Palliative Care Staff Perspectives

The Challenges of End-of-Life Care on Their Professional Practices and Everyday Lives

Natalia Luxardo, PhD O Cecilia Vindrola Padros, PhD O Vilma Tripodoro, MD

This article has 3 goals: To describe the attitudes and experiences of staff on end-of-life care treatment of dying persons, to examine how the staff view their terminally ill patients, and to gather professionals' opinions on how their experiences impact their daily lives. It is a qualitative research inquiry based on a constructivist-grounded theory design. The study subjects were professionals who were part of palliative care services in Buenos Aires city during 2012. A purposive sample of 30 personnel answered an open-ended questionnaire assessing attitudes and perceptions concerning end-of-life. The results showed the following: (a) "Good" deaths were considered those in which physical symptoms were dealt with, where the patient was surrounded or on good terms with family members, and where they were at peace with themselves, any unfinished business, or God. "Bad" deaths were believed to be those where the patient was physically uncomfortable, were within a conspiracy-silence atmosphere, and died alone. (b) The factors in common that staff members identified regarding deaths were the need for spiritual comfort, peace, and acceptance and the need for attaining a deep connection with others. (c) The unexpected issues identified among end-of-life trajectories were the varying attitudes that patients had regarding death. (d) The personal life of the staff was affected by being in charge of end-of-life care decision making.

KEY WORDS

end-of-life, "good/bad" death perceptions, palliative care staff, perspectives, personal experiences, qualitative research

Natalia Luxardo, PhD, is researcher associate, National Scientific and Technical Research Council and University of Buenos Aires, Ciudad de Buenos Aires, Argentina.

Cecilia Vindrola Padros, PhD, is researcher and fellow, Department of Children's Nursing, Faculty of Health and Social Care, London South Bank University, England.

Vilma Tripodoro, MD, is head of Palliative Care, Pallium Latinoamerica and Lanari Institute, Ciudad de Buenos Aires, Argentina.

Address correspondence to Natalia Luxardo, PhD, National Scientific and Technical Research Council (CONICET), Av. de Mayo 1437 1 A (1085), Ciudad de Buenos Aires, Caba, Argentina (palish@hotmail.com).

The authors have no conflicts of interest to disclose.

DOI: 10.1097/NJH.0000000000000036

ittle research from an international perspective has been done to explore palliative care staff attitudes about the care of dying patients and its impact on their personal lives. The provision of specialist-level palliative care involves complex processes that include expertise in communication, managing the medical aspects of the illness, providing expert pain and symptom management, providing emotional support for the dying and their loved ones, and addressing the spiritual and psychological issues of end-of-life care. ^{2,3} Palliative care staff have key bereavement needs and require support regarding endof-life care. 4 Mula 5 maintains that palliative care professionals face many emotionally unsettling situations during their work that challenge their skills in both personal coping and medical decision making, many times dealing with situations too stressful to allow them to process and cope properly with grief since they recall their own—not yet resolved-histories of loss. Thus, their stories, fears, and other issues must be identified. Marshal et al⁶ also confirmed that death, even when expected, triggers different emotions among staff.

The objectives of this research were to (1) describe the attitudes and experiences of staff on the end-of-life care of dying persons, (2) examine how the staff view their terminally ill patients, and (3) gather the opinions of professionals on how their experiences in this specific area impact their daily lives. The research presented here stems from a larger study. The study gives, for the first time in a Latin American context, relevant data regarding the support needed to improve palliative and end-of-life care and the perceptions of staff providing such care. The current study used the framework of sociology of health and medical anthropology's interpretative theories, approaches widely applied in health care settings. Sp

METHODS

This study was a qualitative research inquiry based on an exploratory design. Constructivist-grounded theory⁷ design guided the qualitative phase of a broader research project carried out in 2 settings (Argentina and Spain) during 2012. Grounded theory was chosen as a suitable methodology for this phase of the research because it sought to



produce rich textual descriptions of the experiences of end-of-life-care phenomena in the life-world of palliative care staff. The constructivist approach intends to avoid drawing upon objectivist assumptions founded in positivism but instead draws the focus upon the researchers' position in the research context, interpretive frames, relationship with the participants, field experiences, and modes of generating data.⁸

Subjects

The study subjects were professionals (physicians, nurses, social workers, and psychologists) and volunteers who were part of palliative care services in Buenos Aires city from February to September 2012. As in other qualitative studies, the choice of sample size was based on sufficient numbers to provide insight into the concepts of interest. We approached a purposive sample of 40 participants; 32 subjects returned the questionnaires, yielding 30 usable completed forms. The inclusion criteria of the study subjects were that they had to have more than 2 years of experience providing palliative care and have received formal palliative care training, such as a master's degree or postgraduate courses in the area provided by institutions with legal certificates.

Data Collection Methods

A self-report questionnaire with open-ended questions was administered to staff members of palliative care services to measure the impact of care in health professionals. Openended questions are considered poor in self-administered questionnaires; however, their use minimizes social desirability responses. This was 1 of the most important needs in terms of reliability for this exploratory research, especially because the staff were trained in palliative care principles so there was a permanent risk of "only saying what should be said." We chose a self-administered format because it was noted that participants may respond more truthfully to sensitive questions by using this approach, and it was possible because all of them were literate. Moreover, in comparison with the 2 alternatives (face-to-face and telephone surveys), it is considered more feasible owing to the ease of finding suitable staff and the lower costs (because it requires fewer research personnel). Face-to-face interviews tend to yield higher response rates; however, the permanent and direct contact that 1 of the researchers had with the rest of the staff (as a colleague of the respondents) turned her into a subtle pressure or reminder to respond on time and enriched the research by providing a deeper understanding of end-of-life care from an insider perspective. Furthermore, this strategy could enrich the research by providing a deeper understanding of end-of-life care from an insider perspective and also allowed the mitigation of the problem noted by Thorpe et al¹⁰ that, in survey research, physicians are a professional group from which it is difficult to obtain high responses. In fact, being an insider helped to facilitate trust and confidence and was a follow-up procedure to guarantee the success in the response rates by personal reminders in professional meetings (such as weekly supervisions).

Questionnaire

A questionnaire assessing attitudes, perceptions, beliefs, and experiences concerning end-of-life care was administered to members of interdisciplinary teams of Palliative Care Services. The questionnaire encouraged respondents to write in response to open-ended questions. Writing is inherently reflexive, and people tend to include explanations and interpretation with the description of the experience. The questions were grouped within 3 broader main sections: (1) Staff's attitudes on and experiences of end-oflife care treatment, (2) staff's views of terminally ill patients, and (3) challenges as an end-of-life care provider. We decided that the questionnaire should begin with personal data to ease the respondent into the more emotionally charged questions on end-of-life care and to leave the person's personal demographic to the end because it is usually the most sensitive issue. Participants were asked to write a direct account of 2 or 3 personal experiences of the characteristics they mentioned either for a "good" or a "bad" death. The questionnaire was administered personally and was completely anonymous.

Data Analysis

Data were entered for analysis manually by the main researcher, external to any of the palliative care teams involved. A preliminary interpretation of the text to facilitate coding, usually called immersion, allowed us to identify and transcribe first-order constructs. First-order constructs are the ideas of the participants expressed in their own words or phrases, identifying overlapping responses and connections between them. All the answers were compared. Constant comparative procedures resulted in themes that were coded, grouped, and sorted into categories. Preliminary categories emerged. The open-ended questions produced a larger range of different responses, with categories that were very small or vaguely miscellaneous in nature. Therefore, we needed to introduce broader theories of personal knowledge and experience in the area to group them in more sophisticated categories. To do this, we developed second-order constructs (generated by the researchers). Files were grouped together into a smaller number of broad themes with relevant text materials.

Data cross-checking was carried out in every step of the analysis by corroborating theoretical categories with the original transcripts. The next stage was to read again each question with the pragmatic or experiential information provided by the staff when recalling concrete situations they faced during their practice. By including these incidents



or episodes, we aimed to promote reflexivity and deepen the analysis rooted in their lived experiences. The other researchers examined data by recoding the original transcripts, and in some cases, changes were suggested. Responses that did not fit into an existing category were defined as "others," creating an extremely broad category in many instances. In these cases, new categorization was established.

Reliability and Validity of Results in Terms of Transferability

Procedures for monitoring the credibility of the data included careful data management, peer debriefing, and review of the codes. Some other techniques for meeting standards of rigor and trustworthiness in qualitative research were the clarification with specific examples of their clinical practice, triangulation with other methods, and cross referencing of emerging categories with independent researchers. The triangulation included the combination of the questionnaire with independent sources of evidence: Observations, field notes recorded during the research process, and memos. The information contained in these personal files enabled the reconstruction of conversations and observations in context. The analytical files contained a detailed examination of the ideas that emerged in relation to the research questions. As a qualitative study, this research aims to provide enough details of techniques and findings so other researchers could apply them for analyzing and thinking about other contexts, settings, and situations alike (transferability).

The research protocol was approved by the institutional review boards of the institutions involved (Pallium, CONICET, and Instituto Lanari).

RESULTS

Sociodemographic Characteristics

Twenty-three of the interviewees were women and 7 were men. Regarding age, range was 29 to 72 years, mean was 46 years, median was 44 years, and mode was 36 years. Professions included physicians (10), social workers (6), psychologists (5), nurses (5), and volunteers (4). The places of birth of subjects were Buenos Aires (22), countryside (4), and other countries (4). All of them were from different palliative care services.

Staff's Attitudes and Experiences of End-of-Life Care Treatment

Staff Perceptions Regarding How the Patient and/or Family View End-of-Life Care Delivery

The staff were asked how they would describe good and bad deaths. These were abstract notions of what death should be. They can be grouped into the following main categories that emerged from the analysis: Physical and psychosocial dimensions of palliative interventions, relational aspects (mainly in association with the family), patients' emotional and spiritual issues or concerns, and a miscellaneous category. Good deaths were those in which physical symptoms such as pain were dealt with, where the patient was surrounded or in good terms with family members, and where they were at peace with themselves, their life, any unfinished business, or God. In contrast, bad deaths were those in which the patient was physically uncomfortable, within a "conspiracy-of-silence" atmosphere. Being either for a good or for a bad death, palliative care staff considered professional assistance as the main factor influencing it with 51 examples of a good death and 64 of bad death (the respondents were allowed to select as many examples as they wished). For a good death, existential and spiritual issues were mentioned as the second most important issue. For a bad one, the role of relatives was highlighted.

Experiences of Good and Bad Deaths

The staff members were then asked to supply examples of good and bad deaths they had experienced in their practice. Forty-one examples of good deaths were identified. Some of the incidents that staff recalled were in correspondence with the abstract ideas mentioned before. However, they focused much less on the physical dimensions and were more associated with other issues such as family support and dying in peace. The examples were based mainly on situations they witnessed as professionals and were related to 1 of the following items (many times combined): Last wishes, family caregiving, inner peace, external peace, understanding what is happening, and being in charge of decision-making processes. In their questionnaires, the staff described some of these examples as follows: "Rosa finally died at home surrounded by her family"; "Elvira could express her wish to join her distant sons again and could define what to do with her body after her death"; "Pedro's brother could be contacted. They had the time to talk alone about differences they had in the past. The day after that visit, Pedro died quietly"; and "After getting the virgin image of her devotion, she died."

The respondents identified 43 examples of bad deaths. Most of the examples had to do with the following: Conflicts or bad relationships with family members or friends, anguish toward death, issues related to the disease and the control of symptoms, loneliness during the dying process, and unsuitable medical interventions or negligence.

In the examples they mentioned for real-world good/bad deaths, the professional expertise had a minor role. For good deaths, they valued family support and the surrounding environment, along with spiritual and existential issues. Some of the examples presented by the staff were a patient who was closer again with his brother after 30 years of ignoring each other because of an argument; a woman



who requested a specific Christian virgin image that was in her house and nobody could find it to bring it to her, only after seeing it could she die; a gay patient who, before dying, could forgive his family's discrimination and could leave his inheritance to his boyfriend; an 80-year-old woman who felt the need to confess an infidelity in front of her family and husband; and a patient who transformed the original request for euthanasia into short-term projects—such as attending his son's wedding and writing a book—after the staff's psychosocial interventions.

The bad death examples were related to the lack of family as well as cases of spiritual and existential suffering. This suffering was often associated with pain. One interview read "patient in agony, with existential pain, who asked not to be sedated in order to be able to feel that she was still alive." Another interviewee mentioned: "[I remember] someone with existential suffering, even with strong doses of sedative medication, he was still in pain."

Staff's Views of Terminally III Patients

The second aim of the study was to identify the different ways in which the staff members perceived terminally ill patients and the dying process. The questionnaire asked them to reflect on the issues that patients usually faced, situations that had been unexpected, and the role of spirituality and religion during the end of the patient's life.

Common Aspects in End-of-Life Trajectories

The staff identified common themes regarding the experience of various patient deaths. One of the most frequent factors encountered was the patient's need for spiritual comfort, peace, and acceptance (personally for the patient or for their present condition and what would occur in the imminent future) and the need for attaining a deep and meaningful connection with others. In second place, the staff members mentioned physical deterioration, frustration, and denial as well as the vulnerability of those who were about to die. In third place, they mentioned experiences of anguish, unease, and suffering with a poor response to medical treatment. For staff, life and death were seen as unique, unrepeatable components of life that belonged solely to the individuals experiencing them, "every death is unique and unrepeatable, [it is according to] their own life's terms." Two replies were grouped under the "others" category, and these referred to the hospitalization of death and situations where the patient felt like a burden. Finally, a group of 3 staff members replied that they found common aspects but did not present any details.

Unexpected or Surprising Issues

Another part of the questionnaire asked the staff members to describe those aspects regarding moments of death encountered during their practice that surprised them. In first place, they mentioned the different atti-

tudes that patients had regarding death. They were particularly surprised in those cases where the patient had faced his/her own mortality in positive terms, without fearing death or by patients who decided to fight the disease with new experimental treatments until the end. One interviewee mentioned being surprised by "people that do not fear dying, who prepare themselves for that moment. I remember a man who was very conscious about his death and was obedient with regard to staff suggestions. He was living that process as something completely natural and expected." In second place, they identified issues related to the way in which they died, sudden deaths or deaths that were too prolonged represented the most surprising cases. Finally, they noted factors associated with the arrangements patients made to protect/care for their loved ones, such as arranging the care of children or saying goodbye to their loved ones. One description of this arrangement was "I remember a young mother who asked her single sister to marry her husband after her death in order to be the one who would take care of her children."

Spirituality

When asked about the role of spirituality for the patients and the family during the dying process, 9 staff members replied that spirituality was something that helped to give meaning to life, to make sense of things in relation to their values. Eight people expressed that it helped them with death, to accept it and to adapt to it. Six respondents associated spirituality with strength, 5 associated it with something unique to each person, and 2 indicated that it helped to articulate different dimensions of life.

The Role of Relatives

More than half of the palliative care staff involved in the study viewed the patient's relatives as playing a significant role as the patient approached the end of life. Staff described different roles including how family members accompanied the dying person, provided emotional support, and facilitated the process of the patient's death. Ten respondents indicated that family can have both a positive and a negative impact, noting that in some cases, family members create obstacles to providing needed care or create other challenges during the patient's dying process. Two respondents highlighted the suffering and anguish that family members experience.

Challenges as an End-of-Life Care Provider

The third aim of the study was to identify the different ways in which palliative care specialists view their job and understand the challenges they face on an everyday basis.

Deciding to Become a Palliative Care Specialist

When asked why they decided to become a palliative care specialist, half of the staff members mentioned that they



chose it because of the poor performance of other specialties with regard to end-of-life issues. Nine staff members indicated that they had an interest in dying people because of personal experiences, whereas 4 had ended up in this role indirectly, usually referred by the institution they worked for.

Role of Religion

Most of the interviewees declared that they were religious; 7 said they were not religious, and the remainder decided not to answer this question. The role that religion played during the dying process was described as (1) a factor that allows them to connect with the other person's spiritual side, thus facilitating comprehension; (2) a way of coping with death (provides tranquility and comfort); and (3) an important factor, but one that the interviewees could not define.

Moving Situations

When asked about the situations that emotionally moved them the most, the staff members ranked them as follows: (1) The death of young people, (2) the ineffectiveness of medical interventions, (3) the issues related to the patient's family, and (4) personal connections with patients or situations where the staff member identified with the dying person. Particular situations brought about emotional responses in staff, for some special reason such as identifying with the person or his/her story. One interviewee mentioned a case that had been special, "I enjoyed caring for A, great lover of music, like myself. We spent many times together, listening to operas and discussing them. Before dying she said: 'you have been a good friend to me during this time."

Impact on Personal Life

All of the staff members felt that their life was affected by working as palliative care specialists. Eleven of them felt that it helped them enjoy life and live in the moment. Eight thought it helped them improve their own lives in the sense that it made them work harder to fix social relations, and it promoted personal growth and strengthened their character. Four people said it made them feel useful as they were helping others. Four staff members indicated that it allowed them to work as a team and have a more holistic and interdisciplinary perspective. Three of the staff members decided to focus on the negative aspects of their work as palliative care specialists, mentioning the heavy workload, the conflicts with other team members, and frustrations in the workplace.

Some referred to having developed a black sense of humor with regard to death and dying that was not understood by their relatives or colleagues. For others, working on their own life was a key factor for doing a good job, such as the following observation: "I realised that if you don't work on your own mourning, it's very difficult to help others during this process of dying."

The Best and the Worst

The staff members were asked to identify the best and worst things about their job. The interviewees most highly valued the gratitude expressed by patients and family members, the things they learned on the job, and the possibility of working as a team. When identifying the negative aspects of their job, they talked about the stress produced by deficiencies in the health care system, the difficulties faced while treating some patients, their inability to treat the patient's symptoms (especially pain), and the death of young people. One of the most frustrating and persistent challenges mentioned was undertreated pain. Another major stressor perceived by staff included unmet needs for existential suffering. Physical well-being was the most common strategy reported, followed by professional relationships, taking a transcendental perspective, talking with others, hobbies, personal relationships, personal boundaries, time off work, passion for one's work, realistic expectations, use of humor, and remembering patients.

Some staff mentioned being emotionally overloaded, that is, being overwhelmed and experiencing a feeling of being drained constantly. The frustrations they mentioned were grouped in 3 main categories (verbatim inside hyphens): (1) Palliative expertise and practices—"being too attached to a particular patient is harmful but unavoidable" (physician); "death issues and working in end-of-life care caused me distress and emotional instability requiring treatment and leave of absence from work" (social worker); (2) lack of resources—"there is too much demand, we are completely saturated, and when we can cope it is at the expense of our own health" (nurse); "you need more time to deal with so many demands" (physician); and (3) the failure of the health care system—"hospitals are hostile for people like me, trying to do this kind of job" (social worker); "the worst is dealing with the healthcare system: lack of resources, dehumanisation of the institutions, the negligence of untrained professionals" (psychologist).

DISCUSSION

With regard to good/bad death notions, when the interviewees' answers were compared with those presented in previous research, similar factors were found: Being in control, being comfortable and properly cared for by professionals, having a sense of closure, affirmation of the dying person, trust in care providers, recognition of impeding death, ¹¹ being prepared, ¹² having beliefs and values honored, ¹¹ relationships optimized, ¹¹ appropriateness of death and leaving a legacy, family care, ¹¹ making sense, ¹² having solved unfinished business, ¹¹ respect for their own beliefs under ethical and cultural standards, having a feeling of closure with life, and decision-making process centered on the patient. ¹² The examples provided by the staff depicted the same idea: All spheres of the life of the



person about to die should be taken into consideration by the professionals.

Despite these correlations between the literature and the informants' perspectives about what a good death implies, there are also noticeable issues excluded in the answers. The first relevant aspect in the literature of what a good death means according to Kehl's¹¹ revision is not being a burden for the loved ones, also noticed by O'Hara et al.¹³ This crucial issue is also encountered in patients' perspectives of what a good death implies but was only mentioned twice in the questionnaires of this study. Second, another idea that was scarcely mentioned—and in an ambiguous and blurred way—was the generic term of "therapeutic futility," a concept that has a stronger presence in other studies, also referred to as "avoiding the extension of agony."

In third place, we noticed that, although decreasing throughout the years, in the literature from the 1960s until mid-1990s, the term *good death* was used interchangeably with euthanasia. This association was not found among any of the staff who participated. Fourth, Kehl's treview showed that there is variability in the attributes of what a good death includes because it is something considered individual and dynamic. Nonetheless, this fluidity was not mentioned by any of the professionals, who described the attributes of a good death as inherently stable and fixed. Finally, willingness to establish norms that ensure the respect of the patient's rights, that is, the concept of autonomy in end-of-life decision making, was also absent in the questionnaires.

With regard to the views of their patients' end-of-life moments, the research revealed an open approach to the care of the dying by the staff that is in consonance with the palliative movement, perceiving the process of dying as natural and expected with specific technical and emotional requirements that most of them feel ready to provide when compared with other colleagues outside the "palliative world." However, the assumption of this perceived naturalness of dying as something homogeneous or as an unproblematic issue is not appropriate. The palliative staff still have doubts about it because of the uniqueness they identified in each of them and, despite their training, because they currently feel emotionally touched by some particular deaths in which they have found something of themselves. There are common fears about the process of dying, such as what they consider "unfair situations," patients with unresolved pain, and others that produce complex emotional responses. Sandgren et al¹⁴ also noticed among palliative staff the concern of being emotionally overloaded by dealing with emotionally charged situations. Similar to our study, such events were the death of mothers of young children, the deaths of adolescents, or the death of patients with whom staff developed a strong relationship. Fine et al¹⁵ highlighted areas that need improvement in palliative and end-of-life care, specially physicians' ability to address patient/family emotional issues.

In relation to the pain of the patients, even when substantial evidence demonstrates that palliative care leads to better patient and caregiver outcomes, which include the improvement of symptoms, quality of life, and patient satisfaction, ¹⁶ there are still some professionals who feel frustrated because pain or symptoms were not alleviated. Specifically with bad death examples in real life, they recalled many situations where patients experienced existential pain and, even with all the efforts to alleviate it, not much was achieved. Other scholars ^{17,18} also found this frustration among physicians not being able to treat cancer pain. The most popular suggestion that staff mentioned for these unsettling scenarios was team discussions. In fact, we observed that the use of a broader interdisciplinary team was 1 of the more supportive pillars in their daily labor.

The crucial part played by the family in this process was mentioned with a common word, *fundamental*. The family was seen as important in providing pragmatic and emotional support to patients, but the staff also mentioned the effects of the patient's death on family members. In some cases, the family was also characterized as an obstacle for providing the best care for the patient. They insisted on not telling the truth, on trying new experimental treatments, and so on. However, the negative role played by some relatives was also mentioned as something they felt sorry for or emotionally moved by, especially when it led to the death in isolation of the patient.

Impact on Their Lives

In general terms, the research revealed that the personal life of the staff was affected by being in charge of end-oflife care decision making. In fact, 83% thought about their own demise after working in this area. Right from the start, when selecting this particular area for professional interest, the role played by personal reasons—such as their own unresolved losses—was evident in their discourses. Working with finitude makes them more capable of honoring life, settling priorities, and enjoying each moment. Sinclair's study also demonstrates that clinical exposure to death and dying taught professionals to live in the present, cultivate a spiritual life, reflect on their own mortality, reflect on the continuity of life providing a unique opportunity to discover meaning in life through the lessons of their patients, and an opportunity to incorporate these teachings in their own lives.

The main rewards of doing this job had to do with the sense of feeling good by helping others and receiving gratitude from families. In the research by Wilson et al, ¹⁸ staff placed particular emphasis on teamwork and find it rewarding. Most of the professionals considered themselves religious people. Nonetheless, when they had to put into



concrete terms what being religious means, a broad umbrella with abstract ideas emerged, demonstrating the lack of consensus that exists among them such as concepts of spirituality relating to the integrity of all the dimensions in their life (wholeness perspective), the search for meaning to understand why it had happened to them, and personal journeying to continue learning. Hayden¹⁹ argues that spiritual care is an essential component of palliative and endof-life care provision, but its definition is challenging for staff and carers involved. According to Benito and Barbero, 20 spirituality is inherently relational; it can only be visualized in connection with others, with God, and with life. Others²¹ acknowledged transcendence as an element of spirituality. The main category in relation to this question was the acceptance of the situation—that someone is about to die. A study by Edwards et al²² found spirituality to be linked to relationships and acts of listening and sharing and also 1 of the most difficult issues to address.

Another difficult issue to resolve for staff was cases of psychiatric disorders and violence, either of patients or their relatives. This had to do with the poor articulation that existed between specialties (palliative care, mental health, and psychiatry) at hospitals, resulting in the lack of coordinated interventions. One point that was noted was palliative care staff learning by working in this area. Yamamoto et al²³ found that violent behavior among patients is associated with a significant increase in both physical and psychological burden on informal caregivers. Klassen et al²⁴ noted that health care providers found it challenging to work with angry or rude relatives of cancer patients.

CONCLUSIONS

Methodological challenges were identified, including small, nonrandom, convenience samples; reliance on descriptive analyses; and a dearth of longitudinal research. Thus, more rigorous research is required. However, because it is the first study in the field in Latin America, an exploratory design was useful in generating insight and providing an overview of the perspectives of staff involved in palliative care. There was a gap between what is said and perceived as important for good/bad deaths and what staff finally observed as examples of it in their daily practice. More emphasis was placed on palliative care expertise in abstract notions of death, but they recalled the spiritual and emotional sides of deaths in practice.

The spiritual and religious dimensions were considered very important during this process; however, they were more difficult to put into practice when compared with either technical or relational dimensions. Finally, despite the fact that palliative care is holistic in nature, ²⁵ when the patient context is different from what they are

used to and have been trained to deal with (patients with psychiatric disorders, violent relatives or patients, alcoholism, among others), staff need structural support from the health care system that is not always available.

Thus, we conclude that staff explicitly required more assistance in terms of supervision and time for sharing experiences. As Marshal et al⁶ already pointed out, staff shortages and heavy workloads can lead to staff experiencing frustration and inadequate patient care.

References

- Sinclair S. Impact of death and dying on the personal lives and practices of palliative and hospice care professionals. CMAJ. 2011;183(2):180-187.
- 2. Ryan T, Gardiner C, Bellamy G, Gott M, Ingleton C. Barriers and facilitators to the receipt of palliative care for people with dementia: the views of medical and nursing staff. *Palliat Med*. 2011;26(7):879-886.
- Ellershaw J, Murphy D. What is the Liverpool Care Pathway for the dying patient (LCP)? In: Ellershaw J, Wilkinson S, eds. *Care* of the Dying. A Pathway to Excellence. Oxford: Oxford University Press: 2011:16-31.
- Rome RB, Luminais HH, Bourgeois DA, Blais CM. The role of palliative care at the end of life. Ochsner J. 2011;11(4):348-352.
- Mula C. Supporting family and friends as death approaches and afterwards. In: Ellershaw J, Wilkinson S, eds. *Care of Dying.* A Pathway to Excellence. Oxford: Oxford University Press; 2011:129-141.
- Marshal B, Clark J, Sheward K, Allan S. Staff perceptions of endof-life care in aged residential care: a New Zealand perspective. *J Palliat Med.* 2011;14(6):688-695.
- 7. Tripodoro V, Luxardo N, Veloso V, et al. The Liverpool Care Pathway implementation in Spanish, in Argentina and Spain: staff perceptions description face to end of life. *Med Paliat*. 2013. In press.
- Charmaz K. Constructing Grounded Theory: A Practical Guide through Qualitative Analysis. London, England: Sage Publications; 2006
- Rola A, Higgs J. Using hermeneutic phenomenology to investigate how practitioners learn to communicate clinical reasoning. *Qual Rep.* 2007;12(4):612-638.
- 10. Thorpe C, Ryan B, McLean SL, et al. How to obtain excellent rates when surveying physicians. *Fam Pract.* 2009;26:65-68.
- 11. Kehl KA. Moving toward peace: an analysis of the concept of a good death. *Am J Hosp Palliat Med*. 2006;23:277-287.
- 12. Proulx K, Jacelon C. Dying with dignity: the good patients versus the good death. *Am J Hosp Palliat Med.* 2004;21:116-120.
- O'Hara RE, Hull JG, Lyons KD, et al. Impact on caregiver burden of a patient-focused palliative care intervention for patients with advanced cancer. *Palliat Support Care*. 2010;8(4): 395-340.
- Sandgren A, Thulesius H, Fridlend B, Peterson K. Striving for emotional survival in palliative care nursing. *Qual Care Res*. 2006;16(1):79-96.
- 15. Fine E, Reid MC, Shengelia R, Adelman RD. Directly observed patient-physician discussions in palliative and end-of-life care: a systematic review of the literature. *J Palliat Med.* 2010;13(5): 595-603.
- Smith TJ, Temin S, Alesi E, et al. American Society of Clinical Oncology provisional clinical opinion: the integration of palliative care standard oncology care. *J Clin Oncol.* 2012;30(8): 880-887.
- Dwyer LL, Hansebo G, Andershed B, Ternestedt BM. Nursing home residents' views on dying and death: nursing home employee's perspective. *Int J Older People Nurs*. 2011;6(4):251-260.

Fea

Feature Article

- 18. Wilson E, Seymour J, Aubeeluck A. Perspectives of staff providing care at the end of life for people with progressive long-term neurological conditions. *Palliat Support Care*. 2011;9(4):377-385.
- 19. Hayden D. Spirituality in end-of-life care: attending the person on their journey. *BrJ Community Nurs*. 2011;16(11):546, 548-551.
- 20. Benito E, Barbero J. Spirituality in palliative care: the emerging dimension. *Med Paliat*. 2008;15(4):191-193.
- 21. Melin-Johansson C, Henoch I, Strang S, Browall M. Living in the presence of death: an integrative literature review of relatives' important existential concerns when caring for a severely ill family member. *Open Nurs J.* 2012;6:1-12.
- 22. Edwards A, Pang N, Shiu V, Chan C. The understanding of spirituality and the potential role of spiritual care in end-of-life

- and palliative care: a meta-study of qualitative research. *Palliat Med.* 2010;24(8):753-770.
- Yamamoto Y, Hayashino Y, Yamazaki S, Takegami M, Fukuhara S. Violent patient behavior is associated with bodily pain and a high burden on informal caregivers. *J Gen Intern Med.* 2009;24(10):1085-1088.
- Klassen A, Gulati S, Dix D. Health care providers' perspectives about working with parents of children with cancer: a qualitative study. *J Pediatr Oncol Nurs*. 2012;29(2):92-97.
- 25. Gott M, Seymour J, Ingleton C, Gardiner C, Bellamy G. 'That's part of everybody's job': the perspectives of health care staff in England and New Zealand on the meaning and remit of palliative care. *Palliat Med.* 2011;26(3):232-241.