

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

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

**Brenda L. Cameron, Anna Santos Salas,
Donna deMoissac**

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, & Eisenclas, 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 understand-

ing 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.

References

- Barber, K. (Ed.). (2004). *Canadian Oxford dictionary* (2nd ed.). Don Mills, ON: Oxford University Press.
- Bergum, V. (1994). Knowledge for ethical care. *Nursing Ethics*, 1(2), 72–79.
- Bertolino, M., & Heller, K. S. (2001). Promoting quality of life near the end of life in Argentina. *Journal of Palliative Medicine*, 4(3), 423–430.
- Cameron, B. L. (2004). Ethical moments in practice: The nursing “how are you?” revisited. *Nursing Ethics*, 11, 53–62.
- Cameron, B. L., & Santos Salas, A. (2009). Understanding the provision of palliative care in the context of primary health care: Qualitative research findings from a pilot study in a community setting in Chile. *Journal of Palliative Care*, 25(4), 275–283.
- Canadian Senate. (2000). *Quality end-of-life care: The right of every Canadian. Final report*. Senate Standing Committee on Social Affairs, Science and Technology, Subcommittee to Update Of Life and Death. Ottawa: Author.
- Carson, T., & Sumara, D. (Eds.). (1997). *Action research as a living practice*. New York: Peter Lang.
- Couzos, S., Lea, T., Murria, R., & Culbong, M. (2005). “We are not just participants — we are in charge”: The NACCHO Ear Trial and the process for Aboriginal community-controlled health research. *Ethnicity and Health*, 10(2), 91–111.
- Dachs, J. N. W., Ferrer, M., Florez, C. E., Barros, A. J. D., Narváez, R., & Valdivia, M. (2002). Inequalities in health in Latin America and the Caribbean: Descriptive and exploratory results for self-reported health problems and health care in twelve countries. *Pan American Journal of Public Health*, 11(5/6), 335–355.

- De Lima, L. (2001). Advances in palliative care in Latin America and the Caribbean: Ongoing projects of the Pan American Health Organization (PAHO). *Journal of Palliative Medicine*, 4(2), 228–231.
- De Lima, L., & Hamzah, E. (2004). Socioeconomic, cultural, and political issues in palliative care. In E. Bruera, L. De Lima, R. Wenk, & W. Farr (Eds.), *Palliative care in the developing world: Principles and practice* (pp. 23–37). Houston: IAHPHC Press.
- Derio, L. (2007). *Evaluación del programa nacional de alivio del dolor y cuidados paliativos* [Evaluation of the national palliative care and pain relief program]. XII Jornadas Ministeriales de Alivio del Dolor y Cuidados Paliativos. Santiago de Chile: Ministerio de Salud.
- Dickson, G., & Green, K. L. (2001). Participatory action research: Lessons learned with Aboriginal grandmothers. *Health Care for Women International*, 22, 471–482.
- Fernández, A., & Acuña, G. (1996). Chile: Status of cancer pain and palliative care. *Journal of Pain and Symptom Management*, 12(2), 102–103.
- Freire, P. (2001). *Pedagogía de la indignación* [Pedagogy of indignation] (P. Manzano, Trans.). Madrid: Ediciones Morata, S. L.
- Gadamer, H-G. (1989). *Truth and method* (2nd rev. ed.) (J. Weinsheimer & D. G. Marshall, Trans.). New York: Continuum.
- Gadamer, H-G. (1992). The limitations of the expert. In D. Nisgeld & G. Nicholson (Eds.), *On education, poetry, and history* (pp. 181–192) (L. Schmidt & M. Reuss, Trans.). Albany: SUNY Press.
- Gadamer, H-G. (1996). *The enigma of health* (J. Gaiger & N. Walker, Trans.). Stanford, CA: Stanford University Press.
- Gibson, N., Gibson, G., & Macaulay, A. C. (2001). Community-based research: Negotiating agendas and evaluating outcomes. In J. Morse, J. Swanson, & A. J. Kuzel (Eds.), *The nature of qualitative evidence* (pp. 160–182). Thousand Oaks, CA: Sage.
- Global Forum for Health Research. (2004). *The 10/90 report on health research 2003–2004*. Geneva: Author.
- Grant, E., Murray, S. A., Grant, A., & Brown, J. (2003). A good death in rural Kenya? Listening to Meru patients and their families talk about care needs at the end of life. *Journal of Palliative Care*, 19(3), 159–167.
- Hall, J. M. (1999). Marginalization revisited: Critical, postmodern, and liberation perspectives. *Advances in Nursing Science*, 22(2), 88–102.
- Human Rights Watch. (2009). "Please, do not make us suffer any more . . ." *Access to pain treatment as a human right*. New York: Author. Retrieved January 12, 2011, from <http://www.hrw.org/en/reports/2009/03/02/please-do-not-make-us-suffer-any-more-0>.
- Hyrkas, K. (1997). Can action research be applied in developing clinical teaching? *Journal of Advanced Nursing*, 25, 801–808.
- Instituto Nacional de Estadísticas Chile. (2010). *Evolución de la mortalidad en Chile según causas de muerte y edad 1990–2007* [Evolution of mortality in Chile by cause of death and age 1990–2007]. Santiago de Chile: Instituto Nacional de Estadísticas Sub-Departamento de Estadísticas Demográficas.

- International Association for Hospice and Palliative Care. (2007). The Declaration of Venice: Palliative care research in developing countries. *Journal of Pain and Palliative Care Pharmacotherapy*, 21(1), 31–33.
- International Narcotics Control Board. (2009a). *Narcotic drugs: Estimated world requirements for 2009 – Statistics for 2007*. New York: United Nations.
- International Narcotics Control Board. (2009b). *Report of the International Narcotics Control Board for 2008*. E/INCB/2008/1. New York: United Nations.
- Israel, B. A., Krieger, J., Vlahov, D., Ciske, S., Foley, M., Fortin, P., et al. (2006). Challenges and facilitating factors in sustaining community-based participatory research partnerships: Lessons learned from the Detroit, New York City and Seattle Urban Research Centers. *Journal of Urban Health*, 83(6), 1022–1040.
- Israel, B. A., Schulz, A. J., Parker, E. A., & Becker, A. B. (2001). Community-based participatory research: Policy recommendations for promoting a partnership approach in health research. *Education for Health*, 14(2), 182–197.
- Kikule, E. (2003). A good death in Uganda: Survey of needs for palliative care for terminally ill people in urban areas. *British Medical Journal*, 327, 192–194.
- Medina, E., & Kaempffer, A. (2000). Mortalidad del adulto en Chile [Adult mortality in Chile]. *Revista Médica de Chile*, 128(10), 1144–1149.
- Medina, E., & Kaempffer, A. (2007). Tendencias y características de la mortalidad chilena 1970–2003 [Trends and characteristics of Chilean mortality 1970–2003]. *Revista Médica de Chile*, 135, 240–250.
- Meleis, A. (1996). Culturally competent scholarship: Substance and rigor. *Advances in Nursing Science*, 19(2), 1–16.
- Ministerio de Salud Chile. (2002). Objetivos sanitarios para la década 2000–2010 [Health objectives for the decade 2000–2010]. *El Vigía: Boletín de Vigilancia en Salud Pública de Chile*, 5(15), 2–12.
- Ministerio de Salud Chile. (n.d.). *Garantías explícitas en salud* [Explicit health guarantees]. Retrieved January 12, 2011, from <http://www.redsalud.gov.cl/gesauge/ges.html>.
- Ministerio de Salud Departamento de Estadísticas e Información de Salud. (2010). *Esperanza de vida al nacer (en años) por periodo y sexo. Chile, 1950–2025*. [Life expectancy at birth (in years) by period and sex. Chile, 1950–2025]. Retrieved January 9, 2011, from http://deis.minsal.cl/deis/ev/esperanza_de_vida/index.asp.
- Minore, B., Boone, M., Katt, M., Kinch, P., & Birch, S. (2004). Addressing the realities of health care in northern Aboriginal communities through participatory action research. *Journal of Interprofessional Care*, 18(4), 360–368.
- Olweny, C., Sepúlveda, C., Merriman, A., Fonn, S., Borok, M., Ngoma, T., et al. (2003). Desirable services and guidelines for the treatment and palliative care of HIV disease patients with cancer in Africa: A World Health Organization consultation. *Journal of Palliative Care*, 19(3), 198–205.
- Pablos-Mendez, A., & Shademani, R. (2006). Knowledge translation in global health. *Journal of Continuing Education in the Health Professions*, 26(1), 81–86.

- Santesso, N., & Tugwell, P. (2006). Knowledge translation in developing countries. *Journal of Continuing Education in the Health Professions*, 26(1), 87–96.
- Santos Salas, A.V. (2006). *Nursing practices and the experience of the very ill in the home*. Unpublished doctoral dissertation, University of Alberta.
- Santos Salas, A., & Cameron, B. L. (2010). Ethical openings in palliative home care practice. *Nursing Ethics*, 17(5), 655–665.
- Sepúlveda, C. (2003). Palliative care in resource-constrained settings for people living with HIV and other life-threatening illnesses: The World Health Organization approach. In J. Holloway & R. Seaton (Eds.), *Palliative care in resource-constrained settings for people living with HIV/AIDS and other life-threatening illnesses* (pp. 2–4). Rockville, MD: US Department of Health and Human Services, Health Resources and Services Administration.
- Sepúlveda, C., Marlin, A., Yoshida, T., & Ulrich, A. (2002). Palliative care: The World Health Organization's global perspective. *Journal of Pain and Symptom Management*, 24, 91–96.
- Smith, D. G. (1994). The hermeneutic imagination and the pedagogic text. In D. G. Smith (Ed.), *Pedagon: Meditations of pedagogy and culture* (pp. 99–136). Bragg Creek, AB: Makyō Press.
- Stringer, E., & Genat, W. J. (2004). *Action research in health*. Upper Saddle River, NJ: Pearson Education.
- Uys, L. R. (2002). The practice of community caregivers in a home-based HIV/AIDS project in South Africa. *Journal of Clinical Nursing*, 11, 99–108.
- Van Manen, M. (1997). *Researching lived experience: Human science for an action sensitive pedagogy* (2nd ed.). London, ON: Althouse Press.
- Vega, J., Bedregal, P., Jadue, L., & Delgado, I. (2003). Equidad de género en el acceso a la atención de salud en Chile [Gender equity in access to health care in Chile]. *Revista Médica de Chile*, 131(6), 669–678.
- Vega, J., Hollstein, R. D., Delgado, I., Pérez, J. C., Carrasco, S., Marshall, G., et al. (2001). Chile: Socioeconomic differentials and mortality in a middle-income nation. In T. Evans, M. Whitehead, F. Diderichsen, A. Bhuiya, & M. Wirth (Eds.), *Challenging inequities in health: From ethics to action* (pp. 133–147). New York: Oxford University Press.
- Webster, R., Lacey, J., & Quine, S. (2007). Palliative care: A public health priority in developing countries. *Journal of Public Health Policy*, 28, 28–39.
- Wenk, R., & Bertolino, M. (2002). Argentina: Palliative care status 2002. *Journal of Pain and Symptom Management*, 24, 166–169.
- Wenk, R., De Lima, L., & Eisenchlas, J. (2008). Palliative care research in Latin America: Results of a survey within the scope of the Declaration of Venice. *Journal of Palliative Medicine*, 11(5), 717–722.
- World Health Organization. (1978). *Primary health care: A joint report by the director-general of the World Health Organization and the executive director of the United Nations Children's Fund*. Geneva: Author.
- World Health Organization. (1990). *Cancer pain relief and palliative care*. Geneva: Author.
- World Health Organization. (1996). *Cancer pain relief and palliative care* (2nd ed.). Geneva: Author.

- World Health Organization. (2000). Cancer pain, palliative care and the World Health Organization. *Cancer Pain Release*, 13(1). Available online: www.who.cancerpain.wisc.edu.
- World Health Organization. (2002). Palliative care in Latin America and the Caribbean: Recent actions, new resources. *Cancer Pain Release*, 15(1). Available online: www.whocancerpain.wisc.edu.
- World Health Organization. (2004). *Resolution on cancer prevention and control. WHO/EB114.R2*. Geneva: Author.
- World Health Organization. (2007). *Cancer control: Knowledge into action. WHO guide for effective programmes*. Module 5 (palliative care). Geneva: Author.

Brenda L. Cameron, RN, PhD, is Professor, Faculty of Nursing, University of Alberta, Edmonton, Canada. Anna Santos Salas, RN, PhD, is Postdoctoral Researcher, Faculty of Nursing, University of Alberta. Donna deMoissac, RN, MN, is Nurse Practitioner, Palliative Care Program, Royal Alexandra Hospital, Edmonton.