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Ethical decision-making in nursing homes: Influence of organizational factors

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Abstract
In this article we report findings from a qualitative study that explored how doctors and nurses in nursing homes describe professional collaboration around dying patients. The study also examined the consequences this can have for the life-prolonging treatment of patients and the care of them and their relatives. Nine doctors and 10 nurses from 10 Norwegian nursing homes were interviewed about their experience of decision-making processes on life-prolonging treatment and care. The findings reveal that the frameworks for the professional collaboration and organization of physicians and nurses prevent patient treatment and care complying with ethical considerations and the law. These conditions have a challenging impact on the care of dying patients and their relatives.

Keywords
collaboration, decision-making, end-of-life, substituted decision-maker

Introduction

Currently 15% of those over the age of 80 in Norway live in nursing homes, and it is assumed that the number of people over this age will increase up to the year 2050.[1] It is estimated that 75% of these have been diagnosed as suffering from dementia, and in addition many of them suffer from other severe medical conditions. A high proportion of these patients move between hospitals and nursing homes.[2] There is no Mental Capacity Act in Norway. However, according to the Patients' Rights Act,[3] when a patient is assumed incompetent to consent to treatment, relatives should be included in decision-making processes so that they can provide information about the patient's presumed preferences. A 'living will' is rarely used in Norway, and these are not regulated by law. Norwegian legislation strongly emphasizes collaboration between the physician responsible for medical treatment and other professionals (nurses).[3,4] Guidelines for end-of-life decisions were published in Norway last year; these also strongly emphasize this collaboration.[5]

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Health policy guidelines and frameworks affect treatment and care at the micro level. Although physicians are legally responsible for medical treatment, poor economy in the municipalities and internal political prioritizations often reduce the coverage of doctors in nursing homes to a minimum.[6,7] Nurses are managers, responsible for the running of the nursing homes, and they carry out the medical treatment prescribed by a physician. They represent round-the-clock care, while most nursing home physicians hold part-time positions.

In a previous article, we studied relatives' experience as substitutes in the decision-making process on the issue of life-prolonging treatment. We found that nursing homes lack routines to include patients and next of kin in end-of-life decisions.[8] We have also studied the ethical principles that guide the physicians' and nurses' end-of-life decisions in Norwegian nursing homes: we found that in general doctors and nurses have concurrent attitudes and reasons for initiating life-prolonging treatment. Autonomy is not a major consideration, and their approach is based rather on the principles of benevolence and doing no harm. The practice of physicians and nurses deviates from the attitudes they themselves express. For example the findings showed that relatives were included in decision-making processes on treatment without a prior and adequate assessment of the patient's competence to give consent.[9]

In this article we study how doctors and nurses in nursing homes describe professional collaboration around dying patients. We examine in particular how the organization and external frameworks affect this collaboration, and the consequences this can have for the treatment and care of patients and their relatives.

Background and previous studies

As institutions, nursing homes are faced with exceedingly demanding medical and ethical challenges. These challenges set considerable requirements regarding professional competence and collaboration – internally as well as externally vis-a-vis hospital.[10] In theory, end-of-life care has been prioritized for more than a decade in Norway. Although the need for more professionally-qualified staff in the nursing home sector has been emphasized, the proportion of unskilled workers in these homes constituted more than one-third of the employees in 2008.[10,11] Working in nursing homes has a relatively low status, and many such homes have recruitment problems. Figures show that in 2003 there were 167 nursing home patients per full-time physician, whereas in comparison there was one full-time physician to every other hospital patient.[6,7]

Patients, particularly elderly patients, are dependent on the various levels of treatment being conducted in a continuous chain to ensure that each individual receives good medical treatment and care. Poor collaboration has been revealed between the levels in the Norwegian public healthcare service, and in 2009 a report to the Norwegian parliament was issued.[2] This reform was aimed at ensuring better continuity in the treatment of patients across the various levels to prevent them being shuttled from one part of the health service to another (this reform has not been implemented). The term 'collaboration' in this context entails professional collaboration among the various professions and across institutional borders.[12,13]

Moral distress is a term that has increasingly been used in international literature to describe the gap between ideals and reality in the health sector.[14–18] The results include burnout and a high staff turnover. Both time and the opportunity for professional discussions in nursing homes, as well as training, are necessary to enhance employees' ability to tackle ethical challenges.[6] Care in the terminal phase of life is a prioritized task, and it is important to understand the obstacles that prevent this important duty being fulfilled in the best possible manner.

Method

Informants and recruitment

Nine doctors and 10 nurses from 10 Norwegian nursing homes were interviewed about their experience of decision-making processes on life-prolonging treatment and care in nursing homes (Table 1). The informants

Table 1. Informants' demographic data

Variable	Doctors	Nurses
No.	9	10
Age: mean	44	50.5
Experience (Year*):	11	9.8

(* = mean experience as employee in nursing home)

Table 2. Nursing homes' demographic data

Variable	Location	Number of patients	No. of departments in the nursing home (dementia units)	Total physicians' employment 1 = 100%	Total nurses' employment 1 = 100%
Nursing home					
1	city (< 100 000)	72	3 (1)	0.6	15
2	city (> 200 000)	108	5 (1)	0.8	16
3	Extended built-up area	22	2 (1)	0.2	11
4	Smaller rural district	62	3 (1)	1.0	17.13
5	Extended built-up area	36	4 (1)	0.2	8.5
6	Extended built-up area	31	4 (1)	0.3	13
7	city (< 100 000)	59	7 (2)	0.6	19.5
8	city (< 100 000)	40	2 (1)	0.6	13.27
9	city (< 100 000)	58	3 (1)	0.4	15.75
10	city (> 200 000)	96	6 (2)	0.9	19

were selected by the nurse in charge. The criterion for inclusion was more than one year's employment in the institution.

Research field

Responsibility for the nursing homes is part of municipal management, and the service can vary from one location to another. Most nursing homes in Norway are public and are institutions for patients who need full-time care. To ensure the greatest variation possible in the data collection, the criteria of *purposive sampling* were used as a basis.[19,20] The geographical spread of the nursing homes, the size and type of location, and the size of the homes were key variables (Table 2).

None of the physicians at the 10 nursing homes were employed in full-time positions: most of them were employed one day a week (20% positions). Five nursing homes had several doctors in such 20% positions.

Depending on the size of the nursing home, one to two of the total numbers of nursing positions were held by nursing managers (purely administrative). The nurses were otherwise distributed among the different departments, with up to one man-year allocated to the function of department head. The nurses were employed in 50% to 100% positions.

Registered Nurses in Norway have their general education in nursing from University Colleges (a Bachelor's degree). Authorization as a general nurse is granted to applicants who have successfully completed their nursing training.[4] Further training is available in different areas: geriatrics, psychiatry, palliative care, intensive care, etc. While registered nurses are responsible for the nursing care in hospitals and nursing homes, physicians are responsible for the medical treatment, although they can delegate certain procedures to the registered nurses.

Box 1. Research questions

- What experience of decision-making processes on the issue of life-prolonging treatment do physicians and nurses in nursing homes have?
- How do physicians and nurses describe coordination regarding life-prolonging treatment within the nursing home and externally vis-a-vis hospitals and A&E units?
- What consequences do internal and external professional organization and coordination have for patients and relatives?

Data collection

The in-depth interviews lasted 30–60 minutes. They were recorded on a digital recorder and transcribed by the researcher (AD) immediately after the interviews. An interview guide was developed on the basis of the following research questions (Box 1):

The interview guides (separate ones for doctors and nurses) were thoroughly assessed after each interview and were revised if necessary to permit an in-depth examination of new topics that had arisen in the former interview.[20,21] To ensure ample data, emphasis was placed on allowing the interviewees to relate their experience without proceeding rapidly to other subjects. Only clarifying questions such as 'What did you mean by that?' were asked before they themselves closed the subject.[22] Ten nursing homes had been included when data saturation was obtained. One of the doctors who was approached refused to be interviewed.

Analysis

The analysis in qualitative studies is often exclusively viewed together with the text analysis of transcribed interviews. To ensure the quality/reliability of the study, priority was also given to making an explicit analysis of each stage of the research process.[22] The text analysis of the transcribed interviews is based on the research questions given above.

The interview texts from doctors and nurses were first analysed separately, after which similar subjects were analysed in relation to each other across professional affiliations. This made it possible to examine whether there was consensus or discrepancies in the description of the practice. Key categories related to coordination were: organizational and professional frameworks for coordination within the nursing home, different patterns of professional coordination, treatment responsibility, and coordination with hospitals. These categories are presented as subheadings in the results section.

The authors reviewed and discussed the data material and the text analyses together. In the quotations, N stands for nurse and P for physician.

Research ethics

The study was approved by the Regional Committee for Medical Research Ethics and the Norwegian Social Science Data Services. Written informed consent was obtained from all the participants before the interviews were conducted.

Results

The participants showed a surprisingly deep commitment to the issue of coordination in the decision-making processes on life-prolonging treatment and care. The findings show that both physicians and nurses experienced that they were not always capable of providing patients in the terminal phase of life with acceptable medical help and care, or of giving relatives the necessary care. The general situation regarding professional

coordination was described as marginal within the nursing home. The nursing home physicians also referred to deficient and to some extent censurable conditions regarding professional medical coordination with colleagues in hospitals.

Organizational and professional frameworks for coordination within the nursing home

Organization

At eight of the 10 nursing homes where physician posts were covered by doctors who each held a 20% position (one day per week), the time the physician spent at the nursing home had to include his/her round of medical examinations and medical treatment, conversations with patients and relatives, administration and documentation. The doctors and the nurses describe the general situation for such part-time positions as extremely limited if good processes with the patient and relatives are to be conducted on difficult questions concerning life-prolonging treatment. A representative statement was as follows:

> ... the problem with being a duty doctor is that we're only there one day a week. Perhaps the greatest challenge in handling these patients properly is to avoid exposing them to unnecessary examinations and treatment – and to have time. Time is a major factor in coping with these issues. (GS07P)

The two doctors who held a 60% and a 90% position respectively described coordination within the nursing home as good because they had the opportunity and frameworks to allow coordination with the nurses. This also created a good basis for appropriate processes with patients and relatives. Statements from the nurses confirmed this.

> ... we got a nursing home doctor three years ago. Before that there were five different doctors who each worked one day. A very poor solution because there was no overall perspective in it – they each did their own job and they had five different viewpoints. So it was pretty confusing for the nurses. Now we have the same system in the whole building – the same medical records and the same requirements. It functions very much better and I enjoy my work. A lot of people told me that I shouldn't work in a nursing home, but I find it very challenging. (BS02N)

Competence

At two nursing homes most of the Registered Nurses had undergone continuing education in geriatrics or palliative care. This was described by the physicians as a major factor affecting the quality of the cooperation. They expressed their confidence in the nurses, and emphasized the importance of their competence. At one of the nursing homes where there was an integrated palliative unit, the requirement regarding competence was to the benefit of the entire nursing home:

> It's a big responsibility: it's often a nurse who has all the responsibility and who has to take a quick decision ... Many of the nurses here are taking continuing education in cancer. They're very proficient. The level here is high. Here I meet – not that it belittles others – but it seems that they maintain a high standard here compared with many other places. (HS08P)

On the other hand, one physician described dilemmas with newly-qualified nurses: they could have strong feelings *against* futile life-prolonging treatment, but they retracted and implemented decisions on treating the dying in the nursing home if they experienced that it became professionally demanding.

Good documentation from the nurses, including assessments of futility, was regarded as necessary to enable a physician to give the patients the best treatment. Good documentation also creates a platform for coordination of communication with the relatives. Several physicians referred to censurable conditions at some nursing homes where there was practically no written documentation from the nurses. They put this down to possible poor computer skills, a fact that was confirmed by the nurses.

Different patterns of professional coordination

Professional consensus and good cooperation

At nursing homes where the physicians held high percentage posts, general questions on admission and on life-prolonging treatment were key topics of discussion with the nurses. This formed the basis for discussions about individual patients. Patients were involved when their state of health made it possible. Another central subject was clarification of medical responsibility. This included how the nurses were to handle more or less acute situations outside the physician's working hours for each patient, which led to greater predictability in medical treatment, fluids, nutrition and hospitalization. The patient's medical records were updated on the basis of joint discussions, which simplified dialogue and cooperation with the next of kin.

Professional consensus with limited opportunity for cooperation

The physicians and nurses at nursing homes where the doctors held low percentage positions stated that they had mutual standpoints with regard to treatment. Nonetheless, what occurred in acute situations when patients' conditions deteriorated could be determined by sheer coincidence:

> Then it happened – just two days ago – a patient had a stroke. In the afternoon. When it happened the doctor was here, and the daughter. We were incredibly lucky. If the doctor hadn't been there, if the daughter hadn't been there – or if it had been an unknown nurse or duty doctor – then the nurse would have rung the Accident and Emergency. 'Just bring him in'. Then we'd have had a very undignified situation. (HS08N)

At a nursing home where there were three physicians who each held a 20% position, both the doctor and nurse described how they had jointly reached consensus in the form of a restrictive attitude to life-prolonging treatment. Both the physician and the nurse gave a somewhat vague description of this joint decision, and they described little time to discuss individual patients. This made it more difficult for the doctors to stick to their decision if the relatives requested active life prolonging treatment. On the other side, in certain situations when patients suffered from acute pneumonia, the physician withheld treatment that should be given – because of this consensus. The doctor did not know the patient well enough and there were no individual discussion.

Few professional discussions and limited cooperation

At five of the nursing homes the descriptions from physicians and nurses could indicate that coordination was governed by the tasks that arose from day to day. The nurses ran the home and administered treatment initiated by the doctor. When patients became ill or unforeseen factors emerged, they handled the situation with little prior preparedness. This applied, for example, to spontaneous meetings with relatives who contacted them directly, which in some cases could result in unplanned admissions.

At one nursing home the doctor and nurse gave concurrent information that the physician had the sole responsibility for the treatment since they had too little time for professional coordination. They had no procedures and little coordination regarding the patients, two factors that the nurse missed.

Treatment responsibility

Both physicians and nurses made it clear that it was the physician who had the formal responsibility for the treatment. The only doctor who said that he always resisted pressure from the relatives to provide treatment he considered unacceptable spent considerable time communicating clearly with the relatives.

This physician was one of the two who held a high percentage position. He was responsible for the treatment, and he was therefore concerned about making the responsibility clear to all those involved in the decision-making process. He described close cooperation with the nurses – including the cooperation with relatives. He delegated follow-up of the communication with relatives solely to the nurses, in line with prior discussions. The nurse in the team said:

> ... we listen to the relatives ... they must be heard ... but the doctor has a certain responsibility regardless – he's responsible for the treatment and he takes the ultimate decisions. Even though he asks for advice. It's important to make sure that ... they [the relatives] aren't left with the thought: 'Why didn't I do it ... maybe I could have helped my mother?' They push us more and more, but once they realise that this isn't 'my' responsibility, then most of them think it's OK. (BS02N)

The nurses claimed that too much futile treatment was a result of weak frameworks for the collaboration between doctors and nurses. The doctors who held 20% positions described an ad hoc approach to treatment. In such cases, to prevent futile treatment, the nurses at their own initiative explained the death processes to the relatives:

> It's very important that we approach the relatives and take up the problem ... that we go and talk to them before they have formed a picture of the patient 'lying there starving to death'. We have to explain the process ... I remember talking to them about fluid treatment ... and about pain alleviation in the terminal phase. By giving them time and the explanation they needed I think they realised what we were saying – and they could ask their questions: why we did such and such. We were very comfortable with the situation, and I felt that they were too. (DS04N)
>
> But there's one thing – I think we must build confidence. The relatives must feel confident that we can actually manage this process. What we can do here ... and what the patient needs. (HS08N)

Coordination with hospitals

The physicians who were interviewed directed their sharpest criticism towards their own colleagues. Transferring patients from hospitals to nursing homes as 'treatment completed' cases was the most common way in which patients were admitted to nursing homes. The physicians gave us several censurable examples of how this occurred:

> ... discharge patients senselessly without giving us prior warning. We've had very ill patients discharged on a Friday. With IV and all sorts of advanced treatment. It's totally unmanageable, so we're not very happy about the situation. (DS04P)

The nursing home's physician also doubted to what extent the hospital doctor has had discussion about life-prolonging treatment with the relatives before they send the patient to the nursing home:

> We're in the situation where we receive dying patients from the hospital . . . the hospital says that the treatment of the patient has been completed, but they say nothing about whether they've had any thoughts on the subject, and nothing about whether they've talked to the relatives about it. (BS02P)

This situation was a confusing starting point for the nurses' communication with patients and their relatives. If patients were hospitalized from nursing homes, they could be quickly sent back there without the hospital doctor conducting any examinations. In addition, the duty doctors described with great frustration how in other cases physicians at the hospital initiated futile treatment on ill patients without consulting those who knew them, and without considering whether the patient would benefit from the treatment.

The nurses also reacted to the fact that patients who were admitted for various examinations or, for example, for fractures came back dying with PEG tubes without this having been discussed with the nursing home doctor. Relatives were frustrated when the dying patient was returned to the nursing home. The nurses then had to spend extra time with the relatives to clear up the situation.

At one hospital, physicians in the medical department had contacted the duty doctor to discuss professional issues about admitting nursing home patients from the hospital's catchment area. At another nursing home where the doctor had a high percentage position, he had contacted the anaesthesia department at the hospital to set up training for the nurses in inserting IV tubes. Both examples were personal initiatives taken by doctors in their frustration about, and in the hope of preventing, undesired admissions of old and dying patients that culminated in undignified situations.

Discussion

Our study shows that limited resources, few doctor posts and inadequate staffing in nursing homes undermine good medical treatment and care for patients in the final phase of life and for their relatives.[10,23,24] The physicians, as those responsible for the medical treatment, must have a platform that facilitates professional discussions with nurses on issues related to life-prolonging treatment in general, as well as discussions related to individual patients.[25–27] Such collaboration constitutes an important platform for the provision of high-quality care for the patients and their relatives. The frameworks for the professional collaboration and organization of physicians and nurses prevent patient treatment and care complying with ethical considerations and the law.[3,4,28,29] Duty doctors in nursing homes are in a very difficult position between the role and responsibility assigned to them by the health authorities and the situation and opportunities for collaboration with patients and relatives, with nurses within the nursing home and with hospital doctors. When professional coordination between those involved is weak within the nursing home, the findings show that the main person – the patient – is pushed into the background. Professional discussion and internal consensus in the treatment team are described in literature as important for the professional quality of treatment and care.[25,30] Providing information about diagnosis and treatment is the responsibility of Norwegian physicians but can be delegated to the nurses. However, better conditions for discussions between the responsible doctor and the nurses must be provided as a basis for enabling the nurses to give information to the patients and their relatives.

Patient autonomy is a strong ideal in western health care. When decision-making processes are weak, patient autonomy is easily offended and is not practised in line with clinical ethics and the law. The consequences may be unnecessary hospitalization and burdensome and futile life-prolonging treatment.

A previous partial study showed that doctors and nurses largely have concurrent attitudes and views on life-prolonging treatment.[9] We found in this present study that neither physicians nor nurses have the opportunity to create mutual processes, and that the lack of professional discussion within the team and poor cooperation with the patient and relatives conceal the individual's attitude and responsibility. The result is that the

focus is shifted from the patient to the *relationship* between the various players in a weak decision-making process. We found that a clarification of the roles and responsibility at different levels is required to ensure that patients receive proper treatment and that relatives are included in a caring manner.[25]

Nursing homes and hospitals – what is the right level of treatment?

A previous study showed that physicians and nurses agree that it is best for the dying patient to avoid hospitalization.[9] Thus, our present study reveals that when pressured by relatives physicians frequently hospitalize the patient against their own professional judgement. The nurses could have played an important role in these discussions on the basis of their familiarity with the patient, but their opinion is rarely heard by physicians in part-time positions. Several of the scenarios in our study described nursing home patients and their relatives being shuttled between the primary and secondary services.[31–33] We see that dialogue and documentation between the treating doctor in the nursing home and the hospital is weak.[34–37] The patient's presumed wishes and any statements related to life-prolonging treatment were in some situations subordinated to organizational aspects or were completely ignored when the decision was taken.[38] Moreover, the issue of responsible treatment seems to be subordinated to disagreement on unclear organizational responsibility between the primary and secondary services. Experienced nurses seem to be more consistent in their assessment of unethical futile treatment for individual patients than younger nurses, who may draw back if tasks become complex and demanding. In Norway, a high percentage of the new nurses start their careers in nursing homes.The doctors need support from the nurses in the decision-making processes, but described their frustration when young nurses avoid professional responsibility. Gillespie and Peterson[39] discuss a framework for assisting novice nurses to develop their decision-making skills, and this may be useful in preventing suffering due to undesired hospitalization.

Consequences of poor collaboration

We found that a failure of professional collaboration puts internal loyalty to the test, for example by nurses contacting other physicians in order to have their personal view on treatment level accepted since the doctor accedes to forceful next of kin. We found that lack of professional collaboration within the nursing home gives misplaced power and responsibility to such relatives. When responsibility is not communicated among those involved, and when the processes are ambiguous, we found in a previous study that relatives may assume a responsibility that they do not want but that they feel obliged to take to ensure that their family member receives treatment.[8] Conflicts that arise between healthcare staff and relatives might be caused by misunderstandings due to lack of collaboration between physician and nurse. Furthermore, we found that poor collaboration might reduce the healthcare staff's ability to appreciate the relatives' situation and their reactions to the fact that they are experiencing grief, which in turn may lead to irrational demands for treatment.

We found that failing to assign responsibility for documentation to the nurses also undermines the physician's responsibility for the treatment,[40] and thereby proper care in keeping with ethics and the law.

A restrictive attitude to life-prolonging treatment stemming from basic discussions within the nursing home can undermine the treatment of patients of an advanced age in cases where such treatment is justified. Our data showed that generalization thus becomes a trap since there is no room for discussion on individual patients. Moreover, lack of professional collaboration will hinder optimal palliative treatment of dying old people.[41] Good palliative treatment requires specialized knowledge and cooperation among various involved professionals, both within the nursing home and also in dialogues with, for example, a geriatric or palliative treatment unit in a hospital.[41] During the last decade palliative units in some nursing homes and further education in palliative care have been established in Norway for nurses. Physicians interviewed appreciated this

competence, but realized the limited possibilities of benefiting from this in mutual discussions due to time constraints.

Professionally responsible treatment of nursing home patients, in line with ethics and the law, is not only an individual obligation but also an organizational duty.[3,4] The *responsibility* of both the individual and the organization must be clarified to ensure that nursing home patients and their next of kin are given treatment that complies with ethics and the law.[25]

More focus should be placed on procedures on the possibility for collaboration across the primary and secondary services.[41] We found that insufficient collaboration between these levels is a threat to trustful relationships between patients/relatives and the nursing home staff. Various studies emphasize the importance of good communication among physicians, nurses and the other parties involved in patient treatment to ensure the quality of the treatment and care.[25,29] Furthermore, satisfactory frameworks for professional discussion might give the nursing home as an arena a higher status among both doctors and nurses, which in turn may ensure that the quality of the service will cease to be characterized by unethical and illegal practice.

Not only frameworks, but also competence and knowledge about collaboration, are necessary to ensure dignity in treatment and care.[42] Multidisciplinary collaboration should be based on visible staff members who display professional integrity in their work.[12] The blurring of professional boundaries may lead to the loss of important specialist knowledge, and decision-making processes may become unilateral.[13, 43–45]

Conclusion

This study shows that clinical ethics do not develop in a social vacuum but are affected by external factors. Practice is not in line with the Norwegian legislation, which sets strong guidelines for collaboration.[3,4] The fact that values and norms are influenced by how health care is framed is hardly a phenomenon particular to Norway. A deeper understanding of how organizational factors influence values must be sought in each individual setting. Discussions on ethics must be viewed in the light of the clinical context in order to understand why ethical principles are not followed. Qualitative research has clear limitations and is often criticised for the small samples used. On the contrary, this sample (purposive sampling) from 10 nursing homes has been selected and studied because of its broader relevance.[19,22] As receivers of these results, nurses and other professionals in other nursing homes in both Norway and other countries must assess the information and consider it as a possible working hypothesis rather than as a conclusion.[19]

Matters that are revealed in empirical studies, with subsequent ethical discussion, can bring ethics into the clinical context to which they belong.[46]

Conflict of interest statement

The authors declare that there is no conflict of interest.

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