

Bereaved family members' perspectives on suffering among older rural cancer patients in palliative home nursing care: A qualitative study

S.A. Devik RN, PhD, Associate Professor^{1,2} | O. Hellzen RN, PhD, Professor³ |
I. Enmarker RN, PhD, Professor^{1,3,4}

¹Centre of Care Research, Department of Health Sciences, Nord University, Steinkjer, Norway

²Department of Health Sciences, Nord University, Namsos, Norway

³Department of Nursing Sciences, Mid-Sweden University, Sundsvall, Sweden

⁴Faculty of Health and Occupational Studies, University of Gävle, Gävle, Sweden

Correspondence

Siri Andreassen Devik, Department of Health Sciences, Nord University Namsos, Norway.
Email: siri.A.Devik@Nord.No

Little is known about experiences with receiving home nursing care when old, living in a rural area, and suffering from end-stage cancer. The aim of this study was thus to investigate bereaved family members' perceptions of suffering by their older relatives when receiving palliative home nursing care. Qualitative semi-structured interviews were conducted with 10 family members, in Norway during autumn 2015, and directed content analysis guided by Katie Eriksson's theoretical framework on human suffering was performed upon the data. The two main categories identified reflected expressions of both suffering and well-being. Expressions of suffering were related to *illness*, to *care* and to *life* and supported the theory. Expressions of well-being were related to *other people* (e.g. familiar people and nurses), to *home* and to *activity*. The results indicate a need to review and possibly expand the perspective of what should motivate care. Nursing and palliative care that become purely disease and symptom-focused may end up with giving up and divert the attention to social and cultural factors that may contribute to well-being when cure is not the goal.

KEYWORDS

bereaved family members, home nursing care, palliative care, qualitative directed content analysis, rural, suffering

1 | INTRODUCTION

Palliative home nursing care in rural areas can offer older persons with advanced cancer many benefits, included increased senses of comfort, security and identity (Devik, Hellzen, & Enmarker, 2015). By contrast, long distances and limited health-related human resources pose challenges to providing optimal services in rural contexts (Robinson et al., 2009). Often, to make homecare possible, care services have to rely on family members' contributions of time and energy (Aranda & Hayman-White, 2001; Hudson & Payne, 2008; Williams & McCorkle, 2011). Older rural palliative patients and their family caregivers have described insecurity, lack of control and strain when being in need of care (Duggleby et al., 2010; Wiik, Devik, & Hellzen, 2011). Devik, Enmarker, Wiik, et al. (2013) found that suffering from incurable cancer when

living alone in rural communities meant increased burden caused by the way care was delivered. Still, few rural studies exist in this area.

According to the Finnish nursing theorist Katie Eriksson (1994, 1997), caring can be seen only from a suffering perspective—suffering is the key motif of all caring. In order to alleviate suffering, nurses must understand and apply experiences from the point of view of those involved (Eriksson, 2002). In her work, Eriksson describes three forms of suffering in healthcare—suffering from illness, suffering related to care and suffering related to life. By theoretically separating the concept of suffering, Eriksson raises awareness to patients' experiences of humiliation, guilt and unworthiness in conjugation with their physical suffering. Her operationalisation is, in this study, seen applicable for deducing and exposing experiences from the sufferer's world of which nurses must understand and apply to in order to alleviate suffering.

The alleviation of suffering is also a central goal in palliative care (Wilson et al., 2007), and for persons suffering from advanced cancer, physical, psychological, social and spiritual dimensions can be distinguished (Daneault et al., 2004; Ferrell & Coyle, 2008; Wilson et al., 2007). Yet, the scope of research has primarily encompassed types of suffering and not so much the experience of suffering, and the field continues to be dominated by quantitative studies (Beng et al., 2014; Ellis et al., 2015). Among them, Ellis et al. (2015) found that despite advanced cancer many patients did not perceive that they were suffering, but for those who did, suffering had various faces: avoidable suffering, physical and emotional suffering, suffering as loss and ultimately transformation through suffering. In turn, those authors argued for more attention to how individual patients in different settings experience suffering.

Problems with recruitment are nothing new in palliative care research (Lee & Kristjanson, 2003). Persons in palliative situations may be too ill or unwilling to provide information for themselves (McPherson & Addington-Hall, 2004), and trying to avoid this problem and gain knowledge of the phenomenon from a different perspective, close family members may be perceived as significant informants. Indeed, many family members perform a considerable amount of caregiving and accompany their relatives along the trajectories of their illness. When using family members' survey-responses in palliative care, more agreement surfaces regarding patients' responses to objective items than subjective ones (McPherson & Addington-Hall, 2003; Stajduhar et al., 2011). Meanwhile, by way of a qualitative approach, McPherson and Addington-Hall (2004) found that proxies draw upon different sources of knowledge when evaluating patients' symptoms and expressions. Family members know the history and traits of their relatives. Significant others, who have been in close contact with patients, are better proxies than health professionals are, for some experiences (McPherson & Addington-Hall, 2004). Moreover, qualitative approaches allows for background-stories and reflections that cannot appear in predefined survey alternatives. Based on these arguments and the fact that few studies have addressed experiences from palliative care through the family members' eyes (Melin-Johansson, Axelsson, & Danielson, 2007), we aimed in this study to add knowledge to the field and reach possible messages to improve the alleviation of suffering in this segment of the population.

1.1 | Aim

The aim of this study was to explore bereaved family members' perceptions of suffering in rural-dwelling older persons receiving palliative home nursing care during the last phase of life.

2 | METHOD

2.1 | Design

Situated within the qualitative tradition our study aimed to gather and interpret persons' subjective experiences and their creations' of meaning. The qualitative approach allows for nuances, details and

reflections that we never could have gained by using rigid response alternatives (McPherson & Addington-Hall, 2004; Patton, 2002). Our design employed a directed approach (Elo & Kyngäs, 2008; Hsieh & Shannon, 2005) guided by Katie Erikson's framework on human suffering that we sought to validate or extend. This method accommodates the need to include a more deductive thinking in qualitative research in order to facilitate the development of nursing theory and science (Bergdahl & Berterö, 2015).

2.2 | Participants

This study is based on interviews with bereaved family members of older persons (aged 65 years or older) who died from cancer and received palliative home nursing care in rural communities in Norway. Scattered settlements, primary industry, and sometimes, great distances from densely populated areas characterise Norway's rural context.

District nurses and oncology nurses responsible for coordinating home-based palliative care within their municipalities mediated contact with eligible participants. We included relatives if they had lived with or considered themselves to have been close to the deceased. Time since death needed to be no less than 2 months and no more than 2 years. Eligible participants received written information about the purpose and procedure of the study and contacted the researcher by phone if they wished to participate. We collected each participant's written consent and participants decided upon the time and place for the interview. In all, 10 relatives consented to participate—five daughters, three wives, one sister and one sister-in-law—whose ages ranged from 45 years to 61 years. The deceased included eight men and two women.

2.3 | Data collection

We constructed semi-structured interviews (Kvaale, 2007) to address all the three aspects of suffering described by Eriksson (1994, 1997). We simultaneously formulated questions openly to capture unexpected elements and unique experiences.

Initially we asked the interviewees to speak openly about the last year of their relative's life. As their stories unfolded, we asked more targeted questions about their perceptions of the older person's situation: How did physical pain or afflictions bother him or her? How did he or she interact socially? How do you think he or she generally felt? What do you think was important for him or her in the last phase of life? How did you perceive the home nursing care that was given? In your opinion, do you think that he or she was cared for well during that period? Do you think that something should have been done differently?

One interview occurred in the participant's home. The other nine occurred at the researchers' office. The first author conducted and audiotaped all interviews, which lasted 53–124 min, and transcribed them verbatim. All interviews were performed in Norwegian. The first author also translated the transcripts from Norwegian to English. The other authors checked the translation and confirmed that the meaning

was kept throughout the process. The language in this article is assured quality by professional editing.

2.4 | Data analysis

Directed qualitative content analysis (Elo & Kyngäs, 2008; Hsieh & Shannon, 2005) was chosen for this analysis. The main strength of this deductive approach is that it allows existing theory to be supported and extended (Marshall & Rossman, 1995). By applying Eriksson's (1994, 1997) theoretical framework on human suffering, we aimed to deduce contents of suffering related to illness, suffering related to care and suffering related to life in older rural persons who died from cancer.

The analysis was done manually and involved several steps. We considered the entire interview texts as the unit of analysis. Because we used data from proxies already representing an interpretational level, we decided to seek out the manifest content. All interviews were read several times in order to gain a sense of the whole. We then reviewed the data in search for meaning units that corresponded to or exemplified our predetermined coding scheme (i.e. codes for suffering). In a subsequent step, we inductively analysed meaning units that did not represent suffering, since they appeared to be new categories. We condensed, compared and abstracted all meaning units into subcategories and lastly into main categories. We constantly tested the logic of our analysis by alternating between the transcribed text and the developed categories (Elo & Kyngäs, 2008). The initial analysis, performed by the first author, became the subject of reflexive discussions between all three authors. The de-contextualised findings were re-contextualised, reflected upon and contested by different angles (Malterud, 2001).

2.5 | Ethical considerations

Bereavement is associated with suffering, and its consequences can be both physical and mental (Stroebe, Stroebe, & Schut, 2003). To recall and reflect upon memories can be upsetting for some, whereas others might find it beneficial (Koffman et al., 2012). As such, we exhaustively informed all participants about the study and its procedure. We distributed the interview guide beforehand and secured the necessary time to prepare for the interviews, as recommended by Koffman et al. (2012). The Norwegian Data Inspectorate granted permission for the research (No. 42933).

3 | FINDINGS

The bereaved family members in this study interpreted expressions of their sick relatives to reveal both suffering and well-being. Such content was emphasised in some interviews as being overly characterised by suffering and some by well-being. Our analysis resulted in two main categories with six subcategories as shown in Table 1.

3.1 | Expressions of suffering

3.1.1 | Suffering related to illness

Descriptions of how cancer affected relatives' bodily functions and of experiences with bothersome symptoms were diverse. Participants often described their relatives' pain and fatigue, as well their significant weight loss and trouble with both eating and managing personal

TABLE 1 Overview of the analysis

Interview text	Condensed meaning	Subcategory	Category
As a consequence radiation therapy, he didn't manage to walk again and after that it all went downhill....Soon he was a nursing case and dependent on other's (Wife 60 years old)	Bodily decline reduced him to a nursing case	Suffering related to illness	Expressions of suffering
Except regular morning and evening personal hygiene, and help with medication, few nurses took the time to sit down and actually talk with him. He was anxious and felt alone...He called me on the phone night and day...(Daughter 45 years old)	Feeling left alone	Suffering related to care	Expressions of suffering
He didn't talk much about his feelings...but now and then he drank (alcohol) a lot...maybe because of both pain and hopelessness....Then he was able to cry. (Sister-in-law 61 years old)	Struggling with feelings of hopelessness	Suffering related to life	Expressions of suffering
I had to promise to be there all of the time. He was afraid that the nurses wouldn't understand him. (Wife 60 years old)	Feeling safe when surrounded by familiar people who care	Well-being related to other people	Expressions of well-being
Being at home was the most important thing for him... Here he could be himself. Here, everything was still as usual.... (Wife 60 years old)	Feelings of normality	Well-being related to home	Expressions of well-being
As long as he managed, he wanted us to take our daily walk, if only for just a few metres outside the house. He just had to keep on... (Wife 50 years old)	Still going with the flow	Well-being related to activity	Expressions of well-being

hygiene. They also reported complications following surgery and reactions from cytotoxic drugs. One wife said:

He was in great pain. There were four nights when he couldn't find rest. He didn't sleep or lie down because of the pain.

Meanwhile, another wife reported that:

The tumor in his throat grew and grew, and it became hard for him to swallow.... Just drinking a cup of coffee was difficult.

As the disease progressed, the relatives' ability to maintain independence in performing daily activities such as washing, dressing or going to the toilet deteriorated. Participants often related feeling helpless amid such suffering. One wife said:

On one of the last nights, he couldn't manage to brush his teeth. He had no strength at all. And going to the toilet was troublesome....I saw it....that was the most humiliating for him....not to being able to control himself

3.1.2 | Suffering related to care

Suffering related to care was the kind of suffering most frequently reported. When exemplifying these situations, family members became very emotional. Some could burst into tears, whereas others raised their voices in anger. During the illness period, especially during the last weeks, family members spent much time—in some cases, all of their time—caring for and watching over their relative. Interviewees expressed that advocating for the patient was both natural and necessary. Feelings of mistrust and insecurity were common in response to care-related suffering. These situations occurred both at home and while in contact with the hospital and could relate to different health professionals. For example, one daughter told that her ill parent had been left behind in the hospital's basement after receiving an X-ray. That instance was only one of several similar episodes when this person felt neglected and treated arbitrarily by health professionals at the hospital. As the daughter explained:

He, an old man, became dependent on having one of his family members be with him when admitted to the hospital. I remember having to stay the night with him and then driving to work early in the morning. He had no trust.

Another daughter discussed her mother's trouble with managing daily activities after she had been discharged from the hospital. She was in a bad condition: dizzy, unsteady and incontinent. Because the district nurses only stopped by and provided minimal help the daughter had to take time off from her job and move in with her mother. When the mother broke her leg after a fall, she had to return for another hospital

stay. Shortly thereafter, her condition worsened, and she spent her last days in a nursing home. In the weeks before her death, she was in tremendous pain, yet received minimal of painkillers. Instead, the nurses encouraged her to be more active and some of them even called her lazy. In the daughter's words:

Then, they began to tell her that she should practise more, saying "You are so lazy".... Yes, some of the nurses were that rude...both nurses in the nursing home and district nurses used such language. My mother said, almost in tears "They call me lazy". "No", I said, "You have never been that".

Other family members also reported their relatives' suffering when health professionals underestimated or even neglected symptoms. One wife said:

His pain was not alleviated....they didn't increase the dosage you know. They did not believe that he was in that much pain. The medicine dosage that he used was very low, so they judged that there was no need for an analgesia pump. They increased the tablets only, but it didn't help.... He was desperate....It was hard seeing that much pain and realising that there was no help.

Generally, receiving messages to the effect that nothing more could be done seemed to increase the relatives' suffering. Even if realistic, concrete information was perceived to be important and highly valued, it could raise also feelings of being left alone and let down. One sister-in-law found it highly unethical:

They told him and his wife that if something happened to him now, then there would be no resuscitation. Everything was so cold and final....Later, I heard him tell his brother that he had ordered the doctors to do everything possible to keep him alive—"I will never give up", he said. But his eyes said quite the opposite when he took his brothers hand.

3.1.3 | Suffering related to life

Suffering related to life also emerged in the family members' narratives. Some of the cancer patients expressed sadness, anger and feelings of unfairness in direct ways. Others were perceived to have used more active and sometimes avoidant strategies. In several cases, being strong and even comforting to family members appeared to be crucial. One daughter told that her father always had been a strong person and had never really shown his inner feelings. She observed, however, that he had struggled with sorrow:

But I decided not to confront him....I was afraid to provoke something that could make him feel even worse....so

he could keep his dignity. He wanted to show that he was strong....and he really was!

Most interviewees provided rich descriptions of what their relatives were like before the cancer took hold. With such knowledge, they believed that they could understand how the ill person had felt and coped. Several of the male patients had lived active, busy lives for as long as they could. One wife interpreted her husband's activity to be his "medicine" and way of both coping and preparing for a future in which he could not take part. When lying in bed during his last week, he cried a great deal. She said:

He was very sad....We had planned differently....at least he had believed that he would have more time....It was tough to hear him say, "I won't have it this way—I want to be well"....He could barely keep his eyes open. It was immense powerlessness.

3.2 | Expressions of well-being

3.2.1 | Well-being related to other people

Having family and familiar people around stood out as highly significant for the patients. All interviewees were convinced that their presence and care had contributed to their relatives' well-being. The family members talked about love, practical care, the allocation of their own needs and their knowledge about their relatives' needs. One wife explained:

He lost his voice at the end....I believed that he talked to me, but maybe he didn't....I knew the signs, you know, so even if he didn't say something loudly, I could feel what he meant.

Family members represented people with the knowledge essential to observing and translating their sick relatives' expressions and gestures, and were able to assure adequate alleviation. One wife said that she had promised her husband two things: that he would never be left alone and that he never would be left in pain.

The development of close relationships between the patients and some nurses were also observed at times, and interviewees highlighted the nurses' availability, flexibility and human qualities. One daughter said that her father had put all of his trust in one of the district nurses who had special education in oncological nursing but were less experienced than some of her colleagues:

My father knew and trusted this nurse more than the doctors at the hospital. She lived in our neighbourhood. I think that she was newly qualified, but her human qualities was.... She created safety in the room. And I don't know whether you can learn that at school....We saw the person in her....That was the important thing.

Other stories also showed that some homecare nurses cultivated profound trust and thereby nurtured hope. They managed to instil in the patient feelings of still being on the track. One sister told that her brother's last wish was to take a trip to his cabin in the mountains and the nurse took him seriously and helped him to plan the excursion. The sister stated:

The nurse offered him transportation with an ambulance and discussed other practical arrangements with him. After some thinking, he knew that he wouldn't be able to do it....But just being offered to....it meant a lot.

3.2.2 | Well-being related to home

Four of the cancer patients died in their homes. Though, the other six spent most of their time at home, four died in a nursing home and two died at the hospital. In all cases, the last phase of life was relatively short and the family members believed that that was the reason why they had been able to cope. Being and dying at home were these ill persons' greatest, sometime final wishes. Other than representing a rallying point for known, loved people, home also represented familiar, normal activity. From a couch in his living room, one male patient planned and orchestrated the redecoration of his family's kitchen, while another man had his best armchair placed in front of a window from which he could follow the activity in his workshop. Words like "usual" and "normal" constantly emerged as the family members spoke of their time at home. Amid everything that seemed abnormal—a situation that accompanied the disease—it seemed important to keep the home as normal as possible. In fact, family members tried to avoid or delay having remedies placed around the house. A one daughter related:

Avoiding the sick bed was a great relief. In a way, it would have been too much. She (the mother) simply wanted peace and quiet, and she alternated between the bed in her bedroom and the couch in the living room.

The same daughter also got the impression, that when at home, her mother felt more in control and less inconvenient.

3.2.3 | Well-being related to activity

Continuing their ordinary lives seemed to be of utmost importance to the cancer patients, and family members reported that their relatives carried on with their regular activities and responsibilities until the very end. Inasmuch as their energy allowed, they kept on working, redecorating, travelling, doing housework, and seeing friends and neighbours. A strong will to continue fighting was observed in several cases—for example, one sister-in-law said:

He refused to give up.... He was in the heat of battle. Actually, he was always on his way. He seemed to find comfort in that.

Other than keeping busy with practical activities, living as usual also meant being as usual. For instance, one wife stated that her husband simply wanted them to talk and laugh as they used to.

Well-being was also seen when the ill person had the feeling of being in an active care-plan. Even if improvement by cytostatic drugs or surgery was only illusory or the cause of even greater torment, patients seemed content with it. As one daughter explained:

Perhaps she (the mother) would have been better off without treatment....She became very ill. However, it gave her hope. It would have been awful had the doctor simply shut the door and told her that nothing more could be done. I am so grateful that they gave her a try. I don't care if they fooled us.

4 | DISCUSSION

When asked about their perceptions of suffering in older adults who had received palliative home nursing care, bereaved family members described expressions of both suffering and well-being.

The expressions of suffering found in our study correspond well to the framework of human suffering provided by Eriksson (1994, 1997). Therein, suffering is conceived as a basic part of human existence and can be divided into three dimensions: suffering related to illness, suffering related to care and suffering related to life.

In our study, *suffering related to illness* was represented in expressions of the deteriorated body. This is in line with Eriksson's (1994) conceptualisation, which holds that illness-related suffering is experienced as physical pain originated from a disease or its treatment as well as the spiritual pain from feeling belittled or ashamed due to having a disabled body. In a palliative stage of cancer, illness-related suffering is at its most tangible and perceptible and receives exceptional emphasis by patients' family members and patients (Martinez et al., 2014; Oechsle, Goerth, Bokemeyer, & Mehnert, 2013; Ryan et al., 2013). Though among cancer patients physical pain and quality of life have been found to be associated, a review of literature in the field revealed that no study had explored the relationship (Martinez et al., 2014). Perceptions of physical symptoms in general vary between ill persons, their family caregivers and physicians. Patients' symptoms tend to be underestimated by physicians and overestimated by family caregivers (Oechsle et al., 2013). As such, a close dialogue among patients, family members and health professionals is required to assure the adequate treatment of symptoms.

Another dimension of the illness-related suffering concerned living with an unrecognisable body. As patients' bodies gradually changed and normal functions deteriorated, their family members observed feelings of both dishonour and resignation.

Suffering related to care may be the case if physical symptoms are underestimated or inadequate alleviated. Some of our interviewees described awful moments when their relatives were not relieved of pain. The family members witnessed a huge desperation within their

relatives when this happened. As described by Eriksson (1994), suffering related to care encompasses different forms of neglect, condemnation and punishment during care. For example, the result of being neglected or denied help (e.g. sufficient medication) was perceived to perpetrate a dual pain; being in extreme distress and facing unresponsive doctors or nurses increased anxiety and feelings of disappointment, as well as escalated their physical pain. This finding corresponds with other research stating that patients report being neglected and mistreated by health professionals in different care settings (hospital and community care) (Arman, Rehnsfeldt, Lindholm, Hamrin, & Eriksson, 2004; Berglund, Westin, Svanström, & Sundler, 2012; Devik, Enmarker, Wiik, et al., 2013; Svanström, Sundler, Berglund, & Westin, 2013).

Some interviewees even explained that how some nurses had communicated with their ill relatives was humiliating and disgraceful, as well as rude, unethical and saddening. Beng et al. (2014) reported similar findings of interactional suffering in palliative patients who had experienced unkind communication with healthcare staff. To be sure, poor communication and condescending behaviour from health professionals threaten a patient's human value (Eriksson, 1994) and make him or her more vulnerable in situations when relief is expected (Öhlen, 2004). Hearing that 'nothing else can be done' was another example of poor communication (Beng et al., 2014) also discovered in our study and understood as having a dual meaning; one, that the patient's stage is the final stage and two, that from here, you must travel alone. In some cases, suffering related to care induced feelings of abandonment and social isolation.

Suffering related to the circumstances of *life* is the third way of suffering that Eriksson (1994) describes. This kind of suffering relates to the existential dimension of being human, as well as of living and dying. The nature of suffering is individual, unique and inherent to each person (Krikorian, Limonero, & Mate, 2012) and arguably, such intrinsic suffering can never be fully understood by anyone than the ill patient. Colliander (1987, p. 81) writes, 'Suffering as such lacks any characteristics. The sufferer shows the face of the suffering'. In our study, the family members' impressions of life-related suffering constituted emphatic, emotional reflections. Because their ill relatives tended to silence their thoughts about death and dying and often adopted the role of comforter, the information provided by interviewees emerged from years of reflection, and expressions such as sadness, crying and anxiety were commonly observed. In that sense, suffering was understood to relate to different levels of separation: separation from the future, separation from other people, and separation from normal activity and the flow of life. Illness thus represented an abruptness of life as they knew it—an abruptness of normality.

We interpreted all three kinds of suffering found in our analysis to have resulted in feelings of alienation: alienation from the body, from other people, and from time, propulsion, and progression. Eriksson (2007) claims that suffering is ontological and an inescapable part of life at the same level as interacting with other people and developing as persons. She has furthermore conceived suffering as the human being's struggle between good and evil. In that sense, suffering and well-being are strongly interrelated: one does not come without the

other. Nevertheless, well-being arose independently in our material, not by being equated to the absence of suffering (Fava & Ruini, 2003; Urry et al., 2004).

We found elements of well-being to offer contrasting experiences in our interviews. The gift of contrast is that it allows us to distinguish meaning, and in this case, contrasts of well-being seemed to balance interviewees' meaning making as they narrated. Well-being was interpreted to counteract the alienation inherent to suffering, by representing feelings of connectedness and existing in a "known state"—that is, connected to other people, to a familiar place and to life, time and activity. Based on Heidegger's (1962) notion of homecoming, Todres and Galvin (2010) have developed a theory of well-being that seems to fit well with our findings. Named *dwelling-mobility*, their theory attempts to capture the range of well-being experienced within a coherent existential whole. In their sense, dwelling means a sense of being at home or of rootedness and peaceful harmony. It is described as all of the ways that one existentially comes home to what one has been given in time, space, others, mood and body (Galvin & Todres, 2011; Todres & Galvin, 2010). In our sample, all family members highlighted their ill relatives' urgent wish to stay at home and to be surrounded by familiar people. Similar findings emphasise the importance of having a sense of belonging (Appelin, Brobäck, & Berterö, 2005; Melin-Johansson et al., 2007) and feelings of physical, social and autobiographical insideness related to being at home in a rural context (Devik et al., 2015).

Besides feelings of belonging and connectedness, being at home connoted safety. When seriously ill, one might expect that care from highly qualified health professionals, with all of the technical equipment possibly available at hospitals, would be preferential; however, such was not the case. A person's feelings of safety depended on being surrounded by people who knew and understood his or her signs and who genuinely cared about him or her. In addition to family members, some nurses can also fulfil that role. What seemed critical was these nurses' ability and courage to employ personal and compassionate care. Emerging as a person the nurse became familiar and trustworthy. Specialised oncological training seemed of less importance. Caring in the home differs from care in hospital, and Lindahl, Lidèn, and Lindblad (2011) have highlighted the professional friendship as a response to the needs of patients and their family caregivers at home. This professional friendship may integrate the nurse into the informal social network. The close connections between rural palliative care recipients and their nurses, and the phenomenon of knowing and being known is also described in a study by Pesut, Bottorf, and Robinson (2011). Though, having that mutual knowledge was highly valuable to both nurses and family members, it also raised ethical tensions. The dual personal-professional relationship represented challenges to relational boundaries, confidentiality and anonymity (Pesut et al., 2011). Balancing personal aspects and emotions when encountering seriously ill patients in homecare may cause confusion and distress among nurses (Devik, Enmarker, & Hellzen, 2013). Yet, managing those circumstances appears to be vital to patients' well-being, as shown in our results and those of others (Kirby, Broom, & Good, 2014; Mok & Hiu, 2004).

Other than the well-being that arose when being connected to other people, well-being also related to the physical and environmental home itself. As a well-known place, full of memories and possibilities for adventure (Galvin & Todres, 2011), either literally or visionary, the home was conceived to be a secure base (Milberg, Wählberg, Jakobssen, Olsson, & Friedrichsen, 2012). Todres and Galvin (2010) have proposed the concept of *movement* as a creative restlessness in which a person is called into acknowledging personal possibilities for his or her future. They explain their concept as a kind of energy that can give a feeling of flow, being live and vibrant movement. Even if the future appeared uncertain, most ill persons in our study continued living actively and were engaged in planning their futures. Any stagnation or interruption of normal living was something that they tried to avoid or delay. Family members also stressed the significance of maintaining hope by being offered different kinds of treatment options. Still, when cure in itself might be unattainable, signs of availability from health professionals signalled some kind of hope. In line with Robinson's (2012) findings, honouring hope was not found to necessarily conflict with principles of truthful communication.

Our findings support Eriksson's (1994, 1997) theoretical framework of suffering, as well as indicate a need to review or extend perspectives of what care is or should be motivated by. Even if pain or other physical symptoms are eased, if interactions with nurses or other health professionals have been therapeutic and respectful, and if death and dying have been accepted, then something could nevertheless be missing. Family members in our study described longing and desires beyond the need of relief from suffering. They described important aspects that contributed to their loved one's well-being despite the presence of suffering: feelings of being connected to other people, to their home and to their activity. If suffering is the motive of care, then well-being should be as well, for life is lived and experienced by its contrasts. As Herman Melville once wrote (1851; in "Moby-Dick" p. 53), 'There is no quality in this world that is not what it is merely by contrast. Nothing exists in itself'. As with suffering, well-being is a subjective experience (Rodgers & Cowles, 1997) that needs to be explored and shared.

Eriksson conceives care as a healing act when the relationship between the nurse and patient is developed according to the concepts of communion and sharing (Arman, Ranheim, Rydenlund, Rytterström, & Rehsfeldt, 2015). Based on mutual knowledge and trust, communion in our study was reported to have been experienced in close connection with nurses who were able to share and comply with both suffering and well-being.

4.1 | Methodological considerations

There are several limitations in our study. First, participant recruitment resulted in few interviewees, all of who were women, which might influence the transferability of our results. Defining an adequate sample size seems to be an invariably challenge in qualitative research. Referring to Malterud, Siersma, and Guassora (2015), we consider the "information power" in our study to be reasonably strong according to the aim of the study, the specificity of our sample, the use of

established theory, the quality of the dialogue and the strategy for our analysis.

Second, our findings must be interpreted as a function of the ill relatives' expressions of suffering and well-being and the proxies' interpretation of those expressions. Still, the congruence between family members' and ill persons' opinions of quality of care and life is evaluated to be high (Klinkenber et al., 2003; Larsson, Larsson, & Carlson, 2004). Prerequisites were frequent meetings and shared everyday and care-related experiences (Larsson et al., 2004). Third, time elapsed from death may have allowed some recall bias. One might suspect that with the passage of more and more time, the greater the difficulty of remembering. However, Baktitas et al. (2008) have suggested that proxy perspectives are feasible and can provide important messages for improving palliative oncological care. Tang (2006) also found that family members agreed well with terminally ill cancer patients' reports regarding quality of life. Concordance was greater in terms of functional dependency and symptom distress than in terms of psychological-social-spiritual concerns, though, and in cases of disagreement family members tended to be more negative than the ill persons (Tang, 2006). Being aware that different explanations of the discrepancy are possible—for instance, the mixed emotions in the situation of being a family caregiver—in our study we aimed to supply the field with another perspective. Plus, the intention was to test a theoretical framework on suffering. In that light, directed content analysis may challenge traditional qualitative approaches and be understood as biased simply by being driven by theory (Hsieh & Shannon, 2005). Overemphasising theory has been thought to blind researchers to contextual aspects of phenomena. Moreover, in their generality, grand theories such as Eriksson's could be difficult to test empirically. In our opinion, that aspect further stresses the importance of performing directed approaches, since findings may be clinically useful and contribute to validating or invalidating the theory.

4.2 | Conclusions and implications for nursing

The bereaved family members in this study perceived suffering related to the illness, to care and to life within their ill relatives during their last phase of life. Nursing in this context has still a way to go in raising quality of care, not at least in avoiding the unnecessary suffering. Well-being arose as significant and contrasting elements as the family members talked. Well-being related to other people, to home and to activity of which the essence referred to a state of dwelling-mobility was reported. Our findings argue that nurses in this context must seek patients' and family members' personal experiences of comfort as well as disturbance. Nursing and palliative care that become purely disease and symptom-focused may end up with giving up and divert the attention to social and cultural factors that may contribute to well-being when cure is not the goal.

ACKNOWLEDGMENTS

We extend our thanks to the persons who shared their stories with us.

CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

REFERENCES

- Appelin, G., Brobäck, G., & Berterö, C. (2005). A comprehensive picture of palliative care at home from the people involved. *European Journal of Oncology Nursing*, 9, 315–324.
- Aranda, S. K., & Hayman-White, K. (2001). Home caregivers of the person with advanced cancer: An Australian perspective. *Cancer Nursing*, 24, 300–307.
- Arman, M., Ranheim, A., Rydenlund, K., Rytterström, P., & Rehnsfeldt, A. (2015). The Nordic tradition of caring science: The works of three theorists. *Nursing Science Quarterly*, 28, 288–296.
- Arman, M., Rehnsfeldt, A., Lindholm, L., Hamrin, E., & Eriksson, K. (2004). Suffering related to health care: A study of breast cancer patients' experiences. *International Journal of Nursing Practice*, 10, 248–256.
- Baktitas, M., Ahles, T. A., Brokaw, F. C., Byok, I., Hanscom, B., Lyons, K. D., & Hegel, M. T. (2008). Proxy perspectives about end-of-life care for persons' with cancer. *Cancer*, 112, 1854–1861.
- Beng, T. S., Guan, N. C., Seang, L. K., Pathmawathi, S., Ming, M. F., Jane, L. E., ... Loong, L. C. (2014). The experience of suffering of palliative care patients in Malaysia: A thematic analysis. *American Journal of Hospice and Palliative Medicine*, 31, 45–56.
- Bergdahl, E., & Berterö, C. (2015). The myth of induction in qualitative nursing research. *Nursing Philosophy*, 16, 110–120.
- Berglund, M., Westin, L., Svanström, R., & Sundler, A. J. (2012). Suffering caused by care- patients' experiences from hospital settings. *International Journal of Qualitative Studies on Health and Well-Being*, 7, 1–9.
- Colliander, T. (1987). *Motiv. (Motive. In Swedish)*. Stockholm: Atlantis.
- Daneault, S., Lussier, V., Mongeau, S., Paille, P., Hudon, E., Dion, D., & Yelle, L. (2004). The nature of suffering and its relief in the terminally ill: A qualitative study. *Journal of Palliative Care*, 20, 7–11.
- Devik, S. A., Enmarker, I., & Hellzen, O. (2013). When expressions make impressions—Nurses' narratives about meeting severely ill patients in home care: A phenomenological-hermeneutic approach to understanding. *International Journal of Qualitative Studies on Health and Well-Being*, 8, 21880.
- Devik, S. A., Enmarker, I., Wiik, G. B., & Hellzen, O. (2013). Meanings of being old, living on one's own and suffering from incurable cancer in rural Norway. *European Journal of Oncology Nursing*, 17, 781–787.
- Devik, S. A., Hellzen, O., & Enmarker, I. (2015). Picking up the pieces. Meanings of receiving home nursing care when being old and living with incurable cancer in a rural area. *International Journal of Qualitative Studies on Health and Well-Being*, 10, 28382.
- Duggleby, W. D., Penz, K. L., Goodridge, D. M., Wilson, D. M., Leipert, B. D., Berry, P. H., ... Justice, C. J. (2010). The transition experience of rural older persons with advanced cancer and their families: A grounded theory study. *BMC Palliative Care*, 9, 5. <http://www.biomedcentral.com/1472-684X/9/5>. (Accessed September 20, 2015).
- Ellis, J., Cobb, M., O'Connor, T., Dunn, L., Irving, G., & Lloyd-Williams, M. (2015). The meaning of suffering in patients with advanced progressive cancer. *Chronic Illness*, 11, 198–209.
- Elo, S., & Kyngäs, H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing*, 62, 107–115.
- Eriksson, K. (1994). *Den lidande människan (In Swedish, The suffering human being)*. Stockholm: Liber Utbildning.
- Eriksson, K. (1997). Understanding the world of the patient, the suffering human being: The new clinical paradigm from nursing to care. *Advanced Practice Nursing Quarterly*, 3, 8–13.
- Eriksson, K. (2002). Caring science in a new key. *Nursing Science Quarterly*, 15, 61–65.

- Eriksson, K. (2007). Becoming through suffering—The path to health and holiness. *International Journal for Human Caring*, 11, 8–16.
- Fava, G. A., & Ruini, C. (2003). Development and characteristics of well-being enhancing psychotherapy strategy: Well-being therapy. *Journal of Behavior Therapy and Experimental Psychiatry*, 34, 45–63.
- Ferrell, B. R., & Coyle, N. (2008). The nature of suffering and the goals of nursing. *Oncology Nursing Forum*, 35, 241–247.
- Galvin, K. T., & Todres, L. (2011). Kinds of well-being: A conceptual framework that provides direction for caring. *International Journal of Qualitative Studies on Health and Well-Being*, 6, 10362.
- Heidegger, M. (1962). *Being and time*. (J. Macquarrie & E. Robinson Trans.). Oxford: Basil Blackwell.
- Hsieh, H. F., & Shannon, E. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, 15, 1277–1288.
- Hudson, P., & Payne, S. (Eds.) (2008). *Family carers in palliative care*. Oxford: Oxford University Press.
- Kirby, E., Broom, A., & Good, P. (2014). The role and significance of nurses in managing transitions to palliative care: A qualitative study. *BMJ Open*, 4, e006026.
- Klinkenber, M., Smith, J. H., Deeg, D. J., Willems, D. M., Onwuteaka-Philipsen, B. D., & van der Wal, G. (2003). Proxy reporting in after death-interviews: The use of proxy respondents in retrospective assessment of chronic diseases and symptom burden in terminal phase of life. *Palliative Medicine*, 17, 191–201.
- Koffman, J., Higginson, I. J., Hall, S., Riley, J., McCrone, P., & Gomes, B. (2012). Bereaved relative's views about participating in cancer research. *Palliative Medicine*, 26, 379–383.
- Krikorian, A., Limonero, J., & Mate, J. (2012). Suffering and distress at the end-of-life. *Psycho-Oncology*, 21, 799–808.
- Kvaale, S. (2007). *Doing interviews*. London: Sage.
- Larsson, B. W., Larsson, G., & Carlson, S. R. (2004). Advanced home care: Patients' opinions on quality compared with those of family members. *Journal of Clinical Nursing*, 13, 226–233.
- Lee, S., & Kristjanson, L. (2003). Human research ethics committees: Issues in palliative care research. *International Journal of Palliative Nursing*, 9, 13–18.
- Lindahl, B., Lidén, E., & Lindblad, B. M. (2011). A meta-synthesis describing the relationship between patients, informal caregivers and health professionals in home-care settings. *Journal of Clinical Nursing*, 20, 454–463.
- Malterud, K. (2001). Qualitative research: Standards, challenges and guidelines. *The Lancet*, 358, 483–488.
- Malterud, K., Siersma, V. D., & Guassora, A. D. (2015). Sample size in qualitative interview studies: Guided by information power. *Qualitative Health Research*, 26, 1753–1760.
- Marshall, C., & Rossman, G. B. (1995). *Designing qualitative research*. London: Sage.
- Martinez, K., Aslakson, R., Wilson, R., Apostol, C. C., Fawole, O., Lau, B. D., ... Dy, S. M. (2014). A systematic review of health care interventions for pain in patients with advanced cancer. *American Journal of Hospice and Palliative Medicine*, 31, 79–86.
- McPherson, C. J. & Addington-Hall, J. M. (2003). Judging the quality of care at the end of life: can proxies provide reliable information? *Social Science & Medicine*, 56, 95–109.
- McPherson, C. J., & Addington-Hall, J. M. (2004). Evaluating palliative care: Bereaved family members' evaluation of patients' pain, anxiety and depression. *Journal of Pain and Symptom Management*, 28, 104–114.
- Melin-Johansson, C., Axelsson, B., & Danielson, E. (2007). Caregivers' perceptions about terminally ill family members' quality of life. *European Journal of Cancer*, 16, 338–345.
- Melville, H. (1851). *Moby Dick; The Whale*. London: Richard Bentley.
- Millberg, A., Wählberg, R., Jakobssen, M., Olsson, E. C., & Friedrichsen, M. (2012). What is a "secure base" when death is approaching? A study applying attachment theory to adult patients' and family members experiences of palliative home care. *Psycho-Oncology*, 21, 886–895.
- Mok, E., & Hiu, P. C. (2004). Nurse–Patient relationships in palliative care. *Journal of Advanced Nursing*, 48, 475–483.
- Oechsle, K., Goerth, K., Bokemeyer, C., & Mehnert, A. (2013). Symptom burden in palliative care patients: Perspectives of patients, their family caregivers and their attending physicians. *Supportive Care in Cancer*, 21, 1955–1962.
- Öhlen, J. (2004). Violation of dignity in care-related situations. *Research and Theory for Nursing Practice*, 18, 371–385.
- Patton, M. Q. (2002). *Qualitative research & evaluation methods* (3rd edn). London: Sage.
- Pesut, B., Bottorff, J. L., & Robinson, C. A. (2011). Be known, be available, be mutual: A qualitative ethical analysis of social values in rural palliative care. *BMC Medical Ethics*, 12, 19. <http://www.biomedcentral.com/content/pdf/1472-6939-12-19.pdf>. (Accessed August 3, 2015).
- Robinson, C. A. (2012). "Our best hope is a cure": Hope in the context of advanced care planning. *Palliative and Supportive Care*, 10, 75–82.
- Robinson, C. A., Pesut, B., Bottorff, J. L., Mowry, A., Broughton, S. A., & Fyles, G. (2009). Rural palliative care: A comprehensive review. *Journal of Palliative Medicine*, 12, 253–258.
- Rodgers, B. L., & Cowles, K. V. (1997). A conceptual foundation for human suffering in nursing and research. *Journal of Advanced Nursing*, 25, 1048–1053.
- Ryan, T., Ingleton, C., Gardiner, C., Parker, C., Gott, M., & Noble, B. (2013). Symptomburden, palliative care need and predictors of physical and psychological discomfort in two UK hospitals. *BMC Palliative Care*, 12, 11. <http://www.biomedcentral.com/1472-684X/12/11>. (Accessed August 16, 2015).
- Stajduhar, K. I., Funk, L., Cohen, S. R., Williams, A., Bidgood, D., Allan, D., ... Heyland, D. (2011). Bereaved family members' assessments of the quality of end-of-life care: What is important? *Journal of Palliative Care*, 27, 261–269.
- Stroebe, M., Stroebe, W., & Schut, H. (2003). Bereavement research; methodological issues and ethical concerns. *Palliative Medicine*, 17, 235–240.
- Svanström, R., Sundler, A. J., Berglund, M., & Westin, L. (2013). Suffering related to care—Elderly patients' experiences in community care. *International Journal of Qualitative Studies on Health and Well-Being*, 8, 20603.
- Tang, S. T. (2006). Concordance of quality of life assessments between terminally ill cancer patients and their primary family caregivers in Taiwan. *Cancer Nursing*, 29, 49–57.
- Todres, L., & Galvin, K. (2010). "Dwelling-mobility". An existential theory of well-being. *International Journal of Qualitative Studies on Health and Well-Being*, 5, 5444.
- Urry, H. L., Nitschke, J. B., Jackson, D. C., Dalton, K. M., Mueller, C. J., Rosenkranz, M. A., ... Davidson, R. J. (2004). Making a life worth living. Neural correlates of well-being. *Psychological Science*, 15, 367–372.
- Wiik, G. B., Devik, S. A. I., & Hellzen, O. (2011). Don't become a burden and don't complain: A case study of older persons suffering from incurable cancer and living alone in rural areas. *Nursing Reports*, 1, e3. <http://www.pagepressjournals.org/index.php/nursing/article/view/nursrep.2011.e3>. (Accessed August 4, 2015).
- Williams, A. L., & McCorkle, R. (2011). Cancer family caregivers during the palliative, hospice, and bereavement phases: A review of the descriptive psychosocial literature. *Palliative and Supportive Care*, 9, 315–325.
- Wilson, K. G., Chochinov, H. M., McPherson, C. J., LeMay, K., Allard, P., Chary, S., ... Fainsinger, R. L. (2007). Suffering with advanced cancer. *Journal of Clinical Oncology*, 25, 1691–1697.

How to cite this article: Devik SA, Hellzen O, Enmarker I. Bereaved family members' perspectives on suffering among older rural cancer patients in palliative home nursing care: A qualitative study. *Eur J Cancer Care*. 2017;26:e12609. <https://doi.org/10.1111/ecc.12609>