

"But isn't it depressing?" The Vitality of Palliative Care

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Abstract / A common question about palliative care from those unfamiliar with the work is, "But isn't it depressing?" This view distances palliative care workers from the general public and reflects a deeply held belief that matters associated with death and dying are negative. Published definitions fall short of capturing a full understanding of the work, making it difficult to communicate the meaning of palliative care. This qualitative study examined the experiences of six long-term palliative care workers. Palliative care was described as "a way of living" and, throughout the descriptions, the concept of "vitality" emerged as the core meaning of palliative care. In the current economic environment, where there is competition for health care funding, more widespread agreement about the meaning of palliative care is important if informed decisions are to be made about allocation of resources.

Résumé / Dans le domaine des soins palliatifs, une des questions les plus courantes que l'on nous pose au sujet du travail est « N'est-ce pas déprimant ? » C'est ce point de vue qui distingue les soignants en soins palliatifs du grand public et qui reflète une croyance profondément enracinée que la mort et tout ce qui l'entoure est négatif. Les définitions qui sont citées et reconnues ne parviennent pas à capturer la nature du travail et, de ce fait, il devient encore plus difficile de communiquer aux autres toute la signification des soins palliatifs. Dans cette étude qualitative on examine la nature du travail de six personnes travaillant dans le domaine des soins palliatifs depuis longtemps. Les soins palliatifs y sont décrits comme une « manière de vivre » et à travers les descriptions la notion de « vitalité » émerge comme étant le noyau significatif des soins palliatifs. Dans la situation économique actuelle où la compétition pour des argents pour les soins de santé est forte, il est important que la signification et la nature des soins palliatifs soient de plus en plus propagés si l'on veut que les décideurs prennent des décisions éclairées lors de l'allocation de ressources.

INTRODUCTION

This descriptive qualitative analysis of the experience of six long-term palliative care workers was undertaken to add to our understanding of the meaning of palliative care. Although a

number of authors have discussed the effectiveness of palliative care in alleviating suffering of dying individuals (1-3), the meaning of palliative care may not be well understood. Poor understanding has been demonstrated by, for example, the Palliative Care Council of South Australia, which conducted a survey amongst the general public in which half the respondents were unable to offer some description of palliative care (4). More recently, Palliative Care Australia (PCA) conducted a telephone survey in which three out of four people were found not to understand the meaning of palliative care (5).

Evidence suggests that support for palliative care is worthwhile. Benefits, such as improved quality of life (6), increased family satisfaction with care (7,8), and positive outcomes of bereavement support related to future family well-being (9-11), indicate the value of using palliative care services. There have, however, been reports that current palliative care services fall short of providing for current needs, especially in rural and remote areas (3,12-15), and that the need for services is expanding. In most developed countries, 80% to 90% of palliative care patients have a cancer diagnosis (15-18), and data suggest the prevalence of cancer is increasing (3). Expansion of palliative care services to meet current and future demand appears warranted.

Other issues that highlight the need for understanding of the concept are the recent debates surrounding euthanasia and care of terminally ill people. Palliative care professionals and organizations have clearly stated that palliative care practice does not include the deliberate ending of life (19-21). The public, however, may make false connections between palliative care and euthanasia, with these considered to be one and the same, or to be related care alternatives (22). Controversies over legalization of euthanasia have increased communities' interest in care of the terminally ill and have created opportunities for governments to commit funding to this area of health care.

Uninformed communities, including funders and politicians, may make decisions that result in a lack of support for palliative care and further strain existing palliative care resources, while the need for these services is actually increasing. It is important that palliative care not be misunderstood or diminished because of an inability to articulate the concept. Therefore, research to examine understanding of the meaning of palliative care appears timely.

AIM

The purpose of this study was to describe the meaning of palliative care from the perspective of long-term palliative care workers. Palliative care is delivered, where possible, by interdisciplinary teams. Participants representative of disciplines involved in palliative care provision were, therefore, selected to elicit descriptions of everyday experiences. These descriptions were examined for meaning, attitudes, and feelings about palliative care, guided by the central research question, "What is the meaning of palliative care held by long-term palliative care workers?"

LITERATURE REVIEW

Extensive literature review prior to data collection can predetermine conceptions of the researcher (23). The approach taken in preparation for this study was to examine the literature solely to confirm that a gap in knowledge existed. Although there is a growing body of literature on palliative care, little was found concerning the specific question of this study. Three main areas were considered relevant—definitions of palliative care, studies of palliative care workers, and comparisons of palliative care with other types of care.

Definitions of Palliative Care

A review of the literature revealed several definitions of palliative care, a selection of which is listed in Table 1. Comments of major features are included in the table.

Substantial debate regarding definitions of palliative care among palliative care authors was noted. For example, the World Health Organisation (WHO) definition (24) has been criticized for focusing solely on cancer patients (14), and descriptions of palliative care patients as dying or terminally ill have been criticized for ignoring patients who were concurrently receiving curative treatments (2,25). Associations such as the Canadian Palliative Care Association (CPCA) and PCA (formerly AAHPC), have also recognized definitional difficulties, and have

made several revisions to their definitions of palliative care over time (26–29). Table 1 includes examples of these revisions.

Studies of Palliative Care Workers

Literature related to interdisciplinary palliative care workers was reviewed to determine if this writing might augment definitions or understanding of the meaning of palliative care. Some studies considered occupational stress (30), or roles of a specific discipline such as nursing (31–34). Palliative care workers' descriptions have included service and education needs (35), the meaning of aspects of bereavement services for nurses and volunteers (36), and shared value systems, stress, and coping of palliative care nurses in the conceptual context of the "good death" (37). The studies reviewed showed a variety of aspects of palliative care, but did not include representatives of all disciplines involved in palliative care, and considered only particular aspects of palliative care provision.

Comparisons of Palliative Care with Other Types of Care

Some researchers have attempted to explain palliative care by making comparisons with other types of health care services. Jacobson (38) discussed two complementary systems of cancer patients' treatment—one concerned with cure, the other with the relief of symptoms of an incurable illness. Elements of palliative care were described by making comparisons with curative models, for example, "hospice is not terminal care as usually provided in a traditional acute care system" (38, p.202). This approach provided some comparative explanation of palliative care, but also revealed the difficulties of identifying the elements of palliative care.

The literature review indicated that some attempts have been made to give the meaning of palliative care through definition, descriptions by care providers of aspects of palliative care, and comparison with other types of health care services. However, ongoing difficulties in gaining an understanding of palliative care from the palliative care worker's perspective suggested that there was continued uncertainty about how to articulate adequately the meaning of palliative care.

METHODS

An inductive analysis, using thick descriptions and direct quotations of personal perspectives, was used to discover shared meanings of the experience.

Figure 1 / A SELECTION OF PALLIATIVE CARE DEFINITIONS

Source	Definition	Comment
World Health Organization, 1990 (24)	<p>Palliative care is the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social, and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families.</p> <p>Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with anti-cancer treatment. Palliative care:</p> <ul style="list-style-type: none"> • affirms life and regards dying as a normal process; • neither hastens nor postpones death; • provides relief from pain and other distressing symptoms; • integrates the psychological and spiritual aspects of patient care; • offers a support system to help patients live as actively as possible until death; • offers a support system to help the family cope during the patient's illness and in their own bereavement. 	Major criticism has been that this definition relates to people with cancer.
Woodruff, 1993 (2)	Palliative care provides for all the medical and nursing needs of the patient for whom cure is not possible, and for all the psychological, social, and spiritual needs of the patient and the family, for the duration of the patient's illness, including bereavement care.	Not all patients "for whom cure is not possible" will benefit from palliative care. Separates medical and nursing needs from other needs. Assumes an interdisciplinary approach but fails to acknowledge the team approach.
Canadian Palliative Care Association (CPCA), 1995 (26)	Palliative care, as a philosophy of care, is the combination of active and compassionate therapies intended to comfort and support individuals and families who are living with a life-threatening illness. During periods of illness and bereavement, palliative care strives to meet physical, cultural, and religious values, beliefs, and practices. Palliative care is planned and delivered through the collaborative efforts of an interdisciplinary team including the individual, family, caregivers, and service providers. It should be available to the individual and his/her family at any time during the illness trajectory and bereavement. While many service providers may be able to deliver some of the therapies that provide comfort and support, the service of a specialized palliative care program may be required as the degree of distress, discomfort, and dysfunction increases. Integral to effective palliative care is the provision of opportunity and support for the caregivers and service providers to work through their own emotions and grief related to the care they are providing.	A comprehensive although lengthy definition.
CPCA, 1997 (27)	Palliative care is the combination of active and compassionate therapies intended to comfort and support individuals and families who are living with, or dying from, a progressive life-threatening illness, or are bereaved.	Significantly shortened, this definition was revised from the 1995 version, and in 1998 circulated to representatives throughout Canada. Consensus was not reached.
Australian Association of Hospice and Palliative Care (AAHPC), 1994 (28)	"Hospice and Palliative Care" is defined as a concept of care which provides coordinated medical, nursing, and allied services for people who are terminally ill, delivered where possible in the environment of the person's choice, and which provides physical, psychological, emotional, and spiritual support for patients, and for patients' families and friends. The provision of hospice and palliative care services includes grief and bereavement support for the family and other carers during the life of the patient, and continuing after death.	A cumbersome definition. Physical, psychological, emotional, and spiritual support may not necessarily translate to holistic care.
Palliative Care Australia (PCA) formerly AAHPC, 1999 (29)	<p>Palliative care is specialized health care of dying people aiming to maximize quality of life, and assist families and carers during and after death.</p> <p><i>This definition prefaces the PCA publication of Standards for Palliative Care Provision and is followed by several further statements about palliative care, seven core values for palliative care standards, and six domains (physical, psychological, social, spiritual, cultural and structural) in which palliative care standards are applied.</i></p>	Most recent definition issued by PCA. In this version, the word "hospice" has been omitted. There is no mention of the professional team. Specialized care is not described.

Participants

Long term palliative care workers were purposefully selected on the basis that the meanings and perceptions of palliative care might not have been evident in initial or peripheral experiences of palliative care. The criterion for long term was a minimum of five years experience in the past 10 years in an Australian palliative care service (39).

A sample of six participants was considered sufficient to achieve a comprehensive description of the shared experience of palliative care. Purposive sampling was used to recruit a range of health care workers: nurse, doctor, volunteer (who had received a palliative care volunteer training program), chaplain, counsellor, and an allied health worker, in this case a social worker.

Following approval from the Edith Cowan University Committee for the Conduct of Ethical Research, an information sheet outlining the project and participants' involvement was mailed to each participant. Prior to the first interview, written consent was obtained and participants were informed that they had the right to withdraw from the study at any time.

The six participants shared 69 years of experience working in palliative care services, individual experience ranging from five to 17 years. Five participants worked in Perth. The sixth had never worked in Perth, but had been involved with palliative care services in other cities. All participants had college or university level education, their average age was 48 years, and four of the six participants were female.

Face-to-face, tape-recorded interviews were conducted at each participants' place of choice. Four were conducted in the workplace, one at a participant's residence, and one at the researcher's residence. Each participant was interviewed once only, and interviews lasted approximately one hour. All participants were contacted following their interviews. Five of them asked to view the transcript. Three participants were also sent preliminary analyses of the combined data. None of the participants wished to withdraw any part of their data from the study. Those who reviewed the preliminary analyses confirmed the emergent themes, and agreed that further interviews would not significantly add to the data.

ANALYSIS AND VALIDATION

Analysis of the data occurred throughout the study, guided by the method described by Colaizzi (40). Interviews were transcribed verbatim, and were read to obtain a feeling for and to make sense of the descriptions. Significant statements were extracted, meanings formulated,

then clustered into themes. The themes were integrated into a description of the experience of palliative care, and a core meaning of palliative care for this group of people emerged from refinement of this description.

Throughout the analysis, the researcher paid particular attention to the process of bracketing (23), setting aside preconceptions and allowing the subjectivity of the participants' experiences to emerge. This involved constant reflection and peer debriefing with research colleagues.

Validation of the findings was made by constantly referring themes back to the original transcripts, and by member checks, to establish the truth-value of the emergent themes (40). Another researcher independently reviewed coding of data, and consensus was reached on the meanings elicited from the study. An audit trail was maintained throughout the study by clearly documenting in field notes contextual information, methodological and analytical decisions, processes, and personal responses (41,42).

FINDINGS

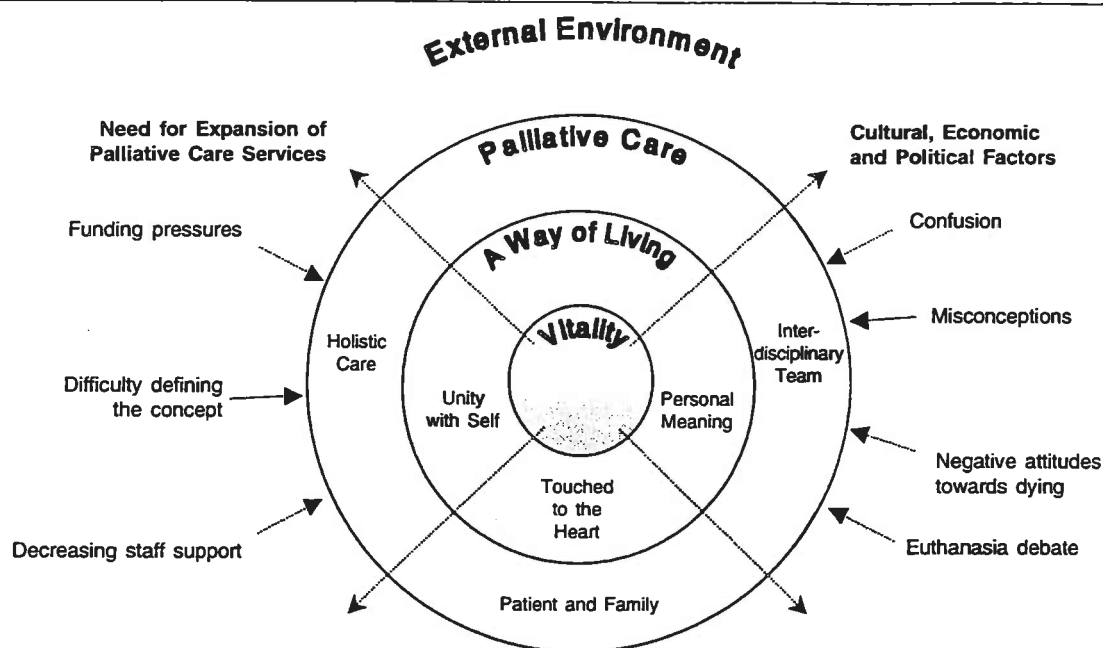
Analysis of the experience of the participants is depicted in Figure 1. This figure reflects the complex integrated layers of experience described by these long-term palliative care workers. The following sections describe the emergent themes within the conceptual framework shown in Figure 1, starting from the core of the experience and moving to the external environment.

Vitality: the Core

Central to the figure is the notion of vitality. Vitality has been defined as "the capacity to live and develop" (43). Vitality is associated with energy, life, animation, and importance (44). These are not concepts commonly associated with palliative care. Throughout the participants' descriptions of their experiences, the notion of vitality was common. Participants displayed animation when describing their experiences, and articulated the importance of their experiences in terms of personal growth for patients, families, and caregivers. Interactions with patients, families, and colleagues were described as meaningful, and the physical workplace as being full of fun and laughter.

Vitality is at the core of Figure 1, radiating out through each of the layers. Participants' descriptions are discussed in the following explanations of the model's layers. The animation of these descriptions provided an understanding of the vitality contained in palliative care experiences for these people.

Figure 1 / CONCEPTUAL FRAMEWORK OF THE MEANING OF PALLIATIVE CARE FOR LONG-TERM PALLIATIVE CARE WORKERS



A Way of Living: the Experience of Being a Palliative Care Worker

The second layer in the figure represents the concept "a way of living". Participants expressed their involvement in palliative care as more than a job, and said that over time their work became part of a way of living. Participants clearly differentiated their workplaces from their personal environments. However, working in palliative care allowed for individual experiences that affected both personal and professional aspects of their lives.

"You have to always be professional and you have to know about your boundaries when you're working with people in palliative care, but at the same time I think it's an area of work that always makes you think. Sometimes it makes you feel an awful lot....That's the thing about engaging you on different levels."

Three aspects of a way of living were identified: unity with self, touched to the heart, and personal meaning.

Unity with Self. Working in palliative care provided an environment in which the individual's inherent values were congruent with the professional values of palliative care.

"It comes back again to these values that are congruent with me, and my life and beliefs. You don't feel like you're putting yourself on hold when you go to work. You can take yourself along and be in there with people at a much more meaningful level."

Participants' descriptions of their jobs clearly indicated the pleasure they experienced.

Touched to the Heart. Participants described emotions that were elicited by experiences encountered in the workplace. These descriptions indicated the depth and personal nature of the emotions.

"I've come away and...something that's almost so precious, so unlike what you experience in the outside world. That intimacy of the moment."

"Most of them [volunteers] have had their hearts touched by something."

Personal Meaning. The experience of working in palliative care provided a strong sense of fulfillment for the participants in this study. They indicated that, as well as allowing personal values to be brought to the workplace, the work itself encouraged personal growth. The lessons from the workplace were considered as adding meaning to the individual's professional and private lives.

"It's also the sense of achievement, when everyone else sees death as such a failure. All kinds of miraculous things happened in the last weeks of life and that you've facilitated some of that....There's...an exquisite edge, that razor's edge between life and death, and where you're very conscious of what you're doing in your own life or what you're not doing."

"But what kept me committed to hospice and palliative care has really been the...belief that it's

much more humane, it's much more compassionate, it's much more rewarding work. It's more meaningful than a lot of the work I've done in the acute care scene."

Vitality of a Way of Living

The "way of living" described by participants included personal connections, significant emotional experiences, and meaning for the individual. Palliative care work was described as a privilege, with involvement providing the opportunity for personal growth and professional fulfillment.

"So the physical presence of this person comes to an end but, you know, the memory lives on...all that the person meant to those lives, whose lives they have touched, lives on. In spite of what you believe on a spiritual level, you know, it's different to each individual, but the preciousness of that moment and that time in a person's life, and if you can just get a glimpse of that then I think that's an absolute privilege. And it's real."

Not only were these experiences perceived as being meaningful and rewarding, but the animation with which these experiences were recounted provided a sense of energy and excitement about the personal opportunities afforded by this work.

"It's very freeing and allows me to explore my own spirituality in the face of what I see on a daily basis and the people that I talk with. So that's exciting, too. Sounds good doesn't it?"

The descriptions of palliative care as a way of living for these participants were interpreted as encompassing a sense of vitality about the experiences. Hence, the figure shows vitality radiating through the second layer of the diagram.

Elements of Palliative Care

The third layer in the figure depicts the concept "palliative care". Definitions of palliative care include three common elements that were expressed by participants in this study: the patient and family, holistic care, and the interdisciplinary team. Descriptions of these elements provided insight into the meaning of palliative care for these long-term palliative care workers.

The Patient and Family. The first element, the patient and family, was interpreted as encouraging patients and families to maintain control over their care and their lives. This was further translated into part of the philosophy of palliative care—to put egos aside, to feel respect for patients as individuals, and to care for them according to the patient's and family's needs and not staff or organization agendas.

"Whatever's important to the patient, we actually fit into that care, without saying, sorry...not allowed....It's like, let's meet these people's need, within reason, because there comes a time when they're not going to have a life left to actually do any of these things. So taking him outside in the wheelchair five times for a cigarette in the day, it's not a chore. It's something they need to do to feel more comfortable with life. And it's important."

"When people come here...they relax. They're cared for in a new way, in a different way, that they're respected as individuals. They're perhaps not treated as a cancer diagnosis, or a motor neuron diagnosis, or whatever they might have, but as people, as human beings, who are much more than the disease, who have that spiritual part of their lives, who have the social part of their life, and who want to continue to keep that whole circle of life continuing. Along with the families who are also able then to participate."

Holistic Care. The second common element described by participants was expressed as a focus on holistic care. This holistic approach included treating patients as individuals, offering them respect and control, and viewing them as whole people and not as physical, emotional, social, and spiritual problems.

"I believe that when a person is dying, it's not just about the body breaking down....All the questions and meanings that come up for people. I just think all of them is engaged in the process of dying."

"That concept of caring for the whole person is really how I understand and explain palliative care. The idea of enabling people to gain as much quality in their life as is possible under the circumstances. That's what we're trying to do. With the...spiritual, social, psychological, physical side of things. Offering that whole kind of care."

The Interdisciplinary Team. The third element mentioned was the interdisciplinary team. The delivery of care was viewed as a team effort and not as individual efforts of professionals from different disciplines. The philosophy of respect and caring for others was demonstrated in attitudes toward team members. Participants felt supported by colleagues, and had not found this teamwork experience in other areas of health care.

"I actually think you work as part of a team, whereas in other areas you might actually be part of the team but really your skills, your expertise is not always recognized....I also think, too, that within palliative care that you actually are better supported amongst your colleagues, although they don't always do it right. I think generally speaking that people understand where you're coming from. Most of the time."

Being part of a team was seen not only as necessary in supporting the individual working

in palliative care, but also in caring for the complexity of needs of the patients and families.

"What I have learnt in becoming involved in palliative care is teamwork....I can't remember who actually said it, that one person cannot be expected to meet all the diverse needs of the dying person and their family. And that might be part of what makes you a survivor in palliative care as well. You can actually, very comfortably integrate into this teamwork environment and find a team you're comfortable with. You're then not only using your own skills and expertise, but also encouraging and facilitating your other trusted team members."

Links with Vitality

The palliative care element "patient and family" was described in terms of respect and support for the individual, with encouragement to achieve family reconciliations, fulfillment of lifetime dreams, and fostering of positive memories.

"[Palliative care is about]...making what is going to be an awful situation no matter what, because somebody's dying, as good as it possibly can be. To leave the memories that are as good as they can possibly be, given that event."

Holistic care was acknowledged to be necessary to achieve the positives of the experience.

"[Palliative care is]...working with others...to provide the best possible care for people who are dying...minimizing symptoms, maximizing quality of life...making it possible for the patients and the family to see some meaning, to gain some positives out of the experience."

The third element, the "interdisciplinary team", was discussed in terms of supportive relationships and respect for team members in a vibrant work environment and amongst people who enjoyed being there.

"It's a ward full of fun and laughter....We've got lots of colour and light....The nurses reflect that. There's a lovely openness. They're full of life. They're not, you know, withdrawn and hiding because they don't fit into other areas of nursing. They're definitely not that. They enjoy being here. That's the thing."

Throughout the descriptions of the positive experiences of personal growth for patients, families, and caregivers, the vitality of palliative care emerged. Patients were well supported, staff professionally fulfilled and personally enriched, and families were left with healthy memories that allowed them to flourish and grow rather than mourn and retreat. Participants agreed that, contrary to the common notion held by people outside the area, the work is not depressing.

"I mean, a lot of people ask how you keep managing to deal with it...the standard thing...you work in palliative care, how depressing....The response is...well, it's sad sometimes, but actually it's much more rewarding than anything else I've ever done."

The External Environment

The outer layer of Figure 1 depicts the external environment in which palliative care is situated. This environment includes political, cultural, and economic factors present in the community. Participants discussed influences that palliative care may have in the external environment, and some of the pressures of external factors on palliative care.

Participants suggested that palliative care promoted health, not only for bereaved individuals, but for communities as a whole.

I'm really interested in the social significance of palliative care, and the necessity of facing death and supporting the bereaved in order to promote health and well-being in people.

They [the bereaved] can look back and see that there were some positives that came out of it....It's long been a hobbyhorse of mine that, if we do it that well and we do bereavement follow-up well, then we're going to reduce the incidence of a whole range of grief-associated illnesses, both psychological and practical problems. I firmly believe that that's the major area of preventative medicine.

Most participants expressed concern regarding economic pressures on health care generally and the perceived impact on palliative care provision. Some areas mentioned were less staff support, competition between services for funding, inadequate funding to provide services in areas of need, lack of support for psychosocial needs including bereavement care, and experienced staff leaving palliative care.

Maybe it's indicative of the health system per se, at the moment...budget, finance, the way accountability is being structured....things like staff support, and you can parallel it sometimes to psychosocial support for patients. It's not always a priority when the other pressures are on.

I've been a little disillusioned since those early years, because I've seen some dreadful tensions, political rivalries and jealousies, and you know...competitive tendering, the forced amalgamation of services, the destruction of programs that were working.

The participants included in this study have continued their involvement with palliative care services whilst experiencing frustration and regret about the current health care funding situation.

Vitality of Palliative Care in the External Environment

The social significance of the outcomes of palliative care described by some participants was interpreted as positive life experience that encouraged growth and enhanced health in the wider community. In this sense, palliative care may be seen as a positive influence on both the individual's and community's capacity to live and develop, again raising the notion of vitality in association with palliative care. Current economic pressures, described in terms of changes to care provision, were of particular concern to participants, who interpreted these pressures as threatening to the vitality of palliative care.

TRANSFERABILITY OF FINDINGS

The positive perceptions and experiences of palliative care reported here may reflect the fact that those interviewed were long-time palliative care providers who had chosen to remain in the specialty area because of their work satisfaction. However, these individuals were deemed to be the most appropriate key informants who could disclose the elements of palliative care and describe it most fully. Although the core concept "vitality" suggested a central positive perspective of palliative care, participants were not hesitant to express negative experiences or concerns about palliative care services, such as lack of funding, worries about abilities to provide high quality care, and acknowledgment of difficult patient care scenarios. This indicated that a "social desirability effect" was not overshadowing their descriptions. The positive viewpoints expressed appeared to be sincere and carefully considered, and indicated that, despite the challenges of care delivery, the core of the work remained energizing and vital.

The extent to which these results can be transferred to other palliative care contexts awaits further study. It is not possible to claim that the results of a qualitative study, such as this, can be generalized. Rather, by reporting these findings, it is hoped they will foster further exploration.

DISCUSSION

Descriptions of the long-term palliative care workers in this study allowed interpretation of the core meaning of palliative care as "vitality". This was expressed in the interpretation of work in palliative care as a way of living, the concept of palliative care itself, and the impact of palliative care on the community.

The notion of vitality does not appear to be captured in the definitions of palliative care shown in Table 1. Examination of these definitions shows that two of them use the term "active" in relation to therapies, and that the WHO (24) definition states that palliative care "affirms life", and uses the phrase "quality of life". Quality of life is also used in the most recent PCA (29) definition. These three terms are consistent with the notion of vitality. However, when used in definitions within the context of "dying people", these terms may not be sufficiently explained to allow the vitality of palliative care to emerge. This is likely, given that perceptions of palliative care may be contrary, such as the notion that palliative care work is depressing.

One study found in the literature used the term "vitalizing" in describing the experience of being a hospice nurse (45). This study provided a structural analysis of the experiences of 18 hospice nurses and, within one of the themes identified as "pursuing meaningful hospice care", described experiences that were both vitalizing and devitalizing. Vitalizing experiences were those with positive connotations, including aspects such as caring in accordance with one's own values, and growing personally and professionally. These concepts were found to have similarities with the elements "unity with self" and "personal meaning", described previously in the concept "a way of living".

One recent qualitative study of five rural palliative care nurses explored a similar theme. Nurses were described as "living palliative care", which involved being required to participate in related activities beyond normal working hours, and a lack of anonymity in small rural communities (46). However, living palliative care appears to differ from the concept of a way of living. The former suggests the individual is recognised as a palliative care worker in numerous aspects of community life and has little choice in assuming this role outside the workplace. In the case of palliative care as a way of living, the individual is described as making a personal connection between the lessons of the workplace and application of those lessons to personal life—making a decision to live one's life congruent with work experiences. Further investigation of rural palliative care professionals with regard to shared meanings of palliative care would add to the current research.

Several other studies of nurses working in oncology or palliative care settings have included descriptions of their finding personal meaning and reward in their work (31,47-49). Some authors have highlighted the social con-

text of caregiving relationships, using the term "professional friendships", which allows for reciprocal communication and caring (49–51). The concept of professional friendships was not explicitly found in the current study, although personal meaning and job fulfillment were well described.

Challenges of palliative care work were extended to palliative medicine by Kearney (52), who suggested that physicians faced a choice of confining themselves to "symptomatology" or to healing in a broader sense. He encouraged physicians to value a deeper level of healing by embracing the human experience for themselves and, in turn, the patients in their care. This concept of "healing" is similar to the idea of finding positive aspects in tragic life-threatening circumstances, such as those described by the psychiatrist Viktor Frankl (53). Frankl drew upon his own experiences of being imprisoned in concentration camps during the Second World War and became founder of the "logotherapy" school of psychotherapy, based on the premise that "man's search for meaning is the primary motivation in his life" (53, p.121). Comments by Kearney and the work of Frankl suggest that people who are facing death feel motivated to search for meaning. The personal growth and family reconciliations mentioned within this study may be indicative of that search for meaning.

Review of the literature revealed that other researchers have discussed several of the aspects identified in this current study. However, the only study to identify the notion of vitality in respect to the experience of working in palliative care, using the phrase "vitalizing experiences", is that of Rasmussen, Sandman, and Norberg (45).

The Future of Palliative Care

Participants in this study, although expressing frustration with external pressures, continue to work in palliative care. Technological advances and new knowledge in palliative care have improved the care available to terminally ill patients, often decreasing suffering and increasing their quality of life (54). However, political and economic pressures that shape decisions about resource allocation have been outlined by Nightingale (55), and emphasize the importance of broad-based informed understanding of palliative care.

Further research is required to explore the meanings of palliative care from the viewpoint of other health professionals, health policy makers, recipients of palliative care services, and general community members. Identification of vitality as the core of palliative care for this

group of long-term palliative care workers has, however, introduced a concept not commonly associated with palliative care.

CONCLUSION

This research has enhanced current definitions of palliative care by explaining the meaning of palliative care in this group of long-term palliative care workers. Contrary to the notion of this work being depressing, palliative care focuses on the positive aspects of living, providing an opportunity for personal growth and enhanced meaning for carers. Identification of the vitality of palliative care for this group of people extends the understanding of palliative care, and may provide direction for future research and health service planning and use.

Date received October 19, 2000; date accepted, April 24, 2001.

ACKNOWLEDGEMENT

The financial support provided by Edith Cowan University in the form of a PhD Scholarship to the first author is gratefully acknowledged. The author also wishes to thank the participants in this study, who not only gave freely of their time, but also provided rich accounts of their ongoing commitment to palliative care.

REFERENCES

1. Saunders C. Foreword. In: Doyle D, Hanks GWC, MacDonald N (eds). *Oxford Textbook of Palliative Medicine*. Oxford: Oxford University Press, 1993; p. v–viii.
2. Woodruff R. *Palliative Medicine*. Melbourne: Asperula, 1993.
3. World Health Organization. *The World Health Report 1997*. Geneva: WHO, 1997.
4. Palliative Care Council of South Australia. *Survey of public awareness of palliative care and hospice services*. Unpublished manuscript. 1998.
5. Palliative Care Australia. *From the desk of the President*. Palliat Care News 1999; Spring: 3.
6. McMillan SC, Mahon M. A study of quality of life of hospice patients on admission and at week 3. *Cancer Nurs* 1994; 17(1): 52–60.
7. Kristjanson LJ, Leis A, Koop, PM, Carriere KC, Mueller B. Family members' care expectations, care perceptions, and satisfaction with advanced cancer care: results of a multi-site pilot study. *J Palliat Care* 1997; 13(4): 5–13.
8. Wakefield M, Ashby M. Attitudes of surviving relatives to terminal care in South Australia. *J Pain Symptom Manage* 1993; 8: 529–538.
9. Cooley ME. Bereavement care: a role for nurses. *Cancer Nurs* 1992; 15(2): 125–129.
10. Kristjanson LJ, Sloan JA, Dudgeon D, Adaskin E. Family member's perceptions of palliative cancer care: predictors of family functioning and family members' health. *J Palliat Care* 1996; 12(4): 10–20.
11. Lewandowski W, Jones SL. The family with cancer. *Cancer Nurs* 1988; 11: 313–321.
12. Commonwealth Department of Health and Family Services. *Background for a National Strategy for Palliative Care in Australia*. Canberra, Australian Capital Territory: CDHFS; 1998. Publications approval number 4066.

13. Health Department of Western Australia. *Palliative Care: the Plan for Western Australia*. East Perth, Western Australia: HDWA, 1997.
14. Kristjanson L. *Generic Versus Specific Palliative Care Services*. A report prepared for the Health Care and Issues Division, Systems for Health Directorate, Health Canada. Unpublished manuscript, 1997.
15. Western Australia Hospice Palliative Care Association. *Palliative Care in Western Australia to the Year 2001*. Unpublished manuscript, 1996.
16. Aranda S. Global perspectives on palliative care. *Cancer Nurs* 1999; 22(1): 33-39.
17. Eccleston R. The consumer's guide to palliative care. *The Australian Magazine* 1997; February 15-16: 10-15.
18. Field D, James N. Where and how people die. In: Clark D (ed). *The Future of Palliative Care: issues of policy and practice*. Buckingham, UK: Open University Press, 1993; pp. 6-29.
19. Ashby M. Hard cases, causation and care of the dying. *J Law Med* 1995; 3: 152-160.
20. Mount B. Morphine drips, terminal sedation, and slow euthanasia: definitions and facts, not anecdotes. *J Palliat Care* 1996; 12(4): 31-37.
21. *Palliative Care Australia*. Position statement on euthanasia. *Palliat Care News* 1999; Autumn/Winter: 13.
22. O'Connor M, Menon M. Palliative care within the euthanasia debate. In: Parker J, Aranda S (eds). *Palliative Care: Explorations and Challenges*. Rosebery, Sydney: MacLennan & Petty, 1998; pp. 160-171.
23. Patton MQ. *Qualitative Evaluation and Research Methods*. 2nd edition. Newbury Park, CA: Sage Publications, 1990.
24. World Health Organization. *Cancer Pain Relief and Palliative Care*. Geneva: WHO, 1990. Technical Report: Series 804.
25. Goodlin SJ. What is palliative care? *Hosp Pract (off ed)* 1997; 32(2): 13-16.
26. Canadian Palliative Care Association. *Palliative Care: towards a consensus in standardized principles of practice*. First phase working document. Ottawa, ON: CPCA, 1995.
27. Canadian Palliative Care Association. *How Close Are We To Consensus? A report on the first cycle of the national consensus-building process to develop national standards of practice for palliative care in Canada*. Full report. Ottawa, ON: CPCA, 1998.
28. Australian Association for Hospice and Palliative Care. *Standards for Hospice Palliative Care Provision*. Perth: AAHPC, 1994.
29. *Palliative Care Australia*. *Standards for Palliative Care Provision*. 3rd edition. Yarralumla: PCA, 1999.
30. Vachon M. Recent research into staff stress in palliative care. *Eur J Palliat Care* 1997; 4(3): 99-103.
31. Byrne D, McMurray A. Caring for the dying: nurses' experiences in hospice care. *Aust J Adv Nurs* 1997; 15(1): 4-11.
32. Carson M, Williams T, Everett A, Barker S. The nurse's role in the multidisciplinary team. *Eur J Palliat Care* 1997; 4(3): 96-98.
33. Davies B, Oberle K. Dimensions of the supportive role of the nurse in palliative care. *Oncol Nurs Forum* 1990; 17(1): 87-94.
34. Dobratz MC. Hospice nursing: present perspectives and future directives. *Cancer Nurs* 1990; 13: 116-122.
35. Sellick SM, Charles K, Dagsvik J, Kelley ML. Palliative care provider's perspectives on service and education needs. *J Palliat Care* 1996; 12(2): 34-38.
36. Marquis R. A qualitative evaluation of a bereavement service: an analysis of the experiences of consumers and providers of services in Australia. *Am J Hosp Palliat Care* 1994; 13(4): 38-43.
37. McNamara B, Waddell C, Colvin M. Threats to the good death: the cultural context of stress and coping among hospice nurses. *Social Health Illn* 1995; 17: 222-244.
38. Jacobsen GA. Hospice: what it is not. *CA Cancer J Clin* 1984; 34: 202-203.
39. Australian Association for Hospice and Palliative Care. *Directory of Hospice and Palliative Care Services in Australia*. Perth: AAHPC, 1997.
40. Colaizzi PF. Psychological research as the phenomenologist views it. In: Valle RS, King M (eds). *Existential-Phenomenological Alternatives for Psychology*. New York: Oxford University Press, 1979; pp. 48-71.
41. Sandelowski M. The problem of rigor in qualitative research. *Adv Nurs Sci* 1986; 8(3): 27-37.
42. Rodgers B, Cowles K. The qualitative research audit trail: a complex collection of documentation. *Res Nurs Health* 1993; 16(4): 219-226.
43. *Webster's New Collegiate Dictionary*. Toronto, ON: Thomas Allen & Son Limited, 1995; "vitality", p. 1309.
44. Chapman RL. *Roget's International Thesaurus Revised*. 4th edition. London: Collins Publishers, 1988; "eagerness", p. 489.
45. Rasmussen BH, Sandman PO, Norberg A. Stories of being a hospice nurse: a journey towards finding one's footing. *Cancer Nurs* 1997; 20(5): 330-341.
46. McConigley R, Kristjanson LJ, Morgan A. Palliative care nursing in rural Western Australia. *Int J Palliat Nurs* 2000; 6(2): 80-90.
47. Cohen MZ, Haberman MR, Steeves R, Deatrick JA. Rewards and difficulties of oncology nursing. *Oncol Nurs Forum* 1994; 21(8 suppl): 9-17.
48. Degner LF, Gow CM, Thompson LA. Critical nursing behaviors in care for the dying. *Cancer Nurs* 1991; 14(5): 246-253.
49. Trygstad L. Professional friends: the inclusion of the personal into the professional. *Cancer Nurs* 1986; 9(6): 326-332.
50. Aranda S. The nurse as coach in care of the dying. *Contemp Nurse* 1997; 6(3/4): 117-122.
51. Aranda SK, Street AF. Being authentic and being a chameleon: nurse-patient interaction revisited. *Nurs Inq* 1999; 6: 75-82.
52. Kearney M. Palliative medicine—just another specialty? *Palliat Med* 1992; 6: 39-46.
53. Frankl VE. *Man's Search for Meaning*. New York, NY: Washington Square Press, 1984.
54. Aranda S. Palliative care principles: masking the complexity of practice. In: Parker J, Aranda S (eds). *Palliative Care: Explorations and Challenges*. Sydney: MacLennan & Petty, 1998; pp. 21-31.
55. Nightingale E. Political and economic challenges. In: Ramadge J (ed). *Australian Nursing Practice and Palliative Care: its origins, evolution and future*. Deakin: Royal College of Nursing Australia, 1998; p.17-28. Professional Development Series No.9.