	.97	.37
Staff provided information on who to turn to if feeling stressed	91.1	8.9	1.98	.24	82.6	17.4	.33	.68
No pain in last month of life	87.5	12.5	.87	.40	81.3	18.8	.22	.71
No difficulty breathing in last month of life	86.5	13.5	.53	.55	80.2	19.8	.06	.86
No anxiety or sadness in last month of life	87.0	13.0	1.98	.18	81.7	18.3	1.00	.32
Experienced no other symptoms at end of life	88.9	11.1	9.72	.003**	82.4	17.6	3.32	.84
Diagnosed with dementia	85.0	15.0	.29	.70	82.6	17.4	2.2	.16
Less than 5 medical conditions	87.0	13.0	2.62	.12	81.8	18.2	1.5	.29
Male family participant	91.9	8.1	4.30	.04*	83.9	16.1	1.160	.35

* $p < .05$ ** $p < .01$ *** $p < .001$

Differences in Respect and Kindness

Significant differences emerged in the experiences of family members. Some felt that the resident had always been treated with respect or kindness and others felt the resident had not, as reported in Table 2. Characteristics of the resident's death, such as occurring outside the facility, occurring in a place that was "home" to the resident, or transfer to hospital in the last month of life, impacted on whether the family member believed that the resident was treated with respect/kindness. The only variable related to the NH environment that was significantly related to the perception of being treated with respect or kindness was the score on the Nursing Facility Family Satisfaction Questionnaire assessing the long-term-care environment (respect: $t(191) = 5.44$, $p = .000$; kindness: $t(193) = 4.54$, $p = .000$).

Communication between the family and staff also played a significant part in perceptions about whether the resident was treated with respect/kindness. Receiving clear information, receiving the right amount of information on the care and condition of the resident, and being kept up-to-date about the condition of the resident significantly influenced perceptions about respect/kindness. The family and/or the resident having played an active role in decision-making resulted in a feeling that the resident had been treated with respect more often than when decisions had been made without input from either the family or the resident. This relationship was not significant for kindness. No variables related to advance care planning, such as having an advance care plan, discussing wishes related to end-of-life care, or feeling that NH staff respected an advance care plan, were significantly related to feelings of being treated with respect/kindness.

Ensuring that the resident received intimate care, such as bathing, dressing, and feeding, and having adequate staff to deliver this care, impacted on family perceptions of whether the resident was treated with respect/kindness. Similarly, when there were staff available to provide the resident with their requisite medications, respect/kindness was more likely to be perceived. Family members who voiced concerns about the care being provided when they were not present were more likely to report lack of respect/kindness.

Attention to the emotional well-being of family members also affected their assessments of respect/kindness. When family members reported that NH staff talked to them about how they might feel after the death of their loved one, when they believed that they had been provided with the right amount of support in dealing with their feelings about the impending death, and when their expectations around end-of-

Table 3 ***Multiple Regression Analysis of Respect Score on Significant Univariate Variables***

Variable	**B**	**SE B**	β
(Constant)	.490	.26	
Died in NH	-.16	.08	-.14
Died in place wanted to	-.04	.05	-.06
Long-term-care environment score	-.002	.004	-.04
Staff knew medical history of resident	.212	.10	.16*
Decisions made without family/resident input	.036	.11	.02
Personal care needs addressed	.246	.06	.32***
Family kept informed of resident's condition	.131	.06	.16*
Nurse never provided confusing information	.111	.09	.103
Nurse provided enough information	.225	.08	.23**
Nurse listened to concerns about care of resident	.236	.19	.14
Nurse responded to concerns	.128	.18	.09
Family had concerns about care when not present	.041	.134	.03
Enough staff to help with activities of daily living	.166	.07	.20
Enough staff to help with medications	.032	.10	.03
Staff provided emotional support to family	.165	.078	.15*
Staff talked about how family might feel after the death	.082	.06	.09
Care provided was what was expected	.011	.07	.01
Resident had other symptoms at end of life	.045	.05	.06
Family member gender	-.009	.05	-.01

* $p < .05$ ** $p < .01$ *** $p < .001$

Table 4 ***Multiple Regression Analysis of Kindness Score on Significant Univariate Variables***

Variable	**B**	**SE B**	β
(Constant)	.737	.410	
Died in NH	-.186	.11	-.18
Died in place wanted to	.070	.08	.09
No hospital transfer in last month of life	.088	.08	.12
Long-term environment score	-.006	.007	-.09
Staff knew medical history of resident	.230	.13	.19
Personal care needs addressed	.205	.06	.24***
Family kept informed of resident's condition	.199	.07	.23**
Nurse never provided confusing information	.228	.07	.21**
Nurse provided enough information	.081	.09	.07
Nurse listened to concerns about care of resident	-.129	.24	.07
Nurse responded to concerns about care of resident	-.398	.21	.29
Family had concern about care when not present	.343	.22	.22
Enough staff to help with activities of daily living	.034	.11	.04
Enough staff to help with medications	.136	.15	.11
Staff provided emotional support to family	.223	.08	.20**
Staff talked about how family might feel after the death	.040	.09	.03
Care provided was what was expected	.108	.11	.11

* $p < .05$ ** $p < .01$ *** $p < .001$

life care were met, family members more likely to indicate that the resident had been treated with respect/kindness.

Finally, differences in the assessment of respect/kindness emerged based on the medical profile of the resident, the symptoms experienced in the last month of life, and the demographic characteristics of the resident and the family member (Table 2).

Predictors of Respect and Kindness

Multiple regression analysis was performed to further examine the relationship between respect/kindness and the variables found to be significant in the univariate analyses. As noted in Table 3, a significant model of respect ($F = 31.01, p = .000, R^2 = .56$) emerged, accounting for 56% of the variation in respect, with independent contributions from the following: staff knowing the medical history of the resident in order to provide care, staff addressing the personal care needs of the resident, family members being kept up to date and informed about the care and condition of the resident, the family receiving the right amount of information about the care of the resident, and family members being provided emotional support by the staff.

Table 4 reports the significant model for kindness ($F = 17.75, p = .000, R^2 = .47$), which accounts for 47% of the variance in kindness, with the following variables entering into the model: addressing the personal care needs of the resident, family members being kept up to date and informed about the care and condition of the resident, being provided clear and concise information by the nurse regarding the care of the resident, and family members feeling they are provided with emotional support by the staff.

Discussion

This study is, to the best of our knowledge, among the first to describe, from the perspective of family informants, how respect and kindness are experienced by NH residents at the end of life. Slightly more than 82% and 78% of respondents indicated that the resident was always treated with respect and kindness. There is no benchmark against which to measure our results and to determine whether our findings are similar to others. Ideally, 100% of persons in care at the end of life will feel they are treated with respect and kindness. However, our results suggest that there are instances when this is not so. Although respect and kindness are highly correlated and many factors associated with one or the other are similar, there are situations in which they are different. It appears that the place of death influences a family member's assessment of whether the resident has been shown respect and kindness. A home death has been identified as a hallmark of a good death and as a goal for most individuals (Gardner & Kramer, 2009; Stajduhar, Allan, Cohen, & Heyland, 2008). In this study, when the death occurred in the NH — the resident's "home" — respect and kindness were more likely to be reported by the family. Family members of residents who did not consider the NH their home and would have wanted to die elsewhere (most frequently identified as their last place of residence before being admitted to the NH) were more likely to report respect and kindness as lacking. It may be that when death occurred outside the NH, or when the resident did not consider the NH "home," either care failed to meet the family's expectations or the family harboured guilt about NH placement. Thus, it may be not that NH staff failed to respect or treat the resident with kindness, but, rather, that the family member's assessment of the resident's treatment by staff was tainted, because of the family's projecting its feelings of having betrayed the resident by placing them in an NH.

Transfer to a hospital in the last month of life also affects a family's perception about whether the resident was treated with kindness, but not their assessment of respect. Families describe an NH resident's transfer to hospital as something they wish to avoid (Wilson & Daley, 1999), yet the literature tells us that between 30% and 60% of NH residents are hospitalized at least once in their last 6 months of life (Menec et al., 2009; Ramroth, Specht-Leible, Konig, & Brenner, 2006). It may be that family members perceive this transfer as burdensome and stressful for the resident and wish the medical care could have been provided in the NH.

It is not surprising that communication, information-sharing, and meeting residents' personal care needs were key factors influencing family members' feelings about whether respect and kindness were shown. These factors were also identified in a study with cardiac patients and their spouses, which found that attention to needs, empathy, provision of information, dignity, care, recognition of individuality, and autonomy were central to the manifestation of respect (Dickert & Kass, 2009). Respect is conveyed by care providers' body language and verbal language; by listening with interest, providing clear information, and asking the family questions that help to uncover the resident's true nature (Browne, 1993; Jonasson, Liss, Westerlind, & Bertero, 2010). As found in the regression analyses, respect is driven by having intimate knowledge of a resident's medical history — that is, knowing something about the individual. Research into aspects of dignity has found that, like respect, dignity is augmented when care providers "know" the resident (Chochinov, 2004). To show kindness is to be caring, considerate, and attentive to residents' needs (Whitbread, 2008). Given that knowing the resident plays such a large role in kindness and respect, exploring ways to promote resident-centred care is essential. Constructing life stories is one way for health-care providers to begin to know the resident as a person, with his or her unique values and needs (Whitbread, 2008). Dignity therapy in particular may be a mechanism for bolstering one's sense of purpose and meaning, and thus one's dignity (Chochinov et al., in press; Thompson & Chochinov, 2008).

Family members reported that receiving emotional support and talking with a health-care provider about how they might feel after the death of their loved one played a role in their assessment of whether the resident was shown respect and kindness. A tenet of palliative care is that the patient and family are the unit of care (World Health Organization, 2010), and responding to the psychosocial needs of family members is an important part of providing quality end-of-life care. Research has shown that there is a synchronicity between resident and family experiences, particularly in the instance of witnessed suffering (Spichiger, 2009). For example, one study found a direct correlation between patients' quality of life before death and the quality of life of bereaved family members (Wright et al., 2008). The study also found that bereaved caregivers experienced poorer quality of life, more regret, and greater risk of developing a major depressive disorder when there were no end-of-life conversations between physicians and the patient or when aggressive interventions were used. In most instances the suffering of family members was proportionate to that of the patient.

In our study, certain demographic characteristics of residents and family participants were significantly related to the perception of whether the resident had been shown respect/kindness. For example, if, during the last week of life, the resident experienced distressing symptoms such as restlessness, agitation, or confusion, family members perceived the person as not being treated with respect. Competently treating these troubling symptoms and relieving distress can be a challenge for health-care providers working in an NH, who often feel helpless to manage such symptoms (Hall, Schroder, & Weaver, 2002; Hanson et al., 2008; Travis, Conway, Daly, & Larsen, 2001). Being witness to a loved one suffering from these symptoms near the end of life is particularly distressing and may cause one to feel dissatisfied with the care being provided. It is interesting to note that male relatives were more likely than female relatives to indicate that the resident was not always treated with respect; no research examining the impact of gender on assessments of respect could be found to corroborate this finding.

Implications for Research, Education, and Practice

The findings of this study have implications for future research, education, and practice. Future research could further examine and explore respect and kindness as they are experienced at the end of life from the perspective of NH residents. Though the perspective of family members is valuable, understanding the congruence between family and resident assessment of respect and kindness will help to distinguish between family perceptions that may be tainted by guilt over placement and the care that is actually delivered. Family members indicated that hospital transfers affected their assessment of whether the resident was treated with kindness; further research with family members could explore factors that influence this perception. Research examining the perspectives of hospital staff caring for transferred NH residents is also warranted, and could provide insight regarding the environment and care ethos into which residents are being placed. Future work could further explore the ways in which nursing communication and the timing of information delivery influence the assessment of respect and kindness in end-of-life care.

With respect to practice and education, it is essential that nurses working in the NH environment develop empathetic relationships with residents and their family caregivers, built on a foundation of respect and kindness. The most significant predictors of sensing respect and kindness in this context were nursing communication behaviours. This requires the development of educational initiatives to help nurses feel comfortable and confident in delivering difficult information about the care and condition of the resident at life's end. As staff consistently identify the provision of emotional support to families as a challenge, ongoing educational initiatives in this realm are also important. Finally, unrelieved symptom distress affects family members' perception of the care being provided. It is essential that NH staff be kept current in their knowledge regarding the detection and treatment of the restlessness and agitation that can occur at the end of life. It is critical that opportunities for ongoing education in palliative care symptom management be provided.

Limitations

These findings must be placed in the context of the study's limitations. The cross-sectional nature of the study precluded assessment of casual relationships. We therefore cannot conclude whether a lack of respect or kindness drove some of the relationships we noted between the variables examined, or vice versa. It may be that what this study has identified are the constituents of kindness and respect. In this regard, the factors identified in the regression models may constitute elements of being kind or respectful towards residents and their families. For example, to be kind or respectful is to anticipate the information that a family needs and to communicate it proactively.

Surveys of bereaved family members are an important tool for assessing quality of care at the end of life. However, previous research indicates that emotions such as grief, guilt, burden, or stress can shape assessments of care, and thus evaluations may reflect the mood or needs of the proxy respondent (Hinton, 1996; McPherson & Addington-Hall, 2003). Therefore, it may be that assessments of respect or kindness are influenced by respondents' wish that their loved one had indeed always been shown this level of caring.

An additional limitation is that the After-Death Interview may not capture the full range of roles that nurses and nursing assistants play in the NH, and thereby omit scenarios that could influence perceptions about respect and kindness. One area that was obviously lacking in the survey was contact and communication with nursing staff. The researchers took steps to remedy this situation by adding a series of questions to address this fundamental area. The low Cronbach's alpha for many of the domains in the After-Death Interview precluded the calculation of domain and problem scores, as suggested by the tool developers. To overcome this limitation, the decision was made to analyze the responses to the individual questions making up the domains.

The non-probability sampling approach and the low response rate by eligible participants could have resulted in a skewed sample, with those who experienced extremes in care perhaps being more willing to participate than those for whom care was "uneventful." However, given the variability across the scores on the After-Death Interview, this does not appear to be the case.

Finally, the use of secondary analysis is not without methodological concerns. The use of secondary data analyses presents researchers with challenges related to how the original data were collected, the sampling procedures used, the relevance of the original data to the questions currently being posed, and shortcomings in the original measurement tools (Clarke & Cossette, 2000). These challenges were largely overcome in this study due to the fact that the original data set was collected by the first author (GT) for her doctoral studies, and she therefore has intimate knowledge of its strengths and limitations.

Conclusion

To be treated with respect and kindness by health-care providers, especially at the end of life, is a fundamental right of all nursing home residents. The finding that there may be instances when respect and kindness are not being shown is troubling, and steps must be taken to correct such lapses in care. Educational initiatives in NHs need to discuss the concepts of respect and kindness and ways to promote respectful behaviour. Due to the paucity of research in this area, further studies of how respect and kindness are experienced by NH residents and families as the end of life draws near are warranted. We must always remember, however, that being human is the only requisite for receiving respect and kindness, both of which are essential to the preservation of one's dignity.

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Happenings

Seven Years of Completing the Circle: End-of-Life Care With Aboriginal Families

Mary Hampton, Angelina Baydala, Carrie Bourassa, Betty McKenna, Gerald Saul, Kim McKay-McNabb, Ken Goodwill, Velda Clark, Jeff Christiansen

Cross-cultural end-of-life health care is described in the literature as a dynamic new direction for research and treatment (Field, Maher, & Webb, 2002; Searight & Gafford, 2005). A recent review of the Canadian literature suggests that there are distinct cultural differences with respect to Aboriginal families (Kelly & Minty, 2007). Over the last 7 years, culturally appropriate end-of-life care with Aboriginal families in the Canadian province of Saskatchewan has been the focus of our research team at the University of Regina. We have learned a great deal about ways in which Aboriginal families are poorly served at end of life by the health-care system and ways in which they could be better served.

Our interdisciplinary team is composed of both Aboriginal and non-Aboriginal academic researchers, Aboriginal guiding Elders, and health-care providers who direct palliative services in our health region and/or services offered at a freestanding bereavement centre in our region. Together we have been able to create space for Aboriginal Elders and community members to speak about culturally appropriate end-of-life care for Aboriginal families.

What Is the Problem?

End-of-life health care is a high-priority international research topic among First Nations peoples due to their growing populations, higher mortality rates, and types of death (Kelly & Minty, 2007). For example, in Saskatchewan the Aboriginal population was estimated to be 14% of the total population in 2001 and is projected to reach 21% by 2017. Although older people in First Nations make up only 3% to 5% of Canada's population, as compared to 11% in the non-Aboriginal population, mortality rates among Aboriginal Canadians of all ages are four to five times those for the non-Aboriginal population (Ross, Fisher, & MacLean, 2000). In Canada in 2001, Potential Years of Life Lost (PYLL), a measure of mortality, was approximately 3.5 times higher for Aboriginal peoples than for the non-Aboriginal population (Allard, Wilkins, & Berthelot, 2004). The main contributing factor in the increased PYLL among Aboriginal peoples is "injuries," which include accidents, suicides, and homicides. The higher mortality rate and growing chronic illness rates (including HIV/AIDS) among Aboriginal peoples suggest a need for culturally appropriate end-of-life health care (Waldram, Herring, & Young, 2000).

Nurses and social workers have expressed a desire to provide culturally appropriate end-of-life health care for Aboriginal families and individuals, but there are formidable barriers in the health-care system. These barriers include difficulties with cross-cultural communication, lack of cross-cultural awareness, organizational barriers within the Western health-care-delivery system, and lack of flexible support (Hampton, Baydala, Drost, & McKay-McNabb, 2009). Thus existing services are underutilized, even in the face of higher mortality rates in the growing indigenous populations.

Description of Our Research

The goal of our research team has been to raise awareness about appropriate Aboriginal end-of-life health care among non-Aboriginal health-care providers. We have produced multiple videos featuring Aboriginal Elders speaking about end of life. Two of these are being widely disseminated: a short video and accompanying PowerPoint presentation for non-Aboriginal health-care providers, and a longer video documenting traditional end-of-life protocol for Aboriginal families (see, for example, http://uregina.ca/hamptoma/). These videos have been well received by health regions, Aboriginal health-care agencies, academic institutions in seven provinces/territories, and more than 75 audiences. Video has proved to be a powerful medium for conveying narratives of Aboriginal Elders and community members to a wide audience.

We have used an "organic" method of video production, identifying knowledgeable Aboriginal Elders at pow-wows. We ask the Elders what messages they would like to convey to health-care providers. This method differs from the didactic, scripted approach to cross-cultural education. Our method is congruent with our goal of raising awareness about traditional cultural beliefs and protocol using traditional Aboriginal ways of knowing and teaching. One of our participating Elders recently passed away; his family requested copies of the completed video and the original interview videotape so that his words could guide them as they honoured his journey. Thanks to the credibility and hard work of our diverse, collaborative research team, we are establishing trust among Aboriginal Elders and communities by proceeding in a culturally appropriate and thus ethical manner (Baydala, Hampton, Kinunwa, Kinunwa, & Kinunwa, 2006; Baydala Placsko, Hampton, Bourassa, & McKay-McNabb, 2006). We are still receiving offers from Aboriginal Elders to share their stories and knowledge with us.

Our research program adheres to research guidelines proposed by the Canadian Institutes for Health Research (CIHR) (2010) and Ownership, Control, Access, and Possession, or OCAP (Schnarch, 2004). We open "ethical space," as suggested by Ermine, Sinclair, and Jeffery (2004), for cross-cultural dialogic inquiry (Hampton et al., 2009). Elders Goodwill and McKenna have guided us on every step of our research journey. We have selected our materials following traditional Aboriginal protocol using prayer and asking for the guidance of Elders. For example, PowerPoint images such as sweet grass used in our education modules have been sanctioned for public use by a group of Elders in our region. Elder Goodwill wrote and recorded the narratives introducing two of our videos and recorded a "farewell song" for another of our videos. These gifts are given by Aboriginal Elders for public consumption in faith and trust. We have followed and will continue to follow Aboriginal protocol as indicated by our guiding Elders and tri-council ethical guidelines (CIHR, 2010).

Knowledge exchange is a fundamental aspect of our research program. We have responded to recent calls for a "cultural shift" in the field of knowledge translation (CIHR, 2008) by using an Indigenous Knowledge System dissemination strategy (Smylie et al., 2004). A significant barrier to accessing appropriate end-of-life services is under-referral by physicians to such services; we expect that increasing knowledge and awareness among non-Aboriginal health-care providers will lead to increased referral. We have chosen video methods of data collection and video production as a means of exchanging knowledge between cultural groups. Wass (2004) reports that the health-care curriculum gives inadequate attention to death, dying, and bereavement. The presentation of educational materials to health-care providers is expected to enhance awareness of the unique bereavement needs of Aboriginal families.

Using videos, PowerPoint presentations, and discussions led by co-presenters, we have provided awareness training to cancer clinics, Alzheimer's societies, palliative care groups, university classes, and nurses-in-training. As we increase the volume of our material and expand our network, our capacity to offer cross-cultural educational support also increases. The regional bereavement centre serves as a space from which to disseminate our material and as a central location from which Aboriginal families can access information for integrated dissemination. Our work is published in peer-reviewed journals, including the *Journal of Palliative Care,* the *Canadian Journal of Nursing Informatics, Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health,* and *The Humanistic Psychologist.* Further research products are posted on our Web site and we continue to present our videos to multiple audiences. Videos can be purchased for a cost-recovery fee of $25 by contacting Mary.Hampton@uregina.ca and a description of our work can be found at http//www.uregina.ca/hamptoma/.

The Next Steps

In the future we intend to connect nationally and internationally with researchers working with First Nations peoples to understand and represent their language and cultural practices at end of life. Furthermore, we are interested in doing action with First Nations, by, for example, bringing palliative care to First Nations, as Dr. Mary Lou Kelley and colleagues are doing (Prince & Kelley, 2006).

Along with these developments, we hope to extend our research to include cross-cultural bereavement care. Research on utilization of services suggests that most Aboriginal individuals receive end-of-life health care in acute-care settings due to traumatic deaths as a result of accidents, suicides, and homicides (Castellano, 2000). These traumatic deaths can lead to complicated grief reactions in survivors. Furthermore, a chronic illness such as diabetes can lead to amputations that result in grief reactions (Allard et al., 2004). We hope to extend our work into the area of assisting bereaved Aboriginal families by offering and documenting culturally appropriate bereavement services in urban and reserve settings.

We have found a desire among health-care providers to achieve greater understanding and a desire among Aboriginal Elders to communicate meanings of bereavement and information about proper protocol when relating to Aboriginal individuals and families who are grieving. While researchers have come to realize that the poor health status of Aboriginal peoples cannot be attributed only to low socio-economic status or individual life decisions, it remains difficult to incorporate the reality of historic stressors and intergenerational trauma into present-day theories of health care. Our research team proposes to generate a model of bereavement care that integrates these realities.

According to the cross-cultural theoretical framework proposed by Berry, Poortinga, Segall, and Dasen (1992), cultural values must be respected and practices must be uniquely adapted if ethnic minorities are to have confidence in the care provided to them (Nyatanga, 2002). We believe that "cross-cultural" is a more appropriate conceptual framework for bereavement work than "intercultural" or "multicultural," since we are attempting to promote understanding *across* or *between* cultural groups (non-Aboriginal and Aboriginal). We intend to focus on the possibilities afforded by dialogue between cultures rather than on "cultural competence." "Cultural competence" is understood in the literature as requiring more than technical skill; it is "an orientation that becomes part of the practitioner's sense of self" (Kleinman & Benson, 2006). The term "culturally appropriate" (respectful, relevant to a specific culture) describes the type of bereavement care that we envisage (Burhansstipanov, 1999).

To meet the guidelines for overcoming barriers to appropriate bereavement care, we will have to address the unique causes of grief in Aboriginal cultures and to provide culturally appropriate bereavement care by including cross-cultural policies in our health-care system (Nyatanga, 2002; Ross et al., 2000).

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Book Review

Cancer on the Margins: Method and Meaning in Participatory Research

Edited by Jennifer J. Nelson, Judy Gould, and Sue Keller-Olaman, 2009
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Reviewed by Jill M. G. Bally

Jennifer J. Nelson, Judy Gould, and Sue Keller-Olaman have effectively collaborated to compile a collection of essays based on findings from numerous research projects undertaken by the Ontario Breast Cancer Community Research Initiative. The content of *Cancer on the Margins: Method and Meaning in Participatory Research* is substantive, and it is presented as theoretical and experiential tools for understanding and becoming familiar with participatory research. The editors have captured and intricately combined the experiences of women with breast cancer from marginalized groups such as Aboriginal, lesbian, francophone, rural, and low-income women, with the complexities, processes, and challenges that are inherent in community-based and participatory research methods.

The table of contents familiarizes the reader with the inner workings of the book, providing an outline that mirrors the qualitative research process, particularly as it relates to participatory research methods. Collectively, the chapters address important epistemological, methodological, ethical, and theoretical issues inherent in designing a study. These include data analysis, the crisis of representation, and the dilemmas related to reflection and reflexivity that exist in participatory research. In addition, the book provides an overview of the possibilities of "moving knowledge," with an emphasis on change and social justice.

Specifically, each of the 12 chapters begins with an introductory map of its content and contains a table highlighting and synthesizing the essential elements of the study or studies embedded in that chapter, such as why the research was conducted, the methods used, and the key findings. On getting started in research with marginalized populations, for example, chapter 1 utilizes the Francophone Women With Breast Cancer Project and the Cottage Dreams Initiative to demonstrate the research process, from drafting research questions, to recruiting participants, to gathering data. The contributors highlight important methodological questions and challenges, such as the role of the researcher, the involvement of the community, and time considerations.

The analysis of the experiences of vulnerable and marginalized women on their cancer journeys, and the position of participatory researchers on collaboratively uncovering these experiences, is enlightening and informative. It provides health professionals, students, and both qualitative researchers generally and participatory researchers specifically with valuable insights into the lives of such populations and offers insight into the processes and conundrums related to participatory research. In keeping with participatory research, the emphasis is placed on the power inequities between researchers and participants and between participants and the communities and health-care structures within which they live and experience health and illness. The reader comes away with an awareness of not only the particular challenges and issues faced by marginalized women on their breast cancer journey but also those experiences that are associated with participatory research. As with participatory research itself, *Cancer on the Margins* is filled with the voices of participants in the form of riveting passages taken from their experiences, and they are seamlessly woven into the contributors' descriptions of the research process. The result is a rich description of the intersection of both journeys — that of women making their way on their unique journey with breast cancer and that of the researcher traversing the ground of community-based and participatory research projects with vulnerable populations. The highlights of this intersection affect the participatory research process. The authors identify these as key considerations and include the development of effective partnerships and capacity-building in the community, shared power, learning and knowledge-generation in working towards social equity, reflexivity, and transformative outcomes.

Most importantly, the editors point out that this book does not purport to resolve all issues and answer all questions. In fact, *Cancer on the Margins* is not a prescription to follow, as one size does not fit all in such emergent and responsive research projects. The value of the book is its insider's perspective and an awareness of the loopholes, considerations, approaches, and challenges that one may encounter in conducting participatory research, as well as the rewards of such work. The contributors present their research projects and, through reflection, pose critical questions about the challenges that emerge within each chapter. Again, the book's usefulness and resonance spring partly from the fact that the contributors are true to participatory research and, indeed, practise what they preach. They reveal their thoughts, reflections, and practices by critically examining each research project presented in order to deliver the experiential tools necessary to build research using similar methods. This process provides ample guidance for the reader to conduct community-based and participatory research and offers adequate information for reflection prior to, during, and after such a project is undertaken.

Overall, *Cancer on the Margins* is a useful and memorable book that easily catches and holds the attention of the reader. It is both provocative and informative. By providing in-depth information about the ins and outs of conducting participatory research with a variety of vulnerable populations, it greatly enhances our understanding of qualitative research methods and the role of the researchers and the participants in sharing and creating knowledge. The editors have captured heartfelt experiences of both participants and researchers in a useful tool for conducting participatory research. As social justice becomes an ever more essential outcome of research in health and illness, this book is an exemplar for research that effects social change and levels the ground between the researchers and the researched. *Cancer on the Margins: Method and Meaning in Participatory Research* is highly recommended for those wishing to pursue research through community-based and participatory methods, for professionals who work with vulnerable and marginalized populations, for policy-makers, and for the general public.

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