

Article

Mutual Needs and Wishes of Cancer Patients and Their family Caregivers During the Last Week of Life

A Descriptive Phenomenological Study

Raffaella Dobrina, MES, RN

Area Science Park, Trieste, Italy

Camilla Vianello, RN

Ospedale SS Giovanni e Paolo, Venezia, Italy

Maja Tenze, MNS, RN

Nursing Director, Pineta del Carso, Trieste, Italy

Alvisa Palese, MNS, RN

University of Udine, Udine, Italy

jhn

Journal of Holistic Nursing
American Holistic Nurses Association
Volume 34 Number 1
March 2016 24–34
© The Author(s) 2015
10.1177/0898010115581936
<http://jhn.sagepub.com>



The last week of life represents an important time for people dying of cancer and their families. To explore the needs and wishes of patients and their caregivers during the last week of life at home, a descriptive phenomenological study was undertaken in a home care facility located in the northeast of Italy. A purposeful sample of participants affected by advanced cancer was included. For each included patient, a family member assuming the role of principal caregiver was also included. A total of 11 dyads (22 people) were selected and interviewed on a weekly basis. A series of qualitative, semistructured interviews was conducted. Each conversation was intended to provide researchers with an overview of the patient's and family caregiver's needs and wishes. The last interview conducted before the patient died was selected and considered for the analysis performed by researchers independently, who then worked closely together for theme triangulations. Needs and wishes in the last week of life were focused on four main themes: (a) Remaining attached to my life ("I wish I was doing things like I used to"); (b) Detaching myself from life, immediately ("I wish this Calvary were over"); (c) Dealing with the dying process ("Waiting in fear"); and (d) Starting to think of life without each other ("Unshared worries"). In order to improve personalized care in the last week of life, nurses are encouraged to assess both patient and caregiver needs and wishes, as well as their reciprocal influence and correspondence, to identify each patient–caregiver unit's unique holistic care priorities.

Keywords: *end of life; home; needs; patients; family caregivers; nursing; Italy*

The last week of life represents a crucial time for people dying of cancer and their families. Patients suffering from advanced cancer are polysymptomatic, and the most common symptoms are also the most severe and clinically relevant, affecting their quality of life (Donnelly & Walsh, 1995; Hermann & Looney, 2011; Peruselli et al., 1999). In addition, emotional problems may worsen (Conill et al., 1997).

Given that the dyad composed of the patient and family caregiver develops greater closeness (Awadalla et al., 2007) as the patient deteriorates, caregiver distress and quality of life worsen, developing into

Authors' Note: Please address correspondence to Alvisa Palese, MNS, University of Udine, Viale Ungheria 20, Udine 33100, Italy; e-mail: alvisa.palese@uniud.it.

an intense burden that reaches its peak during the terminal phase of life (Given et al., 2004; Glajchen, 2012; Stenberg, Ruland, & Miaskowski, 2010). Family caregivers may also report anxiety regarding the future and how to deal the patients' distressing symptoms such as pain; they may be also depressed or in fear regarding increasing financial burdens (Given et al., 2004; Hinton, 1994; Tsigaropoulos et al., 2009).

In the last days of life, specific patient and caregiver wishes and needs may emerge: an early recognition of these by health care professionals might contribute to tailoring effective individual care both for the patient and the caregiver (Tsigaropoulos et al., 2009) assuring a holistic approach (Thornton, 2012). However, health care professionals may find it difficult to understand the patient's needs in the last week of life when the most complex physical and emotional problems arise (Conill et al., 1997; Tallman, Greenwald, Reidenouer, & Pantel, 2012). As a consequence, health care providers assisting patients with advanced-stage cancer do not always respond to patient priorities (Khan, Gomes, & Higginson, 2014).

Several methodological issues have been documented in the evaluation of patient problems and concerns during the terminal stage of life (Tuck et al., 2012). In reporting the quality of life, which should be self-reported, patients may have some difficulties given the lack of motivation, energy, and capacity to concentrate in reading and answering the validated questionnaires that are usually adopted (Bakitas et al., 2008). Aiming to overcome this issue, in the context of the patient-caregiver dyad, some proxy evaluations have been documented through interviews with the caregiver (Teno, 2001). As the situation may change rapidly from moment to moment, and treatments must be individualized, it has also been proposed to gain an in-depth understanding of patient and family needs through end-of-life conversations on a daily basis (Bee, Barnes, & Luker, 2009). More recently, storytelling methods allowing terminal patients suffering from cancer to share personal experiences and achieve a sense of connectedness and intimacy has also been adopted (Tuck et al., 2012).

However, due to the methodological issues mentioned above, little is known regarding the last week of life of patients who are cared for at home. The desires and needs are specific, dependent on many

individual, family, and contextual factors in which care is designed and delivered (Horne, Seymour, & Payne, 2012; Valera & Mauri, 2008).

Therefore, the aim of the study was to explore needs and wishes in the last week of life of patients at home and seek out the views of the family caregivers. Findings may contribute to expanding existing knowledge specific to the last week of life and to supporting nurses in identifying strategies to best address the patient-caregiver priorities, offering a human presence through a holistic approach expressing compassionate, comprehensive, and quality care (Thornton, 2012).

Method

Study Design

According to the sensitivity of the palliative phase, in which people may need to share their experiences which differ from person to person, and requiring a personalized data collection process (Bee et al., 2009), a qualitative method based on Husserl's descriptive phenomenological perspective was adopted (Polit & Tatano-Beck, 2014). Descriptive phenomenology involves direct exploration, analysis, and description of a particular phenomenon (Spiegelberg, 1975) such as experiencing the end of life.

Setting and Participants

The setting was preliminarily selected by approaching a home-palliative cancer care service located in the northeast of Italy.

According to the nature of the study, a purposeful sample was adopted (Polit & Tatano-Beck, 2014) among patients cared for during the study period by the home-palliative cancer care service. Patients affected by advanced cancer who had recently ended or refused further treatment, or for whom no treatment was available, were at least 18 years of age, were sufficiently fluent in the Italian language to understand the interview questions, and had provided informed consent were eligible to participate. For each included patient, a family member assuming the role of principal caregiver, who had also given informed consent, was included.

The recruitment process was continued until data saturation was achieved (Polit & Tatano-Beck, 2014) in accordance with the evaluation expressed

Table 1. Data Analysis as Performed Inside of Each Patient/Family Caregiver Units

Unit	Patient	Family Caregiver	Theme
4	"I would like to do thing that I used to do . . . walking"	"Having a normal life, not having to think of her all the time and getting some rest"	Remaining attached to my life
6	"Being independent"	"I wish I had a normal life; working and staying with my baby"	

independently by two researchers who were in charge of the analysis of the verbatim transcriptions.

Data Collection Process

According to the literature available in the field (Bee et al., 2009) an open nonstandard interview was adopted. A series of qualitative semistructured interviews were conducted by a nurse researcher not involved in delivery of nursing care.

In order to gain an in-depth understanding of their wishes and needs, patients and family caregivers were interviewed separately to encourage them to speak openly of their experience without worrying that they might upset the other person in the dyad. They were interviewed on a weekly basis at home, before nursing care was delivered. Each conversation was intended to provide the researcher with an overview of patient and caregiver needs and wishes. After each interview a summary of the needs and desires was communicated to the registered nurse in charge of the patient care that day, in order to give the opportunity to personalize the nursing care provided.

The open-ended questions were similar for patients and family caregivers, and were based on the following issues: "How are you feeling right now?" "Will you share with me the needs that you perceive in this moment?" "Will you share with me your wishes?" During the first interview, the researcher felt it important to expand on the patient's answers to the question: "How are you feeling right now?" by asking "What is the problem that burdens you most today?" Similarly, while interviewing the first caregiver the researcher added the question: "How is your quality of life right now?" Both questions were then added to the subsequent interviews.

As the interviews were on a weekly basis, patients/caregivers shared their needs and wishes with the researcher who in the subsequent interview has also collected feedback regarding the findings emerged in the previous interview, asking, "Last week you

shared with me the following needs and desires. . . . Have you had the opportunity to satisfy these needs/desires?"

Sociodemographic data (age, gender) as well as the illness period (months, years) since diagnosis and data regarding patient knowledge about diagnosis and prognosis (yes or no) was collected through the clinical records; in addition, information on the amount of hours dedicated to care by family caregivers on a daily basis, as well as their role (e.g., husband, wife), was also collected during the interview.

The interviews were audio-recorded and then transcribed verbatim. According to the study aims, the last interviews before the patients died were selected and considered for the present analysis. The interviews that did not belong to the last week were not included in the data analysis, and they were only used to summarize needs/desires information to the care providers.

Data Analysis and Rigor

According to Awadalla et al. (2007), given that the dyad composed of the patient and family caregiver develops greater closeness in this period, the transcriptions were read in pairs. Then, each emerging theme was categorized with the themes emerging from other interviews read also in pairs. In Table 1, an example of the data analysis process is reported.

Four-step processes were undertaken according to the phenomenological orientation assumed by researchers: bracketing, intuiting, analyzing, and describing (Polit & Tatano-Beck, 2014; Spiegelberg, 1975).

To prevent any misconception, researcher opinions and personal convictions were discussed and bracketed (Polit & Tatano-Beck, 2014).

Researchers read the description of the experience to get a sense of the entire context, re-read the transcriptions, identified the transitions and units of

experience, detected the meaning by relating constituents to each other and to the whole, reflected on the constituents in the concrete language of the participant, transformed concrete language into the language of concepts (researchers' words), and then integrated and summarized the insights into a descriptive structure (themes) to reach a meaning of the experience (Spiegelberg, 1975).

Extracts of patient and caregiver words were included in each theme indicating the number of the interview (e.g., 1) and the unit participant (e.g., U1p, patient; U1c, caregiver). Aiming to obtain credible and consistent findings, an analysis was performed by researchers independently who then worked closely together for theme triangulations (Polit & Tatano-Beck, 2014).

Ethical Issues

The internal review board of the reference hospital approved the project before approaching patients and family caregivers at their homes. The project was also shared with the registered nurses of the home care team with the aim of identifying the best moment and how to address the emerging needs and wishes in the care plan delivered at home. Patients and family caregivers gave their informed consent after having received personalized information on the purpose of the research process. Confidentiality in data collection and analysis was assured.

A maximum degree of flexibility was assured in conducting interviews given the vulnerable circumstances. The interview could be terminated at any time; patients and family caregivers were free to refuse or to postpone the interview to receive daily care before answering the questions.

The interviews were carried out by a researcher educated to support patients and their caregivers with counseling techniques and capable of requesting the intervention of the psychologist when needed.

Findings

Participants

The interviews of 11 dyads (22 people) were selected. Patients were suffering from various advanced cancers and diagnosed during a preceding period extending from 5 years to 6 months. They were on average 54 years old (range = 48-75), and the majority were men (6/11; 54.5%). Eight patients

(72.7%) were informed about their diagnosis and prognosis, with two of them not aware of the dying process even if informed. The remaining three patients (27.3%) were not informed or aware of the diagnosis or the prognosis.

The family caregivers' average age was 50 years (range = 20-75), and the majority were women (8/11; 72.7%). Their main characteristics are reported in Table 2.

Themes

Similar and interconnected themes of needs and wishes have emerged from the transcriptions of patients and family caregivers and these focused on four main themes:

1. Remaining attached to my life: "I wish I was doing things like I used to"
2. Detach myself from life, immediately: "I wish this Calvary was over"
3. Dealing with the dying process: "Waiting in fear"
4. Starting to think of life without me: "Unshared worries"

Remaining Attached to My Life: "I Wish I Was Doing Things Like I Used to." Engaging in everyday life activities was of great significance for patients in their last week of life. Patients feeling "quite well" to "well" ($n = 5$) were able to do the things they were used to before the final stage.

In fact, I am able to cook, see friends and do some gardening. (U1p)

Those patients feeling "bad" to "very bad" ($n = 6$) were suffering from pain and their priority was focused on pain control; moreover, their needs were similarly focused on doing the things they were used to doing, which were reported as follows:

Reading. (U3p)

Walking. (U4p)

Painting. (U2p)

Playing lawn bowling with friends. (U5p)

Being independent. (U6p, U7p)

Table 2. Patients and Family Caregivers Units

	Patient	Family Caregiver
Unit 1	Female, 75 years old Suffering from: lung cancer Interviewed: 5 days before death	Female, 46 years old Role: daughter Care assured: 5-6 hours/day
Unit 2	Male, 65 years old Suffering from: prostatic cancer, bone metastasis Interviewed: 5 days before death	Female, 62 years old Role: wife Care assured: 24 hours/day
Unit 3	Male, 79 years old Suffering from: colon cancer, liver metastasis Interviewed: 7 days before death	Female, 75 years old Role: wife Care assured: 24 hours/day
Unit 4	Female, 48 years old Suffering from: ovarian cancer, bone/breast metastasis Interviewed: 7 days before death	Male, 20 years old Role: son Care assured: 24 hours/day
Unit 5	Male, 75 years old Suffering from: head/neck cancer Interviewed: 7 days before death	Female, 75 years old Role: wife Care assured: 24 hours/day
Unit 6	Male, 62 years old Suffering from: colon cancer, liver/peritoneal metastasis Interviewed: 7 days before death	Female, 33 years old Role: daughter Care assured: 10-15 hours/day
Unit 7	Male, 60 years old Suffering from: glioblastoma Interviewed: 6 days before death	Female, 58 years old Role: wife Care assured: 24 hours/day
Unit 8	Female, 73 years old Suffering from: pancreatic cancer Interviewed: 7 days before death	Male, 75 years old Role: husband Care assured: 10-15 hours/day
Unit 9	Female, 54 years old Suffering from: ovarian cancer, liver/bone/cerebral metastasis Interviewed: 7 days before death	Male, 56 years old Role: husband Care assured: 24 hours/day
Unit 10	Female, 65 years old Suffering from: colon cancer, peritoneal metastasis Interviewed: 6 days before death	Female, 35 years old Role: daughter Care assured: 24 hours/day
Unit 11	Male, 73 years old Suffering from: pancreatic cancer, liver metastasis Interviewed: 5 days before death	Female, 46 years old Role: daughter Care assured: 10-12 hours/day

While for those with the ability to do everyday things, doing everyday life activities was a source of satisfaction and well-being; for those without the ability to do everyday things, it was a source of burden. Therefore, having a normal life and being able to do everyday things, emerged as a desire:

I know my illness is getting serious, but through my great will, I will get better. . . . I only need to get some strength back and get this pain under control, so I can get up and do all the nice things I used to do, and start an "almost" normal life again. (U8p)

The desire of normality, doing routine daily activities, was expressed also by family caregivers:

I wish I had a normal life; working and staying with my baby. (U6c)

Having a normal life, not having to think of her all the time and getting some rest. (U4c)

Some patients were aware that they could not accomplish everything they once did because the end of life was approaching; therefore, they were trying to negotiate what was most important.

I know I don't have much time left, but I try to keep calm and do the things I used to do even if I have to re-evaluate them. (U3p)

Also for the caregivers, the perception of an imminent end of life, aside from the need to carry on with usual activities, was the need to

Stay with him or her, as much as possible. (U2c, U3c, U5c, U8c, U9c)

What burdened most patients and caregivers was not being able to carry out daily activities (e.g., “walking” [U4p]), pleasant activities (e.g., “Laying on a boat in the sun” [U4p]), as well as activities related to their job (“Teaching my students!” [U8p]). As a consequence, the burden affects also the caregivers who had to deliver greater daily care, reducing the space devoted to their personal lives.

Detach Myself From Life, Immediately: “I Wish This Calvary Was Over.” Several participants were overwhelmed by the burden of the illness and the dying process.

The weight of uncontrolled symptoms such as pain, confinement to bed, and the need to ask for the smallest things was hard on patients. Family caregivers were encumbered by all the demands of care giving, which were worsened when their beloved was bed-ridden or his/her pain was difficult to manage.

Those patients reporting feeling “bad” to “very bad” indicated it was due to severe pain or to feeling fed up with the illness:

I can’t take it anymore. (U4p, U10p)

Family caregivers also reported feeling “bad”; their quality of life was “low” to “sufficient” taking care of the loved ones from 5 to 24 hours a day.

The major concerns of these patient–caregiver units regarding the progress of the illness was mirrored intimately and regarded painful death:

I’m afraid I will die from pain. (U5p, U7p, U8p)

I’m afraid she will die suffering. (U1c, U2c, U3c, U5c, U7c, U8c)

Patients wished to die soon so that they would not have to suffer any more:

I know I will die soon, but I was hoping not to suffer so much. . . . I wish all this could be over soon! (U11p)

. . . So this Calvary would be over! (U10c)

However, the perception of the Calvary (the biblical site of crucifixion; used to describe a painful ordeal in waiting for death) was not only motivated by pain or disruptive symptoms but also by the perception of being a burden on the family:

What burdens me most is not being independent any more, to depend on others and being a burden to my family. (U7p, U9p)

Conversely, in other units where patients did not report feeling a burden, family caregivers reported feeling “bad” with “low” to “very low” quality of life. These caregivers also reported feeling very tired, and “in jail” while caring for their beloved ones 24 hours a day. One caregiver reported having no personal needs:

. . . because I don’t exist anymore! (U3c)

Dealing With the Dying Process: “Waiting in Fear.” For patients and their family caregivers who had mentioned impending death, even though they chose to be at home, death generated a lot of fear. Some fears concerned the dying process with patients reporting:

I know everything about my illness, I know I will die soon, but I am just a little scared . . . after all, who is not afraid of dying? (U1p)

I wish everything would be over soon, but at the same time death frightens me. (U11p)

Similar fear was reported by caregivers:

I’m afraid he could die at any moment. . . . I don’t know how this is going to happen, so I go check on him all the time to see if he’s breathing! (U5c)

The fear of this experience was even more intense when patients had uncontrolled pain. However, even when there was freedom from pain, the process of death and dying generated a lot of fear in patients who felt unprepared:

I know what is going on, that I must die, I just would like to know how much time I have left to live and the way I will die. (U7p)

Expecting death and fearing it at the same time was closely connected to the perception of waiting, both for patients and caregivers: for the patients it was difficult to wait without doing anything,

It’s exhausting to wait for death without anything to do about it. . . . I feel worthless and frustrated! (U7p)

While for caregivers, the waiting was perceived as an important opportunity to be together, they wondered how much more time they would have with their loved one.

Having someone close to share the difficulties that the dying process presents was significant to participants. Caregivers felt that the burden perceived was less burdensome if shared with the family:

My quality of life is quite good. . . . I have a big family and we support and give courage to each other. (U11c)

Likewise, an only child caring for her mother reported:

My quality of life is low, everything is so burdensome. . . . I wished I had a brother or sister to share this burden with! (U6c)

Starting to Think of Life Without Me: "Unshared Worries." Although the family still encouraged patients that "things will be better soon," patients reported that they were aware of what was happening:

Everybody around me tells me I will recover . . . but I know this time I'm not going to make it! (U10p)

Patients shared their experience characterized as a vicious cycle. They perceive their families as concerned as they were becoming a burden.

I'm worried about my family because I see they are worried and I don't want to be a burden. (U9p)

To protect family members, patients preferred not to talk with them about the end of life:

I'm very worried, I'm dying but I don't want to talk to my family about it, so not to worry anybody. (U1p)

Their thoughts turned to what would happen when they were not there anymore:

I'm worried about my wife who, if I die, won't be able to take care of herself. (U5p)

I'm worried that my sons will find themselves alone. (U10p)

If I die I know my brother will suffer a lot. (U8p)

Open communication about concerns inside the patient–caregiver unit was limited.

No, I didn't share this with my wife.

However, the caregivers had the same concerns as patients; they were also worried because they did not feel prepared:

I don't know what may happen. (U5c, U7c)

Discussion

The dying process leads patient–caregiver units into becoming both physically and emotionally close. This particular bonding regards the patient and his or her family caregiver as a "unit" in the last week of life (Awadalla et al., 2007). Therefore, the interviews were analyzed as patient–caregiver units.

Four themes have emerged: in the first two (Remaining attached to my life: "I wish I was doing things like I used to"; Detach myself from life, immediately: "I wish this Calvary was over"), explicit needs and wishes have emerged. In the remaining two (Dealing with the dying process: "Waiting in fear," Starting to think of life without me: "Unshared worries") implicit needs and wishes such as receiving support in the process of waiting for death, in dealing with intense fear and pain, as well as in sharing worries in the patient–family caregiver unit, seem to require a more complex and detailed understanding process.

Patients in their last week of life felt that the need to engage in everyday activities was still very important, as already documented in the available literature (Svidén, Tham, & Borell, 2010). When this was not possible, patients expressed being overwhelmed by the burden of the end stage of life. While some patients found ways to reevaluate expectations, other patients nearing death experienced needs that were unrealistic and difficult to perform, such as "playing lawn bowling with friends" or "being independent," thus worsening their quality of life. Despite acknowledging the therapeutic value of hope, especially in individuals with a life-threatening illness, as outlined by others (Alidina & Tettero, 2010) while coping during times of intense physical and psychological distress, patients seemed oriented

toward having a normal life more than preparing for death. In accordance with the literature, helping patients in wellness and normal activities while facing death was found to maintain patient integrity at the end of life (Horne et al., 2012). Other authors (Montoya-Juarez et al., 2013; Reed, 2010) outlined the importance of health care professionals in reframing patient hopes by helping them identify new wishes and realistic goals. These could be achieved by involving patients in everyday activities with lowered expectations concerning performance—enabling patients to feel a sense of competence even in their last days of life (Svidén et al., 2010). Where simpler needs are expressed, such as reading or moving more, not fully supported by burdened family caregivers, the assistance of volunteers may be useful.

Pain in the last week of life distressed both patients and family caregivers physically and psychologically, as already documented (Given et al., 2004; Tallman et al., 2012; Tsigaropoulos et al., 2009). The needs of these patient–caregiver units were all focused on pain relief. Studies have reported that people assign high priority to freedom from pain during the end-of-life period in order to have what is perceived as a “good death” (Downey, Engelberg, Curtis, Lafferty, & Patrick, 2009; Steihauser et al., 2000). In our study, pain frightened patients and family caregivers and led them to think about a “bad death.” Families and patients, in addition to the concerns about undertreatment of pain, also described anticipatory fears regarding pain control. Some participants were terrified, and the process of dying was represented by a painful ordeal (Calvary). A “good death” includes providers capable of recognizing in advance these issues (Steihauser et al., 2000), and protect patients and their caregivers from feeling angry, sad, despairing, helpless, useless and powerless, and frustrated (Bee et al., 2009; Glajchen, 2012).

Patients in our study were not all fully informed about their diagnosis or prognosis; this was due either to the family caregivers’ will or their own. In some cultures, physicians or families, or both, deem full disclosure prejudicial to the patient (Bruera, Neumann, Mazzocato, Stiefel, & Sala, 2000). In Italy, in particular, the disclosure rate is low and medical decisions are often mediated by the family since communication of diagnosis and prognosis to patients is viewed as harmful and cruel

(Giardini et al., 2011). However, in our study, even uninformed patients in their last week of life showed awareness that death was close. These patients were not seeking more information on the progress of the illness, confirming that as patients get closer to the end, their preference for prognostic information declines (Giardini et al., 2011). However, according to previous literature, patient and caregiver information needs showed a tendency to diverge as the illness progressed, with family caregivers needing more, and patients wanting less information (Parker et al., 2007).

During the process of “waiting for death,” previously documented in the literature (Philip et al., 2014), family caregivers reported their main need was to stay with the patient 24 hours a day. Caregivers were aware that death was close and may not have wanted to miss any moment of the precious time left. The power of presence in healing suffering is well described by Saunders (2006). Palliative health care teams should consider the degree of kinship and profile of family caregivers (e.g., age, background) to arrange each unique patient–caregiver unit’s support against psychological distress (Dobrina, Tenze, & Palese, 2014; Given et al., 2004).

Preparing for death drags patients and caregivers into a state of fear. The fears expressed varied from the fear of suffering, to the fear of the unknown, to the fear of loneliness, which have been well described in Deeken (2009) as a source of spiritual pain. Findings show that the units were not aware of their spiritual care needs. Interviews (Reblin, Otis-Green, Ellington, & Clayton, 2014) may have helped participants express the fears that death and dying provoke, and to receive support from the researcher.

Participant awareness of the imminent separation from their loved one, and of the unknown, triggered worries that mostly remained unshared to avoid further suffering and burdens within the patient–caregiver unit. In Singer, Martin, and Kelner (1999), similar worries were allayed when dying patients shared their concerns with loved ones, making patients feel less isolated in the face of death. Nurses should encourage communication between patients and family caregivers as a unit that may become a special place where patients and families, as suggested by Reed (2010), may develop a mutual process of the creation of meaning and sharing to reduce psychological distress.

Study Limitations and Strengths

The study has involved patients and family members aimed at better understanding their needs and wishes at the end of life. Researchers were also in a privileged position to have access to the experiences of a stage of life that is extremely personal and still rather unknown. They also had the opportunity to observe the intimacy of the patient–caregiver units in their homes. However, a purposeful sample of the dyads participated in the study, living in a specific Italian context in accordance with the urban area covered by the health care team selected in the study. Therefore, a more extensive process of sample recruitment, involving different cultural and social contexts, is suggested.

The interviews were made on a weekly basis; therefore, the researcher in each of the subsequent interviews collected feedback asking the patients and caregivers the degree of satisfaction achieved toward the needs and wishes expressed in the week before, and this may have introduced a bias regarding the last interview. In addition, the Italian–English translation of participant interviews as well as some cultural issues (e.g., the meaning of Calvary in the Catholic culture) may affect reader comprehension of some findings.

Implication for Practice and Research

As emerged in the findings, patients often expressed unrealistic wishes and needs, and palliative care nurses may help by conveying more appropriate goals to patients coping with end-of-life issues. In addition, with the aim of achieving a more holistic approach in the last week of life, nurses are encouraged to assess both patient and caregiver wishes and needs, as well as their reciprocal influence, to identify each patient–caregiver unit's unique priorities. Family caregivers showed awareness of the power of presence with their beloved family member. Therefore, nurses might encourage the presence of family caregivers. Communication between caregivers and patients should be encouraged by nurses as a unit that may become a special place where sharing end-of-life suffering gives meaning to the dying process.

Collecting and reflecting systematically on the stories and on needs and wishes of patients at the end of life is fundamental to developing a dignified

death (Wasserman, 2008). Nurses may play a greater role in developing more research in the field aimed at advancing available knowledge.

Conclusions

Patients in their last week of life have reported that engaging in small everyday life activities was very important. Findings revealed that waiting for death generates different types of worries and fears that are important for nurses to identify and address singularly, in order to cope with spiritual pain. Moreover, unshared worries worsened the quality of life of patients and caregivers.

Patients and family caregivers witnessed the complexity of the end-of-life process, between longing for death and craving for independence, yet picturing separation from others. Special bonding within patient–caregiver units, particularly in the complicated last week of life, would suggest considering them as a unit.

Nurses caring for patients and families at home are in a unique position to recognize and address the complex needs at the end of life. Their closeness with the patients gives an opportunity to capture different insights and data regarding needs and wishes. Nurses also have the privilege of leading patients and families in the process, as a professional and as a member of a multidisciplinary team. Without competent nursing care, the risk of reducing the complexity of life at its end, around technical issues and mechanical approaches aimed at assuring basic needs or intervention. A human presence and a holistic approach are the core mission of the nurses in offering care to patients and families at the end of life.

References

- Alidina, K., & Tettero, I. (2010). Exploring the therapeutic value of hope in palliative nursing. *Palliative Support Care*, 8, 353-358.
- Awadalla, A. W., Ohaeri, J. U., Gholoum, A., Khalid, A. O., Hamad, H. M., & Jacob, A. (2007). Factors associated with quality of life of outpatients with breast cancer and gynecologic cancers and their family caregivers: A controlled study. *BMC Cancer*, 19, 102.
- Bakitas, M., Ahles, T. A., Skalla, K., Brokaw, F. C., Byock, I., Hanscom, B., . . . ENABLE Project Team. (2008). Proxy perspectives regarding end-of-life care for persons with cancer. *Cancer*, 112, 1854-1861.

- Bee, P. E., Barnes, P., & Luker, K. A. (2009). A systematic review of informal caregivers' needs in providing home-based end-of-life care to people with cancer. *Journal of Clinical Nursing, 18*, 1379-1393.
- Bruera, E., Neumann, C. M., Mazzocato, C., Stiefel, F., & Sala, R. (2000). Attitudes and beliefs of palliative care physicians regarding communication with terminally ill cancer patients. *Palliative Medicine, 14*, 287-298.
- Conill, C., Verger, E., Henriquez, I., Saiz, N., Espier, M., Lugo, F., & Garrigos, A. (1997). Symptom prevalence in the last week of life. *Journal of Pain Symptom Management, 14*, 328-331.
- Deeken, A. (2009). An inquiry about clinical death—Considering spiritual pain. *Keio Journal of Medicine, 58*, 110-119.
- Dobrina, R., Tenze, M., & Palese, A. (2014). An overview on palliative care models and theories. *International Journal of Palliative Nursing, 20*, 75-81.
- Donnelly, S., & Walsh, D. (1995). The symptoms of advanced cancer. *Seminars in Oncology, 22*, 67-72.
- Downey, L., Engelberg, R. A., Curtis, J. R., Lafferty, W. E., & Patrick, D. L. (2009). Shared priorities for the end-of-life period. *Journal of Pain Symptom Management, 37*, 175-188.
- Giardini, A., Giorgi, I., Sguazzin, C., Callegari, S., Ferrari, P., Preti, P., & Miotti, D. (2011). Knowledge and expectations of patients in palliative care: Issues regarding communication with people affected by life-threatening diseases. *Giornale Italiano di Medicina del Lavoro ed Ergonomia, 33*, 41-46.
- Given, B., Wyatt, G., Given, C., Sherwood, P., Gift, A., DeVoss, D., & Rahbar, M. (2004). Burden and depression among caregivers of patients with cancer at the end of life. *Oncology Nursing Forum, 31*, 1105-1117.
- Glaichen, M. (2012). Physical well-being of oncology caregivers: An important quality-of-life domain. *Seminars in Oncology Nursing, 28*, 226-235.
- Hermann, C. P., & Looney, S. W. (2011). Determinants of quality of life in patients near the end of life: A longitudinal perspective. *Oncology Nursing Forum, 38*, 23-31.
- Hinton, J. (1994). Can home care maintain an acceptable quality of life for patients with terminal cancer and their relatives? *Palliative Medicine, 8*, 183-196.
- Horne, G., Seymour, J., & Payne, S. (2012). Maintaining integrity in the face of death: A grounded theory to explain the perspectives of people affected by lung cancer about the expression of wishes for end of life care. *International Journal of Nursing Studies, 49*, 718-726.
- Khan, S., Gomes, B., & Higginson, I. J. (2014). End-of-life care—What do cancer patients want? *Natural Review of Clinical Oncology, 11*, 100-108.
- Montoya-Juarez, R., Garcia-Caro, M. P., Campos-Calderon, C., Schmidt-RioValle, J., Gomez-Chica, A., Marti-García, C., & Cruz-Quintana, F. (2013). Psychological responses of terminally ill patients who are experiencing suffering: A qualitative study. *International Journal of Nursing Studies, 50*, 53-62.
- Parker, S. M., Clayton, J. M., Hancock, K., Walder, S., Butow, P. N., Carrick, S., . . . Tattersall, M. H. (2007). A systematic review of prognostic/end-of-life communication with adults in the advanced stages of a life-limiting illness: Patient/caregiver preferences for the content, style, and timing of information. *Journal of Pain and Symptom Management, 34*, 81-93.
- Peruselli, C., Di Giulio, P., Toscani, F., Gallucci, M., Brunelli, C., Costantini, M., . . . Higginson, I. J. (1999). Home palliative care for terminal cancer patients: A survey on the final week of life. *Palliative Medicine, 13*, 233-241.
- Philip, J., Collins, A., Brand, C. A., Moore, G., Lethborg, C., Sundararajan, V., . . . Gold, M. (2014). "I'm just waiting . . .": An exploration of the experience of living and dying with primary malignant glioma. *Supportive Care in Cancer, 22*, 389-397.
- Polit, D. F., & Tatano-Beck, C. (2014). *Fondamenti di Ricerca infermieristica* [Fundamentals of nursing research]. Milano, Italy: McGraw-Hill Education.
- Reblin, M., Otis-Green, S., Ellington, L., & Clayton, M. F. (2014). Strategies to support spirituality in health care communication: A home hospice cancer caregiver case study. *Journal of Holistic Nursing, 32*, 269-277.
- Reed, S. M. (2010). A unitary-caring conceptual model for advanced practice nursing in palliative care. *Holistic Nursing Practice, 24*, 23-34.
- Saunders, C. (2006). Foreword. In B. R. Ferrell & N. Coyle (Eds.), *Textbook of palliative nursing* (pp. 60-68). New York, NY: Oxford University Press.
- Singer, P., Martin, D. K., & Kelner, M. (1999). Quality end-of-life care: Patients' perspectives. *Journal of the American Medical Association, 281*, 163-168.
- Spiegelberg, H. (1975). *Doing phenomenology: Essays on and in phenomenology*. Dordrecht, Netherlands: Martinus Nijhoff.
- Steinhauser, K. E., Christakis, N. A., Clipp, E. C., McNeilly, M., McIntyre, L., & Tulsky, J. A. (2000). Factors considered important at the end of life by patients, family, physicians, and other care providers. *Journal of the American Medical Association, 284*, 2476-2482.
- Stenberg, U., Ruland, C. M., & Miaskowski, C. (2010). Review of the literature on the effects of caring for a patient with cancer. *Psychooncology, 19*, 1013-1025.
- Svidén, G. A., Tham, K., & Borell, L. (2010). Involvement in everyday life for people with a life threatening illness. *Palliative Supportive Care, 8*, 345-352.
- Tallman, K., Greenwald, R., Reidenouer, A., & Pantel, L. (2012). Living with advanced illness: Longitudinal study of patient, family, and caregiver needs. *The Permanent Journal, 16*, 28-35.

- Teno, J. M. (2001). Quality of care and quality indicators for end-of-life cancer care: Hope for the best, yet prepare for the worst. In: K. M. Foley & H. Gelband (Eds.), *Improving palliative care for cancer* (pp. 96-131). Washington, DC: National Academic Press.
- Thornton, L. (2012). The importance of holistic nursing in end-of-life care. *Beginnings*, 32(2), 18-19.
- Tsigaropoulos, T., Mazaris, E., Chatzidarellis, E., Skolarikos, A., Varkarakis, I., & Deliveliotis, C. (2009). Problems faced by relatives caring for cancer patients at home. *International Journal of Nursing Practice*, 15, 1-6.
- Tuck, I., Johnson, S. C., Kuznetsova, M. I., McCrocklin, C., Baxter, M., & Bennington, L. K. (2012). Sacred healing stories told at the end of life. *Journal of Holistic Nursing*, 30, 69-80.
- Valera, L., & Mauri, C. (2008). The family context in end-of-life is a resource to know and support: Some reflections. *Giornale Italiano di Medicina del Lavoro ed Ergonomia*, 30, 37-39.
- Wasserman, L. S. (2008). Respectful death: A model for end-of-life care. *Clinical Journal of Oncology Nursing*, 12, 621-626.
- Raffaella Dobrina**, MES, RN, is an advanced nurse, expert in palliative care nursing. During the research project, she was a researcher in the Pineta del Carso Palliative Center.
- Camilla Vianello**, RN, is a clinical nurse, and researchers in the time of the project, devoted to the data collection.
- Maja Tenze**, MNS, RN, is the Nursing Director of the Pineta del Carso Hospital, expert in resources management and aimed at improving the clinical nursing care at the bedside.
- Alvisa Palese**, MNS, RN, is an associate professor in Nursing Science at University of Udine (Italy).