

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

Brenda L. Cameron and Anna Santos Salas

B Cameron (corresponding author): Faculty of Nursing, University of Alberta, 7-80 University Terrace, Edmonton, Alberta, Canada T6G 2T4, brenda.cameron@ualberta.ca; **A Santos Salas**: Faculty of Nursing, University of Alberta

Abstract / This pilot study looked at the provision of palliative care in the context of primary health care in a developing setting in Chile. *Research objectives:* The study aimed to delineate the experience of palliative care from the perspective of patients and health care professionals; to examine primary health care as a propitious milieu for palliative care in developing countries; and to generate opportunities for international collaboration between Chile and Canada. *Methodology:* The study followed tenets of hermeneutic phenomenology and participatory research. Research activities included audio-taped, in-depth individual interviews and participant observation in the home. *Results:* Patients expressed contentment with the services provided by the program. The support of family members, friends, neighbours, and the palliative team was critical to their home care. Health care professionals showed great enthusiasm for keeping the palliative care program going in the primary health care setting despite limited resources. They followed WHO and national guidelines for symptom relief and involved families in the care of the sick person. *Conclusion:* The provision of palliative care through primary health care increases access in developing countries.

Résumé / Ce projet pilote portait sur la prestation des soins palliatifs dans le contexte des soins de santé primaires dans un milieu en voie de développement au Chili. *Objectifs de recherche:* Cerner l'expérience des soins palliatifs du point de vue des patients et des professionnels de la santé; analyser le contexte des soins de santé primaires comme milieu propice aux soins palliatifs dans les pays en développement; et créer des opportunités de collaboration internationale entre le Chili et le Canada. *Méthode:* L'étude s'est déroulée selon les principes de phénoménologie herméneutique et de recherche participative. Les activités de recherche comprenaient des interviews individuels approfondis enregistrés et des rencontres avec les participants à la maison. *Résultats:* Les patients étaient satisfaits des services de soins qui leur était dispensés dans le cadre du programme. Selon eux, le support

des membres de la famille, des amis, des voisins et de l'équipe de soins palliatifs était essentiel pour dispenser les soins palliatifs à domicile. Les professionnels de la santé quant à eux étaient enthousiastes à l'idée de poursuivre la prestation de soins palliatifs dans le cadre des soins de santé primaire en dépit des ressources limitées. Ils ont adopté les lignes de conduites de l'OMS pour le contrôle de la douleur et ils ont mis à contribution les membres des familles pour les soins du malade. *Conclusion:* Dans les pays en développement la dispensation des soins palliatifs par le réseau des soins primaires en augmente l'accès pour les malades.

INTRODUCTION

The provision of palliative care to persons with cancer has been one of the priorities of the World Health Organization's Cancer Control Programme (1, 2). In the region of the Americas, palliative care has been a key component of the cancer control initiative (3, 4). Palliative care may be the only treatment choice for people with cancer in many countries (2, 5, 6), and it has recently been declared a basic human right (7). Yet inequities in access to palliative care services continue to exist around the globe (6-10). Limited access to pain relief is one of the most salient indicators of these inequities (11-13). Barriers to access include weak pain relief and drug policies, inefficient drug delivery systems, lack of training, fear of using controlled drugs, the unnecessarily high cost of drugs, and policy gaps, to name a few (13, 14). According to the World Health Organization (WHO), approximately 80 percent of those with illnesses such as cancer do not have access to adequate pain relief (15). Palliative care providers in low-resource settings face these inequities on a daily basis (9, 16). Combined with poverty, limited resources, and lack of infrastructure, the inequities

constitute grave constraints to access to palliative care in developing settings (17-19).

With this in mind, we designed a pilot study to develop a situated understanding of the challenges and inequities that families and primary health care (PHC) professionals face in the context of terminal illness in a low-resource area of Concepción, Chile. After completing the pilot study, we undertook a larger project, funded through the Canadian Institutes of Health Research Global Health Research Initiative, which enabled us to address the findings from the pilot study. Canadian palliative care practitioners and Chilean PHC professionals actively participated in the larger Global Health Research Initiative (GHRI), resulting in a two-way clinical and research exchange that continues to evolve. The pilot study was key to our implementation of the GHRI; it assisted us with partnership development and provided us with grassroots knowledge of the local situation. In this article, we report our findings from the pilot study. Our research team included one established researcher from Canada with a strong background in hermeneutics and clinical oncology, and a junior researcher from Chile with a solid clinical trajectory in palliative care and developing expertise in hermeneutics (she was the senior researcher's doctoral student at the time of the study).

Background to the Study

Chile is a middle-income Latin American country with a population of close to seventeen million. This population has an average life expectancy of 78 years (20). Cardiovascular diseases and cancer, respectively, are the first and second leading causes of death (20, 21); the latter show a tendency to increase (22). Chilean economic indicators reveal sustained growth and reductions in poverty rates (23). Yet a wide gap persists between rich and poor, and this hinders access to housing, education, and health care (24-27).

Chile's palliative care program was launched in 1994, and over the last decade it has brought a significant increase in morphine consumption (28, 29). Chilean and Latin American rates of morphine consumption are still far from optimal (30). In Chile these are on the rise due to the implementation of the Chilean health care reform of 2000-10 (21, 28, 31). In line with the Alma-Ata Declaration (32), and since Chile's return to democracy, there has been a growing trend to develop PHC. This move has enhanced access to health care and prompted the shift from a biomedical perspective to a family health approach. The incorporation of the palliative care program at the PHC level has taken place gradually throughout the country.

In Concepción, the program was launched first in rural PHC hospitals and then in urban PHC centres, giving hundreds of patients and their families access to palliative care in the community over the past 10 years.

Goals and Objectives of the Pilot Study

Our pilot research study was designed to facilitate an understanding of the context of palliative care in a developing setting and also to explore ways to build an international collaborative partnership between Canadian and Chilean palliative care practitioners and researchers. It was planned as a small offshoot of a larger doctoral research study on the experiences of persons receiving palliative care at home in Edmonton and their palliative home care nurses (33). Funding for the pilot study in Chile was secured through the University of Alberta Endowment Fund for the Future.

The primary goal of the pilot study was to understand the provision of palliative care in the context of PHC. A related aim was to generate opportunities for further international collaboration with Chile in the areas of public health, nursing, and palliative care. The study received ethics approval from the University of Alberta Health Research Ethics Board (as a second phase of the larger Edmonton study) and from the Universidad de Concepción Faculty of Medicine Ethics Committee. It had three research objectives: to delineate the experience of palliative care from the perspective of patients and PHC professionals as well as barriers to access to palliative treatments in the context of a developing country; to examine the PHC milieu as a propitious one in which to provide palliative care in a developing country; and to generate opportunities for further international collaboration between palliative care practitioners and researchers in Chile and Canada.

METHOD

Published studies addressing the experience of individuals in palliative care from a qualitative perspective are few (34-36). The Canadian Senate has recommended the development of innovative and participatory research approaches to advance our understanding of end-of-life care (37). Experiential data from patients and PHC professionals was important to this pilot study, as our goal was to understand palliative care practices as well as to initiate a practice/knowledge discussion process. The study followed a qualitative method — specifically, hermeneutic phenomenology as explicated by van Manen (38).

Hermeneutic phenomenology incorporates an interpretive (hermeneutical) and a descriptive (phenomenological) approach. Rooted in the

philosophical tradition of the human sciences, it is a philosophical framework that helps elucidate the primordial elements of human experience (39). Van Manen states that researchers in professional disciplines are recognizing "the importance of interpretive models...[to] best understand human beings from the experiential reality of their life-worlds" (38, p. xi). Hermeneutic research follows a process of mutual learning and understanding. The hermeneutic process is not complete until we see how the emerging understandings apply to our situation in a concrete way (40, 41).

The tenets of participatory research also guided us as we undertook the study. A participatory approach assisted us to address emerging concerns about undertaking research in another context as well as the ethical challenges of working with vulnerable populations. Justo discusses how a participatory approach diminishes the risk of exploitation of vulnerable people as it enables participants to better grasp the elements of the research process (42). Tenets of participatory research include: shaping the study in response to the context of its participants (43), monitoring potential side effects of participating in the research (43), discussing the research agenda with participants (44), and maintaining the conversation with participants as the research process unfolds (45). Having a member of the palliative care network in Concepción as one of the researchers helped us to tune the study to the setting. We discussed the orientation of the study and our research activities with leaders of the PHC team to address potential concerns and, if necessary, to revise the research protocol. We also adhered to the standards for conducting research with human beings specified by the Tri-Council Policy Statement (46) and by WHO (47).

Our research approach encouraged clinicians to share aspects of their practice that facilitated or challenged the delivery of palliative care. The conversational nature of the hermeneutic approach gave participants the confidence to discuss their practice concerns and practical ways of addressing them.

Study Setting

The study took place within the palliative care program of Chile's Concepción Province. We gained access to participants through one of the PHC centres (*consultorios*) in the Chiguayante district, where a palliative care team was in place and where cancer was the leading cause of death. This centre served a population of 33,000, the majority of whom were low-income. The main activities of the palliative care team were making home visits, holding outpatient clinics, and providing after-

hours medical care through the centre's emergency primary care service (Servicio de Atención Primaria de Urgencia, or SAPU). After obtaining ethics and administrative approval, we described the study to the team and provided them with written information in the form of a letter. The team recommended patients as study participants. Potential participants and their family members were approached by the palliative nurse from the PHC team. We asked for written consent from participants at the outset of the study. In Chile, people are not always aware of their cancer diagnosis, so, to avoid causing participants unnecessary distress, we did not use the word "cancer" in the information letter or the consent form. Instead, we made reference to "people in palliative care." The clinicians informed us about cancer diagnoses and patient awareness and approved the wording we chose. PHC professionals, patients, and family members who consented to participate in the study took part in the research activities.

Sample

A purposive sample — three adults receiving palliative care through the *consultorio*, two family members, and two PHC professionals (a physician and a nurse) — was selected for the pilot study. Participating patients had a diagnosis of late-stage cancer and were physically able to engage in conversation. The family members were living with their sick relatives at the time of the study; one patient lived alone. The physician and the nurse were at the time the main health care providers involved in the delivery of palliative care.

Research Activities

Research activities included participant observation in the home and individual audio-taped conversations. The consenting nurse and physician were observed by one of the researchers on their visits to patients' homes. They also participated in one audio-taped, in-depth conversation of approximately 45 minutes. The two were invited to comment on their experience of working in palliative care and the barriers they encountered to providing that care. In keeping with a hermeneutic approach, conversations were unstructured; questions were used only as prompts to facilitate dialogue. Opening questions included: "How would you describe your experience with patients in palliative care?"; and "What are some of the obstacles you have faced in delivering palliative care?"

Patients participated, at home, in several conversations with the researchers. The researchers usually made their notes after the visit. These notes included contextual information (for example, the fact that a participant was feeling low due to family troubles), and they assisted the

researchers as they analyzed and wrote up their findings. When present, family members joined the conversation. No conversations were held exclusively with family members. Conversations were unstructured, and questions were used as dialogue prompts. Opening questions included: "What has your experience been like during this time?"; "What is it like to be at home while you are ill?"; and "How have others responded to your experience?" Patients were also invited to comment on the barriers to medical treatment they had encountered. Conversations were conducted in Spanish and subsequently transcribed. The interviews were conducted by the Chilean researcher. During a research trip to Chile, the Canadian researcher met with the clinical team and the study participants and took part in conversations with them in the patients' homes and the *consultorio*.

Data Analysis

Data was analyzed according to the hermeneutic phenomenology approach (38). The initial analysis was done by the researcher who conducted the research activities; it was then revised and deepened by both researchers through dialogue and writing; finally, it was refined through conversations with the clinicians conducted over the next year. From a hermeneutic viewpoint, dialogue and writing are crucial to the process of analyzing research data and arriving at a deeper understanding of experience. Variations in human experience are taken into consideration so that a robust description can be presented.

The analysis of the text followed the process of thematic analysis as explicated by van Manen (38). First, the transcripts and notes were read to capture primary meanings in light of the research questions. Second, they were read to identify phrases that were particularly revealing of the experience of patients and PHC professionals. Finally, a careful, sentence-by-sentence reading was undertaken to identify particularly revealing statements. The analysis also involved examining the language of participants; attention was directed toward the etymology of Spanish words and the use of colloquial expressions.

RESULTS

Here we present a summary of our research findings in relation to each of our three objectives.

Objective 1

The first objective was to delineate the experience of palliative care from the perspective of patients and PHC professionals as well as barriers to access to palliative treatments in the context of a

developing country. Overall, patients expressed contentment with the palliative care services provided by the *consultorio*. A significant element of their experience was the fact that some were not aware of their cancer diagnosis. This was stressful for the health care professionals, because although they felt that communicating such a diagnosis to a patient would cause that patient distress, they also believed that by not informing the patient they would prevent him or her from engaging fully in the situation. Another striking finding was how scarce resources were for patients and their families. Although the health centre provided services and medications for free, participants had trouble accessing other supports — such as bedsores mattresses, mobility-enhancing equipment, or medications (such as laxatives) not available at the centre. Participants also reported a limited capacity to afford nutritious meals or basic housing; one patient lacked potable water and sanitary facilities. While this situation was overwhelming for patients, home support provided by relatives and neighbours tended to compensate for it. Such support generally consisted of visiting, cooking, reading aloud from the Bible, housecleaning, washing clothes and bedding, assisting with basic nursing needs, driving, paying bills, and running errands. The generosity of the neighbours was impressive. In one case, a landlord decided not to charge a patient rent during his illness.

Study participants tended always to be accompanied by family members, friends, or neighbours. The neighbours of one patient who had no family living nearby assisted him in managing his daily needs; still, he did occasionally feel abandoned. In this case, health care professionals stepped in to take care of the patient's daily needs, bringing him toiletries, pillows, clothing, and even food. Patients expressed a wish for the health care professionals to visit them more often, yet they acknowledged that there were other patients who needed their care too.

Another integral element of the patients' experience was related to the cancer itself. Patients and their family members talked about the overwhelming experience of hearing the diagnosis, enduring medical treatments, and suffering the symptoms and dramatic changes that occurred as their illness progressed. The case of 32-year-old Laura, once captain of a community soccer team, illustrates the ups and downs of the experience. Diagnosed with an inoperable brain tumour, Laura had to stop playing soccer due to severe stroke-like symptoms. Radiation therapy and chemotherapy enabled her to remain independent, although she suffered from severe hearing loss in one ear and speech difficulties. While

undergoing treatment, Laura stayed in a volunteer-operated home for cancer patients. During this time, she began to come to terms with her health situation and the physical disabilities that came with it. Yet returning home was difficult; she found it hard to settle in. In her own words, "No me hallaba en mi casa" ("I couldn't find myself at home"). Laura's statement reflects the fact that this catastrophic disease had destabilized all facets of her life. She had the support of her mother and sister, who were her main carers, and of one volunteer, who visited her weekly. These three women encouraged her as she confronted many hardships. With the assistance of the *consultorio* nurse, Laura's sister learned to administer the treatments Laura needed. Periodic visits to the *consultorio* and medical and nursing visits to Laura's home helped Laura to stay as independent as possible and to remain at home until the end. Laura was a woman of immense strength, and she kept going under extremely adverse conditions. Her will to live and the care she received combined to give her a life in the midst of poor prognoses and discouraging episodes. She greatly exceeded all survival expectations.

Health care professionals involved in the delivery of palliative care were very enthusiastic about maintaining the program despite the scarcity of resources, and despite the fact that they were not engaged in palliative care on a full-time basis and so had to contend with patient care loads from other programs at the centre. This was a major constraint, as their time to make home visits was limited, and they often had to obtain a supervisor's approval for the visits. Yet in their practice they showed how committed they were to alleviating patients' suffering and how hard they struggled to find the time to attend to patients' urgent needs. This sometimes led them to make home visits after hours, although they saw this as an extraordinary measure. During these visits, they demonstrated their compassion for each person in his or her unique situation. Their close involvement was evident in their reports, in which they showed an unwillingness to forget a patient's drama, even in their private lives. Their struggle was due in part to the lack of a 24/7 palliative care service in the city. This lack was partially compensated for by the SAPU program, through which palliative care patients or their relatives could request assistance.

A major concern for these health care professionals was their sense that their palliative care knowledge was inadequate. They saw this as a constraint when faced with clinical situations such as complex pain, morphine intolerance, and persistent constipation. Although training had been

provided when the program was launched at the PHC level, the employee turnover rate and the changing policies of the health authority had resulted in a training deficit. In their practice, the professionals we spoke to relied on their clinical knowledge and the knowledge they had acquired through experience, but they were sometimes overwhelmed with questions about the best course of action to take and could only respond by calling a palliative care specialist or writing a referral. Practice often presents complex situations that require the professional to act immediately on advanced clinical knowledge, and the professionals in our study experienced their lack of palliative care training as a hindrance to the effective management of these situations. Breakthrough pain management, constipation assessment, prophylaxis, treatment, and issues related to the cancer diagnosis represented concerns that could have been resolved with the pertinent training.

The health care professionals also reported their desire to enhance teamwork with their colleagues as a way of ensuring the flow of care with patients and families. They believed that competing work demands were an impediment to this, because they prevented team meetings from being held as often as they should. This reduced their opportunities to conduct clinical reviews and undergo debriefing. They often used coffee breaks as an occasion to vent their emotions.

The physician and the nurse shared their personal stories of going the extra mile for some patients. At times, they involved their own families in fulfilling a patient's needs. They might give a patient clothing belonging to a member of their own family, ask their spouses for after-hours rides to a patient's home, or phone a very ill patient or his or her family members on a weekend. They expressed an ethical need to support some patients through their last days. Young or lonely patients evoked such fondness on the part of the professionals that they felt compelled to support them in times of medical need, no matter the time of day or day of the week. However, they also recognized that such a level of involvement was not sustainable; they would gently negotiate their interventions with their families, but they would eventually have to let go of their desire to see patients during family time, perhaps exchanging a home visit for a phone call.

Except in the case of one family, where family members gave the team contradictory messages about the patient's state, neither the physician nor the nurse reported any barriers to the delivery of palliative care. On the contrary — they believed that the family support received by their patients was remarkable and enabled the care.

Objective 2

Our second research objective was to examine the PHC milieu as a propitious one in which to provide palliative care in a developing country. There are several challenges to providing palliative care through PHC, among them the turnover rate of primary care physicians (since newcomers are not often trained in palliative care), the shortage of nurses, and budget constraints (the *consultorios* fall under municipal jurisdiction, and there are inequities between the poor and the rich municipalities). But the pilot study did illuminate the effectiveness of providing palliative care through PHC. In identifying the highlights of this model, we relied on our research and clinical experience; our perspective was also enriched through ongoing conversations with local PHC clinicians.

Among the advantages of providing palliative care through PHC is the fact that the centre is close to patients' homes, easing access to care and communication between the team and the patients' families. The family health approach aligns well with palliative care, as it facilitates a better understanding of the family situation in the context of a terminal illness. Family members are often already acquainted with the health care team due to past health-related episodes, and this eases the team's entry into the patient's home. The care provided to the terminally ill patient by family members and neighbours is another advantage of PHC, although we recognize that this can increase the burden on these carers. Still, although caring for a sick person at home can be exhausting, family members often express a desire to stay close to their relative to the end. The family members who participated in this study were quite concerned about the condition of their relatives and seemed willing to accept the role of carer. In any case, in Chile, palliative beds are scarce, and most patients must remain in their homes. The support of family members and other volunteers greatly assisted PHC professionals in caring for their patients in the home and in facilitating a home death. Lastly, coverage of palliative care under the health care reform ensures both timely access and financial protection for patients and their families. This means that they have a right to care at no cost and can thus redirect their limited resources to other life priorities.

Objective 3

Our third research objective was to generate opportunities for further international collaboration between palliative care practitioners and researchers in Chile and Canada. Through this study, we realized the need to generate inter-

national partnerships between palliative care practitioners and researchers from diverse settings. These partnerships are a pedagogical vehicle for knowledge-exchange activities. Through these activities, participants can come to respect, recognize, and integrate one another's expertise and understanding. The pilot study in Chile — together with the Edmonton study and our partnerships with the teams in Edmonton and Concepción — were the pillars of the larger Global Health Research Initiative. The GHRI became the venue for an international knowledge exchange, allowing practitioners to continue to examine the experiences of patients and PHC professionals, exchange practice modalities, and discuss issues of global access to palliative care. International clinical partnerships and two-way exchanges help to build responsive programs that encompass the perspectives of the poor and marginalized, ensuring timely and effective access to health care for all.

DISCUSSION

Our findings from this study increased our understanding of palliative care practice in the PHC context in Concepción Province, Chile. As it developed, the province's palliative care program reflected established principles of palliative care (48). PHC professionals strove to follow the WHO analgesic ladder and Chilean guidelines for symptom control (49). They also placed great emphasis on family and community involvement in caring for the terminally ill and offered support to relatives and neighbours who provided care throughout the course of the illness. The fact that these professionals had insufficient time to devote to palliative care cases due to other work demands reflects the need to allocate professional hours to the palliative care program.

While funding to support palliative care in the PHC setting is limited, the basic costs related to palliative treatments are covered, and this eases the financial burden that families of the terminally ill must bear. Also, health care professionals are creative in their efforts to provide the best possible care at the lowest possible cost. Palliative care programs in developing countries report similar challenges (50-54). Financial constraints compel palliative care practitioners and policy-makers in developing countries to formulate low-cost delivery models (50). The provision of palliative care through PHC is an affordable initiative that increases access in the community (55). As we stated earlier, support given to the terminally ill by their relatives and neighbours has well supplemented the care provided to them by the PHC centre, making it possible for them to remain at home —

close to their loved ones, in familiar surroundings — during their illness. Home-based palliative care, including treatment for pain and other symptoms, is now a global trend in the developing world (1, 18).

The findings of our pilot study highlight the need for education in palliative care. Training initiatives for palliative care providers are urgently needed to ensure that high-quality palliative care is available to the terminally ill (30). Chile's Ministerio de Salud (Ministry of Health) has funded a palliative medicine specialization program (56), but this has been available mainly to tertiary care providers. PHC professionals still lack access to formal training programs, and they have voiced their need for knowledge about state of the art palliative care practice so that they can offer comprehensive care. Stakeholders must work in partnership with primary care clinicians, researchers, and palliative care experts to develop low-cost training initiatives for these professionals.

Whether or not to inform patients about a diagnosis of terminal cancer is a difficult question for clinicians. It is common in Latin America for such patients to remain unaware of their condition (50), as within local cultures family members tend to avoid breaking the bad news to protect the patient from undue distress. The manifold implications of a patient remaining ignorant of his or her condition make it difficult for the health care team. Within the context of their relationship with a patient, team members experienced this as a profound ethical struggle. Yet their knowledge of the patient gave them a basis on which to determine how and when to approach the issue, and in this sense it allowed them to enact the ethical moment, which is integral to health care practice (57).

Our study has also provided a means to further shape our research plans, which include the international mobility project and the active practice exchange with clinicians. Future research endeavours emanating from this pilot study, the Edmonton study, and the larger GHRI project include the development of an ongoing virtual and on-site exchange of clinicians, the delineation of comprehensive indicators of palliative care practice, and the organizing of participatory knowledge-exchange workshops to translate research findings into practice.

STUDY LIMITATIONS

In general, pilot studies are limited in scope due to their small sample size and short duration of research. The close engagement of the researchers with their subjects and the anecdotal quality of the data they collect could be seen as another limitation. Yet within the interpretive inquiry research

tradition, these are necessary conditions, and potential emerging biases are offset through dialogue, participation, and empowerment. While we acknowledge its limitations, the study does provide us with a window onto the daily life of practitioners and patients in the context of community-based palliative care in a low-resource setting, and through this it gives us a glimpse of the larger palliative care picture in the zone. In Concepción Province, there are several PHC centres that serve an average of four to eight patients on a monthly basis. While the numbers are small, together these centres are providing care to the majority of the population in need of palliative care and report excellent coverage indicators (31). The pilot study deepened our understanding of how palliative care works in small communities and revealed the difference palliative care can make to the well-being of patients and families.

CONCLUSION

This pilot study gave us a local perspective on the realities of palliative care provision in a developing setting in Chile. Engaging directly with health care professionals, patients, and families was key to the implementation of this study, and it facilitated the development of the larger global health research project. The fact that one of the researchers was a native of the study setting gave us foreknowledge of the local nuances of practice. Without this knowledge, more time would have been needed to establish a relationship with the health care team, as team members had to get a sense of who we were before they could present the research study to their patients — our potential participants. We met with clinicians and supervisors who were very supportive of research, and this benefited us from the beginning as it facilitated the participation of patients and families, who received us warmly.

Data collection lasted only two months. We would have preferred a longer duration, as it would have allowed us to follow the patients and their families through the illness. We stayed in touch with the clinicians, who kept us informed about participants who passed away in the subsequent months or years. The patient who was alone had been very touched by the Canadian researcher's gift of a toy bear. We learned that after his death, this little bear was all his daughter took home with her.

In sum, the relationships we built were essential to achieving the goals of this pilot study. The clinicians were reassured to know that our intention was to understand their practice and not to call it into question; this made them feel safe in

voicing their concerns and fears. The patients and their families genuinely engaged with us, and their graciousness was a precious gift — they gave us an open window onto the sacredness of their lives. In the end, we learned that knowing or not knowing their diagnosis was a matter of secondary concern for the patients. Having somebody provide them with pain relief, treat their symptoms, and ensure that they were not alone at home were the things that mattered most.

Ensuring access to palliative care is a major step toward attaining social justice in health care (58). The findings of our study are a small contribution to worldwide efforts to achieve equity for our populations and to reduce the unequal distribution of global wealth.

ACKNOWLEDGEMENTS

The pilot research study was funded by a seed grant from the University of Alberta Endowment Fund for the Future. The GHRI was funded by a Canadian Institutes of Health Research Global Health Research Pilot Project Grant for strategic initiatives. We thank both institutions for their generous support.

We thank the generous support of Chiguayante Primary Health Care Centre in Concepción, Chile, and the palliative care team to undertake this study. We are grateful to patients and families for their gracious hospitality.

Date received, September 14, 2008; date accepted, June 14, 2009.

REFERENCES

- World Health Organization (WHO). National cancer control programmes: policies and managerial guidelines. 2nd ed. Geneva: WHO; 2002.
- World Health Organization (WHO). Resolution on cancer prevention and control. Geneva: WHO; 2004.
- De Lima L, Bruera E. The Pan American Health Organization: its structure and role in the development of a palliative care program for Latin America and the Caribbean. *J Pain Symptom Manage* 2000; 20(6): 440-448.
- Pan American Health Organization Noncommunicable Diseases Program. La actividad de la OPS en el campo de las enfermedades no transmisibles. *Rev Panam Salud Pública* 1997; 2(6): 420-427.
- World Health Organization (WHO). Symptom relief in terminal illness. Geneva: WHO; 1998.
- World Health Organization (WHO). Cancer control: knowledge into action. WHO guide for effective programmes, module 5 (palliative care). Geneva: WHO; 2007.
- International Association for Hospice and Palliative Care, Worldwide Palliative Care Alliance, World Hospice Palliative Care Day. Joint declaration and statement of commitment on palliative care and pain treatment as human rights, 2008. Available from: http://www.hospicecare.com/resources/pain_pallcare_hr/docs/jdsc.pdf
- Doyle D. The world of palliative care: one man's view. *J Palliat Care* 2003; 19(3): 149-158.
- De Lima L, Hamzah E. Socioeconomic, cultural, and political issues in palliative care. In: Bruera E, De Lima L, Wenk R, Farr W, editors. *Palliative care in the developing world: principles and practice*. Houston: International Association for Hospice and Palliative Care; 2004. p. 23-37.
- Sepúlveda C, Marlin A, Yoshida T, Ulrich A. Palliative care: the World Health Organization's global perspective. *J Pain Symptom Manage* 2002; 24(2): 91-96.
- Adams V. Access to pain relief: an essential human right. A report for World Hospice and Palliative Care Day, 2007. London: Help the Hospices for the Worldwide Palliative Care Alliance; 2008.
- Report exposes wide-scale lack of access to essential analgesics. *J Hosp Palliat Nurs* 2008; 10(1): 9-10.
- International Narcotics Control Board. Report of the International Narcotics Control Board for 2008. New York: United Nations; 2009. Available from: http://www.incb.org/pdf/annual-report/2008/en/AR_08_English.pdf
- Human Rights Watch. "Please, do not make us suffer any more...": access to pain treatment as a human right. New York: Human Rights Watch; 2009 Mar 3. Available from: http://www.hrw.org/sites/default/files/reports/health0309web_1.pdf
- World Health Organization (WHO) Access to Controlled Medications Programme. World Health Organization briefing note. Geneva: WHO; 2007 Mar 1-4.
- Bruera E. Palliative care in Latin America. *J Pain Symptom Manage* 1993; 8(6): 365-368.
- Olweny C, Sepúlveda C, Merriman A, et al. Desirable services and guidelines for the treatment and palliative care of HIV disease patients with cancer in Africa: a World Health Organization consultation. *J Palliat Care* 2003; 19(3): 198-205.
- Sepúlveda C. Palliative care in resource-constrained settings for people living with HIV and other life-threatening illnesses: the World Health Organization approach. In Holloway J, Seaton R, editors. *Palliative care in resource-constrained settings for people living with HIV/AIDS and other life-threatening illnesses: presentations from the 14th international conference on the care of the terminally ill, Montreal, Canada, October 2002*. Rockville (MD): US Department of Health and Human Services, Health Resources and Services Administration, HIV/AIDS Bureau; 2003. p. 2-4.
- De Lima L. Advances in palliative care in Latin America and the Caribbean: ongoing projects of the Pan American Health Organization (PAHO). *J Palliat Med* 2001; 4(2): 228-231.
- Ministerio de Salud Departamento de Estadísticas e Información de Salud Chile. Indicadores básicos de salud Chile. Santiago de Chile: MINSAL-DEIS; 2007. Available from: <http://deis.minsal.cl/deis/indicadores/indi2007.pdf>
- Ministerio de Salud Chile. Objetivos sanitarios para la década 2000-2010. *El Vigía: Boletín de Vigilancia en Salud Pública de Chile* 2002; 5(15): 2-12.
- Medina E, Kaempffer A. Mortalidad del adulto en Chile. *Rev Med Chile* 2000; 128(10): 1144-1149.
- Gobierno de Chile Ministerio de Planificación y Cooperación. Distribución del ingreso e impacto distributivo del gasto social. Santiago de Chile: MIDEPLAN; 2007. (Serie análisis de resultados de la encuesta de caracterización socioeconómica nacional [CASEN 2006]; no. 2).
- Arteaga O, Thollaug S, Nogueira AC, et al. Información para la equidad en salud en Chile. *Rev Panam Salud Pública* 2002; 11(5): 374-385.
- Vega J, Hollstein RD, Delgado I, et al. Chile: socioeconomic differentials and mortality in a middle-income nation. In: Evans T, Whitehead M, Diderichsen F, Bhuiya A, Wirth M, editors. *Challenging inequities in health: from ethics to action*. New York: Oxford University Press; 2001. p. 123-137.
- Vega J, Bedregal P, Jadue L. Equidad de género en el acceso a la atención de salud en Chile. *Rev Med Chile* 2003; 131(6): 669-678.
- Dachs JNW, Ferrer M, Florez CE, et al. 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 Am J Public Health* 2002; 11(5): 335-355.
- Ministerio de Salud. Piloto AUGÉ 2004: documento para la aplicación del sistema AUGÉ en las redes de atención del sistema nacional de servicios de salud. Santiago de Chile: MINSAL; 2004.
- Rico MA. Palliative care in Chile. *Eur J Palliat Care* 1997; 4(4): 138-139.

30. De Lima L. El empleo de analgésicos opiáceos para aliviar el dolor del cáncer. *Rev Panam Salud Pública* 1997; 2(2): 142-145.
31. Derio L. Evaluación del programa nacional de alivio del dolor y cuidados paliativos: XII jornadas ministeriales de alivio del dolor y cuidados paliativos. Santiago de Chile: Ministerio de Salud; 2007.
32. World Health Organization (WHO). 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: WHO; 1978.
33. Santos Salas A. Nursing practices and the experience of the very ill in the home [dissertation]. [Edmonton]: University of Alberta, 2006.
34. Fowler FJ, Coppola KM, Teno JM. Methodological challenges for measuring quality of care at the end of life. *J Pain Symptom Manage* 1999; 17(2): 114-119.
35. Stewart AL, Teno J, Patrick DL, et al. The concept of quality of life of dying persons in the context of health care. *J Pain Symptom Manage* 1999; 17(2): 93-108.
36. Yedidia MJ, MacGregor B. Confronting the prospect of dying: reports of terminally ill patients. *J Pain Symptom Manage* 2001; 22(4): 807-819.
37. Standing Senate Committee on Social Affairs, Science and Technology (Canada). Quality end-of-life care: the right of every Canadian. Final report of the subcommittee to update "of life and death." Ottawa: Senate of Canada; 2000. Available from: <http://www.parl.gc.ca/36/2/parbus/commbus/senate/Com-e/upda-e/rep-e/repfinjun00-e.htm#5>. Advance Directives
38. van Manen M. Researching lived experience: human science for an action sensitive pedagogy. 2nd ed. London (ON): Althouse; 1997.
39. Cameron BL. Understanding nursing and its practices [dissertation]. [Edmonton]: University of Alberta, 1998.
40. Gadamer HG. Truth and method. 2nd rev. ed. Weinsheimer J, Marshall DG, translators. New York: Continuum; 1989.
41. Carson TR. Closing the gap between research and practice: conversation as a mode of doing research. *Phenomenol Pedagog* 1986; 4(2): 73-85.
42. Justo L. Participatory research: a way to reduce vulnerability. *Am J Bioethics* 2004; 4(3): 67-68.
43. Minkler M. Ethical challenges for the "outside" researcher in community-based participatory research. *Health Educ Behav* 2004; 31(6): 684-697.
44. Israel BA, Schulz AJ, Parker EA, et al. Community-based participatory research: policy recommendations for promoting a partnership approach in health care research. *Educ Health* 2001; 14(2): 182-197.
45. Kemmis S, McTaggart R. Participatory action research. In: Denzin NK, Lincoln YS, editors. *Handbook of qualitative research*. 2nd ed. Thousand Oaks (CA): Sage; 2000. p. 567-605.
46. Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, Social Sciences and Humanities Research Council of Canada. Tri-council policy statement: ethical conduct for research involving humans. Ottawa: Public Works and Government Services Canada; 2005. Available from: <http://www.pre.ethics.gc.ca/english/policystatement/policystatement.cfm>
47. World Health Organization (WHO) Research Ethics Review Committee. Ethical standards and procedures for research with human beings. Geneva: WHO; 2009. Available from: <http://www.who.int/ethics/research/en/>
48. Twycross R. *Introducing palliative care*. 4th ed. Abingdon (UK): Radcliffe Medical; 2003.
49. Ministerio de Salud Chile. Programa alivio del dolor y cuidados paliativos: normas nacionales. Santiago de Chile: MINSAL; 1998.
50. Bertolino M, Heller KS. Promoting quality of life near the end of life in Argentina. *J Palliat Med* 2001; 4(3): 423-430.
51. Kikule E. A good death in Uganda: survey of needs for palliative care for terminally ill people in urban areas. *BMJ* 2003; 327(7408): 192-194.
52. Rajagopal MR, Palat G. Kerala, India: status of cancer pain relief and palliative care. *J Pain Symptom Manage* 2002; 24(2): 191-193.
53. Ramsay S. Raising the profile of palliative care for Africa. *Lancet* 2001; 358(9283): 734.
54. Wenk R. Direct medical costs of an Argentinean domiciliary palliative care model. *J Pain Symptom Manage* 2000; 20(3): 162-165.
55. Fernandez A, Acuña G. Chile: status of cancer pain and palliative care. *J Pain Symptom Manage* 1996; 12(2): 102-103.
56. U. Mayor y MINSAL: inauguran primer programa de medicina paliativa. *Diario Mayor: noticias en línea*. Santiago: Universidad Mayor; 2006. Available from: http://www.diariomayor.cl/001home_315.htm
57. Cameron BL. Ethical moments in practice: the nursing "How are you?" revisited. *Nurs Ethics* 2004; 11(1): 53-62.
58. Benatar SR. Just healthcare beyond individualism: challenges for North American bioethics. *Camb Q Healthc Ethics* 1996; 6(4): 397-415.