

Life-prolonging treatment in nursing homes: how do physicians and nurses describe and justify their own practice?

A Dreyer, R Førde, P Nortvedt

Section for Medical Ethics,
Department of General
Practice and Community
Medicine, University of Oslo,
Norway

Correspondence to

Anne Dreyer, Aalesund
University College/Section for
Medical Ethics, Department of
General Practice and
Community Medicine, University
of Oslo, Bredelia 8, Aalesund
6018, Norway; aod@hials.no

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ABSTRACT

Background Making the right decisions, while simultaneously showing respect for patient autonomy, represents a great challenge to nursing home staff in the issues of life-prolonging treatment, hydration, nutrition and hospitalisation to dying patients in end-of-life.

Objectives To study how physicians and nurses protect nursing home patients' autonomy in end-of-life decisions, and how they justify their practice.

Design A qualitative descriptive design with analysis of the content of transcribed in-depth interviews with physicians and nurses.

Participants Nine physicians and ten nurses in 10 nursing homes in Norway.

Results and interpretations Assessment of the patient's competence to consent to treatment is almost absent. The physicians build their practice on the principles of beneficence and nonmaleficence. Nurses tend to trust the patients' rejection of life support, even when the patients have difficulty speaking or suffer from dementia. Relatives were, according to the health personnel, included in decision-making processes to a very limited extent. However, futile life support is sometimes provided contrary to the physicians' judgement of what constitutes the patient's best interest on occasions when they are pressurised by next of kin.

Conclusions The study reveals a need to improve decision-making routines according to ethical ideals and legislation. Conflicts between relatives and healthcare professionals in the decision-making process deflect the focus from searching for the best possible treatment for the terminal patient. Further discussion is required as to whether the concept of autonomy is applicable in situations in which the patient is impaired and dying.

INTRODUCTION AND BACKGROUND FOR THE STUDY

To give good quality care to dying patients in nursing homes includes making the right—although ethically challenging—decisions concerning the limitation of potentially life-prolonging treatment. In addition to respect for patient autonomy in the end-of-life situations, care for the relatives also requires moral attention.^{1,2}

Norwegian legislation gives dying patients the right to refuse life-prolonging treatment. When a patient is unable to make medical decisions, this legislation gives relatives the opportunity to consent to treatment that is in line with the patient's presumed or actual wish(es).³ International literature reveals that a change in practice is required to protect patient autonomy in the decision-making process concerning life-prolonging treatment.^{2,4}

However, we have little knowledge of end-of-life decision making in Norwegian nursing homes. In a previous paper, we have focused on how the relatives of 20 patients who died in nursing homes experienced their role in the decision-making process.⁵ According to the relatives, none of the institutions seem to have procedures or guidelines for including relatives in the decision-making process. The interviews showed that the relatives were frequently not included in consultations with healthcare personnel until immediately before the patient was dying. The interviews also revealed low awareness among the relatives of whether or not the patient had been capable of making decisions and that sometimes at the relatives' request the patients had been given active treatment against the patients' previously expressed wish. Furthermore, the interviews also revealed poor knowledge among the relatives about end-of-life issues, that is what happened when the patient stops eating and drinking.^{6,7} Our conclusion was that communication with relatives on end-of-life issues needs to be improved in nursing homes.^{7,8} However, relatives' statements from qualitative in-depth interviews are subjective and built on experience in a period of distress.^{1,9} Therefore, the relatives' perspective must be supplemented with the perspectives of healthcare personnel. The aim of this paper is to present how doctors and nurses in nursing homes describe and justify their own practice concerning end-of-life treatment. How is patient autonomy protected, and what values are the professionals' decisions built on?

METHOD

The study has a qualitative approach. Ten different nursing homes in Norway were included in the study based on purposive sampling that seeks maximal variation in the qualitative selection in order to bring out different aspects of the topic being studied.^{10–12} Table 1 shows demographic data of the nursing homes.

Informants

Nine physicians and 10 nurses from the nursing homes from which the relatives were recruited (table 2) were interviewed about the decision-making process related to limiting life-prolonging treatment. The interviews with the healthcare personnel did not deal with the 20 dying patients whose relatives were included in the first part of the project.

Data collection

The in-depth interviews lasted 30–60 min. They were recorded on a digital recorder and transcribed

Table 1 Nursing homes' demographic data

Variable: location	Patients (Total number)	No. of departments in the nursing home (Units for demented)	Physicians' employment 1 = 100% (No. of physicians)	Nurses' employment 1 = 100%
City (>200 000)	108	5 (1)	0.8 (2)	16
City (>200 000)	96	6 (2)	0.9 (1)	19
City (<100 000)	72	3 (1)	0.6 (3)	15
City (<100 000)	59	7 (2)	0.6 (3)	19.5
City (<100 000)	40	2 (1)	0.6 (3)	13.27
City (<100 000)	58	3 (1)	0.4 (2)	15.75
Extended built-up area	22	2 (1)	0.2 (1)	11
Extended built-up area	36	4 (1)	0.2 (1)	8.5
Extended built-up area	31	4 (1)	0.3 (1)	13
Smaller rural district	62	3 (1)	1.0 (5)	17.13

by the researcher (AD) immediately after the interviews. An interview guide was developed on the basis of the following research questions:

- ▶ What experience do doctors and nurses have with decision-making processes concerning questions of life-prolonging treatment where the patient is not competent to give consent?
- ▶ How do physicians and nurses describe their practice regarding life-prolonging treatment?
- ▶ What reflections and reasons lie behind the professionals' actions in relation to life-prolonging treatment?
- ▶ What role and involvement do relatives have in such issues?

The sequence of the interviews with relatives, doctors and nurses was random in order to secure in-depth data about the decision-making processes. The interview guides (separate guides 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,^{12 13} that is the first interview with a doctor revealed that real assessment of competence to consent to treatment was absent. The topic 'assessment of competence' was then included in the following interviews. It seemed easy for both the doctors and the nurses to talk about medical and practical topics, but in order to reveal reflections on their (own) practice and ways of reasoning, some leading questions had to be asked.^{10–12} Ten nursing homes were included when data saturation was obtained; hence one of the doctors approached refused to be interviewed.

Analysis

The text analysis of the transcribed interviews was conducted in different phases: the text was first condensed without adding or removing significant elements, after which it was coded in meaning units and in turn the codes were connected to themes underlying the research questions.¹³ Datasets from physicians' and nurses' interviews were analysed separately at this phase. To secure the internal validity between the themes, codes and the underlying text (the transcribed interviews), a constant comparative approach was used.^{11 12} Further analysis of the themes and the coded text, that is re-reading over and over again and supplementing with written comments, generated three categories based on the research questions. These are presented

as subheadings in the results section. As validation, all transcribed interviews were read twice after the analysis and discussed with the co-authors.

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

Despite realising the need to cooperate with the relatives to prevent conflicts related to life-prolonging treatment, only one of the doctors claimed to include the patient (whenever possible) and relatives in a genuinely mutual process during the entire stay in the nursing home (BS02L). Conversations on admission, including the relatives, were rarely arranged, though both the doctors and the nurses realised the important impact such meetings might have on the decision-making processes in end-of-life situations.

Assessment of competence and securing patient autonomy

Only two of the physicians presented an adequate, theoretically-based understanding of the concept of 'competence to consent'. These two physicians were aware that competence often changes and must therefore be repeatedly assessed, and they stressed the importance of assessing different levels and areas of competence. One example mentioned was a demented woman's consistently expressed resistance to one of her daughter's proclaimed role as the nearest relative:

A patient can be inside her world of dementia, but be clear as crystal in relation to her heritage—and at the same time be unable to find her room. She can be partly able to take different decisions, and then she has to be heard. You can suffer from severe Alzheimer's disease, and still be able to decide which of your three daughters you want to participate in the decision-making process concerning your end-of-life treatment (BS02L).

Words used by the other physicians when asked about what an assessment of competence entails include: demented, conscious, awake, lucid, quick etc. The content and practical consequences of the concept, however, were blurred. The nurses emphasised that they normally spend more time with the patients than the doctor, and that they strive to uncover the patient's wishes and preferences. They claimed that they understand the patient's non-verbal communication, even when it is weak. The nurses seemed to go beyond the scope of definitions of competence and were seeking the expressed preferences in each separate situation:

Table 2 Informants' demographic data

Variable	Doctors	Nurses
No.	9	10
Age: mean	44.0	50.5
Experience (year*):	11.0	9.8

*Mean experience as employee in nursing home.

There was a demented patient, she pressed her lips together and refused to eat and drink any more. It was obvious that she had come to the end. Then we gave her a choice. She did the same when we came to give her pills with a spoon. I said that this is medicine that will take away your suffering and pain and will not prolong your life. She opened her mouth and swallowed the pills (CS03S).

Only two of the doctors said that they as part of their routines tried to determine the patient's own opinion about life-prolonging treatment before the patient became impaired. The other doctors did not seem to search for the patients' preferences. When life-prolonging treatment is being questioned, most doctors may ask the relatives for their opinion. Thus our findings reveal that the physicians are more focused on the relatives' opinion than on protecting the patient's autonomy. The physicians' statements revealed that they experience relatives' wishes as based on a mixture of empathy with the suffering patient, their own personal needs, grief, and guilty conscience.

Beneficence and nonmaleficence

Except for two physicians who used ethical reasoning throughout the entire interview, it seemed to be difficult for the other doctors and all the nurses to *explicitly* describe their practice and the values and justifications on which this practice was built, even when asked directly.

Doctors and nurses describe their view of life-prolonging treatment in relation to the principles of beneficence and nonmaleficence and, as already mentioned, to a much lesser extent on the principle of respect for patient autonomy. The physicians emphasised the importance of giving the appropriate treatment and preventing suffering:

... in this nursing home we have one thing in mind, to avoid suffering, to make life as good as possible for the old person.... (CS03L).

One component of beneficence is recognising the right time to withdraw life-prolonging treatment:

And those patients we have to diagnose in order to avoid prolonging the dying process.... Where we absolutely must aim at a dignified end for the patient and where relatives get enough time to say goodbye and to accept this in a natural way (GS07L).

Advancing age was not a reason to withhold treatment, that is if a 95 year-old man who moved around daily in his wheelchair got pneumonia, he would be given antibiotics. "If the situation is altered and becomes more severe, treatment is begun/started if you believe it is a hurdle to overcome..." (AS01L).

The doctors expressed that it was more difficult to withdraw treatment already started than to withhold treatment when the dying process had begun. The nurses to a greater extent than the doctors claimed to act as the patients' advocate when they tried to protect the elderly from futile treatment prescribed by the physician who was pressurised by the relatives. Doctors and nurses had all experienced the harmful side effects of medical treatment in dying patients.

If an IV has been started, we have observed that it will not be stopped until the patient is unconscious. And then problems with gurgling occur, and I have to reduce the drop speed... It should be stopped earlier—or not started at all. It seems that the doctors fear the relatives (AS01S).

Two doctors based their decisions on the principles of beneficence and do-no-harm when they claimed to resist pressure from relatives to provide futile and harmful medical treatment.

And forcing liquids on a (dying patient) who does not really need them—it becomes like treating the relatives... Many

relatives think it's absolutely awful to see their old people not getting liquids. But it's not the relatives we're treating. We treat them by giving them information (CS03L).

One nurse said that many of her nurse colleagues were afraid to administer the appropriate morphine doses ordered by the physicians for suffering patients, because they feared they could be the person responsible for the final dose (AS01S).

Relatives as decision makers

As already mentioned, the interviews revealed that the nurses and doctors were more focused on the relationship with the relatives, sometimes at the expense of respecting the wish of the patient or the patient's best interests. Frequently, disagreement may occur when the relatives ask for more extensive treatment than that prescribed. Eight of the physicians said that they often start futile treatment such as IV hydration, antibiotics, hospitalisation and medical examinations only to please the relatives. Both physicians and nurses described unnecessary hospitalisation as harmful to the fragile, dying patient. In spite of this, they did not always resist the pressure from the next of kin to hospitalise the patient even though they judged it to be contrary to the patient's interests. The physicians described silent pressure from relatives to treat the patient actively for as long as possible. A physician describes his moral distress in such situations:

It often happens that these patients are hospitalised when their condition has worsened—and the patient himself is not competent to say anything—and then the patient dies in a corridor or in a three-patient room connected to a lot of tubes and on a ventilator. We want to prevent such scenarios... (GS07L).

Two doctors were of the opinion that a reason for hospitalisation was if the family did not agree with the medical assessment he had made. In such cases the best interest of the patient was not a topic, but the hospital functioned as a second opinion for the physician in the nursing home.

Eight doctors mentioned that one reason to make decisions that were against their medical judgement was that dissatisfied relatives may contact the media. However, one of the physicians had a strategy to avoid this: continuous and good communication with the relatives:

The media is not contacted if nobody disagrees. You have to work for a common understanding among the relatives that this is the best way to handle the situation. The prognoses, the total situation that it is unethical not to accept that life has come to an end. The key is to communicate this very early; too much life-prolonging treatment has been started (DS04L).

One doctor was aware of the conceptual misunderstanding among the relatives, and that addressing this could be important:

Some of the relatives have an idea that to withhold or withdraw treatment is to kill the person. That is not what we are doing. I can sometimes sense that when talking with them. Then it is important to make such misunderstanding explicit—and kill the myth. To think that my old mother was killed because treatment was withheld; this must be a terrible thought to live with (JS10L).

This statement reveals deep concern for the relatives.

DISCUSSION

The results confirm findings presented in a previous paper in the journal based on interviews with relatives about decision-making processes in nursing homes.⁵ Relatives are rarely included in mutual decision-making processes when the patients

are incompetent to consent to treatment. Focus on patient autonomy is crucial for respecting the integrity of the individual patient.^{14–16} This current study shows, however, that the patient's autonomy is not protected in the manner required by the Norwegian legislation of 1999 and according to key principles of medical ethics^{3 5 17–19}: patients are treated as incompetent to make decisions even though they are capable of doing so. Our findings reveal that doctors still work according to paternalistic ideals when they are seriously searching for the best treatment for the patient, including palliative relief. We found high moral attitudes among physicians and nurses built on the principles of beneficence and do-no-harm.²⁰

The preferences of old patients regarding life-prolonging treatment are unstable and seem to change when death is imminent.^{21 22} This makes it difficult to know what an incompetent patient would have wanted in the actual end-of-life situation.^{23–26} Other studies have confirmed that proper assessment of decision-making competence in patients in end-of-life decisions is scarce.²⁷ If the patient is not competent, according to Norwegian legislation: "Information may be obtained from the patient's next of kin in order to determine what the patient would have wanted".³ The patient's presumed preferences are then the main premises for establishing a good decision-making process.

It is in our opinion thought-provoking if the relatives' demand for extended and life-prolonging treatment is given precedence over what the physicians consider to be in the interest of the patient and even what is known about the patient's presumed wish.⁵ Thus, under pressure from relatives, doctors do not advocate the patients' rights in the manner required according to the best interest principle. This is problematic both ethically and legally.^{3 6 17–19 28}

The study underpins that a well-arranged decision-making process with relatives is crucial to attain optimal medical treatment and care for the dying patient if the patient lacks decision-making competence.^{4 8 29–33} This may also form part of good care for the relatives, and it may increase the necessary trust among the involved parties. A well-arranged decision-making process may reveal a lack of knowledge among the involved parties, that is relatives' lack of knowledge about end-of-life issues, and healthcare personnel's lack of knowledge about the patient. Clarification of ethical issues may also be necessary, that is the distinction between euthanasia and withholding life-prolonging treatment and the fact that adequate pain-relieving treatment is not ethically problematic although it may seem to hasten death.^{34 35} A good process includes a qualified assessment of decision-making competence, a planned conversation at the time of admission, meetings and discussions between the patient, relatives (if requested by the patient or justified by the staff), physicians, nurses and others included in the team.^{2 36}

In various areas of care for the terminal and seriously ill elderly person, there is a need for increased knowledge among staff.⁸ This includes more knowledge, research and training in how to judge the level of decision-making competence among patients, as well as knowledge about end-of-life care and palliative treatment. Nurses regarded incompetent patients' resistance to medical treatment and nutrition as forceful and reliable.³⁷ Examples of such situations included refusing manual feeding, disconnecting the PEG, patients clearly stating that "enough is enough".^{37–39} But what constitutes a reliable statement from an incompetent patient? If a patient is suffering from severe Alzheimer's and refuses food, is there any good reason for forcing him or her to eat? This question is deduced from the results and may disclose the need for training in the staff since refusing food is often part of a terminal stage of Alzheimer's.¹⁶

Guidelines for end-of-life decision making are now available in Norway and should be used to secure a well-arranged decision-making process at the end of life in nursing homes.⁴⁰ Using these guidelines may make difficult decisions easier and relieve the burden of moral distress.^{8 41}

This qualitative study reveals new knowledge about the decision-making process in Norway in nursing homes and about issues that must be addressed in further research in order to improve procedures and ethical competence.

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Competing interests None.

Ethics approval This study was conducted with the approval of the Regional Ethical Committee, Norway.

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