

Acting with dedication and expertise: Relatives' experience of nurses' provision of care in a palliative unit

Å. GRØTHE, R.N., M.C.H.C.,¹ STIAN BIONG, R.N., DRP.H.,² AND E.K. GROV, R.N., PH.D.³

¹Haralds plass Deaconess University College, Bergen, Norway; Sunniva Center for Palliative Care, Haukeland University Hospital, Bergen, Norway

²Buskerud University College, Faculty of Health Sciences, Drammen, Norway

³University of Oslo, Faculty of Medicine, Department of Nursing Science, Oslo, Norway; Sogn og Fjordane University College, Department of Health, Førde, Norway

(RECEIVED April 29, 2013; ACCEPTED June 26, 2013)

ABSTRACT

Objectives: Admission of a cancer patient to a palliative unit when near the final stage of their disease trajectory undoubtedly impacts their relatives. The aim of our study was to illuminate and interpret relatives' lived experiences of health personnel's provision of care in a palliative ward.

Methods: A phenomenological/hermeneutic approach was employed that was inspired by the philosophical tradition of Heidegger and Ricoeur and further developed by Lindseth and Nordberg. The perspectives of the narrator and the text were interpreted by highlighting relatives' views on a situation in which they have to face existential challenges. The analysis was undertaken in three steps: naïve reading, structural analysis, and comprehensive understanding, including the authors' professional experiences and theoretical background.

Results: Six subthemes appeared: the dying person, the bubble, the sight, the cover, the provision for children's needs, and the availability of immediate help. These components were further constructed into three themes: the meaning of relating, the meaning of action, and the meaning of resources. Our comprehensive understanding of the results suggests that the most important theme is "acting with dedication and expertise."

Significance of results: The following aspects are crucial for relatives of cancer patients hospitalized in a palliative ward: time and existence, family dynamics, and care adjusted to the situation. Our study results led to reflections on the impact of how nurses behave when providing care to patients during the palliative phase, and how they interact with relatives in this situation. We found that cancer patients in a palliative unit most appreciate nurses who act with dedication and expertise.

KEYWORDS: Palliative care, Relatives, Lived experience, Cancer, Palliative ward

INTRODUCTION

People with cancer comprise one of the largest patient groups in need of palliative care. In Norway, 90% of the patients in palliative units have a cancer

diagnosis (Norwegian Directorate of Health, 2012). Cancer is endemic among the aged, so the increase of its incidence has grown along with the growth in the size of this cohort of the population. Newly discovered adjuvant and multimodal treatments now mean a much longer survival trajectory (Hewitt et al., 2008). However, 45–55% of these cancers are incurable (Hewitt et al., 2008.). Some cancer diagnoses mean shorter survival times or turn into

Address correspondence and reprint requests to: Stian Biong, Buskerud University College, Drammen, Norway. E-mail: stian.biong@hibu.no

the palliative phase immediately after a patient receives the diagnosis. The number of cancer patients dying at home has been stable in Norway over the last 20 years (Statistics Norway, 2012). The definition of palliative care takes into account the process of palliation, which begins with recognition of an incurable condition and continues until the patient dies: "Palliative care is the active, total care of the patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of social, psychological, and spiritual problems is paramount" (European Association for Palliative Care, 2005). Palliative care is further defined as interdisciplinary in approach and encompasses both the patients and their family (EAPC, 2005).

Availability of relatives is a crucial factor in managing palliative care at home. Research on relatives, especially those assuming the role and function of primary caregivers for a cancer patient, has been given attention during the previous two decades (Andershed, 2006; Grov et al., 2006a; Given et al., 2011). The interconnectedness between patients and relatives comprises a significant relatedness, where the patient's condition has a great impact on relatives' experience of distress and vice versa (Hodges et al., 2005). Several studies have noted that partners of cancer patients need practical help and emotional support since they live in the same household (e.g., Kuijjer et al., 2002). Daly et al. (2009) reported on the needs of older caregivers and found that lack of family support, tight daily schedules, and health impairment among caregivers affected their burden and were related to depression and fatigue. For younger caregivers, lack of time meeting family obligations and appointment fatigue represented challenges, especially for females (Miederma & Easley, 2012). Relatives as caregivers were emotionally vulnerable during the patient's palliative phase, which created challenges for health personnel in closely guiding them through the process (Quest & Bone, 2009; Van Ryn et al., 2011). Relatives might solve their difficulties by "weaving balance into life" in addition to respite and follow-up by health personnel in nursing homes, home care services, and hospices (Hodge et al., 2012; Northouse et al., 2012). Due to the life/death uncertainty that patients face during the palliative phase, caregivers reported having enhanced levels of anxiety and greater concerns about the future (Grov et al., 2005). The experience of caregiver burden has been described as having a significant association with depression (Grov et al., 2006b) as well as with symptoms of mental health strain (Ostlund et al., 2010). In a qualitative study by Steinhauser et al. (2000a), 12 focus group interviews with informants (with

patients, relatives, and health personnel) were performed, and six main components of the experience of a good death revealed: (1) pain and symptom relief, (2) well-documented treatment tracks, (3) good preparation for death, (4) enough time to review life, summarize life history, and say goodbye to family and close friends, (5) availability of commitment from family and friends, and (6) patient experience of being a complete person despite their frailty and dependence on others. In their large survey, which included 1,400 patients, relatives, and health personnel, a list of important factors were ranked (Steinhauser et al., 2000b). All respondents reported preparing for death and completing unfinished business as main factors. In another study with the same focus, patients and family caregivers highlighted trust in health personnel, especially the medical doctor responsible for treatment, in addition to support, open and effective communication, and continuity of care (Heyland et al., 2006). They described the importance of person-centered care for patient and family, and thus the need for arranging specific care trajectories.

At the organizational level, international studies have shown that relatives are satisfied with the caring function available at hospices and in palliative units (Lecouturier et al., 1999; Rollison & Carlsson, 2002; Steele et al., 2002; Miceli & Mylod, 2003; Gelfman et al., 2008). Several studies have explored the caring provided to patients during the palliative phase. One Swedish study described relatives' function as primary caregivers in a home-care setting (Linderholm & Friedrichsen, 2010) and demonstrated the importance of the opportunity for primary caregivers to express their experiences and their ability to stay connected with health personnel in order to enhance collaboration. Care and support were found to be essential for relatives who had previously been diagnosed with cancer and were now caring for a partner with the disease (Onishi et al., 2005). Communication between relatives and health personnel has been emphasized in many studies (Gagnon et al., 2002; Brobäck & Bertero, 2003; King et al., 2004; Milberg & Strang, 2004). Keegan and colleagues (2001) found that lack of respect and nonrecognition of dignity on the part of health personnel can have longlasting repercussions and create added burden for relatives after a patient's death.

As far as we know, no study focusing on relatives' descriptions of how they experienced the provision of care in a palliative ward has been undertaken in a Norwegian context. The aim of our study, therefore, was to illuminate and interpret relatives' lived experiences of the provision of care by health professionals in a palliative unit. The research

question was formulated as “How is meaning constructed in caring narratives.”

METHOD

Epistemological Considerations and Design

We employed the qualitative research method (Karlberg et al., 2002) in order to construct meaning in terms of relatives' experiences of provision of care by health professionals in a palliative ward from a phenomenological perspective, which included refraining from making judgments about the facts and remaining open to what the narratives revealed. This kind of understanding relates to Heidegger's (1992) “being in the world,” that is, being related to both the external and internal worlds in time and space (Ashworth, 2006; Sarvimäki, 2006). Drawing on the tradition of phenomenology, Ricoeur's (1976) interpretation theory holds that gaining knowledge and meaning about lived experiences cannot pass directly from one person to another, but is constructed through the hierarchical interpretation of text (Ricoeur, 1976). Such an interpretation integrates explanation and understanding into a dialectic rooted in the properties of text. This movement, the hermeneutic circle, is described as a nonlinear process, involving intuitive guessing at the meaning of the whole, followed by explanation of the parts, and then a move toward a comprehensive understanding of the whole (Ricoeur, 1976). We found such a phenomenological/hermeneutic approach useful when we analyzed and interpreted how the meaning of the relatives' experiences of health professionals in a palliative ward was constructed through personal narratives.

Narrative theory involves the most basic way to create meaning from human experiences by narrating them and presenting them to others (Polkinghorne, 1988). This is especially so if the narrative is about life events that involved a disruption between the ideal and reality, the self and society (Riessman, 1993). We regard having a dying family member to be such a disruptive experience. We therefore assessed a narrative design as an appropriate and useful method of inductively analyzing and understanding how the meaning of a social phenomenon can be constructed from biographical accounts (Mishler, 1986). We felt that if our interpreted understanding can affect people's perceptions of such a situation, we might be successful in integrating the horizon of the narrator and that of the readers of the present article. Such scientifically based knowledge might prove important if it contributes to new perceptions and the development of novel services of-

ferred to relatives in a palliative ward, especially when they face existential challenges.

Participants

A purposeful sampling strategy was utilized to identify potential participants. The sample was selected from records at the palliative ward, which include documentation on patients previously hospitalized on the unit. We mailed the closest family members listed on each patient record. We reached out only to relatives who had experienced the death of a family member admitted to the ward for a minimum of three days within the last two years. During the data collection period, 54 patients died on the palliative care ward. Thirty information letters were sent to relatives. Among these, two wrote back to say they did not want to participate, and one called to refuse participation due to fatigue. A total of six family members decided to participate. A reminder was sent to those not responding within three weeks, but none got back to us.

The available and interested family members gave their informed consent prior to the interviews. Informants included either adult children or partners of a deceased patient, all defined as the closest relative. Participants included three women and three men in the age range between 40 and 69 living in an urban area. Three were partners, two were daughters, and one was the son of the deceased.

Data Collection

The qualitative research interview is an appropriate tool for investigating individual experience (Kvåle & Brinkmann, 2009). Our interviews took place in facilities preferred by the participants and were performed by the first author. They were unstructured, and participants were asked to associate freely on the basis of one opening question: “Can you please tell me the story of how you experienced the health professional while being a relative in a palliative ward?” The interviews took the form of a conversation, that is, the interviewer did not play the role of *expert* and, in line with Denzin and Lincoln (2003), encouraged participants to narrate as freely as possible. The interviewer asked other questions to further develop the narration, such as: “What happened next?” “Can you remember any other details?” or “How do you reflect on this?” We took the position that active, respectful, and sensitive listening is a prerequisite to creating a context for narration (Alma & Smaling, 2006). In addition, some previously prepared follow-up questions were then asked. The interviews lasted between one and two hours and were tape-recorded and transcribed verbatim by the first author. Associations and experiences

from both the dialogue and nonverbal communication that took place during the interview were noted in order to ensure that these initial impressions would contribute to later interpretations.

The regional committee for medical research ethics decided to handle our application to the Norwegian Social Science Data Service (NSD), since the participants were not patients. Once the NSD approved the study, participants were provided with both written and verbal information before agreeing to participate. In cooperation with the palliative ward, individual psychosocial follow-up was planned and offered after the interview, if necessary.

Data Analysis

In the Nordic countries, an empirical method for entering the hermeneutic circle inspired by Ricoeur's (1976) philosophy has been developed and applied by Lindseth and Norberg (2004). This method emphasizes the dialectic movement between understanding and explanation, and between the text as a whole and its parts, in order to get at the meaning of a studied phenomenon. It consists of three different, yet interwoven, steps: naïve reading, structural analysis, and comprehensive understanding.

Step 1. Naïve reading is regarded as a first conjecture of the text. Lindseth and Norberg (2004) emphasize that it guides and provides direction for the following structural analysis. In our naïve reading, each transcribed interview was repeatedly read by researchers with an "open mind," which means keeping a phenomenological attitude and dispensing with what might be taken for granted in order to grasp the intuitive sense of the meaning of the text as a whole. The focus was on a relative's experiences of provision of care by health professionals and the relative's needs and wants while the patient was in a palliative ward.

Step 2. Lindseth and Norberg (2004) point out that there are several kinds of structural analyses that can be used to explain a text by identifying and formulating meaning units, subthemes, and themes. The meaning units ought to be reflected upon, and with reference to the naïve understanding as background, sorted into subthemes according to their content. The concepts we used to describe these units were expressed in everyday language directly from the text. Assisted by the coauthors, the subthemes were reflected upon, examined, and interpreted into higher-level content of meaning, forming themes. This might be described as a process of going back and forth between naïve understanding and construction of meaning units and subthemes, until all were captured and formulated in different themes.

A theme was defined as a thread of similar meaning that interpenetrated one or several subthemes.

Step 3. The process of interpreting the text as a whole means that we again tried to delve into the text and recontextualize it (Lindseth & Norberg, 2004). In order to maintain clarity between our findings and the discussion, we chose not to include illuminating literature as part of this step. We formulated the main theme of the study by reflecting on the themes in relation to the research question and the authors' backgrounds. This represented a comprehensive understanding, or the main interpretation, of the meaning comprehended from the studied phenomena.

RESULTS

The Naïve Reading

The immediate understanding of the text revealed that the relatives' experience concerned the *society*, the *ward*, the *family*, the *nurses*, and the *dying process*. From the relatives' perspective, the high educational level among nurses represented the content of the *society*. Nurses were described as a community that represented insight, passion, and safety. When describing the palliative unit — the *ward* — the rest of the staff represented quality, and were associated with confidence and sufficiency. Relatives described their experience of the organization in the ward as linked to a system of preparedness. Additionally, relatives stated that they felt comfortable and were treated as unique persons. As *family*, the relatives were caught up in an unpleasant condition of crisis, described as if the outer world had stopped existing. In this state of being, and considering the progress of the palliative phase, consciousness about the fact of facing the death of a family member increased. Their focus was therefore on the relationship between family members, especially connected to a relationship to any children involved. Relatives described the nurses as the only reference group of health personnel and talked about how the *nurses'* provision of care affected their sense of crisis. Relatives reported a high awareness of cues representing nonverbal signs of security or insecurity in the provision of care. The way nurses were dressed and the way they behaved and talked were examples of such cues. If a nurse was overactive, relatives felt their helping role to be obstructive. When nurses were available immediately, relatives felt confident and safe. Regarding the *dying process*, relatives stated that nurses acted confidently based on the complexity and seriousness of the patient's condition, which was obvious and different compared to nurses' functions in the other hospital wards.

Structural Analysis

The structural analysis began with identification of relevant core narratives of the text related to the research question. Twenty-nine core narratives were collected, and they were organized according to their content and reduced into six subthemes: the *dying person*, the *bubble*, the *sight*, the *cover*, *care for children's needs*, and *availability of immediate help*. The process continued with capturing the differences among them and what they expressed. From this process of abstraction, three themes conveying meaning were developed: the meaning of relating, the meaning of action, and the meaning of resources.

In the following, the presentation of findings will be structured according to the meanings assigned to the three themes, and thus constitute an interpretive filter through which subjective experience is conveyed. For obvious reasons, we chose the most relevant quotes to explain the themes.

The Meaning of Relating

The constructed meaning of relating concerned relatives' experiences of being seen and met by nurses (subthemes: bubble and care for children's needs). The nature of the relationship between relatives and their inner and outer worlds was present after admittance to the ward, characterized as being "in their own space." This is interpreted as crisis mode, with increased isolation from the external world, at least shortly after arrival:

I wasn't myself, not then and not since then, so it was a crisis. We were told that we were strong and level-headed, but that was how it seemed from the outside, maybe (. . .) We installed ourselves in the room, and there we were, as many as four, five, six. There was only us. Everything outside ceased to exist. Nurses went in and out of the room, but the most important thing was us in this (. . .) yes, this bubble."

This narrator metaphorically expressed the crisis as being in a *bubble*. A bubble is thin and frail and can easily burst. To prevent themselves and the family from bursting this bubble, relatives initially after arrival, and for some time afterward, were preoccupied with handling relationships within the family, and had to keep this focus to gain resources to meet the new and different challenges of daily life. This internal focus and attention also influenced the relationship with the nurses. In this situation, nurses were described as "just walking in and out of the room," indicating that relatives did not, or could not, engage with them at this point in time.

On the other hand, the bubble might be interpreted as a kind of protection from the outside world. While relatives experienced being inside the bubble, nurses were outside, caring and performing activities for the patient, and on behalf of the patient and the relatives. By allowing relatives to stay inside the bubble, nurses demonstrated patience and respect for their need for space.

Nevertheless, a bubble is also to a certain extent flexible. When nurses signaled special interest in relatives' children, they assumed a position where the first crisis in the initial bubble could be developed by broadening relationships, and from where the relatives again could begin to relate to the external world, that is, to the nurses:

The nurses said that we could just take the children with us. They learned the names of all of us. I was impressed, and I feel that it was genuine, that they cared. I noticed it with our youngest grandchild. It was important for him that a couple of nurses took him away and said "let's do something," or else they just found a glass of juice or something. This was very important for him.

From this account, we understand the meaning of relating as a process, where initially the nurses should allow for relatives to arrange what has to be organized and make decisions for themselves inside the bubble. The nurses paid close attention to the children of the family as a way of developing the situation to allow for the external world to be part of relatives' relationships. At a symbolic level, we understand this to be part of relatives' adjustment to a new situation and a new future. As part of this future, children should also have some good memories from this time on the palliative ward. These memories are linked to nurses' actions. Initially, they are cued by verbal interactions, as when nurses learned the names of the whole family, and their later caring actions had important consequences for relatives' experiences.

The Meaning of Acting

The constructed meaning of acting concerned relatives' experiences of what the health professionals actually did or did not do in different situations (the *sight* and the *dying person*). We found that acting was strongly related to whether or not relatives accepted a nurse in the first place:

She stood in the door and looked in, with that shawl round her neck as though (. . .) there was no one else who had that. No, I had never seen anyone else with a shawl like that round their neck. I then thought, you are not the right person here.

How, and with what focus, the nurses carried out their actions was also something the relatives reacted to:

I found her annoying. She made too much noise in the situation. My mother was not so interested in these flowers. That was not exactly where she was at just then (. . .) She reckoned that it was a positive impulse in the situation, but it did not work — not for us, nor for my mother.

If the nurse was accepted by the relatives, further observations could be carried out. Observations were described as linked to forms of knowledge the relatives lacked, and therefore a very important part of nurses' actions. However, to communicate about what nurses observed was not always part of their actions, and leaving it out was something that could place stress on relatives:

It only took one more glance before the nurse saw that she [mother] was afflicted. I felt that she [mother] had already begun to be confused on Tuesday. From then, I felt that we, as relatives, did not get information about how the illness could develop. I knew nothing at all. We had no idea.

By having knowledge about what was happening with the dying person, nurses could communicate their observations, and thus create a feeling of safety for relatives:

A nurse sees the signs. They understand what is happening. I did not understand that her feet began to get cold, and that meant something. They looked into the room and asked: "Is there anything you wonder about?" It was fantastic. We just needed to ring the bell, and they came at once. It was very reassuring.

From this account we understand the meaning of acting as dependent on the relatives' acceptance of a nurse. Prior to this, nurses needed to get in position to act by showing respect for the relatives' need to be inside their bubble for sometime. Given the position and this acceptance, they could include relatives in the process of observations and actions in a more balanced manner, always explaining the signs and symptoms, or, if necessary, leaving the relatives alone, and always capable of reacting promptly if needs be. This would require additional resources available to the staff.

The Meaning of Resources

The constructed meaning of resources concerns the context and environment of being admitted to the

palliative ward (the *cover* and *availability and immediate help*). The context of a palliative ward made a great and positive difference for relatives, which led to feelings of relief and safety. The attitudes shown by nurses reinforced relatives' impression of the spiritual and physical resources available on the ward, in addition to the knowledge and skills demonstrated by the staff:

It made me tired making sure that things were done correctly (. . .) Here they could actually say to her [mother], "Yes, we know that you are ill." There it was: "We are not sure whether you are ill, you just need to exercise." There was a very big difference. It was a relief for Mother to hear: "We know that you are ill."

The narrator indicates that there is a qualitative difference between being a patient or relative on an ordinary ward compared to a palliative one. Resources in the form of amount of staff constituted another difference when relatives compared their experiences with ordinary wards:

We came from the hospital, where the number of staff was much smaller, especially at night. There were two members of staff there for many patients, while here there were fewer patients and more members of staff, and this (. . .) My mother asked for this and that all the time. She would suddenly sit up in bed, then she would lie down in bed. It was not difficult to get help straight away.

To get help quickly when needed seemed to be of importance in shaping relatives' experiences of quality of care, as well as individualized help:

Sometimes she [mother] had a lot of pain; sometimes she had an epileptic fit. We had a room next to the nurse's room, so they came straight away. Here they saw when she had a fit. She got treatment to make the fits weaker and less frequent.

As part of the palliative context and environment, relatives explained they felt that the organization and teaching by nurses was important, and we interpret this to be a kind of protection — a *cover* — for relatives when nurses follow a plan in caring for patients and dealing with relatives:

I must say that they had a clear system. I remember that they did things according to a plan. She [mother] was looked after. I don't remember being informed about a special plan, but I noticed that they did things according to a plan, and they did

everything they could. Moistening her mouth (. . .) Yes, everything was available for her all the time. We noticed that the nurses were up-to-date about everything.

From this we can understand the context and environment of individual actions taken by the nurse as a combination of knowledge and personal dedication. Both aspects influenced the experience of relatives. They understood that in this type of ward the spirit of the staff was a significant resource:

I asked one of the nurses at the reception desk after the funeral: “How do people manage to work here so long?” It must be very tiring. She said that people enjoyed their work very much, and stayed a long time, and that the people who work here are interested in their work. Yes, that is right. That is just how it was, and how they seemed to be.

Comprehensive Understanding

Comprehensive understanding — integrating naïve reading, structural analysis, and authors’ professional experiences and theoretical background — was conceptualized as the main theme of our study and denoted “acting with dedication and expertise.” Being an expert refers to *what* the staff did, or did not do, and dedication to *how* they did it, in this context. Proficiency made relatives feel safer and dedication made the care individualized, even if the ward

seemed to be run under an overarching plan. Being an expert and dedicated to caring were grounded in relationships where the nurses accepted the family’s needs and addressed their internal processes. Focusing on children could later facilitate new relationships for the relatives to the outer world. However, the nurses’ proficiency and dedication were also grounded in the relatives’ acceptance of the individual nurse. When accepted by relatives, nurses could act with expertise in a dedicated manner with all the human and technical resources available. To be able to perform proficiently and in a dedicated manner while supporting dying people and their relatives, the leadership must be willing to provide resources in terms of highly educated staff and the state-of-the-art equipment necessary for palliative care on an institutional ward.

Figure 1 depicts a model of comprehensive understanding. The main theme was conceptualized as “acting with dedication and expertise,” connecting relatives’ experiences of the relationships within the family and between family and nurses, and the actions (or inaction) of the staff while on the ward, and the spiritual and material resources available there.

DISCUSSION

The aim of our study was to illuminate and interpret some relatives’ lived experiences of the provision of care by health professionals in a palliative ward, and to investigate how meaning was constructed from caring narratives. The main finding is that relatives’ positive experiences are greatly facilitated when they perceive the nurses to be acting with dedication and expertise. From our own experience as nurses and our personal experience as relatives of a dying family member, we relate this finding to the aspects of *time and existence, family dynamics*, and the importance of receiving *care adjusted to the situation*.

Time and Existence

To define a patient as dying is often a great challenge to health professionals, and the process of reaching this terminal phase differs for each individual, so no definitive information can be given to relatives on this matter (Given et al., 2011). However, being admitted to a palliative ward indicates that the time left is limited. Nordøy et al. (2006) reported that the expected time remaining before death varies from a few days to some weeks in these situations. Uncertainty about the length of time left and about the exact process that leads toward death represented by a person hospitalized in a palliative

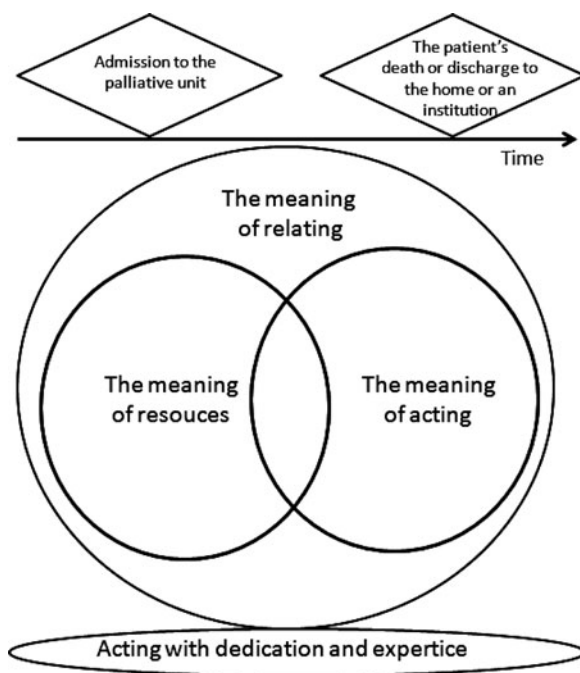


Fig. 1. Model of relatives’ experiences of nurses’ caring in a palliative ward.

ward may increase relatives' desire to better use the limited time available within the family circle and to construct some boundaries between them and the external world. This was described in our study as being in a "bubble." It seemed important that nurses respect this, as it could be seen as necessary and important to adjusting to the new state of being. From a Heideggerian view (Sarvimäki, 2006), a human being exists in time and space and in the temporal unfolding and creating of a life course. This being-in-the-world happens in the everyday world. However, a relative in a palliative ward is not in their everyday world. The practical affairs of nature, everyday things, and acting in an ordinary, pre-reflective manner do not seem to be possible. This can be understood, as Sarvimäki suggested, as "not being at home in the world." "Being at home in the world" is held by Heidegger (1992) as being in an interpreted world. Living in time and space inside the bubble may help relatives to adjust and interpret their new situation and gradually understand and open up to what they had heretofore tried to hide — the unexpected death of a loved one.

Our participating relatives expressed the importance of being given information about the illness and the course of the illness when there was little time left. This helped them cope with the existential challenges that inevitably crop up. This finding is also in line with previous research about relatives' need for information related to serious illness (Ashbury et al., 1998; Fitch, 2005; Fitch & Allard, 2007). The results of our study confirm that there is a great difference between ordinary hospital departments and the palliative ward in terms of death being a main theme of conversation. Gulbrandsen (2008) points out that little research has been done about the importance of good communication in specialized health services. He also maintains that it is still a common conception that conversation takes up too much time in the practical clinical setting. Acting with dedication and expertise in a palliative setting includes taking the initiative to talk to relatives about time and existence.

Health personnel with adequate knowledge about an individual patient and their condition are the people best suited to tell relatives that death is imminent (Saunders & Platt, 1999). A surprising finding from our study is that information about the time left, and the fact that death was imminent could be experienced as not good enough in the palliative ward. It seemed challenging to maintain continuity and high-quality care when dealing with relatives' existential needs just before the death of their family member.

The findings from this study demonstrate that relatives were satisfied when the patient received

help when and as needed. This meant that nurses took the patient seriously when he or she called for help, and that the patient did not have to wait. Several informants described time in a negative sense when it took too long to receive help, or when relatives perceived the nurses as being annoyed or insecure. From a philosophical perspective, Stern (2004) maintains that staff and relatives meet intersubjectively, as two individuals "in the present moment" — in other words, *now*. His point is that the core of all work with relationships is that the two subjects meet in the "now." Acting with dedication and expertise in this type of unit is, according to Stern's perspective, related to a nurse's ability to perceive things and act "now."

Family Dynamics

Having the family present was important for all participants. By actively focusing on the children, nurses helped relatives adjust to the transition from being in the bubble to relating more to the outside world once again. Our experience is that many relatives can be insecure about their role due to the internal dynamics of the family. Five of our relatives had children or grandchildren. The families often do not know what was best for the children nor about how the young ones can receive assistance (see Schjoedt et al., 2008). Our study shows that acting with dedication and expertise is particularly related to ensuring that the children of the family are recognized and taken care of. One important way of doing this is through small, practical things, like giving them biscuits and juice. Studies have confirmed that such things can have a long-term positive impact on children (Kvåle, 2006). It was also important for the relatives in our study that nurses knew the children's names and that the staff talked directly to them when they visited.

Yennurajalingam and colleagues (2008) found that it was important to talk with families in a palliative ward about the final phase of life, and that they experienced less stress when the conversations took place with the patient present. Bruera et al. (2009) reported the importance of communication in facilitating positive family dynamics. Both the patient and relatives are under extreme emotional stress, and open communication is fundamental to maintenance of family relationships. Information needs to be dispensed about such things as the patient's medications, the patient's condition, and why the patient can behave in an erratic or confused way due to the disease or the side effects of cancer treatment. Patient and family satisfaction are often largely related to their understanding of what is happening. Increased understanding is related to how the

situation is handled. Relatives who understand the various interconnections can gain an increased sense of coherence and thus experience less stress and strain (Antonovsky, 1987). Acting with dedication and expertise involves nurses acting in a manner that enhances a family's sense of coherence.

Care Adjusted to the Situation

We sought to explore relatives' experience of the provision of care by health professionals from various disciplines. The findings revealed by Heyland et al. (2006) ranked trust in health personnel, especially the medical doctor responsible for treatment, of high importance within palliative care. However, the informants in our study referred to nurses only, perhaps because this health discipline was the main one available for them on the ward. Based on findings from our study, several perspectives on the caring situation emerged. One was of a nurse who was described as noisy, who always embellished things. With her, provision of care was interpreted as hectic, as "overcare," rather than comfortable or appropriate care adjusted to the situation. Another nurse who spruced herself up and overdressed aroused feelings of vulnerability and distress (Grovet al., 2005).

Our study shows that acting with dedication and expertise and facilitating person-centered care (McCormack & McCance, 2010) is related to contextual and environmental factors. From a relative's perspective, this includes the spiritual and ethical values of the nurses involved. One participant told a story about a nurse's lack of skill. This nurse was not a member of the permanent ward staff, but was hired from a temporary staff recruitment agency. She was wearing a shawl that was not part of the regular uniform. Her body language clearly communicated that she was insecure and had little to contribute to the situation. The way in which this nurse looked into the room was interpreted as showing that she was not capable of acting with dedication and expertise. The participant quickly recognized this, and this made her feel insecure. This confirms the importance of having what Benner (1984) calls experts on a ward when dealing with such complex problems. Benner uses the terms "novices" and "experts" in describing nursing skills. Novices are staff with little experience, who have more than enough to do with the basic practical tasks provided for patients. Because of their long practical and personal experience, experts are able to perceive a patient's total situation and not just focus on routine matters (Benner, 1984).

One finding from our study is that relatives understood that there was a routine to the work on the

ward. Having nurses who followed a plan fostered trust; relatives felt they could depend on such staff members. Routines to be employed in nursing and care services were developed during the late 1980s in the United States (Ellershaw & Wilkinson, 2003). At the time our interviews were carried out, the ward employed the Liverpool Care Pathway (LCP), which is a routine for care of terminally ill patients and their relatives. LCP offers an opportunity for a systematic approach, and has been introduced for all expected deaths in many different settings. Based on our findings, we recommend such systems be adapted to highlight the necessity of a nurse's individual and professional judgment as an important part of acting with dedication and expertise.

The relatives in our study reported that they were satisfied with the relief of patients' symptoms. This meant that they themselves could relax more and take less responsibility for the sick person. Correct medication for adequate pain control is one very important example. Terminal care departments receive patients with symptoms and discomfort that are particularly complex, and staff members need to have extensive knowledge about symptom management (Norwegian Directorate of Social Health, 2012). Based on the findings of our study, it seems that this goal was reached. When relatives in the study used the word "treatment" to describe making seizures weaker and less frequent, we interpret this as indicating that medications were administered in appropriate fashion and at the times when patients needed them.

The importance of nurses' practical skills was supported by the findings of Kvåle (1999). Her study showed that cancer patients give highest priority to good technical skills and treatment provided in an appropriate manner. Acting with dedication and expertise means working according to routines and anticipating situations. Skilled staff perceive the patient's total situation and act accordingly (Benner, 1984). Our study also complements the research done by Steinhauser et al. (2000a). Our findings bring new insight and content to different perspectives on their six main components describing the experience of a good death with regard to "preparing for death," "time to review life," and "availability of commitment with family and friends."

Our participants reported that nurses on their ward were highly educated and were engaged and interested in their professional field. We understand this to be the essence of being dedicated. When relatives experienced serious situations, they reported their impressions of the performance of nurses. They also took the initiative to talk with the staff about what made nurses able to cope with such a

serious and complex job for an extended period of time. There is reason to believe that the great variation in tasks helps the staff to feel content with their jobs, and this leads to increased interest in the nursing field. Additionally, we assume that the nurses act according to the worthy values and principles embedded in the foundations of palliative care. In this interpretation of our study findings, it seems reasonable that the relief of pain and suffering in a patient is of great importance for relatives. According to the definition of palliative care (from Latin *palliare*, to cloak), the active total care offered to patients in palliative units is meant to provide a haven where suffering can be ameliorated or “covered.”

Methodological Considerations

The purpose of our study was to contribute to the body of knowledge within palliative care focusing on relatives' lived experiences of the provision of care in a palliative ward. No generalizations can be drawn from this material, however. Our results might lead to hypotheses and in-depth knowledge about a very specific sample: relatives of cancer patients hospitalized in a palliative ward. No data about the circumstances regarding patients' deaths were collected, so that future studies should include such information.

Clinical Implications

We recommend that nurses be aware of the way they behave with relatives of cancer patients in a palliative ward. It seems important that staff expertise be highlighted, and when recruiting nurses to palliative units in the hospital, the challenge is to find expert and experienced nurses who are able to act in a dedicated fashion.

CONCLUSION

It is clearly vital that relatives experience the nurses in a palliative care unit as acting with dedication and expertise. This form of action seems to be dependent on the relationship between nurse and family, as well as on the dynamics within the family. Contextual and environmental factors are related to the possibilities of acting with dedication and expertise. It is also important for nurses to adopt a family perspective and make arrangements for the family's presence, both practically and emotionally. Relatives of patients who are in the palliative phase of their treatment and have little time to live need to be approached by professional staff who see the patients' and families' total needs, who can adequately assess the situation, have sufficient time, and bring a wide range of skills with them. Complex and challenging situ-

ations make it important for nurses to have time and courage. Our relatives found that the nurses who provided the best possible help took the time to listen to their needs. In addition to skills related to the disease and its course, the staff also require abilities in dialogue and forming relationships, particularly with children. Overall, relatives' most desire personnel with sensitivity skills who act with dedication and expertise.

REFERENCES

- Alma, H.H. & Smaling, A. (2006). The meaning of empathy and imagination in health care and health studies. *International Journal of Qualitative Studies on Health and Well-Being*, 1(4), 195–211.
- Andershed, B. (2006). Relatives in end-of-life care, part 1: A systematic review of the literature the five last years, January 1999–February 2004. *Journal of Clinical Nursing*, 15(9), 1158–1169.
- Antonovsky, A. (1987). *Unraveling the mystery of health*. San Francisco: Jossey-Bass.
- Ashbury, F.D., Findlay, H., Reynolds, B., et al. (1998). A Canadian survey of cancer patients experiences: Are their needs being met? *Cancer Prevention Control*, 2(3), 129–132.
- Ashworth, P.D. (2006). Seeing oneself as a carer in the activity of caring: Attending to the lifeworld of a person with Alzheimer's disease. *International Journal of Qualitative Studies on Health and Well-Being*, 1(4), 212–225.
- Benner, P. (1984). *From novice to expert*. San Francisco: Addison-Wesley Publishing Company.
- Brobäck, G. & Berterö, C. (2003). How next of kin experience palliative care of relatives at home. *European Journal of Cancer Care*, 12(4), 339–346.
- Bruera, E.R., Dev, L., Emanuel, E.J., et al. (2009). Overview of symptom control in the terminally ill cancer patient. www.utdol.com/online/content/topic.do?topicKey=endolif/5152&view=print. (Accessed on September 16, 2012).
- Daly, B.J., Douglas, S., Lipson, A., et al. (2009). Needs of older caregivers of patients with advanced cancer. *Journal of the American Geriatric Society*, 57(Suppl. 2), 293–295.
- Denzin, N.K. & Lincoln, Y.S. (2003). *Collecting and interpreting qualitative materials*. Thousand Oaks, CA: Sage.
- Ellershaw, J. & Wilkinson, S. (2003). *Care of the dying: A pathway to excellence*. Oxford: Oxford University Press.
- European Association for Palliative Care (EAPC) (2005). *Definition of palliative care*. <http://www.eapcnet.org/about/definition.html>.
- Fitch, M. (2005). Needs of patients living with advanced disease. *Canadian Oncology Nursing Journal*, 4(15), 230–242.
- Fitch, M. & Allard, M. (2007). Perspectives of husbands of women with breast cancer: Information needs. *Canadian Oncology Nursing Journal*, 17(2), 79–90.
- Gagnon, P., Charbonneau, C., Allard, P., et al. (2002). Delirium in advanced cancer: A psychoeducational intervention for family caregivers. *Journal of Palliative Care*, 18(4), 253–261.

- Gelfman, L.P., Meier, D.E. & Morrison, R.S. (2008). Does palliative care improve quality? A survey of bereaved family members. *Journal of Pain and Symptom Management*, 36(1), 22–28.
- Given, B.A., Sherwood, P. & Given, C. (2011). Support for caregivers of cancer patients: Transition after active treatment. *Cancer Epidemiology, Biomarkers & Prevention*, 20, 2015–2021.
- Grov, E.K., Dahl, A.A., Moum, T., et al. (2005). Anxiety, depression, and quality of life in caregivers of patients with cancer in late palliative phase. *Annals of Oncology*, 16(7), 1185–1191.
- Grov, E.K., Fosså, S.D., Tønnessen, A., et al. (2006a). The Caregiver Reaction Assessment: Psychometrics and temporal stability in primary caregivers of Norwegian cancer patients in late palliative phase. *Psycho-Oncology*, 15, 517–527.
- Grov, E.K., Fosså, S.D., Sørebo, Ø., et al. (2006b). Primary caregivers of cancer patients in the palliative phase: A path analysis of variables influencing their burden. *Social Science of Medicine*, 63(9), 2429–2439.
- Gulbrandsen, P. (2008). God kommunikasjon — også for legenes skyld! [Good communication — necessary for the medical doctor as well as the patient!] [In Norwegian]. *Tidsskrift for den norske legeforening*, 24, 2840–2842.
- Heidegger, M. (1992). *Existence and being*. Göteborg, Sweden: Daidalos.
- Hewitt, M., Greenfield, S. & Stovall, E. (Committee on Cancer Survivorship: Improving Care and Quality of Life Institute of Medicine and National Research Council) (2008). *From cancer patient to cancer survivor: Lost in transition*. Washington, DC: The National Academies Press.
- Heyland, D.K., Dodek, P., Rocker, G., et al. (2006). What matters most in end-of-life care: Perceptions of seriously ill patients and their family members. *Canadian Medical Association Journal*, 174(5), 627–633.
- Hodge, F.S., Itty, T.L., Cadogan, M.P., et al. (2012). “Weaving balance into life”: Development and cultural adaptation of a cancer symptom management toolkit for Southwest American Indians. *Journal of Cancer Survivorship*, 6(2), 182–188.
- Hodges, L.J., Humphris, G.M. & MacFarlane, G. (2005). A meta-analytic investigation of the relationship between the psychological distress of cancer patients and their carers. *Social Science and Medicine*, 60(1), 1–12.
- Karlberg, I., Hallberg, L. R.-M. & Sarvimäki, A. (2002). Introduction and aims of the book *Health, public health and research on public health*. In *Qualitative methods in public health research: Theoretical foundations and practical examples*. L.R.-M. Hallberg (ed.), pp. 13–38. Lund: Studentlitteratur.
- Keegan, O., McGee, H., Hogan, M., et al. (2001). Relatives’ views of health care in the last year of life. *International Journal of Palliative Nursing*, 7(9), 449–456.
- King, N., Bell, D. & Thomas, K. (2004). Family carers’ experiences of out-of-hours community palliative care: A qualitative study. *International Journal of Palliative Nursing*, 10(2), 76–83.
- Kuijjer, R.G., Buunk, B.P., Ybema, J.F., et al. (2002). The relation between perceived inequity, marital satisfaction and emotions among couples facing cancer. *British Journal of Social Psychology*, 41(Pt. 1), 39–56.
- Kvåle, K. (1999). *Pasienten vil ha teknisk dyktighet — sykepleierne vil lytte* [The patient wants technical skilled nurses — the nurses emphasize listening] [In Norwegian]. *Sykepleien*, 10, 60–64.
- Kvåle, K. (2006). Den omsorgsfulle sykepleier slik pasienten ser det [The caring nurse — the patient’s perspective] [In Norwegian]. *Vård i Norden*, 79, 15–19.
- Kvåle, S. & Brinkmann, S. (2009). *Interviews: Learning the craft of qualitative research interviewing*. Los Angeles: Sage.
- Lecouturier, J., Jacoby, A., Bradshaw, C., et al. (1999). Lay carers’ satisfaction with community palliative care: Results of a postal survey (South Tyneside MAAG Palliative Care Study Group). *Palliative Medicine*, 13(4), 275–283.
- Linderholm, M. & Friedrichsen, M., (2010). A desire to be seen: Family caregivers’ experiences of their caring role in palliative home care. *Cancer Nursing*, 33(1), 28–36.
- Lindseth, A. & Norberg, A. (2004). A phenomenological hermeneutical method for researching lived experience. *Scandinavian Journal of Caring Sciences*, 18(2), 145–153.
- McCormack, B. & McCance, T. (2010). *Person-centred Nursing: Theory and practice*. Chichester: Wiley-Blackwell.
- Miceli, P.J. & Mylod, D.E. (2003). Satisfaction of families using end-of-life care: Current successes and challenges in the hospice industry. *American Journal of Hospice and Palliative Care*, 20(5), 360–370.
- Miederma, B. & Easley, J. (2012). Barriers to rehabilitative care for young breast cancer survivors: A qualitative understanding. *Supportive Care in Cancer*, 20(6), 1193–1201.
- Milberg, A. & Strang, P. (2004). Exploring comprehensibility and manageability in palliative home care: An interview study of dying cancer patients’ informal carers. *Psycho-Oncology*, 13(9), 605–618.
- Mishler, E.G. (1986). *Research interviewing: Context and narrative*. Cambridge: Harvard University Press.
- Nordøy, T., Thorsen, L., Kvikstad, A., et al. (2006). Ernærings og væskebehandling til pasienter med ikke —kurbel kreftsykdom (Nutrition and hydration for patients with non-curable cancer). *Tidsskrift for Norsk Lægeforening*, 5(126), 624–627.
- Northouse, L., Williams, A.L., Given, B., et al. (2012). Psychosocial care for family caregivers of patients with cancer. *Journal of Clinical Oncology*, 30(11), 1227–1234.
- Norwegian Directorate of Health (2012). *Nasjonalt handlingsprogram med retningslinjer for palliasjon i kreftomsorgen* (National action programme with guidelines for palliative care for patients with cancer). Oslo: Sosial- og helsedirektoratet.
- Onishi, H., Onose, M., Okuno, S., et al. (2005). Spouse caregivers of terminally ill cancer patients as cancer patients: A pilot study in a palliative care unit. *Palliative and Supportive Care*, 3(2), 83–86.
- Ostlund, U., Wennmann-Larsen, A., Persson, C., et al. (2010). Mental health in significant others of patients dying from lung cancer. *Psycho-Oncology*, 19(1), 29–37.
- Polkinghorne, D.E. (1988). *Narrative knowing and the human sciences*. Albany: State University of New York Press.
- Quest, T.E. & Bone, P. (2009). Caring for patients with malignancy in the emergency department: Patient–provider interactions. *Emergency Medicine Clinics of North America*, 27(2), 333–339.
- Ricoeur, P. (1976). *Interpretation theory: Discourse and the surplus of meaning*. Fort Worth: Texas Christian University Press.
- Riessman, C.K. (1993). *Narrative analysis*. London: Sage Publications.

- Rollison, B. & Carlsson, M. (2002). Evaluation of advanced home care (AHC): The next-of-kin's experiences. *European Journal of Oncology Nursing*, 6(2), 100–106.
- Sarvimäki, A. (2006). Well-being as being well: A Heideggerian look at well-being. *International Journal of Qualitative Studies on Health and Well-Being*, 1(1), 4–10.
- Saunders, C. & Platt, M. (1999). Pain and impending death. In *Textbook of pain*, 4th ed. P.D. Wall & R. Melzack (eds.), pp. 1113–1122. London: Churchill Livingstone.
- Schjoedt, B., Haugen, F.D., Straume, M., et al. (2008). Familien [The family]. In *Palliasjon: Nordisk lærebok [Palliation: Nordic handbook]*. S. Kaasa (ed.), pp. 89–114. Oslo: Gyldendal Norsk Forlag.
- Statistics Norway (2012). *Dødsårsaker 2011*. <http://www.ssb.no/emner/03/01/10/dodsarsak/> and <https://www.ssb.no/statistikkbanken/selectvarval/saveselections.asp>. (Accessed on February 25, 2013).
- Steele, L.L., Mills, B., Long, M.R., et al. (2002). Patient and caregiver satisfaction with end-of-life care: Does high satisfaction mean high quality of care? *American Journal of Hospice and Palliative Care*, 19(1), 19–27.
- Steinhauser, K.E., Clipp, E.C., McNeilly, M., et al. (2000a). In search of a good death: Observations of patients, families, and providers. *Annals of Internal Medicine*, 132(10), 825–832.
- Steinhauser, K.E., Christakis, N.A., Clipp, E.C., et al. (2000b). Factors considered important at the end of life by patients, family, physicians, and other care providers. *The Journal of the American Medical Association*, 284(19), 2476–2482.
- Stern, D.N. (2004). *The present moment in psychotherapy and everyday life*. New York: W.W. Norton & Company.
- Van Ryn, M., Sanders, S., Kahn, K., et al. (2011). Objective burden, resources, and other stressors among informal cancer caregivers: A hidden quality issue? *Psycho-Oncology*, 20(1), 44–52.
- Yennurajalingam, S., Dev, R., Lockey, M., et al. (2008). Characteristics of family conferences in a palliative care unit at a comprehensive cancer center. *Journal of Palliative Medicine*, 11, 1208–1211.