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Priority dilemmas in dialysis: the impact of old age

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ABSTRACT

Aim: This study explores priority dilemmas in dialysis treatment and care offered elderly patients within the Norwegian public healthcare system.

Background: Inadequate healthcare due to advanced age is frequently reported in Norway. The Norwegian guidelines for healthcare priorities state that age alone is not a relevant criterion. However, chronological age, if it affects the risk or effect of medical treatment, can be a legitimate criterion.

Method: A qualitative approach is used. Data were collected through semistructured interviews and analysed through hermeneutical content analysis. The informants were five physicians and four nurses from dialysis wards.

Findings: Pressing priority dilemmas centre around decision-making concerning withholding and withdrawal of dialysis treatment. Advanced age is rarely an absolute or sole priority criterion. It seems, however, that advanced age appears to be a more subtle criterion in relation with, for example, comorbidity, functional status and cognitive impairment. Nurses primarily prioritise specialised dialysis care and not comprehensive nursing care. The complex needs of elderly patients are therefore often not always met.

Conclusions: Clinical priorities should be made more transparent in order to secure legitimate and fair resource allocation in dialysis treatment and care. Difficult decisions concerning withholding or withdrawal of dialysis ought to be openly discussed within the healthcare team as well as with patients and significant others. The biomedical focus and limitations on comprehensive care during dialysis should be debated.

Situations involving inadequate health services where healthcare personnel have to disregard old patients basic needs are frequently reported, more so in community healthcare than in hospital care services.¹ The ageing population is growing² and consequently we will see more people with advanced age in need of advanced technological interventions such as dialysis.³ Increasing numbers of patients will present a variety of caring needs and complex comorbidity. This development may lead to moral challenges in priority-setting on a micro level and requires increased clinical knowledge, as well as ethical decision-making skills among healthcare personnel.^{3,4} Only a limited amount of research focus on priority dilemmas at the bedside with regard to people with advanced age in need of dialysis treatment. The Norwegian guidelines for priority-setting have asked for more knowledge about the rationale behind clinical priorities.⁵ In this paper we examine what clinicians experience as the most pressing priority dilemmas in dialysis treatment and care for older people.

In order to distribute limited healthcare resources fairly, prioritisations delaying or reducing treatment and care may be legitimate.⁶⁻⁹ According to the Norwegian guidelines of healthcare prioritisations and the Patient's Rights Act, every citizen has an equal right to healthcare services, regardless of age, gender, residence, social status, ethnicity or self-inflicted illness.^{5,10,11} The guidelines are based on three criteria: severity of illness, benefit of treatment and cost-effectiveness. Severity of illness and acute life-saving care have initial priority but must be related to the effects and cost of treatment.⁵ Although age is generally not considered a legitimate priority criterion in Norwegian healthcare priorities, it may still be legitimate to consider age as a priority criterion under certain circumstances. However, the guidelines are unclear about how and to what degree age should be considered, and they do not clearly distinguish between chronological and biological age. There is a concern that there seems to be a growing tendency that older patients are discriminated against in healthcare priorities—more than is legitimate when their level of comorbidity and potential risk is taken into account.^{1,12-16}

Researchers have from different perspectives highlighted dilemmas with regard to discrimination against old people in healthcare priorities.^{17,18} Chanda and colleagues have examined the rationale behind using age as priority criterion for dialysis treatment. They concluded that comorbidity and functional status are more accurate and effective factors than chronological age.¹⁹ In a UK study, Reed and colleagues found that older people's complex needs were not always adequately met in specialised wards with specialised nurses.²⁰ Caring for older people includes knowledge and skills, and also personal characteristics.^{20,21} In our study, Pedersen and colleagues found that dominating considerations, ideals and operating conditions did not give sufficient weight to older patients' needs.¹⁵ They also discovered that clinical prioritisations were described as being dominated by adapting traditional biomedical approaches to the operating conditions. Varkey and colleagues emphasised that in medical education there seems to be a gap in the curriculum regarding the special needs of older patients,²² which may influence how the special needs of older people are met in clinical priorities. Nortvedt and colleagues²³ found that the role of the humanistic and holistic clinician was suffering from severe resource pressure. Many physicians and nurses struggled with neither being able to do enough nor attending to the comprehensive needs of older patients. Dharmarajan and colleagues found that units with personnel skilled

in caring for elderly dialysis patients increased the quality of life of these patients.²⁴

Research emphasises the awareness of when dialysis might prolong suffering. Deciding if, or when, to withhold treatment requires thorough ethical deliberation and complex decision-making.¹⁵ In a prospective British study, Lamping investigated the outcome, quality of life and cost in patients more than 70 years old who were receiving dialysis. Eighty per cent of those from 70 to 74 years of age had more than one year of survival after starting dialysis treatment. The mental quality of life for these patients was reported to be as good as that of the general elderly population. However, their physical condition naturally was rated poorer. In the same study, it was stated that even if the cost of dialysis treatment was high, dialysis patients were no more in need of primary care than people in general who were in the same age range.²⁵ In another British study, Stanton found quite the opposite, concluding that dialysis was a notoriously expensive health technology that rated poorly in terms of prolonged quality of life for older people.²⁶

As these studies show, there is no clear consensus when researching the impact of age as a priority criterion for dialysis treatment.

METHOD

This study is part of a larger research project focusing on prioritisations in healthcare for old people, using both a quantitative and a qualitative approach.^{1 13 25} This particular paper is based on one fraction of the qualitative study. The complete qualitative part consists of in-depth interviews with 45 healthcare personnel. The intention was to gain in-depth data about clinical priorities in the healthcare services for older people.

Of the 45 respondents, there were five physicians (three women and two men) and four nurses (all women) working in renal wards. Interviews with these nine informants constitute the main data of this article. The five physicians ranged in age from 48 to 61 years, with 17 to 30 years' experience working as physicians. The four nurses' ages ranged from 26 to about 55 years, with 4 to 30 years' experience working as nurses. All informants were interviewed once and came from hospitals in the east, west and north Norway.

The interviews were based on a semistructured interview guide, focusing on prioritisation dilemmas in dialysis and renal medicine in relation to age. Other important topics were professional criteria for prioritisation, the impact of available resources on medical treatment and nursing care, and the values inherent in the priority decisions. The term "dilemma" was used in a colloquial sense, and may refer to dilemmas in a strict moral philosophical sense⁶ or to other ethical challenges relating to clinical prioritisations.

ANALYSIS

The data were subjected to hermeneutical analysis of the content of the interviews.²⁷ All interviews were taped and transcribed verbatim before closer readings. As a result of the first readings, an analysis guide with the major themes was made. This guide became the basis for further analytical condensation and structuring of the main findings.²⁸

ETHICAL CONSIDERATIONS

This study has followed common ethical norms for empirical research.^{9 29} All participants gave their voluntary, informed and written consent to participate. Approval of the Regional Ethics

Committee was not necessary, since all the informants were healthcare personnel. The study was approved by the Norwegian Social Science Data Services.

RESULTS

Dilemmas concerning withdrawal and withholding of treatment were prominent, especially how to identify and deal with dialysis treatment that seems to prolong suffering rather than improve quality of life. Other important priority dilemmas were related to the limiting of comprehensive nursing care, strongly affecting the older patients with complex needs. Age as a criterion for priorities manifested itself rather subtly and obliquely and was in general presented together with other relevant factors, such as patients' comorbidity, functional status or cognitive impairment.

Dilemmas concerning withholding and withdrawing of dialysis treatment

The most urgent ethical issues for the informants were decisions concerning withholding or withdrawing active renal treatment. What would be a dignified versus an undignified life for the patient was an important issue in these decisions. When deliberating the actual treatment, the informants were concerned with the patients' quality of life. However, the assessment of the patients' expected quality of life, and whether treatment was dignified or not, was largely based on the clinicians' "objective" biomedical deliberation, not on the patients' subjective experience. When treatment was considered meaningless or futile, clinicians expressed a strong moral commitment to prioritise a quiet and peaceful death:

Sometimes I think, afterwards, that this patient could after all have been better off without the offer of dialysis treatment ... That we see it as undignified; that patients arrive from a nursing home on a stretcher, lying moaning and groaning for four hours during dialysis, three times a week, and then being taken back to a nursing home on the stretcher again. You might ask yourself, is this a dignified life? (Physician)

Both physicians and nurses discussed the issue of over-treatment in the interviews. This was experienced as especially problematic when the patient was frail and had a terminal illness. At this point, it seemed that the dialysis only prolonged the suffering and the process of dying, rather than adding quality days to the patient's life.

When you see that the patient coming in is not doing well, and is supposed to have dialysis no matter what ... There is something about being allowed to die when the time comes. Sometimes I think we should have withdrawn treatment a little earlier. (Nurse)

Physicians and nurses felt that withdrawing initiated treatment was more difficult than withholding or not initiating treatment. Withdrawing treatment was perceived to be extremely difficult, particularly because of the grave consequences of such a decision.

When I say no to treatment, it seems very decisive. It is difficult to make these decisions. It is a question of life or death. (Physician)

Dilemmas involving futility of treatment and end-of-life decisions contributed to a practice "erring on the side of life":

My experience is that it is a lot easier to say yes than to say no, and that we start treatment on too many patients. It is extremely hard to end something already started. (Physician)

Even when the physicians and nurses from a professional point of view judged that the patient would obviously not benefit from the treatment, withholding treatment could be difficult. When relatives wanted the treatment to be continued, these decisions were even harder. According to physicians and nurses, the standpoint of relatives (and patients) might cause difficulties, particularly when they did not agree with the medical decisions or if there was disagreement within the family. Unfortunately, prolonging treatment that the clinicians regarded as meaningless or futile was a relatively frequently experienced phenomenon.

It is this that sometimes complicates it a little for us ... According to new laws of patients' rights, relatives shall decide in cases where patients are not competent to take care of their own interest, and even when they are competent, the relatives should be heard in all this. And this sometimes complicates the case, particularly in situations where family members do not agree within the family. And, if someone then says yes, we probably start a treatment we should not have started in the first place. (Physician)

Chronological age as a priority criterion

Neither physicians nor nurses reported that age alone was the one and only reason for not giving a patient dialysis treatment. Biological age was of far more importance and interest than chronological age. However, if the patient was very old, the clinicians were more reluctant to start treating an old person than a younger person. This was reported to be the case even if the younger person was frail with a serious history of chronic illness and cognitive impairment.

It is not like I stand in a situation where I have to choose *this* patient and *not that* patient. It is not that kind of prioritisation. I would, rather, say that the situation is more about whether or not it is ethically right to prolong life at any price. And, I will say, that the condition of the patient matters more than chronological age. (Physician)

Medical criteria and the physicians' own experience were central when deciding whether to start dialysis treatment or not. Factors relevant to the medical judgements were prognosis, comorbidity, general functional status and level of cognitive functioning. If a patient had dementia or other severe malign diseases, the physicians were more restrictive about starting treatment. Some of the interviewees regarded moderate or severe chronic cognitive impairment as a relative contraindication, while others described it as an absolute contraindication, warranting unilateral decision-making. Some physicians said that if the patient lived permanently in a nursing home, they were more reluctant to start dialysis treatment, since those patients most often had complex comorbidity and cognitive impairment.

Pressure on resources—limitations on comprehensive nursing care

Limitation of time created dilemmas for the nurses in particular. The nurses quite frequently experienced having to ignore essential and basic nursing care because of a lack of time.

It is the older patient, who sits in a wheelchair—and then it takes longer time to move them over in the chair or bed, and this means they have to wait longer before we help them, since it is easier to help the others first. This implies that we many times treat patients unequally. Not always, but this does happen quite often. (Nurse)

The nurses in particular mentioned elderly patients from nursing homes who needed assistance with their meals. Patients were often offered a meal during dialysis time. But, because of limited time, this was a meal benefiting the ones who could eat without assistance:

I asked [the head nurse] if I should help the old patient to eat, but she said that we don't do that here—it is beyond our duties here. We don't help people to eat here ... I see it very often that those who are not familiar with working with elderly patients do not see their needs. They just put the glass of water on the table and don't help those who need a hand, which are often the elderly. (Nurse)

Despite the fact that transportation back and forth from the nursing home to the hospital might take several hours, patients might not be given food if they were unable to eat by themselves during their 3–5-hour stay in the dialysis ward. One physician thought the nurses were overly focused on the technical aspects of the dialysis treatment and overlooked other aspects of the patients' needs. However, these kinds of focus or prioritisation seemed to bother at least some of the nurses. Some nurses were very much concerned about not having enough resources to give the patients necessary and comprehensive care.

DISCUSSION

The data indicated that questions concerning withdrawal of active treatment were the most pressing dilemmas for physicians and nurses working with old patients in need of dialysis. Often it seemed that the physicians judged withdrawal of treatment to be in the patients' best interests. Still, this decision was morally difficult to make, since it was so decisive. Decisions about life and death represented a major responsibility for the physician as the final decision-maker. Somehow it seemed as if the clinician's view of the patient's best interests conflicted with actual treatment and thereby led to a prolongation of undignified treatment and of suffering and, to some extent, to overtreatment.

The questions revolving around dignity and indignity were of crucial importance and created moral dilemmas for the physicians and nurses. Then again, what is a dignified life and who is to tell when it is no longer dignified? The patient's best interests and quality of life must be in focus when the continuation of dialysis is being considered. The risk of prolonging suffering instead of prolonging a good life must always be of major concern in medical care.²⁴ To estimate other people's quality of life, especially in an intensive care situation, has been shown to be difficult.³⁰ As a rule, patients' wishes and autonomy must be taken into account. The patient's voice ought to be heard when decisions are being made about whether to offer dialysis treatment. If patients' condition or cognitive competence prevent them from participating in the decision, families must be consulted. Including the involved parties demands an open dialogue, illuminating all aspects, between the involved parties—for example, patients, families, physicians and nurses. However, in Norway the final decision is the physician's responsibility. An open dialogue would very likely open up for

the values at stake; it may show different opinions, uncover uncertainty and may lead to an even more thorough moral reasoning and decision-making with regard to treatment.

The findings in our study also indicated that inadequate use or overuse of dialysis was a problem to some extent. There are situations when dialysis is no longer compatible with meaningful treatment and dignified patient care. Our findings indicate that continued meaningless or futile treatment is to some degree a serious problem. We propose that an open dialogue and useful structures for a transparent decision-making process will contribute to resolving some of this dilemma. Furthermore, we believe that guidelines that support the clinicians in the decisions-making process of withholding or withdrawing dialysis treatment should be formulated.

There seemed to be variations as to what degree cognitive impairment influenced clinicians' decisions whether or not to start dialysis treatment. The quality of life of cognitively impaired patients was not the major focus of this deliberation. Physicians emphasised the patients' ability to cooperate and understand as being more crucial. Suboptimal operating conditions, such as scarcity of skilled nursing personnel, might make it more difficult to provide sufficient and adequate care to frail or confused older patients, thus making dialysis unfeasible. Refusal of dialysis treatment to cognitively impaired patients seemed to be a combination of a clinical judgment as well as a matter of resources. There are many nuances and degrees of severity to consider when evaluating cognitive impairment and, obviously, also in the physical and mental status of nursing-home patients. These nuances have to be considered in priority decisions regarding dialysis. In order to avoid discrimination against cognitively impaired patients, or avoiding treatment of patients when dialysis might not have any positive impact, these nuances must be documented and considered.

Older patients are often in need of comprehensive nursing care. Some of the nurses experienced discomfort, sensing that insufficient care increased the patient's suffering. It also appeared that comprehensive care was not always given priority, even when it was clearly indicated. One may wonder whether prioritisation dilemmas in dialysis wards are part of a trend towards specialised care and responsibilities. This question was raised in other parts of this study, where the role identification of professionals, and nurses in particular, were questioned.^{1 13 23} As mentioned earlier, there is, in specialised care, a risk that the individual needs of older patients can be ignored. Is this a consequence of specialisation, with the paradoxical result that the patients' comprehensive needs are not taken care of? Do the nurses and physicians in renal wards restrict their responsibilities to more technical or biomedical tasks? In Norwegian healthcare, we unfortunately see a tendency where working with advanced medicine and technology generates a higher status, and comprehensive care for old people does not get the same attention or status.³¹ This development may account for some of the lack of awareness we found towards comprehensive care in our study. Additionally, the physicians and nurses working with such specialised treatment and care might sometimes develop a "tunnel vision", where the organs on which they are focusing and the problems directly connected with these are given attention and priority. Assistance with eating was not offered by the nurses even though they were aware of the patients' needs. One nurse said that feeding was "beyond their duty", thus attempting to justify a dubious collective practice with principled reasoning. Given that it frequently was the old and fragile patients who needed some help with eating, this also

reveals an obvious discrimination against elderly patients. It is a paradox that basic caring needs were neglected, when at the same time there seemed to be overuse of dialysis treatment for patients who instead needed palliative terminal care. This lack of comprehensive care might also be a consequence of an educational gap in the education of healthcare personnel. More attention to the special needs of the elderly in the education of physicians and nurses might have positive effects on empathy and attitudes in the clinical practice of caring for the elderly.²²

Findings in our study may confirm a tendency to discriminate against elderly patients in priorities of healthcare services, and in particular against elderly people living in nursing homes. It is important, however, to note that withholding of treatment for elderly patients living in nursing homes was usually based on clinicians' considerations relating to biological age. Physicians and nurses emphasised that an 80-year-old patient could have a similar biological age to that of a 60-year-old, and vice versa. It was emphasised that patients in nursing homes who had not received dialysis treatment were frail, had multiple diagnoses and experienced serious reduction of both physical and cognitive status. However, there is evidence that if dialysis wards have competent personnel and suitable equipment to care for the old and fragile dialysis patient, these patients, too, gain an improved quality of life and greater benefit from treatment.²⁴

There are reasons to question how the principles of justice and equality for patients are met in dialysis treatment for elderly patients. The principles of justice require that equal cases are treated equally and that only relevant differences may cause differences in treatment options.⁶ Discriminating against patients on the basis of age alone violates principles of justice and equality. Just and fair treatment options are fundamental rights based on international human rights.¹¹ The Norwegian guidelines on prioritisation open the way for age to be taken into consideration together with other relevant aspects, such as patient comorbidity, benefit of treatment and cost-effectiveness.⁵ As other researchers have argued,^{4 19 26} the decisive factor should be biological age and not chronological age. Moreover, it is the patient's preferences combined with the physical and cognitive status that should count when deciding whether or not to start treatment.⁴ A clearer distinction between biological and chronological age ought to be emphasised in the Norwegian guidelines for priority-setting. We believe that a more explicit distinction will give a valuable emphasis for clinicians on what is of importance when making priority decisions about dialysis for elderly patients. Furthermore, it will support healthcare administrators when planning individual healthcare for elderly patients in need of a variety of healthcare services.

Our findings have shown that old and fragile patients, and in particular cognitively impaired patients, do not always get their complexity of needs met, while younger patients, being more self-reliant, do not experience the same problems. One may of course ask if a younger patient with very complex caring needs will get these needs fulfilled. Our study has not answered that question, and further research is needed. There is clearly a need for more research, with a focus on prioritisations and criteria in healthcare for old patients. The criteria must be fine-meshed and attuned to the physical and cognitive functions of old people.

CONCLUSIONS

The clinicians interviewed in this study pointed out that deciding whether to withhold or to withdraw dialysis treatment presents important ethical challenges and that such decisions might cause both underuse and overuse of resources.

Overtreatment seemed to be relatively common, and sometimes this resulted in prolonged suffering of patients and excessive use of resources. Objective biomedical criteria seemed to have preference over the patient's subjective judgment and perception of quality of life. A more open dialogue concerning withholding and withdrawal of dialysis treatment seems to be needed.

This study has indicated that the dialysis treatment and care offered are not properly adjusted to the needs of older patients and that there is a need for more holistic focus on nursing care in dialysis treatment. Elderly patients are at risk of being discriminated against when priority decisions regarding dialysis are being made. We have seen that these services are not well adjusted to the needs of old patients, especially if broad categories such as cognitive impairment, comorbidity and nursing home residency are used uncritically. Just allocation of resources requires transparent use and critical discussion of priority criteria, also on a micro level.

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