

Preserving dignity in end-of-life nursing home care: some ethical challenges.

Abstract

Introduction. A central task in palliative care is meeting the needs of frail, dying patients in nursing homes. The aim of this study was to investigate how healthcare workers are influenced by and deal with ethical challenges in end-of life care in nursing home. **Method.** The study was inspired by clinical application research. Scientific researchers and clinical co-researchers collaborated to shed light on clinical situations and create a basis for new practice. **Findings.** The analysis resulted in the main theme, ‘Dignity in end-of-life nursing home care’, and the sub-categories ‘Challenges regarding life-prolonging treatment’ and ‘Uncertainty regarding clarification conversations’. **Discussion.** Findings indicate that nursing homes do not provide necessary organizational frames for the team approach that characterizes good palliation, and therefore strive to give dignified care. **Conclusion.** Ethical challenges experienced by healthcare workers are closely connected to inadequate organizational frames.

Keywords: qualitative design, life-prolonging treatment, clarification conversations, organizational frames

Introduction

Although maintained quick death with well-managed control at the end-of-life phase is often seen as the ideal, most of us will die slowly with gradual deterioration and increasing dependence on others¹.

In Norway, 48 per cent of the population end their lives in a nursing home². Due to frailty, most of them have reduced capacity to make autonomous decisions in their latest stage of life. More than 80 per cent are suffering from dementia³ and will therefore have difficulties expressing their wishes and preferences regarding treatment and care.

The holistic perspective of the hospice movement has had a major impact on care in the final phase of life. Palliative philosophy emphasizes the patient's right to be a unique person until the end and underscores the importance of supporting the family. Good palliative care responds to the patient's needs and is planned in dialogue with the patient and his/her next of kin. To preserve dignity in these situations is an important and complex task demanding solid knowledge, sensitivity and flexibility¹. Although dignity is central in nursing, there is no conceptual consensus in the philosophical literature. Empirical research, however, indicates that staff attitudes and behaviour, the physical care environment and organizational culture are factors that can potentially promote or diminish dignity in care⁴. A study on fostering dignity in the care of nursing home residents⁵ found that acknowledging each resident's unique individuality, personal influence and voluntarily participation is essential.

Good palliative care should be given irrespective of where and to whom. It is argued, however, that older people with illnesses other than cancer do not have the same access to such care as other groups^{1,6}.

International research on ethical issues in nursing homes is sparse⁷, but in the Scandinavian countries, there has been an increasing number of studies in recent years addressing amongst other issues the impact of quality of care for dying patients. These studies represents a valuable contribution to the understanding of ethical challenges^{8,9}, nurses' and physicians' practice regarding life-prolonging treatment and how their practice is influenced by organizational factors¹⁰⁻¹² and perspective¹³. Staff and family relationship is spotlighted¹⁴.

From the perspective of nursing home residents, the greatest threat to dignity was that staff did their best and that deficiencies lay in the way the work was organized and staffed¹.

Moreover, nursing home staffs reported perceiving a wide gap between the ideals expressed at the social level and the means at their disposal for realizing them¹. Studies conclude that little focus is placed on the patient as the main person in the decision-making process regarding life-prolonging treatment^{10,12} and that routines are poor for including next of kin^{10,12}. Barriers to proper care at the end-of-life are associated with inadequate organizational structures and lack of knowledge in nursing homes^{1,11,13}.

Healthcare workers who strive to give patients in nursing homes a dignified end-of-life care are therefore in a demanding position. The aim of this study was to investigate how healthcare workers are influenced by and deal with ethical challenges in end-of-life care in nursing homes.

Method

The study is part of a larger research project on the topic of ethical challenges in care for the older patients in community health services. It has a qualitative and empirical design and is inspired by clinical application research, a method based on hermeneutic research understanding. Scientific researchers and clinical co-researchers take part in groups and collaborate over time in a hermeneutic research process to gain knowledge of a phenomenon¹⁵.

The context was a medium-size municipality in Norway with approximately 20, 000 inhabitants. There were two nursing homes, one with 48 rooms and five units, and one with 51 rooms and 7 units. The clinical co-researchers brought in situations from their practice, and

through description, reflection and interpretation of theoretical knowledge, the research staff created a basis for a new action.

Data Collection

Four research groups were established and met 15 times, three to four times each at regular intervals during the period of one year. Each group consisted of six to eight clinical co-researchers (24 women and 2 men), and two scientific researchers. Employees with different health profession background: registered nurses, enrolled nurses, physiotherapists and managers, and from different sectors of the municipal health care services, were the clinical co-researchers in the groups. In the fourth group, the clinical co-researchers were managers at various levels. This variety of backgrounds and experience constituted the clinical co-researchers' (hereafter called the clinicians) pre-understanding.

The scientific researchers (hereafter called the authors) are nurses at PhD level with experience in elderly care. The authors led group sessions. The focus was on ethical dilemmas that the clinicians experienced in their work. Situations were described, reflected on and interpreted on the basis of theoretical knowledge. Alternative practices were outlined, tried out between meetings and then were reviewed and re-discussed.

Analysis

Group interviews were audio taped, transcribed and preliminarily analysed after each collection. We conducted a hermeneutical interpretation in line with Gadamer¹⁶. Care ethics and ethical and legal principles constituted the theoretical understanding and the interpretative perspective from which the authors reviewed the findings.

We read through the entire text to obtain a general impression. We conducted a preliminary analysis and presented it to the clinicians in a validation seminar. They provided suggestions that were incorporated into the findings. The content was thematized, and the main theme, 'Dignity in end-of-life nursing home care', emerged after interpretation of the categories 'Challenges regarding life-prolonging treatment' and 'Uncertainty regarding clarification conversations'.

All authors followed the analysis process and used discussion to reach consensus on the interpretation of data.

Research Ethical Considerations

We conducted the study in compliance with the intentions of the World Medical Association Declaration¹⁷ and standard ethical guidelines and principles¹⁸. The municipal healthcare manager approved the study and gave permission for the healthcare staff to participate. In an initial meeting, we informed participants about the study, told them that participation was voluntary and that confidentiality would be maintained. They signed an informed consent

form. Confidentiality was maintained throughout the study. The Norwegian Social Science Data Services (NSD) (project number 24401) approved the study.

Findings

We present the findings of the study through a description of the main theme and the categories and subcategories that emerged in the analytic process described above.

Dignity in end-of-life nursing home care

The clinicians' overarching attitude was palliative, in the sense that they mainly focused on making the patient's end-of-life phase as comfortable as possible, neither prolonging nor shortening it.

The word dignity was mentioned several times during group meetings. The participants used the word to denote an overall value, aim or goal of the participants in their daily work with dying old patients. Although things were challenging at times, they gave the impression that they had the best intentions for their patients: *We want to help, we want to soothe and to make their life as good as possible... ..A dignified life as long as they live, that's what is important.*

Uncertainty regarding life-prolonging treatment. Although the clinician's attitude was palliative, they experienced some topics or situations as dilemmas, and in these situations, they often felt insecure about what was the right thing to do. Questions regarding life-prolonging treatment were discussed in different group meetings.

A recurrent issue was the limited and fragmented role of the physician. A general practitioner worked part-time in the nursing home one day a week, and could sometimes, but not always,

be consulted during weekdays. On weekends and holidays nurses had to contact physicians on the emergency ward. As a result, nurses experienced fragmentation of responsibility and challenges regarding communication, decision-making and documentation. A typical situation was when infections occurred in older patients with late-stage incurable diseases and nurses felt they had limited decision-making competence. Clinicians attempted to be as prepared as possible: For patients staying on a permanent basis, the physician often communicated with the family and came to an agreement about what to do in different situations that might occur. When the physician was unavailable, however, the nurses had to call the emergency ward, and physicians there were not familiar with the patients or their medical status. If the personal preferences of the patient and their next of kin not known or not documented, nurses sometimes experienced that decisions were made and treatment was carried out based on an insufficient rationale. In addition, the physicians at the emergency ward were often too busy to see the patients themselves or even to speak to the nurses directly. The emergency nurse would give the nursing home staff information pertaining to decisions and prescribed procedures that would later be passed on to the patient's family. If the next of kin did not agree with the decision, nurses sometimes felt they were caught in the middle of a to-and-fro exchange: *I felt that the emergency physician's decision was so difficult for the family to accept so I said I could call the regular physician the next day. But he was still not available, so I once more called the emergency, and the physician on duty came to see the patient*, one participant said. Nurses felt badly about the lack of preparedness that decreased the quality of care for patients and their families. In their opinion, things should already have been talked through with the patient and next of kin as a support for agreed decisions.

Intravenous nutrition or liquids to dying patients was not practiced, but a recurrent dilemma was the use of nutritional supplements. The clinicians often experienced that the old patients, most often those in the final stage of dementia, showed increasing disinterest in food and liquids, and at a certain point would refuse to eat by keeping their mouth shut when someone tried to assist them in eating. They interpreted this behaviour as a sign of approaching death, and as a more or less conscious decision on the part of the patient, a decision they accepted and did not try to pressure or coerce the patient in any way. Usually the patients accepted liquids rather than food, a situation exploited by some nurses, who gave them nutritional supplements instead of water or other fluids. They were not certain whether the patients needed this or not, or if it would prolongs their life or not. Expression like *most of us agree that they do not feel hunger and at least some times, they get a lot of energy from it...she was never left in peace* are examples of their insecurity. They sometimes found it difficult to know whether the patients were hungry or not: *Do you want to taste this? Yes, she says, and the food just stays in her mouth.* In addition, they often found it difficult to assess whether or not the patients were really in the very last stage of life. They had previous experienced that the condition of patients they considered as dying could change for the better for a period before a final deterioration. The supplement was given more or less arbitrarily. There were no institutional guidelines to regulate the practice, but in the community, there was an expert team on nutrition and a coordinator of palliative care available. A consultation with the coordinator reinforced their previous understanding that older patients in this situation seldom felt hunger and thirst, and that disinterest in eating and drinking should be accepted at this stage of illness. This was some help, but the uncertainty surrounding nutritional needs still remained to a certain extent. The physician was restrictive on a principal basis, but was neither directly involved in decisions regarding individual patients, nor engaged in making guidelines. Some nurses used supplements because they found it appropriate to support life as

long as possible, while others felt this way of supporting patients was too radical, or constituted trickery or coercion. This lack of consensus remained an unsolved dilemma and led to arbitrary practice amongst the staff members and to a certain discord between colleagues. They involved the patients by being as sensitive as possible to the nonverbal signs they gave, and by interpreting these signs as wisely as they could. Next of kin were not involved in the assessment and decision-making. Financial concerns were also an aspect that the clinicians took into account. They did not like the thought of spending money on something that the patients maybe did not benefit from.

Uncertainty regarding clarification conversations. Care on a daily basis was organized as a primary care system; all nurses, whether registered nurses or enrolled nurses, had a primary responsibility for a small group of residents. Recently it was decided that this responsibility should include admission conversations with the resident and next of kin within a short time after the new resident was admitted. The physician had no part in it. Issues regarding death and dying, including preferences pertaining to medical treatment and heart/lung resuscitation were to be a part of this conversation. The intention was to address these issues at an early stage, before the resident became too sick or weak to participate in decision-making. The clinician shared the intentions, but questioned the way this issue was organized. The role of the enrolled nurses was discussed in particular, and it was argued that they were given a responsibility beyond their competence, in spite the fact that the team nurse was willing to participate. Participants argued that end-of-life questions should be part of a more medically focused consultation between physician, patient and team nurse. At least one physician had expressed interest in addressing these topics. In addition, some clinicians were not convinced about the whole idea of advance conversations: *It is a strange thing to address*

these questions at admission, because it is a process....Most [relatives] will prefer [life-prolonging] treatment [at this stage] but as time goes by they may change their mind.

The clinicians acknowledged the need for organizational guidelines but at the same time stressed a need for sensitivity and individual judgment and expressed a critical attitude towards formalizing these issues: *You have to be very sensitive; is this the right time to talk about it? It is something that cannot always be planned.* Through the group discussion, a need for better processes regarding organizational aspects of communication with residents and families on end-of-life issues emerged, and they decided to bring these questions into formal meetings.

Discussion

The aim of this study was to investigate how healthcare workers are influenced by and deal with ethical challenges in end-of-life care in nursing home. In this section, we will discuss the categories presented above.

Dignity in end-of-life nursing home care

Caring for dying patients is a central part of nursing home care. In this study, the overall value and practice of clinicians was palliative. Their aim was to make the patient's life as dignified as possible, although they experienced some ethical challenges in their efforts to realize this value. This is in line with dilemmas described in the literature. Holm and Husebø⁶ claim that although older dying people often lose the capacity and freedom to make choices, they do not thereby lose their dignity, which emerges and is either confirmed or violated in an interpersonal encounter with healthcare personnel. Nurses tend to be lonely strugglers striving to do the right thing, a position that frequently results in a feeling of uncertainty and being caught in the middle between too much responsibility and too little formal power to act¹⁹.

Uncertainty regarding life-prolonging treatment. The clinicians in this study focused on making patients' lives as comfortable as possible, in line with WHO's guidelines to prevent under-treatment for older people suffering from chronic diseases, to affirm life and regard dying as a normal process, and neither to hasten, nor to prolong it²⁰. Nevertheless, clinicians experienced some insecurity regarding life-prolonging treatment. Similar findings are described in the literature⁸.

Nurses in this study experienced a dilemma when infections occurred in older patients with a late stage of incurable disease and reduced or eradicated decision-making competence. A review study showed that nurses held a key position in end-of-life decision-making processes. They often initiated processes but perceived their role as diffuse and wished to be more clearly involved²¹. Another study found that nurses were committed to the coordination of life-prolonging treatment and care. Nevertheless, they were more likely than doctors to include resident preferences in care decisions, and this often left them feeling caught 'in the middle' between the resident, relatives and other professionals⁷.

Clinicians in our study felt insecure about whether nutritional support was needed and useful. This is in line with a study by Bryon et al.²¹ showing divided opinions among nurses regarding artificial provision of hydration and nutrition in late stage patients with dementia. Anorexia and weight loss are common in advanced disease and are viewed as very visible signs that the disease is progressing²². The final stage of dementia represents an illness where the body cannot utilize liquids or food. Providing nutrition through tubes or intravenous liquids has little or no impact on the state of health and does not have a life-prolonging effect²³. In the Norwegian national guidelines for limiting life-prolonging treatment in serious

ill and dying patients, these interventions are seen as futile treatment that should not be used²⁴. However, the form of nutritional supplements used in our study is not explicitly mentioned. When older patients, often in the final stage of dementia, refused to eat and drink, the clinicians in this study saw it as a sign of approaching death and as a more or less conscious decision on the part of the patient that they respected by not pushing. This is in line with Bryon et al.²¹ who found that nurses regarded incompetent patient's resistance to nutrition as forceful and reliable. The clinicians sometimes also felt insecure as to whether the patients were dying or not. According to Harris,²⁵ end-of-life care for older people suffering from chronic progressive diseases is often extended, and it is especially difficult to identify the terminal phase of demented patients due to the disease trajectory. In addition, clinicians felt bad about spending money on something that the patients maybe did not benefit from. There were no institutional guidelines regarding the use of nutritional supplements, and the role of the physician was limited. A study by Dreyer et al.¹¹ found that nurses claimed that too much futile treatment was a result of weak frameworks for the collaboration between doctors and nurses. According to national guidelines for discontinuing life-prolonging treatment,²⁴ decisions must be taken in a process that includes the physician, nurse and patient or the patient's representatives.

Uncertainty regarding clarification conversations. The findings show that lack of preparedness decreased quality of care, and clarification conversations was used to increase it. According to Husebø and Husebø²⁶ recurrent, open and preparatory conversations that include the patient, next of kin, clinician and caregivers is the best solution to the challenges of providing older patients with a dignified end of life.

Studies underline the need for early clarification, and it is suggested that the wishes and preferences of the patient and next of kin should be specified already in an admission conversation^{14,27,28}. This is not common practice, however, partly because it is regarded as a delicate issue¹⁴. In contrast, Husebø and Husebø²⁶ claim that the most suitable time is when someone, whether patient, next of kin, carers or clinician, ascertains that death is approaching.

An intervention study in an acute geriatric ward in hospital, where conversations took place between the patient and a physician, showed positive patient experiences²⁷. We have not found intervention studies in nursing homes. It is reported that nurses most often carry out this type of conversation, and the importance of physician's participation is emphasized¹⁴. All parts, especially healthcare workers, are responsible for initiating these conversations, but the main responsibility lies with clinicians²⁶. Enrolled nurses are the largest group of employees in nursing homes²⁴. Findings in our study indicate that enrolled nurses were assigned responsibility beyond their competence when put in a position with responsibility for clarification conversations. It was argued that end-of-life questions should be part of a more medically focused consultation between physician, patient and team nurse. This view is in line with the guide concerning palliative care for older people who suffer from progressive chronic disease²⁰, where a team approach is emphasized to address the needs of patients and their families. Enrolled nurses are more or less absent in guidelines and research literature, but Gjerberg et al.¹¹ found that carers without formal nursing education often feel insecure and therefore tend to avoid these situations.

The clinicians in our study acknowledged the need for organizational guidelines but at the same time stressed a need for sensitivity and individual judgment, and expressed a critical attitude towards formalizing these issues. Some clinicians were not convinced about the

whole idea of clarification conversations. This is in line with Husebø and Husebø²⁶ who use the term preparatory instead of clarification, a distinction with a certain importance.

Ethical, as well as legal and clinic-oriented guidelines and standards have been established in recent years within the Norwegian health care context. The Norwegian social- and health directory²⁹ has defined guidelines for palliation in cancer care, where demands for services, organization, employees and facilities are described. Even nursing homes without a special palliative unit must be able to perform basic palliative care for all patients in nursing homes. In addition, they must develop and ensure procedures for pain- and symptom relief. Experiences with standards are promising, but not sufficient. Continuous updating of professional skills and knowledge is also necessary³⁰.

In line with research literature, our findings showed a need for better processes regarding organizational aspects of communication with residents and families. The lack of meeting points and processes between patients, next of kin and staff undermined quality¹³. Although healthcare workers in nursing homes experience satisfying relations in end-of-life nursing¹⁴, poor communication between healthcare workers, patient and family can lead to difficulties^{12,30}. The inclusion of the resident in decision-making was found to be challenging, and residents were least involved when their capacity was questionable⁷. In such instances, the nurses saw themselves as strong advocates for the resident's wishes and consequently played a greater role in decision-making, especially when dementia was present. Dreyer¹⁰ points out that clarifying roles appears to be the key to preventing conflicts. According to Ternstedt¹ a caring culture promoting dignity is characterized by rituals built on a dynamic interplay between staff and client, and there may be a connection between stereotyped interplay and competence level. The competence level of employees working in nursing homes is an important prerequisite for ensuring quality in end-of-life nursing home care. A

literature review explored major discrepancies between the advanced competence expected in policy documents and the actual competence as described in the research literature^{31,32}.

According to Wille & Nyrønning³⁰ it is a prerequisite in palliative care that the physician arrange for continuity so that treatment can be carried out and adjusted on a daily basis.

However, research found physicians' lack of time to be a major barrier to decision-making³³ and communication with relatives³⁴. In eight of ten Norwegian nursing homes, doctors held a 20 per cent position, which is described as extremely limited for good processes¹¹. When access to physicians was high, good coordination of care¹¹ and a higher prevalence in the presence of guidelines for nursing homes¹⁴ was described.

Methodological discussion

The study is inspired by clinical application research, a method where scientific researchers and clinical co-researchers over time collaborate by taking part in groups. The continuity and common understanding that this method makes possible seemed to enrich the data and thereby strengthen the study. Even richer data could have emerged if the field period had been longer. It is a strength that all authors followed the analysis process and used discussion to reach a consensus on the interpretation of data. The settings have been described as nursing homes in a Norwegian context, and have transferability to similar contexts.

Conclusion

The study showed that while providing end-of-life care in nursing homes, clinicians strived to preserve dignity for their dying old, frail and often cognitively impaired patients. In their effort to meet expected standards of palliative care, they experienced issues regarding life-

prolonging treatment and clarification conversations with patients and next of kin as ethically challenging. The findings are in line with research indicating that nursing homes do not provide necessary organizational frames for the team approach that is known to characterize qualitatively good palliative care. It seemed that the role of the physicians was too limited; the enrolled nurses were assigned responsibility beyond their competence, and the nurses played a central and demanding coordinating role between the patients and their relatives on the one hand and the physicians on the other.

Conflict of Interest Statement

The authors declare that there is no conflict of interest.

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