

# Being a nurse in nursing home for patients on the edge of life

Reidun Hov PhD, RNT, RN (Assistant Professor)<sup>1</sup>, Elsy Athlin PhD, RNT, RN (Professor)<sup>2</sup> and Birgitta Hedelin PhD, RNT, RN (Senior Lecturer and Professor)<sup>2,3</sup>

<sup>1</sup>Hedmark University College, Faculty of Health Studies, Elverum, Norway, <sup>2</sup>Karlstad University, Department of Nursing Sciences, Karlstad, Sweden and <sup>3</sup>Gjøvik University College, Department of Nursing, Gjøvik, Norway

*Scand J Caring Sci; 2009; 23; 651–659*

## Being a nurse in nursing home for patients on the edge of life

Nurses in nursing homes care for patients with complex health problems that need to be followed up by medical treatment. Most patients benefit from the treatment, but for some the treatment seems only to lengthen their death process. Sometimes questions are raised as to whether life-sustaining treatment should be withheld/withdrawn. Decisions related to such questions are difficult to make as some patients are 'on the edge of life', which is understood as a transition between living and dying with an unpredictable outcome, whether the illness will lead to recovery or dying. The aim of this study was to acquire a deeper understanding of what it is to be a nurse in a nursing home for patients on the edge of life. The research design was qualitative, based on hermeneutic phenomenology. Fourteen nurses at two nursing homes were interviewed twice. The result shows that when facing a patient on the edge of life, the nurses were challenged as professionals and as human beings.

Two main themes were identified, which included two sub-themes each. The first main theme: 'striving to do right and good for everyone' included the sub-themes 'feeling certain, but accompanied by uncertainty' and 'being caught between too much responsibility and too little formal power'. The second main theme: 'being a vulnerable helper – the prize and the price', contained the sub-themes 'needing emotional protection in professional commitment' and 'feeling undervalued in spite of professional pride'. The essence was: 'being a lonely and enduring struggler between opposite poles'. The findings revealed paradoxes in nurses' work which might threaten nurses' professional identity and put heavy demands on their professional performance. There is a need for formal involvement in end-of-life decisions from nurses, further education and support to nurses related to patients on the edge of life.

**Keywords:** the edge of life, nurses, nursing homes, hermeneutic phenomenology.

*Submitted 2 July 2007, Accepted 8 July 2008*

## Background

Nurses in nursing homes care for patients with a vast complexity of needs (1, 2). In Norwegian nursing homes about 50–70% of the patients are suffering from dementia (3), and each patient have on average four active diagnoses that need to be followed up by physicians' medical treatment (4). Medical and life-sustaining treatments, such as antibiotics, cardiopulmonary resuscitation, nutrition, fluids, and hospitalization, make possibilities to prolong many patients' lives. However, for some the treatment seems inappropriate as it is considered only to prolong the patient's death process (5). Some patients are interpreted to

be in transition between living and dying with an unpredictable outcome, whether the illness will lead to recovery or dying. Cook et al. (1999; 6) have described this period as the time where many patients need 'to declare themselves' by showing clearer prognostic signs whether survival is possible or death is imminent. If during this period the patient shows no progression towards recovery, or if clear signs of dying appear, questions of withholding or withdrawing life-sustaining treatment often are raised. In this article this state is defined as 'the edge of life'.

It might be difficult to predict whether a patient will die and to decide whether the treatment should be withheld/withdrawn (7). Research in nursing homes related to end-of-life decisions shows variations between countries, but also between nursing homes, with regards to frequency and restrictions of different kinds of treatment (8–10). Regarding limitations of life-sustaining treatment, studies show restrictions in the hospitalization of seriously ill and dying patients (11), in the use of cardiopulmonary resuscitation (12, 13) and antibiotics

### Correspondence to:

Reidun Hov, Hedmark University College, Faculty of Health Studies, 2418 Elverum, Norway.  
E-mail: reidun.hov@hihm.no

(14). Moreover, the withholding or withdrawing of artificial fluid and nutrition is widely practised in nursing homes (15, 16).

There is no doubt that physicians are responsible for medical decisions, but the decisions may impact on nursing care as nurses have a responsibility to carry out physicians' orders and are involved in their consequences. No matter what kind of medical treatment the patients receive, nurses' official mandate is to give them good nursing care, which involve promoting life and health or a dignified death (17).

Research has shown that nurses play an important role in providing care and treatment for patients on the edge of life, and that this particular care situation puts heavy demands on nurses (18). However, the research has focused on nurses' experiences in an intensive care unit (19). In nursing homes research about end-of-life care has focused on decision-making and ethics (e.g. 7, 20, 21). No studies were found with focus on nurses' experiences related to nursing care for patients on the edge of life in a nursing home context. However, one older study showed that nurses who cared for terminally ill older people identified when to stop treatment, and the appropriateness of life-sustaining treatment as the most prominent ethical difficulties. These nurses experienced moral distress in which powerlessness and discouragement were found to be the most frequent feelings (22).

## Aim

The aim of this study was to acquire a deeper understanding of what it is to be a nurse in a nursing home for patients on the edge of life.

## Design and method

A qualitative research design was chosen with a phenomenological approach. The goal of phenomenology is to describe lived experiences (23), which corresponded well with the aim of our study. The ideas behind the phenomenological methodology chosen are inspired by 'hermeneutic phenomenology', which acknowledges interpretation of lived experiences (24). We adopted this method as we are of the opinion that researchers cannot put aside or bracket their own personal preunderstandings. However, we agree that an examination and dislodging of

presuppositions are required in order to explore the participants' experiences in as unbiased a way as possible (24).

## Setting

Norwegian nursing homes are facilities within the responsibility of municipalities that provide care for fragile, older people who are unable to stay in their own homes. This study was carried out at two nursing homes in Norway, one (A) in a small town and the other (B) in the countryside. In nursing home A, there were two units with 30 patients in each. Nursing home B had four units with 22–29 patients in each. The units had beds for general care of older patients in needs of long-term care, except one short-time unit which acted as an intermediate and a rehabilitation unit. Both institutions had some beds for patients with dementia and temporary accommodation. One unit had two beds for palliative care. The scheduled time for attendant physicians was regularly once a week. At other times, the patient's general practitioner was contacted during the daytime and the physicians at the emergency department were called during evenings, nights, and weekends. Table 1 shows the amount of patients, nurses, enrolled nurses, assistants, and attendant physicians in the two nursing homes.

## Participants

After approval from the chief administrative officer in each municipality the head nurses or the first author (Reidun Hov) informed the nurses verbally and in writing about the study.

The participants were purposefully included according to the following criteria: Registered Nurses, differences in sex, shifts, overall experience as nurses and in nursing homes, and postgraduate education (cf. 24). Fourteen nurses who met these criteria and reported their interest in participating were included in the study. This gave six nurses from nursing home A, and eight from B. Only one man participated. Eleven nurses worked day and evening shifts, one had only day shifts, and two had evening shifts. Six participants were Registered Nurses, and eight were clinical nurse specialists. Of these, two specialized in geriatric nursing, one in palliative care, and five had completed postgraduate education in other areas. Two of the nurses

**Table 1** Patients, nurses, enrolled nurses, assistants, and attendant physicians in the nursing homes

<i>Nursing ahome</i>	<i>Units</i>	<i>Patients</i>	<i>Registered Nurses</i>	<i>Enrolled nurses and assistants</i>	<i>Physicians' hours/week</i>
A	2	60	20 persons (plus three vacancies; 16,9 positions)	58 persons (plus two vacancies; 27,9 positions)	14 – shared between two physicians
B	4	99	39 persons (24,3 positions)	111 persons (54,2 positions)	30 – shared between five physicians

had more than one speciality. The median years of work as Registered Nurses were 14 (1–33); and the median years of work in the nursing homes were 9 (1–25).

### Data collection

The participants were individually interviewed twice by Reidun Hov, about 1 hour each time. The interviews were conducted during 2005, and took place at the nursing homes during the participants' working hours. The participants were invited to describe cases where questions to withdraw or withhold life-sustaining treatment were raised, and when decisions concerning the treatment, according to them turned out in a positive direction for the patient, when decisions did not, and how they had wanted them to be. They were free to talk about as many cases as they wished. After describing a case, each participant was given the opportunity to choose which aspects related to their experiences should be further deepened. All interviews were tape-recorded and transcribed verbatim by Reidun Hov. The first interviews were transcribed immediately afterwards, and read with the question of research in mind to find out if anything should be further illuminated. If so, follow-up questions were raised in the second interviews. The participants were also free to reflect upon what they wanted to elaborate on from the previous interview.

### Data analysis

The hermeneutic phenomenological analysis was inspired by Van Manen (1997; 24). Several steps were involved in order to determine sub-themes, main themes, and the essence from the participants' descriptions. Examples from the analysis are shown in Fig. 1.

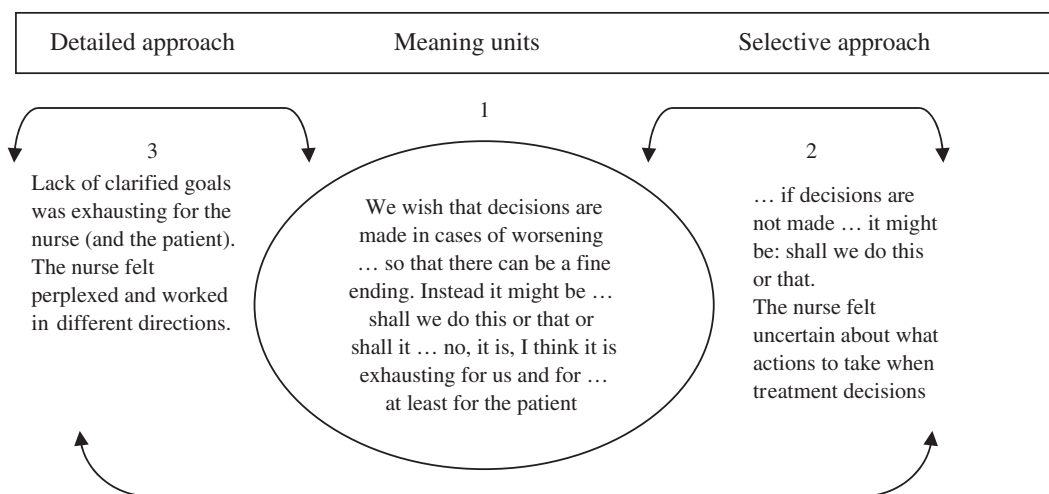
All interview tapes were repeatedly listened to, transcribed, read, and re-read. A holistic approach was

used for all transcripts to find an overall and fundamental meaning of the phenomenon. Furthermore, each interview was read in its entirety to obtain an understanding of what the text conveyed. Then phrases and sentence clusters that seemed to be thematic for each interview were marked as meaning units. In the selective approach we asked: What does this meaning unit reveal (thematically) about the phenomenon? In the detailed approach, preliminary themes constructed in the selected approach were controlled, nuanced, and deepened by asking: What does this really reveal about the nature of the phenomenon?

Meaning units and preliminary themes were read and re-read, combined and reduced, written and re-written, until a basic structure was found. This basic structure was grouped into main themes and sub-themes. After the processes of intuitive and reflective writing the essence emerged (cf. 18).

### Trustworthiness

In order to enhance trustworthiness, criteria such as credibility, auditability, and fittingness were used (25). Credibility was improved by various means. Researcher credibility (26, 27) was enhanced through the researchers' continual reflections and discussions about the topic, in order to identify and bridle their presuppositions (cf. 28). After each interview the interviewer summarized the impressions of what the participant had related and what the interview had accomplished in relation to the aim of the study. To verify and clarify what the interview was about, the interviewer or the participant made summaries throughout and at the end of each interview as well as at the beginning of the second interview (cf. 25). Credibility was also enhanced by supporting the findings with quotations from the interviews, and by the participants' recognition of the preliminary findings (cf. 29).



**Figure 1** Example from the data analysis showing how a selective and detailed approach of meaning unit was structured and related in the analysis process (not linear).

To enhance auditability, Van Manen's (1997; 24) modified descriptions of analysis were described and exemplified. Fittingness was enhanced by various strategies. In order to strengthen a comprehensive description of the phenomenon, the sampling aimed at including participants with different experiences from the phenomenon under study (27). Furthermore, two of the transcripts were analysed separately, compared, and discussed by the three authors. Throughout the analysis the authors also discussed data related to the holistic approach, meaning units, selective approach, detailed approach, and essence. Preliminary findings were recognized by nurses in home care, palliative care, and in other nursing homes when these findings were presented to them verbally in order to further strengthen the fittingness (cf. 25).

### *Ethical considerations*

The study was reported to the Norwegian Social Science Data Services and conducted in accordance with their regulations and those of the International Council of Nurses' codex of nursing research (30). This meant that participants' voluntariness, integrity, and confidentiality were taken into consideration. All nurses were labelled 'she' to avoid identification of the only male.

## **Results**

The analysis revealed an essence, two main themes and four sub-themes, which captured the experiences of being a nurse in a nursing home for patients on the edge of life (Table 2).

### *Striving to do right and good*

The nurses cared very much for the patients and were concerned about doing what was right and good for them. Often the question emerged: What is right and good, and for whom? The analysis revealed conflicting views. Sub-themes in this main theme were 'feeling certain, but accompanied by uncertainty' and 'being caught between too much responsibility and too little formal power'.

**Table 2** Essence, main themes, and sub-themes of the phenomenon

Essence	Being a lonely and enduring struggler between opposite poles
Main theme	Striving to do right and good
Sub-theme	Feeling certain, but accompanied by uncertainty
Sub-theme	Being caught between too much responsibility and too little formal power
Main theme	Being a vulnerable helper – the prize and the price
Sub-theme	Needing emotional protection in professional commitment
Sub-theme	Feeling undervalued in spite of professional pride

*Feeling certain, but accompanied by uncertainty.* The nurses considered themselves to be those who knew the patients' situations best. Through their formal education, experience as nurses and continuous, close and often long-lasting contact with many of the patients they thought that they had gained important professional competence to assess patients' conditions and to register changes. Mostly the nurses felt that they understood the patients' wishes:

In a way I had a strong feeling that this lady didn't want to live any more; and I thought that even if she is very demented, she expresses that now, now, she had lived as long as she wanted. Because every time she went to get some food, this was so obvious. She only waved us away; she tightened her lips.

Certainty was enhanced when the nurses agreed with and understood the justification of a decision, and could clear their thoughts in dialogue with colleagues. As this seldom occurred, certainty was almost constantly accompanied by a feeling of uncertainty. Thinking of patients, who had unexpectedly continued to live even when curative treatment was withheld or withdrawn, caused uncertainty. Furthermore, a lack of clear criteria for when curative treatment was inappropriate, as well as economic restrictions about consultation with physicians, would maintain uncertainty.

Uncertainty was heightened when a nurse questioned decisions that seemed to be accepted by her colleagues. In such cases the nurse could doubt her professional skills, feel out of step, and withdraw from the ward fellowship. She could also look for support wherever she expected to find it. Disagreements among colleagues were experienced as great emotional strain:

To work with dying patients, to come to an agreement about things and move along together is not always simple. I get distressed, and I experience it as more exhausting than to have to do something that in a way falls outside ... what I perhaps would have done if I had decided.

Delayed decisions and the lack of clear goals added to the nurses' uncertainty. At the same time, they felt constant pressure from enrolled nurses and assistants to give clear directives about the daily care of the patients. Such circumstances drained the nurses' energy as they might have to work in conflicting directions; give terminal care and life-sustaining treatment/care simultaneously to the same patient. The nurses often felt that whatever they did would be a mistake:

It was such a lengthy process and it was terribly painful for the patient and his relatives, because we didn't manage to make a clear decision about what we should do, and we were limping around ... Sometimes he got his medicine, sometimes we did this, sometimes that, and it was exhausting.

*Being caught between too much responsibility and too little formal power.* The nurses were well aware of their responsibility and were mostly happy to accept it. The responsibility was however experienced as being a heavy burden when questions concerning curative treatment or not were in focus. Often the nurse felt alone because physicians seemed not to prioritize patients in nursing homes. Then she felt forced to take the responsibility of the physician:

You are left behind with a responsibility that is not yours. Something that you should not be forced to do, I almost said ... It is you who have to take action [and say to yourself] what do I do? Because you might be quite alone ...

The nurses wanted to have a formal influence on end-of-life decisions. They felt that this hardly occurred in daily reports, team-meetings and accidental discussions, or in the physician's weekly visit. This could make the nurses feel forced to justify and stand up for decisions they had no part in or did not understand. When the nurses tried to communicate their views, it depended on the individual physician whether their viewpoints were taken into consideration. Sometimes the nurses felt powerless when the important knowledge they thought they had about a patient was neglected. At other times they felt uncomfortable when a physician made decisions in line with their opinions without assessing or discussing the patient:

If I told that physician, 'I don't think he needs parenteral hydration. Shouldn't we rather give palliative treatment?' Then the physician might say, 'Ok.' You can say that we are mini-doctors who only need a boss to authorise it on paper, and that is challenging.

When nurses disagreed on decisions, they did not always argue their opinions or raise discussions with those who were responsible. Instead they gave the patients intensified care as compensation for the 'wrong' decision. Other times a nurse could feel as if she was the only one who took responsibility for the patients' best interests, and she felt that she fought against colleagues, physicians, and even against relatives. Patients who in some way differed from the others – younger, dying, extremely suffering, or lonely – made greater claims on the nurse's responsibility:

Those who had assessed him beforehand had decided that he should not get any more treatment. But it is absolutely terrible that this happens. I could not let this man die, and he would have died if I hadn't done anything. He had no one else [than the nurse] to fight for him.

Too many unsatisfying experiences in connection with physicians' end-of-life decisions, made the nurses sometimes make treatment decisions on their own. In order to do what they thought was best for the patients the nurses were willing to defy formal systems and physicians' orders:

We simply gave her less [tube feeding] than the physician had ordered because she was so tormented,

and it took a long time before we managed to convince the physician that it was best to cut down a little. In that case it was in a way ... not directly the physician against us, but our perceptions differed.

#### *Being a vulnerable helper – the prize and the price*

Facing an afflicted and powerless patient on the edge of life challenged nurses both as professionals and as human beings. Sub-themes in this main theme were: 'needing emotional protection in professional commitment' and 'feeling undervalued in spite of professional pride'.

*Needing emotional protection in professional commitment.* Being exposed to patients who were hovering between life and death was experienced to be personally and professionally developing. When the consequences of a patient's treatment were a good life, and the nurses' actions corresponded with the patient's wishes, the nurses felt successful and professional. Because they felt committed to the defenceless and suffering patients, they often exposed themselves to distressing tasks:

I have a simple philosophy that I go to the patient who is most ill, so I was by his side very much. And we [the staff] agreed that it was extremely distressing; none of us really wanted to do it [life sustaining tube feeding], but when I was at work, I mostly did it.

It was difficult to find an appropriate balance between proximity and distance, and some patients touched the nurses to such an extent that their thoughts were preoccupied with patients' concerns even off duty. When a patient died, the nurses could feel grief that they mostly had to manage alone. Sometimes when the nurses caused what they perceived as needless suffering to patients they experienced themselves as tormentors, and could feel shortcomings and guilt:

Every day when I did it, it was hard. Because I felt I was doing something that he [the patient] did not wish, but I simply did it. I felt the work was meaningless, because the only purpose was to make him survive for a little while against his wishes. It gave me nothing. I thought it was unworthy that this treatment he didn't want was forced upon him.

Caring for the patients where end-of-life questions were in focus could be experienced as so troublesome that some nurses had been off sick or wanted to change their occupation or workplace. Some of the nurses described physical reactions:

My stomach tightens. Therefore I get pains. I lose my appetite, [and] I get this lump in my chest.

The nurses protected themselves in different ways. They sometimes justified the execution of treatment that had not been agreed upon by saying that the patient did not resist, or by regarding the carrying out of conflicting treatment as practical procedures. Other times they with-

drew from patients by pushing work over to others, by hospitalizing the patient or by ignoring what they thought the patients needed to talk about:

... It is easier to change sheets and wash the patients than to talk with them about death.

Some nurses focused on the reputation of the institution or the risk of reprisal as arguments for stopping or maintaining treatment. Experienced nurses also described their anxiety as newly trained nurses and how they could strive to escape from dying patients by arguing in favour of maintaining treatment:

I had never experienced someone who had died before, so I was scared to death that she might die on my duty. I didn't know how I would react or what I should do! ... I thought it was quite right to try treatment as long as possible. In a way it was okay that she died with a needle in her arm.

*Feeling undervalued in spite of professional pride.* To have the official instruction to nurse a patient back to life or to a peaceful death gave the nurses a feeling of being honoured. They were proud of being close to the patients and possessing important knowledge about patients' needs. Even if the nurses mostly relied on their clinical judgements, some nurses wanted more expert guidance about professional ethics and palliative care.

In spite of nurses' professional pride and autonomy, the traditional hierarchy between physicians and nurses was apparent. The nurses felt inferior when they wasted precious time contacting a physician, when they felt expectations to follow physicians' orders without any discussions, and when physicians brushed the nurses' arguments aside.

A hierarchy was also experienced among the nurses themselves; among nurses working on different shifts, but also between newly qualified nurses and their more experienced colleagues. A feeling of being second-rate was experienced in relation to nurses in emergency departments and hospitals. The feeling of being undervalued by their nurse colleagues arose for instance when the nurses felt unfairly criticized. This could happen when they consulted physicians in good faith because of missing documentation about decisions regarding the patient's treatment, or when the nurses did not manage to resist physicians' orders to hospitalize terminally ill patients. Although the nurses felt hurt, they mostly let it pass in silence:

When I called the hospital then [they said] why ... what was the intention when you hospitalised him? Eh, no, yes, no, no ... I understand what you say, I said. What should I say? I quite agree with you? But I didn't think I could say that. No, I understand this, I said. I felt sooo stupid! And [they thought] ... do you have an empty head? Can't you see that a patient is terminal? Then I had to be loyal [to the physician's decision].

*Essence: being a lonely and enduring struggler between opposite poles*

The essence of being a nurse in a nursing home caring for patients on the edge of life appeared as 'being a lonely and enduring struggler between opposite poles'. The nurses' alliance with the patient, and their loneliness and vulnerability when struggling to act in the patient's best interest, was apparent through the whole analysis. The nurses were also concerned about being good colleagues, being loyal to the institution and to the physicians' decisions, and doing what they considered patients' relatives desired. Furthermore, they wanted to be content in their work and feel good. The nurses tried by various means to attain these ends, but felt pulled between providing good and bad nursing care as there were frequent conflicts of interest. Whatever they did, they felt that someone was let down, which added to the distress in their work. However, it was evident that nurses showed a high level of patience in putting up with inadequate organizational systems.

## Discussion

This study aimed at deepening our understanding of what it is like to be a nurse in a nursing home for patients on the edge of life. The most striking impression of the findings was how the nurses often worked in ambiguous or uncertain situations which promoted paradoxical activities and emotional stress. Wallerstedt and Andershed (31) highlighted the demands on the nurse's role to handle frequent changes between caring for patients in a palliative and in a curative phase. The nurses' role in our study could be even more challenging as the patients were neither clearly in a curative nor in a palliative phase. Paradoxical experiences in the care of dying patients have been found in other studies (32, 33), even if certainty/uncertainty has not been described as the reason for negative experiences which were found in our study.

Even if the nurses repeatedly tried to stand up for what they thought was the patient's interests towards physicians, relatives, and nursing leaders, they too often did not. Their uncertainty and feelings of powerlessness might be reasons for their silence, as moral certainty has been found to be related to 'standing up' and 'speaking up' (34). In our study nurses' silence might also be signs of disillusion or habits, but it could be a self-protecting strategy as well, as nurses who have reported misconduct are shown to be exposed to stress and professional reprisals (35). However, silence might also be problematic, as it can cause emotional health problems to nurses (36). Nurses' silence might cover up unsatisfying institutional systems and uphold a practice that at times might border on being illegal (37).

The nurses' driving power seemed to be anchored in their wish to do good in accordance with the patients' desires and conditions. If they could not, a feeling of

shortcoming and guilt was experienced, especially when treatment or care caused the patients what was interpreted as meaningless suffering. Witnessing suffering is found to be the core problem for nurses when caring for patients at the end of life (38). Furthermore, studies have shown that when nurses were hindered by others from giving the good care they intended to give, or had to carry out undesired treatment, they were exposed to value conflicts and moral distress (39–41). The heavy burdens that the nurses in our study have illuminated should be a finding to be noted as this might lead to flight from the place of work, health risks, and burn out (42, 43). This could mean a lack of highly competent nurses to perform good nursing care in nursing homes.

Our study highlighted the nurses' comprehensive responsibility, which included the nurses' experiences of themselves as ultimately accountable for patients, and their self-assumed duties, to at times carry out tasks that were the physicians' responsibilities. This is in accordance with a study by Peter et al. (44), showing how nurses felt forced to pick up the work of absent physicians. The nurses in our study also had diverging loyalties and had to adjust their care to medical orders, institutional requirements, colleagues, patients' (supposed), and relatives' desires. This put them in an 'in-between position' which previously has been described as giving possibilities to influence decisions and perform good nursing care (45). This in-between position could increase nurses' and patients' burdens as well (46). For instance, the nurses in our study sometimes handled such situations by taking the responsibility in their own hands and kept the patients away from physicians' judgements to prevent them from what they perceived as 'wrong' decisions. According to Bishop and Scudder (45), such actions are 'risk taking', but excellent nursing practice as they aim to foster patients' well-being. However, it might as well have happened that the patients in nursing homes were harmed as they were withdrawn from medical judgements and treatments. The nurses also put themselves at risk when they exceeded their professional responsibility (cf. The Health Personnel Act, 1999).

The nurses experienced that the patients had a strong appeal to them as fellow human beings, and it was difficult to find a balance between nearness and distance. Nurses' close relationship and emotional involvement with the patient might prevent them from acting in a clear-sighted and rational way. It has been claimed that distance is necessary when making decisions which have grave consequences for others (47). However, being close and concerned in nursing care does not mean that adequate decisions are impossible, but in order to act professionally the ability to sometimes take a step back for critical reflections must be present (48).

Sometimes the nurses needed to protect their own sanity and construct acceptable explanations for their actions.

However, some of the reported self-protecting strategies might be incompatible with good nursing care such as avoidance or withdrawal, rationalization, and justification. Similar coping mechanisms are found by others (40, 49). Self-protecting strategies might minimize the nurses' emotional stress, but lead to an unconcerned and cold attitude towards the patients (50).

The nurses in our study were frequently excluded from the decision-making process even if they thought that they knew what was right and best for the patients. This conflicts with studies which have shown the necessity of early discussions about a patient's status, advance care planning, and interdisciplinary teamwork related to end-of-life decisions (51–53). As shown by Campbell et al. (54), the nurses in our study claimed that they could add important contributions to the decision-making process. May be it is timely to establish routines concerning end-of-life decisions, in which nurses are included?

The findings in our study reflected nurses' feelings of being undervalued by physicians and colleagues. It is pointed out that devaluation of nurses' contributions could put them at risk of suffering damaged identities (47), and that good quality in nursing care depends on nurses' professional pride (55). Therefore, it must be of utmost importance to offer support to nurses in nursing homes, focusing on self-esteem and professional pride. Methods which have been found successful include, e.g. group supervision (56) and assertiveness training (57, 58).

## Methodological reflections

In accordance with phenomenological research this study relied on nurses' descriptions and reflections in order to understand the phenomenon 'from the inside' (24). One limitation in the study might be that it was mostly female nurses who were represented as informants, but as the gender perspective was not a focus, we do not know anything about this issue. However, if the majority of informants had been men, the patterns of findings might have been different. Another limitation might be that nurses from only two nursing homes were included. However, we consider the sample as adequate because a nurse's experience of caring for a severely ill patient in a nursing home is always unique and can never be iterated.

The method used in the analysis was adopted from Van Manen (24). Even if his overall descriptions of phenomenological assumptions fitted well with our beliefs, we found his examples of the steps of the analysis to be few and unclear, especially the relations between the selective and detailed approaches. We have therefore tried to make our own strict descriptions of the analysis in order to offer ideas to others about how to follow the process, and perhaps to inspire a discussion about the method.

## Conclusion and relevance to clinical practice

This study has shown that nurses' situation in nursing homes when caring for patients on the edge of life may be highly distressing and put heavy demands on their professional performance. The nurses' strong commitment to patients, and their loyalties to relatives, physicians, colleagues, and their own values, pulled them between different and sometimes incompatible interests. The findings have illuminated the nurses' struggle to handle the conflicts and have shown that their strategies were sometimes contradictory to good nursing care. Even if the effects of stressful work situations are already well known, this study has contributed to the understanding of what the stress factors are when nursing patients on the edge of life. This study shows that there are needs for improvements in order to reduce the burdens on nurses, to empower them to sometimes defy the system, and cope with the challenges. This study also shows that it is time to highlight a formal role of nurses in end-of-life decisions. Education focusing on palliative care, conflict management, cooperation, and ethical reasoning is important, and so is support for the nurses.

This study has given insights that bring a deeper understanding about the issues under study, and the knowledge gained might be transferable to similar contexts or groups. It has also offered ideas for further research, such as finding out what needs for nursing care patients have when being on the edge of life.

## Acknowledgements

The authors are grateful to the nurses who participated and shared their important experiences and to the leaders of the nursing homes for making it possible to carry out this study. The authors also thank Assistant Professor Ian Watering, Hedmark University College, for comments and revision of English language, and Hedmark University College for financial support.

## Author contributions

Reidun Hov, Elsy Athlin, and Birgitta Hedelin have been involved in the entire research process. Reidun Hov performed data collection, transcriptions, data analysis, and drafted the manuscript. During the process of analysis Reidun Hov, Elsy Athlin, and Birgitta Hedelin continually discussed preliminary findings, and all participated in writing the manuscript.

## References

- Institute of Medicine. *Approaching Death: Improving Care at the End of Life*. 1997, National Academy Press, Washington DC.
- Sandman PO, Wallblom A. Characteristics of the demented living in different settings in Sweden. *Acta Neurol Scand Suppl* 1996; 94: 96–100.
- Engedal K, Haugen PK. The prevalence of dementia in a sample of elderly Norwegians. *Int J Ger Psychiatry* 1993; 8: 565–70.
- Husebø BS, Husebø S. Nursing homes as arenas of terminal care: practical aspects (in Norwegian). *Tidsskr Nor Lægefor* 2005; 125: 1352–54.
- Leland J. Advance directives and establishing the goals of care. *Palliative Care* 2001; 28: 349–63.
- Cook DJ, Giacomini M, Johnson N, Willms D. Life support in the intensive care unit: a qualitative investigation of technological purposes. Canadian Critical Care Trials Group [comment]. *CMAJ (Ottawa)* 1999; 161: 1109–13.
- Enes SPD, de Vries K. A survey of ethical issues experienced by nurses caring for terminally ill elderly people. *Nurs Ethics* 2004; 11: 150–64.
- Gessert CE, Chalkin DR. Rural–urban differences in end-of-life care: the use of feeding tubes. *J Rural Health* 2001; 17: 16–24.
- Laakkonen M, Finne-Soveri H, Noro A, Tilvis R, Pitkala K. Advance orders to limit therapy in 67 long-term care facilities in Finland. *Resuscitation* 2004; 61: 333–39.
- Solloway M, LaFranche S, Bakitas M, Gerken M. A chart review of seven hundred eighty-two deaths in hospitals, nursing homes, and hospice/home care. *J Palliat Med* 2005; 8: 789–96.
- Dobalian A. Nursing facility compliance with do-not-hospitalize orders. *Gerontologist* 2004; 44: 159–65.
- Reynolds K, Henderson M, Schulman A, Hanson LC. Needs of the dying in nursing homes. *J Palliat Med* 2002; 5: 895–901.
- Ackermann RJ, Kemle KA. Death in a nursing home with active medical management. *Ann Long Term Care* 1999; 7: 313–19.
- van der Steen JT, Ooms ME, van der Wal G, Ribbe MW. Withholding or starting antibiotic treatment in patients with dementia and pneumonia: prediction of mortality with physicians' judgement of illness severity and with specific prognostic models. *Med Decis Mak* 2005; 25: 210–21.
- Onwuteaka-Philipsen BD, Pasman HRW, Kruit A, van der Heine A, Ribbe MW, van der Wal G. Withholding or withdrawing artificial administration of food and fluids in nursing-home patients. *Age Ageing* 2001; 30: 459–65.
- The A, Pasman R, Onwuteaka-Philipsen B, Ribbe M, van der Wal G. Withholding the artificial administration of fluids and food from elderly patients with dementia: ethnographic study. *BMJ* 2002; 325: 1326–29.
- Henderson V. *The Nature of Nursing: A Definition and its Implications for Practice, Research, and Education*. 1966, Macmillan, New York.
- Hall EOC. A double concern: Danish grandfathers' experiences when a small grandchild is critically ill. *Intensive Crit Care* 2004; 20: 14–21.
- Hov R, Hedelin B, Athlin E. Being an intensive care nurse related to questions of withholding or withdrawing curative treatment. *J Clin Nurs* 2007; 16: 203–11.



- 20 Travis SS, Loving G, McClanahan L, Bernard M. Hospitalization patterns and palliation in the last year of life among residents in long-term care. *Gerontologist* 2001; 41: 153–60.
- 21 Kayser-Jones J, Schell E, Lyons W, Kris AE, Chan J, Beard RL. Factors that influence end-of-life care in nursing homes: the physical environment, inadequate staffing, and lack of supervision. *Gerontologist* 2003; 43: 76–84.
- 22 Kyba FC *Moral Problems and Ethical Decision-Making in the Nursing Care of Elders: Reported Experiences of Registered Nurses in Selected Texas Critical Care Units and Nursing Homes [PhD, Dissemination]*. 1990, Texas University, Texas.
- 23 Speziale H, Carpenter D *Qualitative Research*, 3rd edn. 2003, Lippincott Williams & Wilkins, Philadelphia.
- 24 Van Manen M. *Researching Lived Experience. Human Science of an Action Sensitive Pedagogy*, 2nd edn. 1997, The Athlone Press, London, Ontario, Canada.
- 25 Polit DF, Beck CT. *Essentials of Nursing Research. Methods, Appraisal, and Utilization*, 6th edn. 2006, Lippincott Williams & Wilkins, Philadelphia.
- 26 Patton MQ. *Qualitative Evaluation and Research Methods*, 3rd edn. 2002, Sage Publications, Thousand Oaks, CA.
- 27 Sandelowski M The problem of rigor in qualitative research. *Adv Nurs Sci* 1986; 8: 27–37.
- 28 Dahlberg K, Dahlberg H. Description vs. interpretation – a new understanding of an old dilemma in human science research. *Nurs Philos* 2004; 5: 268–73.
- 29 Colaizzi P. Psychological research as the phenomenologist views it. In *Existential– Phenomenological Alternatives for Psychology* (Valle RS, King M, eds.), 1978, Oxford University Press, New York, 48–71.
- 30 ICN. *Professional ethical guidelines and ICN's ethical regulation for nurses [Norwegian]*. 2001, The Norwegian Nurses' Association, Oslo.
- 31 Wallerstedt, Andershed B. Caring for dying patients outside special palliative care settings: experiences from a nursing perspective. *Scand J Caring Sci* 2007; 21: 32–40.
- 32 Hayes C. Ethics in the end-of-life care. *J Hosp Palliat Nurs* 2004; 6: 36–45.
- 33 Pattison N. Integration of critical care and palliative care at the end of life. *Br J Nurs* 2004; 13: 132–36.
- 34 Wurzbach ME. Acute care nurses' experiences of moral certainty. *J Adv Nurs* 1999; 30: 287–93.
- 35 McDonald S, Ahern K. The professional consequences of whistleblowing. *J Prof Nurs* 2000; 16: 313–21.
- 36 McDonald S. Physical and emotional effects of whistleblowing. *J Psychosoc Nurs Ment Health Serv* 2002; 40: 14–27.
- 37 The Health Personnel Act. *Act of 2nd July 1999 no. 64 Relating to Health Personnel etc.* 1999 [cited 12 June 2007]; available from: <http://odin.dep.no/hod/engelsk/regelverk/p20042245/042051-200005/index-dok000-b-n-a.html>.
- 38 Oberle K, Hughes D. Doctors' and nurses' perceptions of ethical problems in end-of-life decisions. *J Adv Nurs* 2001; 33: 707–15.
- 39 Georges J-J, Grypdonck M. Moral problems experienced by nurses when caring for terminally ill people: a literature review. *Nurs Ethics* 2002; 9: 155–78.
- 40 van Rooyen D, Elfick M, Strumpher J. Registered nurses' experiences of the withdrawal of treatment from the critically ill patient in an intensive care unit. *S Afr J Nurs* 2005; 28: 42–51.
- 41 von Post I. Perioperative nurses' encounter with value conflicts. *Scand J Caring Sci* 1998; 12: 81–88.
- 42 Altun I. Burnout and nurses' personal and professional values. *Nurs Ethics* 2002; 9: 269–78.
- 43 Meltzer LS, Huckabay LM. Critical care nurses' perceptions of futile care and its effects on burnout. *Am J Crit Care* 2004; 13: 202–08.
- 44 Peter EH, Macfarlane AV, O'Brien-Pallas LL. Analysis of the moral habitability of the nursing work environment. *J Adv Nurs* 2004; 47: 356–47.
- 45 Bishop AH, Scudder JR. *Nursing Ethics. Therapeutic Caring Presence*. 1996, Jones & Bartlett Publisher, Boston.
- 46 Varcoe C, Hartrick G, Pauly B, Rodney P, Storch JL, Mahoney K, McPherson G, Brown H, Starzowski R. Ethical practice in Nursing – Working the in-betweens. *J Adv Nurs* 2004; 45: 316–25.
- 47 Peter E, Liaschenko J. Perils of proximity: a spatiotemporal analysis of moral distress and moral ambiguity. *Nurs Inq* 2004; 11: 218–25.
- 48 Paterson JG, Zderad LT. *Humanistic Nursing*. 1988, NLN Publications, New York.
- 49 Badger JM. A descriptive study of coping strategies used by Medical Intensive Care Unit nurses during transitions from cure- to comfort-oriented care. *Heart Lung* 2005; 34: 63–68.
- 50 de Araújo, da Silva M, Francisco M. Nursing the dying: essential elements in the care of terminally ill patients. *Int Nurs Rev* 2004; 51: 149–58.
- 51 Anderson RA, McDanile RR. Intensity of registered nurse participation in nursing home decision making. *Gerontologist* 1998; 38: 90–100.
- 52 Forbes S, Bern-Klug M, Gessert C. End-of-life decision making for nursing home residents with dementia. *J Nurs Scholarsh* 2000; 32: 251–58.
- 53 Hildén H-M, Louhiala P, Honkasalo M-L, Palo J. Finnish nurses' views on end-of-life discussions and a comparison with physicians' views. *Nurs Ethics* 2004; 11: 165–78.
- 54 Campbell ML, McHaffie H. Prolonging life and allowing death: infants. *J Med Ethics* 1995; 21: 339–44.
- 55 Bjørkstrøm M *The Professional Nurse (in Swedish)*. Doctoral Thesis. 2005, Karlstad University, Karlstad.
- 56 Hansebo G, Kihlgren M. Carers' interactions with patients suffering from severe dementia: a difficult balance to facilitate mutual togetherness. *J Clin Nurs* 2002; 11: 225–36.
- 57 Dodd S-J, Jansson BS, Brown-Saltzman K, Shirk M, Wunch K. Expanding nurses' participation in ethics: an empirical examination of ethical activism and ethical assertiveness. *Nurs Ethics* 2004; 11: 15–27.
- 58 Timmins F, McCabe C. Nurses' and midwives' assertive behaviour in the workplace. *J Adv Nurs* 2005; 51: 38–45.