ORIGINAL ARTICLE

Nursing care for patients on the edge of life in nursing homes: obstacles are overshadowing opportunities

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Background. Patients in nursing homes have comprehensive needs for nursing care and medical treatment. Most patients benefit from the treatment, but some are 'on the edge of life'-in a borderland between living and dying with an unpredictable outcome, and questions are sometimes raised whether to withhold/withdraw curative treatment.
Aim. The aim was to describe nurses' conceptions of good nursing care, and how this could be carried out for patients on the edge of life in nursing homes.
Design. In order to discover variations in the nurses' understandings a phenomenographic approach was chosen. Phenomenography is concerned with qualitatively different ways of conceiving a phenomenon.
Methods. Fourteen nurses from two nursing homes were individually interviewed twice. A phenomenographic analysis was used.
Results. The outcome-space included two main categories. The first, 'good nursing care is to meet patients' needs for dignity,' included three description-categories: needs for 'preparedness', 'human relationship' and 'bodily comfort and safety'. The second, 'opportunities were overshadowed by obstacles' in carrying out nursing care encompassed three description-categories: 'organisational factors,' 'relational factors' and 'personal factors'.
Conclusions. This study shows nurses' conceptions of the importance of good nursing care for comforting patients on the edge of life.
Implications for practice. Several obstacles related to resources, communication, cooperation and nurses' professional strength and power need to be overcome if good nursing care can be performed.

Key words: nursing care, nursing home care, palliative care, qualitative methods

Introduction

Patients living in nursing homes have a significant loss of physical and mental functioning and a considerable need for medical treatment and nursing care (Hall *et al.*, 2009; Kirkevold & Engedal, 2009). Three groups of patients have been described (Wunderlich *et al.*, 1995) representing different goals of care: patients admitted for rehabilitation who are expected to be discharged to their homes, patients with advanced progressive diseases who are expected to die within a short time, and chronically ill and functionally disabled patients usually spending the rest of their lives in a nursing home. For the last group, maintenance or improvement of their functional status is the overall goal, but deterioration and death are inevitable outcomes (Forbes, 2001). Even if the goals are initially clear, these may be changed when a patient's state alters, either from cure to support or *vice versa*. The change of goals may be a complex process as some patients show only vague prognostic signs as to whether they are recovering or dying (Hov *et al.*, 2009). Cook *et al.* (1999) have described that many patients need time to 'declare themselves' by showing clearer prognostic signs whether they are going to continue living or are dying. In this article, patients in this state are understood to be 'on the edge of life' as they are on a borderline between living and dying with an unpredictable outcome. During this process of declaration, questions of withholding or withdrawing life-sustaining treatment are often raised.

Even if several clinical signs can suggest that a patient is dying (Waldrop & Kirkendall, 2009), decisions about withholding or withdrawing curative treatment are found to be difficult for health-care personnel, fraught with dilemmas concerning the appropriateness and timeliness of treatment (Mueller *et al.*, 2004; Hov *et al.*, 2007). One reason might be that the consequences of a 'wrong' decision are so grave. A lack of curative treatment is supposed to hasten a patient's death, whereas treatment intended to prolong the patient's life may conflict with the goal of a peaceful death. Another reason might be anchored in an often occurring lack of knowledge about a patient's own preferences for living or dying (Gillick *et al.*, 1999). Patients can prospectively participate in determining the use of different life-saving treatments by means of advanced directives (AD) (Mion & O'Connell, 2003), but the interpretation and use of ADs may vary (Suri *et al.*, 1999; Gessert & Calkins, 2001; Monturo & Strumpf, 2007). Patients who are able to express their preferences may refuse or request limitations of medical treatment (Mueller *et al.*, 2004), but their wishes are found to be contradictory or ambivalent (Cicirelli, 1997; Sahlberg-

Blom *et al.*, 2000). Furthermore, these patients ideally should be offered advanced care planning as a precondition for good end-of-life care, but research has shown that the practice of this varies (Engel *et al.*, 2006).

Studies have focused on end-of-life care in nursing homes (Cartwright, 2002; Froggatt & Payne, 2006). Even if the findings of these are not especially related to nursing care, they demonstrate important areas of concern for nurses. According to Hanson *et al.* (2002), dying in nursing homes is characterised as a peaceful acceptance with little pain and other symptoms. However, there is quite an extensive body of research revealing the opposite.

Studies have reported physically uncomfortable patients with pains, respiratory problems, fatigue, incontinence and deficient personal hygiene. Furthermore, agitation, restlessness, social isolation, depressed mood and anxiety have often been noted (Forbes, 2001; Hall *et al.*, 2002; Reynolds *et al.*, 2002). Another study stresses the need for improvement of patients' cultural needs, communication and medical treatment (Kayser-Jones, 2002). This literature review shows a comprehensive body of research regarding end-of-life care for patients in nursing homes, yet nursing research about seriously ill patients on 'the edge of life' and their situation and needs in nursing homes is still scarce. Therefore, this study was aimed at describing nurses' conceptions of good nursing care, and how this could be carried out for patients on the edge of life in nursing homes. The research questions were as follows:

- What is good nursing care with regard to these patients' needs, and how are these needs met?
- What are the opportunities for nurses to give good nursing care?

Method

To discover variations in the nurses' understandings, a phenomenographic approach was chosen. The aim of phenomenography is to identify, describe and systematise the different ways people experience, conceive or understand significant aspects of reality (Marton, 1981). Phenomenography makes a distinction between what something is (the first-order perspective) and how something is conceived to be (the second order perspective). The second-order perspective is fundamental in phenomenography, as it deals with individuals' conceptions of how a phenomenon appears to them (Marton & Booth, 1997). According to Marton (1996), there is a limited number of qualitatively different ways of understanding a phenomenon, and the focus is on groups of people rather than individuals. The main outcome of the analysis is 'categories of description', which describe

similarities and differences of individual conceptions of the phenomenon under study. The findings are presented in an 'outcome space', which illuminates the logical relationships among the categories (Barnard *et al.*, 1999). An often-used method for data collection in phenomenography is individual interviews with one or few questions (Sjöström & Dahlgren, 2002), and the way the informants respond to the questions forms the basis for further questions.

The context of the study

This study was conducted in nursing homes in Norway. Norwegian nursing homes are facilities for providing care in the communities (MEDLEX, 2006). Some nursing homes have beds for palliative care, rehabilitation, temporary and intermediate stay, which also include curative treatment, and most of them have at least one unit for patients with dementia. The patients have on average four medical diagnoses each that need to be followed up by physicians (The Norwegian Medical Association, 2005). In addition, about 80% of the patients are found to have a dementia (Selbekk *et al.*, 2007). Compared to other countries in Europe, Norway is reported as having the highest percentage (about 42%) of the population dying in nursing homes (Husebø & Husebø, 2005; Statbank Norway, 2008). Nursing-care services and personal care are available 'around the clock', characterised by a low number of Registered Nurses (RNs) who provide the care together with enrolled nurses/assistants, and a limited time for physicians to provide medical treatment.

The study setting

Two nursing homes in two municipalities, A in a small town and B in the countryside, were chosen to participate in the study after permission from their chief administrative officers was provided. Nursing home A consisted of two units (with a total of 60 beds) and B of four units (with a total of 99 beds). The patients were older people with multiple diseases, many suffering from cognitive impairment. Besides long-term care, both institutions had some beds for patients with dementia, for rehabilitation, intermediate care and temporary accommodation. One unit also had two beds for palliative care. The units were run by means of team nursing with about one RN per unit during daytime, and for evenings, nights and weekends about one RN per nursing home. There were six to nine enrolled nurses/assistants per unit during daytime, and three to six enrolled nurses/assistants during the other shifts. Each unit had one attendant physician who was present for seven hours once a week. At other times, the

Table 1 Characteristics of the informants

	Nursing home A	Nursing home B
Number of informants/gender	6 (♀)	8 (7♀, 1♂)
Median years of work as Registered Nurse	18 (6–29)	11 (1–32)
Years of work in nursing home	9 (6–13)	9 (1–25)
Number of informants with specialisation in nursing	3	5

patients' general practitioners or other physicians in the primary health-care team were on call.

Participants

One of the researchers (RH) informed the RNs at the nursing homes about the study. Thereafter, the head nurses distributed written information about the study to all nurses. A purposeful sampling technique was used to recruit participants, taking account of differences in gender, work experience, levels of education and shifts. Fourteen nurses who met these criteria and reported their interest in participating were included in the study (Table 1).

Data collection

The participants were individually interviewed twice by RH, about one hour each time. The interviews took place at the nursing homes during the participants' working hours. They were invited to talk about cases when questions about withholding or withdrawing life-sustaining treatment were raised and the decisions turned out the way they desired for the patients, and also, when decisions did not turn out how they had wanted them to be. After describing a case, the research questions were further deepened. In the second interview, follow-up questions were raised based on topics that needed to be clarified or deepened. The participants were also free to reflect upon whatever had come into their minds with regard to the previous interview. All interviews were tape-recorded and transcribed verbatim by RH.

Analysis

A phenomenographic analysis was carried out inspired by Hyrkäs *et al.* (2003) (Table 2).

This process of analysis moved back and forth between the entire interview text and its parts, and between the different steps of analysis, and was carried out in close collaboration with the research group (RH, BH, EA).

Table 2 The analysis of data inspired by the steps as proposed by Hyrkäs *et al.* (2003)

- The entire material was read in order to acquire an overall picture. Comments related to the research questions were marked
- The comments were compared with the content of the interviews
- The comments were grouped in pools of meaning
- Similarities and differences of the pools of meanings were compared, conceptualised and further tested for emerging categories by comparing them with the entire material
- Descriptions of categories were identified and formulated
- The interrelationships of categories of descriptions were found by relating them to each other and to the aim of the study

Ethical considerations

The study was conducted in accordance with the Ethical Code for Nurses and Nursing Research (Northern Nurses' Federation, 2003; ICN, 2007). This meant that participants' voluntariness, integrity and confidentiality were taken into consideration. All informants were labelled 'she' in all written documents to avoid identification of the only male participant. The study was reported to the Norwegian Social Science Data Services.

Findings

Two main categories were found: 'Preserving the patient's dignity' (Table 3) and 'Obstacles overshadowing opportunities' (Table 4), which were strongly connected because the obstacles for good nursing care could cause unmet needs for the patients.

Preserving the patient's dignity

This main category shows good nursing care based on the individual patient's needs. The descriptions were grounded in the nurses' conceptions of professional values and of the patient's situation. Preserving the patient's dignity was understood as meeting each patient as a whole and unique person, and giving appropriate treatment and nursing care. This meant being helped when struggling with existential questions, surrounded by caring and loving people and as far as possible relieved from pain and suffering. The description-categories capture the nurses' conceptions of important needs to be met with regard to the patient's dignity: their needs for 'preparedness', 'meaningful relationships' and 'bodily comfort and safety'. They also describe the patient's condition and abilities related to the specific needs.

The subcategories describe the variations in nursing care and their consequences for fulfilment of the patient's needs.

Need for preparedness

This description-category shows the nurses' conceptions of meeting the patient's need for preparedness for the future as an important aspect of dignity, whether it concerned living, dying or what was to come after death. It described the patient's struggle for meaning and hope, and for being relieved from anguish.

According to the nurses, the patients' abilities to understand what the situation really meant influenced their opportunity to be prepared. A few patients could indicate verbally or nonverbally that they were consciously aware, but most often they were unable to express themselves clearly. Some patients seemed to struggle hard, but it was difficult to know what they were struggling for, and their expressions were understood as anxiety, despair and denial. Several patients appeared exhausted and discouraged and seemed to withdraw, whereas others looked peaceful and prepared for what was to come.

Reconciliation vs. hopelessness
These subcategories show how variations in nursing care could lead to reconciliation or hopelessness for the patient.

Table 3 Nurses' conceptions of good nursing care related to the patient's needs, and how the needs were met

Main category	Preserving the patient's dignity		
Description-category	Need for preparedness	Need for meaningful relationship	Need for bodily comfort and safety
Sub-categories	Reconciliation vs. hopelessness	Togetherness vs. abandonment	Relief vs. affliction

Table 4 Nurses' conceptions of obstacles and opportunities to provide good nursing care

Main category	Obstacles overshadowed the opportunities		
Description-category	Organisational factors	Relational factors	Personal factors
Sub-categories	Staffing and insufficient routines	Cooperation and communication	Nurses' inner strengths and nurses' loyalties

The variations were described as relating to how well the patients were informed and supported, and how well their wishes were expressed, interpreted and followed.

Most often the patients were incapable of responding to information and imparting their wishes. If a patient's wishes for treatment and care were stated and written down beforehand, this could be facilitating, but this was seldom the case. Cooperation about plans and aims in the health-care team and with relatives was stressed as extremely important. The nurses considered that some patients received treatment and nursing care in line with their (supposed) needs and wishes, but too often incongruence occurred:

He had expressed that he did not wish to be kept artificially alive, when he was unable to swallow; but for the sake of the family, we had to give him intravenous nourishment. His death process was prolonged, but we did it, against his will.

Most patients were stressed to be in need of support to get a hold of reality. In spite of this, few nurses mentioned that they talked directly to the patients about their situation, and about meaning and hope. Instead they focused on daily events in their communication with the patients. The patients' religious needs were also mentioned as a dimension of good nursing care:

I asked whether he wanted to talk with a priest, but he just was not up to it, and I had to respect that, but I said to him: there is nothing to bar me from praying together with you, and then we prayed. Afterwards he seemed to be so content.

Need for a meaningful relationship

This description-category shows nurses' conceptions of meeting the patient's needs for a meaningful relationship as another part of dignity. Even if some patients expressed a need for solitude, the nurses conceived that the patients usually wanted to have someone at their bedside. Some patients were able to express their desires in words, or they grasped the nurses' hands, would not let them go, shouted out when they were alone, and seemed calmed when a nurse was present.

Togetherness vs. abandonment
These subcategories show how variations in nursing care affected the patients and how the patient's needs for human relationship could be met, leading to togetherness or abandonment. The nurses stressed the significance of talking to patients who were unconscious and cognitively impaired. They could express their presence by touching and holding a patient's hand and 'tuning in' their voices. The nurses also conveyed the importance of respecting a patient's wish for

solitude, and not to leave patients who were dying alone. Yet this could happen:

… a physician decided to hospitalise him, and he died in the hospital after a few hours, and when we sent him away, no-one followed him.

Family members were usually by the patient's side, but sometimes so intensively that the nurses had to reduce the number and duration of visits. The patients' social contact with relatives and friends often faded away, because of geographical distance, death of a spouse, relatives' withdrawal or when the patient's ability to communicate decreased. The nurses were well aware of the presence of relatives as an aspect of good care and that those, too, could need support to stay by the patient's side:

She [the daughter] spent most of her time with us. Then I said to her that now I will go to her [mother's] room, will you come with me... And I explained what I did [mouth care]. 'Is this something that I can do', she said... Afterwards she said that she had felt so helpless and frightened, only sitting by the bed.

For some patients, their relatives could be totally absent and in those cases, the nurses took on the role of the patient's family. They also sometimes established a system of primary contacts to increase the opportunity to get to know the patient and the relatives. In spite of all their attempts, many patients were seen as being lonely and abandoned.

Need for bodily comfort and safety

This description-category shows nurses' conceptions of how meeting the patient's needs for bodily comfort and safety could be a dimension of dignity. The nurses described the patients as exposed and their bodies as fragile. They were regarded as incapable of managing their needs themselves, and therefore totally dependent on around-the-clock care. Complications were described as arising from medication, malnutrition and immobility, and many patients' afflictions seemed to make them introverted and frail. The patients were described as moaning or whimpering with bodily restlessness, distorted faces and pinching eyes, and few were described as being comfortable and free from pain.

Relief vs. affliction
These subcategories show how variations in nursing care could affect the patient's comfort and safety, leading to either relief or affliction. The nurses emphasised the necessity to identify each patient's desires, capabilities and needs, and to work out an appropriate care plan. To a great extent, a patient's comfort and safety were seen as depending on the

individual nurse's interventions, based on her observations, assessments and judgements:

His [the patient's] general practitioner had decided to withdraw curative treatment, and he was admitted to the nursing home to die, but [for me] he did not look as if he was dying. After several efforts, I succeeded in convincing the attendant physician and … when he [the patient] was relieved from pain, he woke up and wished to be hospitalised. [and survived].

The nurses expressed that they often succeeded in comforting the patients through essential nursing care, such as helping with comfortable positions, caring to protect the skin and intensifying mouth care. The nurses also described how they tried to enhance patients' autonomy by encouraging them to express desires about personal hygiene, appropriate dressing and appearance. Fostering a good atmosphere in the patient's room was emphasised. The patient's need for relief was not always thought to be met through pain-relieving medications. This could especially happen when treatment was continued against the patient's (supposed) desires, or when inadequate treatment was ordered:

I knew that he would die soon because of these sores and the deficiency in circulation and all the complications. We gave him morphine, but still I'm sure he felt tortured, and I cannot understand why they absolutely had to give him intravenous nourishment.

Obstacles overshadowed opportunities to carrying out good nursing care

This main category shows that even though the nurses knew a lot about how to carry out good nursing care for patients on the edge of life, and sometimes could do this, obstacles often overshadowed the opportunities. The description-categories illustrate the nurses' conceptions of obstacles that were related to 'organisational', 'relational' and 'personal' factors. The subcategories show that if the factors described were adequate and sufficient, nursing care could be satisfying; if not the patients' needs were unmet.

Organisational factors

This description-category shows that the way a patient's needs could be met by nursing care depended on how the nursing homes were staffed as well as on routines.

Staffing and routines
These subcategories show how the most notable obstacles to good nursing care were considered to be the lack of competent and concerned personnel, as well as lack of knowledge about the individual patients. The informants

described inadequate resources as having too few RNs, but first and foremost they stressed the unavailability of physicians as the main concern. Frequent changes of attendant physicians and a delivery system without an explicit patient assignment were seen as causing discontinuity of care and were often described as resulting in misinterpretations and misunderstandings that increased the patients' suffering. Little flexibility in the health-care system, financial cutbacks and lack of time were mentioned as other reasons why patients were sometimes inappropriately treated or died alone.

Routines were described as insufficient with regard to medical examinations of patients, both on their admission to the nursing home and in follow-up checks of long-term patients. Other defective routines concerned clarification and documentation of patients' preferences related to life-sustaining treatment, and the lack of regular team-meetings and proper rooms for confidential discussions was conceived as often resulting in vague goals, followed by conflicting treatment and care.

Relational factors

This description-category shows that meeting patients' needs could be hindered by shortcomings in cooperation and communication with patients, relatives and health-care personnel.

Cooperation and communication
These subcategories show that the nurses considered that decisions about treatment and care should be a matter of teamwork, but that nurses were usually excluded from decisions about end-of-life treatment. Sometimes conflicting views about the goal of the patient's treatment and care could prolong the patients' suffering. Mostly the nurses thought that their opinions were in accordance with the patient's, but that these could diverge from those of relatives, physicians and other members of staff. Opinions among nurses could also be conflicting, which made them give the physicians differing or contradictory information. Deficiencies in cooperation with home nurses, general practitioners and personnel in hospitals could create problems in the planning and performance of nursing care, and was often felt to cause delayed or 'wrong' decisions.

Communication about death and dying was usually conceived as a natural part of the working culture, but conflicts among the staff about withholding and withdrawing of treatment hindered such communication. To be honest and open in communication with patients was experienced as extremely difficult when their wishes about life-sustaining treatment or not were unclear.

As the physicians were usually infrequently present at the nursing homes, the nurses often were the ones responsible when relatives asked for the information or wanted to discuss the patient's treatment and care. This communication was experienced as particularly demanding when unexpected questions about a patient's curative treatment or not arose, when there were conflicting views, or when questions about the appropriateness of a patient's life-sustaining treatment had to be discussed by telephone.

Personal factors

This description-category shows that good nursing care was extremely dependent on the individual nurse's inner strengths and loyalties. When these failed, the patient's wellbeing and safety could be jeopardised.

Nurses' inner strengths and nurses' loyalties
These subcategories show that caring for patients on the edge of life often was conceived as putting heavy demands on the nurses, both related to their inner strengths and their loyalties. Sometimes these demands could be too hard to endure, and to protect themselves the nurses might withdraw emotionally from the patient. Hospitalising a patient was also mentioned as a way to 'get rid of the problem'. To stand up for the patient's best interests in all situations was described as difficult. Sometimes a nurse could let a matter rest and not speak out even if it was obvious that insufficient systems and working conditions hindered adequate treatment or care. The nurses often missed professional support to discuss and confirm their assessments of patients, and to cope with their emotional distress when they were hindered from carrying out professional care.

The nurses often told about conflicts when their loyalties were split between patients, physicians, organisations and their own values. They considered that their obligations to the law required their complying with physicians' prescriptions even if this meant that their loyalty to the patient and their own values was betrayed. Mostly they carried out the prescribed treatment, but it could also be the case that they carried out treatment that differed from the physician's order when they were convinced that their assessment was in the patient's interests.

Discussion

This phenomenographic study aimed at describing nurses' conceptions of good nursing care and the opportunities to achieve this goal for patients on the edge of life in nursing homes. The findings showed that nursing care for these patients could be challenging as the nurses did not really know whether the patients would continue to live or were dying. In spite of this, the nurses considered that they understood the patient's needs for care and knew how to meet these, but the opportunities to carry out this care were often overshadowed by obstacles.

Preserving the patient's dignity, which was highlighted as good nursing care, was not a surprising finding because respecting a patient's dignity is a fundamental value in nursing care (Fry, 1994; ICN, 2007), as well as in the philosophy of end-of-life care (Latimer, 1991; Chochinov *et al.*, 2002). The nurses in our study spoke about their struggle to meet each patient's dignity, but they often failed. This again reveals the tension between what the ideal of caring for dying people should be and how it is practised.

The difficulties in performing good nursing care were considered to be closely related to a shortage of economic and human resources, seen as an insufficient number of competent personnel. This meant that also patients on the edge of life could be left without adequate support and care, which has previously been reported in studies of end-of-life care in nursing homes (Froggat & Hoult, 2002; Goodridge *et al.*, 2005; Jablonski & Wyatt, 2005).

The physicians' unavailability, which was stressed by the nurses in our study, could cause missing or inadequate medical assessment and treatment. This problem, which was probably related to organisational or financial factors, is also well-known from previous studies (Travis *et al.*, 2002; Vohra *et al.*, 2006). According to Seedhouse and Gallagher (2002) institutions with insufficient resources are undignifying, and inappropriate. As such, our study further highlights the imperative of politicians and health-care managers taking the allocation of adequate resources to nursing homes into consideration.

Nurses' conflicting loyalties was a notable finding. The nurses often took the responsibility of absent physicians in medical questions to give the patients good quality care. This working situation, based on nurses' loyalty to the system, might contribute to the patients' safety, but could also hinder patients from receiving adequate medical treatment and nursing care (Hov *et al.*, 2009). The findings also shed light upon the necessity for nurses in nursing homes to work on retaining loyalty to the patients. This could be carried out by regular reflections in the team about nurses' responsibilities and nursing philosophy in the care for patients on the edge of life. It is claimed that if nurses do not engage in such reflections, the nature of nursing will be determined by stronger forces, whatever they may be – political, administrative or the opinions of other health-care professionals (Johnson, 2004).

Despite the frequency of deaths that occur in nursing homes, the philosophy, policies and regulations are mainly

targeted to rehabilitative and restorative care (Parker-Oliver *et al.*, 2004). According to Johnson (2005), this approach might have produced perceptions of death as signs of failure of care and given rise to a death-denying culture within nursing homes, which might conflict with the needs of a dying person. The findings in our study supported this assumption. A possible improvement in many nursing homes could be made by integrating ideas from palliative care not only into standards of end-of-life care, but also into nursing care of seriously frail or ill patients when uncertainty exists whether the patient will survive or not. The ideas of palliative care are to improve the quality of life for patients with life-threatening illness and their families through prevention and relieving problems of physical, psychosocial and spiritual aspects (Davies & Higginson, 2004). This could give opportunities to focus on the patient and the family as a whole, decrease pain and suffering, reduce unnecessary and unwanted medical care and regard dying as a normal process (Baer & Hanson, 2000; Buchanan *et al.*, 2004; Davies & Higginson, 2004).

Previous studies have pointed out that good end-of-life care requires cooperation and teamwork (Hanson *et al.*, 2002; Travis *et al.*, 2002). This was also found to be the case with regard to patients on the edge of life. The nurses asked for scheduled team-meetings to discuss and recognise patients' needs and to point out a course of care based on clear goals. Hence, our study supports the study of Bern-Klug *et al.* (2004), where physicians asked for other health-care professionals' views on the importance of clear goals in end-of-life care. One implication could be to emphasise the responsibility of nurses in nursing homes to clarify the patient's preferences, document them and communicate them to those who are involved in their treatment and care. Perhaps it is time to reinforce Taylor's statement from 1995 that for the patients' sake, nurses should take a leading role in bringing clinicians, patients and families together to negotiate decision making and care planning for patients on the edge of life.

In accordance with other studies about end-of-life care (e.g. Kayser-Jones *et al.*, 2003; Tishelman *et al.*, 2004), our study about good nursing care for patients on the edge of life to a great extent depends on the individual nurse's competence, values and loyalties. However, these factors are not enough. Organisation, staffing and routines, as well as cooperation and communication in the team are imperative for high-quality care. This highlights the important role of nursing leaders in establishing appropriate systems for the employment of nurses, organising nursing care and cooperation in the team around these patients.

In line with other studies (Buchanan *et al.*, 2004; Storch, 2004; Whittaker *et al.*, 2006), our study stressed the nurses'

needs for support in the care of their patients. Nurses need comprehensive knowledge and training to manage good life-saving and end-of-life nursing care. Studies of clinical supervision where nurses are given the opportunity to reflect on themselves as professionals and persons, are found to be valuable to build-up nurses' strength and increase their self-awareness (Hyrkäs & Paunonen-Ilmonen, 2001; Severinsson, 2001; Lindahl & Norberg, 2002). Clinical supervision is also found to improve nurses' awareness of their influence on quality and safety of care with regard to patients in nursing homes (Hansebo & Kihlgren, 2004). The nurses themselves and the leaders too have a responsibility to arrange for nurses' professional development and the proficient performance of nursing care (The Health Personnel Act, 1999; Working Environment Act, 2005; ICN, 2007).

Methodological reflections

This study has some limitations. The choice of informants is debatable, as the research question took its point of departure in the patients' needs, seen through the eyes of the nurses. Perhaps the findings would have been different if patients had been interviewed. However, similarities between the findings in our study and patient-related findings in other studies (Kuhl, 2002; Enes & de Vries, 2004; Shih *et al.*, 2006) support the trustworthiness of the study.

Trustworthiness was also strengthened by interviewing the nurses twice. This procedure could clear up misunderstandings and further deepen understanding as well as discovering more conceptions related to the aim and further deepening them. As data were collected from only two nursing homes, there may be a risk of bias related to local circumstances. However, as generalisation is not relevant in qualitative studies, the question is rather how well the findings fit in with other settings and groups, and how well they fit in with the data (Sandelowski, 1986). In this study, fittingness was substantiated by the collaboration in the research group through the entire research process. The informants and the context were also described as precisely as possible, which might increase the readers' possibilities of assessing the fittingness of the findings related to other contexts.

Conclusions

This study is important as it takes its point of departure in the nurses' conceptions of the individual patient's needs. The findings show that the nurses were well aware that good nursing care means preserving the patient's dignity. The findings also stress that the care could be obstructed by organisational, relational and personal factors. The gap between the nurses'

ideals and ambitions to carry out good nursing care and reality was obvious.

It would be valuable to focus future research on relatives' views of good nursing care related to this group of patients. More research is also needed on this area of practice, as viewed from the perspective of nursing leaders and staff nurses.

Implications for practice

- Nurses, nurse managers and educators need to engage in competence development concerning nursing care for patients on the edge of life in nursing homes.
- Developments also need to focus resources, such as adequate and competent personnel, systems for open communication and cooperation and supportive systems to underpin nurses' professional strength and power.

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Contributions

Study design: RH, EA, BH; data collection and analysis: RH, EA and BH and manuscript preparation: RH, EA, BH.

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