

# Autonomy at the end of life: life-prolonging treatment in nursing homes—relatives' role in the decision-making process

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## ABSTRACT

**Background:** The increasing number of elderly people in nursing homes with failing competence to give consent represents a great challenge to healthcare staff's protection of patient autonomy in the issues of life-prolonging treatment, hydration, nutrition and hospitalisation. The lack of national guidelines and internal routines can threaten the protection of patient autonomy.

**Objectives:** To place focus on protecting patient autonomy in the decision-making process by studying how relatives experience their role as substitute decision-makers.

**Design:** A qualitative descriptive design with analysis of the contents of transcribed in-depth interviews with relatives.

**Participants:** Fifteen relatives of 20 patients in 10 nursing homes in Norway.

**Results and Interpretations:** The main findings reveal deficient procedures for including relatives in decision-making processes. Relatives have poor knowledge about the end of life, and there is little discussion about their role as substitute decision-makers for patients who are not competent to give consent. Few relatives understand the concept of patient autonomy. In Norway the treating physician is responsible for patient treatment. When relatives are included in discussions on treatment, they perceive themselves as responsible for the decision, which is a burden for them afterwards. This qualitative study describes relatives' experiences, thus providing important information on the improvement potential with the main objective of safeguarding patient autonomy and caring for relatives.

**Conclusion:** The study reveals failing procedures and thus a great potential for improvement. Both ethical and legal aspects must be addressed when considering patient autonomy.

During recent decades medical developments have made it possible to prolong the life of many patients. Redrawing the boundaries for the natural process of dying increases the number of ethical issues concerning the limitation of treatment at the end of life.<sup>1,2</sup>

A Norwegian study from 2002 showed that among a random sample of 1616 physicians, 40.1% and 53.5%, respectively, had terminated life-prolonging treatment at the wish of the patient him/herself or of relatives.<sup>3</sup> Overtreatment can result if the discussion on futile treatment is not taken up, and in the literature overtreatment is a topic that has been addressed far less than the limitation of life-prolonging treatment.<sup>4</sup>

According to Norwegian legislation,<sup>5</sup> patients who are capable of making their own decisions have the right to refuse medical treatment. Section 4.6 of the Patients' Rights Act gives relatives of patients who are not competent to give consent the opportunity to consent to treatment or care that is in line with the patient's presumed or actual consent. The question is whether the right to consent in clinical practice is implemented in accordance with the Act's intentions. When the patient is no longer competent to give consent, it is crucial that the patient's wishes and views on the issue are known. Substitute decision-makers may be a doctor, nurse and/or relative, but in Norway it is still the physician who has the final word regarding decisions on medical treatment.<sup>5,6</sup>

Many patients with dementia live in nursing homes and are completely or partly incapable of giving consent, which means that people other than the patients themselves must take decisions on medical treatment on their behalf.<sup>7</sup> Research into these topics is needed.<sup>8</sup> International studies in which relatives are interviewed show that much is still required for the quality of the decision-making processes to lead to adequate protection of patient autonomy.<sup>9-11</sup> Little research has been done so far in Norway on relatives' participation in end-of-life decisions for their elderly loved ones.

The approach chosen here is only one perspective: this study maps relatives' impressions and experiences of decision-making processes when life-prolonging treatment is limited in Norwegian nursing homes. Key questions are how the patient's autonomy is protected and how the relatives of dying elderly people have experienced their involvement in decisions on life-prolonging treatment.

## METHODS

The study has a qualitative approach. Relatives who had discussed life-prolonging treatment with healthcare personnel were recruited by nurses to take part in semistructured in-depth interviews in the departments chosen for the study. Purposive sampling seeks maximal variation in the qualitative selection in order to bring out different aspects of the topic being studied.<sup>12-14</sup> The selected nursing homes were spread demographically to attempt to include cultural variations: one small and one large town, several extended built-up areas in the west of Norway and a nursing home in a smaller rural district inland. None of the institutions included had procedures for conversing with patients or relatives on admission or guidelines for including relatives in the decision-making processes.

## Informants

Fifteen relatives of a total of 20 nursing home patients over the age of 75 years from 10 different nursing homes in Norway were interviewed about limiting life-prolonging treatment. The interviews were held 2–12 months after the death of the patient.

The average age of the patients on death was 86 years. The relatives were children, spouse or children-in-law of the deceased. None of the participants had a healthcare background. Although in the written information sent to the nursing homes we asked for relatives of patients who had not been competent to give consent, when the interviews started it transpired that eight out of 20 patients were in reality totally or partly capable of giving consent until shortly before they died. This in itself was an interesting finding: competence to give consent seems to be something that healthcare personnel who work among old and ill patients do not naturally consider. The study therefore also gained a focus on the decision-making processes concerning patients who were capable of giving consent.

## Data collection

The in-depth interviews lasted 30–60 minutes. They were recorded on a digital recorder and transcribed immediately afterwards. An interview guide was developed as a result of literature studies, personal experience from the field as a clinical nurse, and contact with nursing homes as an arena for student nurses. The interview guide was also assessed and, if appropriate, revised after each interview to permit an in-depth examination of new topics that had arisen in the previous interview.<sup>12 13</sup> As it often transpired that the relatives had little awareness and knowledge of the legal and ethical aspects of competence to give consent and of their own role as participants in the decision-making process, leading questions had to be used to identify their reasons for their views on the patient's treatment.<sup>14</sup> As confirmed in interview 15, little new information emerged after 14 interviews. The term "data saturation"<sup>15</sup> can thus be applied to the following research questions:<sup>15</sup>

1. How do relatives experience decision-making processes in the issues of limiting life-prolonging medical treatment, hydration and nutrition and hospitalisation?
2. What role and involvement do relatives have in such issues?
3. What reflections and reasons lie behind relatives' views on treatment in decision-making processes in which the patient is not competent to give consent?

## Analysis

All stages in the research process were put into the context of the research questions. It can thus be said that the analysis was part of the progression from planning the study to writing the article, and was thus a continuous dialectic process between the parts and the whole.<sup>14 15</sup> 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 into meaning units that in turn led to subcategories. In the event of doubt about the content, these subcategories were grouped and compared with the underlying text by a constant comparative approach to secure the connection between the codes and the content.<sup>12 13</sup> An analysis and review of them generated four categories, presented as subheadings in the Results section. As validation, all the transcribed interviews were read and the analysis was discussed with two co-authors.

## Research ethics

The study was approved by the Regional Committee for Medical Research Ethics and the Norwegian Social Science Data Services. Full written and verbal information on the study was given to the nursing home manager and the nurse who contacted the relatives for participation. Written informed consent was obtained from all the participants before the interviews were conducted. They were told that the interview could be stopped at any time with no consequence for them. The interviewer (AD) was not on the staff of any of the nursing homes and did not report any content of the conversations to the employees. Full anonymity was ensured by removing all identifiable details from the written material. Table 1 shows demographic data on the informants and table 2 shows demographic data on the patients.

## RESULTS

The interviews reveal that none of the relatives were asked about the patients' wishes and values with the purpose of including them in important decisions concerning the end of life. The involvement of relatives in decision-making is weak and their overall role is ambiguous.

All the relatives who took part in the study visited the nursing home regularly. Several relatives reported that they had not understood the situation when the patient was approaching death.

Table 3 shows the topics discussed in the conversations between doctors, nurses and relatives

Nearly half the patients were completely or partly competent to give consent, yet regardless of this, consideration for and focus on the patient's competence to give consent appeared to be almost non-existent when the doctor and nurse involved relatives in information and discussion on treatment.

Statements from relatives reveal their lack of basic knowledge of several areas related to the end of life in nursing homes. They were left with questions about the treatment given—questions to which they could not find answers. Our study suggests that few relatives had reflected on the patient's autonomy and competence to give consent and on the possibility of directly involving competent patients.

## Conversations on admission

When conversations did take place early in the process, these occurred after the relatives themselves had initiated them in order to acquire information. The relatives said they would have liked a meeting on admission.

None of the relatives of patients with severe Alzheimer's were asked about their knowledge of the patient's end-of-life preferences during the initial stage at the nursing home.

## Relatives as participants in decision-making processes concerning life-prolonging treatment

Relatives were seldom contacted until the patient's condition deteriorated, and even then the contact did not seem to follow from any established routines. Their role in these spontaneous conversations was highly ambiguous. Only in a few cases was the relatives' knowledge of the patient's preferences sought and

**Table 1** Informants' demographic data

Variable	Men	Women	Total
No	8	7	15
Age (years) mean	59.5	58.5	59

**Table 2** Patients' demographic data

Variable	Patients with dementia	Patients presumed competent	Total
No	12*	8	20
Men	2	5	7
Women	10	3	13

\*This includes three stroke patients with uncertain competence to give consent due to aphasia.

discussed in relation to the consequences this should have for further treatment. Otherwise the relatives depended largely on the doctor's decisions there and then, and apparently reflected little on whether this was in line with the wishes of the patient. However, few relatives knew what the patient would have wanted, and most of the relatives said they had never discussed death with those close to them:

"There was a sort of taboo on talking about death." (C03P1)

None of the patients had a written "living will".

### Limitation of treatment

#### *Relatives of dementia patients*

Four of the respondents were aware of the patient's clearly expressed reluctance to undergo futile life-prolonging treatment. For two of them this knowledge had clear implications when the question of life-prolonging treatment arose. The relatives made the patient's wishes known, although this knowledge was not requested by the doctor and nurse. The patient's wish was then respected.

Antibiotics were frequently mentioned by them as an example of treatment that was limited. Several were asked for their own opinion on the treatment, although having had little or no contact with the doctor previously. This was not connected to any question of their knowledge of the patient's preferences. Those who consented to the doctor's suggestion to limiting treatment without asking questions then felt responsible for the medical decision:

"He got pneumonia. This was the first time I got the question that I felt was really quite tough: 'We'll give him an antibiotic cure, and if that doesn't work then it doesn't work.' And we prepared ourselves for the worst. Yes, it was unusual—you just aren't ready for this sort of thing. Even though he was terribly weak I felt as if I was signing his death warrant." (J10P1)

#### *Relatives of patients competent to give consent*

Relatives who were informed that antibiotics were limited were uncertain as to whether this was right, but few asked questions. In several situations the old people had been competent to give

consent until the infection suddenly struck, and they had clearly had an acceptable or good quality of life. One son relates his doubt about the doctor's decision, which may also have been against the patient's wishes:

"Apart from the fact that he couldn't stand up or move around or look after himself he was fine in every way. He was so looking forward to Christmas when he was coming home to us. Then he suddenly fell very ill. It was quick. I'm not sure about the assessments they made and what happened when he got ill. But it was quite quick, so we were told that the doctor saw no point in treating him with antibiotics." (H08P2)

Two relatives explicitly asked for the antibiotics to be continued when the physician suggested withdrawing treatment. In one case it developed into a deadlock between the relatives and the staff, and in the second case the doctor disagreed with the relatives and hospitalised the patient to let others take the decision on further treatment. Both these patients were competent to give consent but were not included in any discussion. When relatives are not presented with treatment limitation until the patient deteriorates, several of them fight to ensure that all available treatment is implemented.

"... And then she (the nurse) says that the doctor has decided that we should try another two weeks on antibiotics, but then we will withdraw all treatment. 'Such is life' she says—I called the chief nurse and voiced my opinion very explicitly: I demand that he is treated with this and that! We fought like warriors.... We crushed drugs and hid them in coffee and in bread, made porridge, and forced him to eat. We really did..." (I09P2)

### Hydration and nutrition at the end of life

#### *Relatives of dementia patients*

At several of the nursing homes drink lists were kept for patients with advanced dementia. This revealed a patient's low liquid intake. At one nursing home the drink lists had consequences: the physician prescribed intravenous liquid for dementia patients. The relative did not question this because she presumed it was done on medical grounds. This was done without any discussion with relatives:

"It just hung there when we came." (A01P1)

Even though some patients were not competent to give consent, they expressed their reluctance to be fed clearly and verbally, while others rejected food by refusing to open their mouths. As the patients had dementia, the relatives doubted the absolute truth of the signs they gave, and several relatives forced the patients to eat and drink.

**Table 3** Topics discussed in the decision-making process according to doctors, nurses and relatives

Variable	Relatives of patients with dementia	Relatives of patients presumed competent	Total
No	12	8	20
Competence (patient)	1	1	2
Relatives' role in the decision-making process	0	0	0
Medical treatment	6	3	9
Hospitalisation	1	1	2
Hydration/nutrition	4	3	7

### Relatives of patients competent to give consent

Several relatives of patients who were competent to give consent requested intravenous liquid when the patient was dying because they were afraid the patient was thirsty. Two mentioned explicitly that they had read about people dying of thirst in nursing homes and feared that this would happen to their family member. In some cases relatives changed their minds once the nurses told them that it was natural to stop drinking at the end of life, which led to intravenous treatment not being initiated.

### Hospitalisation

The threshold for admitting patients to hospital just before death seemed to be low. Six of the 12 patients with dementia were hospitalised at the end of life for suspected strokes and infection. In two cases it was the doctor on emergency duty who prescribed hospitalisation, and in the four other cases it was the patient's regular doctor. The hospitalisation was not discussed with the relatives.

### Relatives' degradation of patients competent to give consent

Relatives overcame patients' resistance to eating. In two cases relatives pressed the competent patient to eat, wash more often and sit up when he/she was unwell. Even though the staff pointed out that the patient was capable of giving consent, the relatives had little understanding of the patient's autonomy. The interviews show that relatives demonstrated a high degree of paternalism vis-à-vis the patients, but the employees seldom drew attention to this even though they must have been aware of the situation. Two quotations illustrate two relatives' attitudes:

"We could read the paper together—and I would say: 'Have you read it?' And she had read it! We could discuss things she was interested in.... The employees have been very reluctant to make her do things against her will. It's ethics of course.... We, on our side, have been very explicit that sometimes they could have used more pressure on her.

But she stated clearly: 'I am not hungry. I don't want to go on anymore.' I have to admit that I felt that it was good for her to get some food. No, discussing such matters with her—was no use." (B02P1)

"We had to fight. Of course you have to. It's like with kids—they turn their head and refuse to eat. You can't just say 'He doesn't want anything.' You just have to keep trying." (I09P2)

### Relatives' reasons for their views on life-prolonging treatment

Several relatives were prepared for life-prolonging treatment not being initiated because the relatives could see how the old people were suffering. However, not all the relatives acted in the patient's best interests. In the interviews some of them said that personal preferences, feelings and viewpoints could dominate. Some wanted life-prolonging treatment because they were afraid of the loss they would experience. Others had lost one of their parents earlier, had not done enough for the dying parent then, and wanted to do "everything possible" so that they would not be left with a bad conscience again.

### In retrospect

After their close family member had died, many of the relatives struggled with doubt and unease about their involvement in the decision-making process—regardless of whether the patient had had dementia or had been completely or partly competent to give consent. Some were plagued by the thought that their

consent to the doctor's suggestion about limiting treatment was motivated by selfishness.

### DISCUSSION

This study explores relatives' subjective impressions and experience; it does not reveal absolute or generalising truths.<sup>12–14</sup> Another paper will present the interviews with the healthcare personnel of the same patients. To improve current practice, we consider it important to acquire knowledge about how relatives understand their role and how they experience being participants in the decision-making processes of patients in the terminal phase of life in nursing homes. The findings show clear weaknesses in how relatives are included in these processes. Relatives are not contacted for discussion until the patient's condition deteriorates and his/her life approaches its end.

Respecting patient autonomy at the end of life is a major value in professional ethics. Legally, Norwegian patients who are approaching death have a high degree of self-determination. This study has detected deviations from both legislation and ethical ideals: relatives are included in decision-making processes on treatment without the patient's competence to give consent being explicitly addressed by healthcare staff. Relatives of competent patients were given information about the patient and were involved in discussions on treatment without the patient consenting to their involvement.

In this paper the patients' competence is assessed by their relatives only, and in retrospect. Although this is no objective measure, relatives may be the best persons to notice changes in their loved ones' mental capacity. A continuous assessment of the patient's competence to give consent is necessary to enable the patient's autonomy to be respected.<sup>16</sup> In our view there is also reason for concern if it is true that patients who claim to have a good quality of life do not get necessary and probably effective treatment because the treating staffs responsible regard the treatment as futile. This indicates that not only does overtreatment occur but also undertreatment, which clearly calls for better decision-making processes in Norwegian nursing homes.<sup>17 18</sup>

### The important conversation

Several international studies emphasise the importance of a conversation on admission, both to establish early relationships with the patient and relatives and to map patients' preferences and their treatment and care expectations in the terminal phase of life.<sup>19–23</sup> An admission conversation includes an initial assessment of the patient's competence to give consent, and documentation of preferences regarding any hospitalisation, life-prolonging medical treatment and different nutritional measures.<sup>24–26</sup> Furthermore, this conversation can be viewed as part of the care for relatives, when their requirements for knowledge and information about the end of life are charted and met.<sup>27–31</sup>

Few of the interviewed relatives were aware of the patient's expressed wishes about the end of life, and death had been a taboo subject. An important normative question is therefore what role relatives should have. It is doubtful whether anyone other than the person involved can express wishes about treatment in a situation he or she has never experienced before.<sup>32 33</sup> One major argument against the relatives' role as substitute decision-makers is that they themselves may have competing preferences—a fact confirmed in several of our interviews. They could be exhausted, they questioned their own motives, and afterwards they had a bad conscience because they



felt they had considered their own feelings more than those of the dying relative. This is a heavy burden to bear, and these findings support the (paternalistic) attitude of the majority of Norwegian healthcare staff: it is wrong legally, and might also be wrong morally, to give them responsibility for life/death decisions.<sup>34 35</sup>

The fact that the information given to relatives and the interaction between them and the healthcare staff are arbitrary is both ethically and legally problematical. Healthcare staff's lack of concern about the patient's wishes and the relatives' role in this context represents a threat to proper treatment and care. When relatives are unprepared for approaching death, conflicts and intense demands for active life-prolonging treatment arise.<sup>29 36</sup> In this process the patient is not the objective of the treatment but becomes a medium in inappropriate communication and is forced to undergo undesired treatment; ie, more than half the dying patients in the study were hospitalised—several as a result of disagreement between relatives and the physician.<sup>9 37 38</sup>

The best interests standard<sup>1</sup> is the approach that in our view provides the best opportunity to make decisions on treatment that most closely fulfil the patient's wishes.<sup>16</sup> In brief, it states that those who possess medical responsibility must carefully assess what provides the greatest benefit among the various treatment alternatives in the situation and must view this in relation to the patient's presumed wishes based on knowledge of the patient as a person.<sup>33 39</sup> Here family members can bring important subsidiary input that shows a wider picture of the patient.<sup>40 41</sup> Care staff also frequently acquire good knowledge of patients and should contribute to the process.<sup>18 29</sup> An analysis of elderly people in hospital showed that 70.8% of those admitted and 78% of the critically ill wanted their family together with the physician to decide rather than this being done on the basis of their previously stated wishes.<sup>42</sup> This might place the value of a "living will" in a critical light.<sup>43 44</sup>

A major question is why a patient's autonomy is not protected in the manner required by both legislation and ethics. Lack of respect for the elderly in western society may represent general grounds for the fact that the paternalistic attitude of the relatives does not encounter resistance even from healthcare professionals, which may be due to these staff members' lack of ethical skills.<sup>9 45 46</sup> There is a need for routines as well as a written guide on the issue of limiting the life-prolonging treatment of patients who are not competent to give consent.<sup>18</sup>

**Competing interests:** None.

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