

Accepting or declining dialysis: considerations taken into account by elderly patients with end-stage renal disease

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ABSTRACT

Background: Elderly patients with end-stage renal disease have to make a difficult decision whether or not to start dialysis. This study explores the considerations taken into account by these patients in decision-making regarding renal replacement therapy.

Method: In-depth interviews were conducted to gain an enhanced understanding of the considerations in treatment decision-making. Fourteen patients aged 65 years or older participated in the interviews, of whom 8 patients had made the decision to start, and 6 patients the decision to decline, dialysis.

Results: All participating patients had a variety of health problems, but appeared to have normal cognitive functions. Patients who declined dialysis were older and more often men and widow(er)s compared with patients who accepted dialysis. Patients chose to start dialysis because they enjoyed life, were not prepared to face the end of life, felt they had no other choice or had care-giving responsibilities for family members. Patients declined dialysis because of the speculated loss of autonomy, their age-associated decrease in vitality, distance from dialysis center and reluctance to think about the future.

Conclusion: Results suggest that patients' deci-

sions to decline or accept dialysis are not based on the effectiveness of the treatment, but rather on personal values, beliefs and feelings toward life, suffering and death, and the expected difficulties in fitting the treatment into their life.

Key words: Decision-making, Dialysis, Elderly, End-stage renal disease, Qualitative research

INTRODUCTION

In the last few decades, the number of elderly with end-stage renal disease (ESRD) has increased in many European countries. In The Netherlands, the number of patients aged 65 years or older starting renal replacement therapy increased from 509 in 1993 to 1,010 in 2007 (1). Elderly patients with ESRD are confronted with the difficult decision to either undergo comprehensive dialysis treatment that will most likely prolong their life, or to decline dialysis which could mean dying sooner (2).

A few studies have been published on the number of patients who decided to *withdraw* from dialysis once treatment was initiated (3, 4). Information, however, on the number of patients who decided *not to start* dialysis despite the

medical need to do so, is as far as we know not available. Furthermore, the studies that examined the factors affecting eligibility for dialysis are all from the perspective of the physician. These studies found that physicians attach great value to prognosis, anticipated quality of life, treatment burden (4, 5) and the patient's preferences (6, 7). Other studies demonstrated, however, that physicians do not always have a good understanding of their patient's preferences (8, 9). Little is known about the preferences regarding dialysis of older ESRD patients themselves. The aim of the current study is to explore the considerations taken into account by patients aged 65 years or older with respect to the question of whether or not to start dialysis treatment.

METHOD

Patient sample

Patients were approached at the renal failure outpatient clinic or dialysis center of our university medical center by the nurse or the nephrologist. At this clinic, all patients are offered a multidisciplinary (nephrologist, dialysis nurse, social worker, dietitian and dialysis access coordinator) predialysis program consisting of information about the dialysis; the choice (if possible) of peritoneal dialysis, home hemodialysis or in-center hemodialysis; an orientation session regarding the dialysis unit; and a home visit by the social worker. Elderly patients with comorbidities will also be informed about the possibility of declining dialysis treatment. The patients who decline will be offered a conservative treatment aimed at treating (diet and medication) and controlling the symptoms of kidney failure. These patients also remain under the treatment of the multidisciplinary predialysis team. During all stages, patients will be stimulated to be active in decision-making.

A purposive sampling strategy was used. Patients were eligible to participate if they were aged 65 or over, appeared to have normal cognitive functioning and recently had made a decision regarding whether or not to start dialysis. Ten patients who had made the decision to start dialysis and 10 patients who had made the decision to decline dialysis were approached. Eight patients who had made the decision to start dialysis (some of these patients had recently started treatment) and 6 patients who had made the decision to decline dialysis agreed to participate. Reasons for nonparticipation were that the patient did not want to talk about the decision (n=3), had hearing problems (n=1) or was not available for inclusion (n=2).

Data collection

Patients were approached for in-depth interviews. All interviews were conducted by the same interviewer (A.V.) while visiting the patient at his/her home. The interviews were aimed at revealing the patients' considerations in treatment decision-making. In addition, patients were asked questions about the information on dialysis they had received from their health care providers, as well as questions about their current health status, history of illness and the process of diagnosis they had undergone. Follow-up questions were used to elicit more information about the informants' narratives. The data collection, data ordering and data analysis were interrelated processes (10). Each interview was audiotaped and lasted between 30 and 90 minutes.

Data analysis

The interviews were transcribed immediately after each home visit. Transcriptions were summarized by the researcher. Analyses occurred concurrently with data collection. Themes that were identified in early interviews were taken up during the following interviews. Transcriptions were read thoroughly and independently coded by 2 researchers (A.V. and D.K.). Themes were identified and discussed until agreement was reached.

RESULTS

Patients who declined dialysis were older and more often men and widow(er)s than patients who accepted dialysis (Tab. I). The presence of children, the limitations experienced in daily life and the number of comorbidities were comparable in both groups.

All patients were treated by a nephrologist for 6 months or more, and, except for 1, they were all known to have had kidney failure for at least 1 year.

Patients who accepted dialysis treatment

The required change in daily routine and the coercive character of treatment "you can never skip" were viewed as an enormous limitation in freedom. *"What really upsets me is that your life is completely upside down if you do dialysis ... I can not live with the idea that others basically rule my life...."* It was also difficult for patients to cope with the awareness that the preservation of life is dependent on a life support machine. In spite of this awareness, most patients did not hesitate regarding the decision of whether

or not to start dialysis, but perceived dialysis as a way of staying alive. Patients who decided to start dialysis indicated that they would make the same decision again today. Patients were also questioned as to whether they would choose to start dialysis under any other circumstances. Some patients answered this question in the affirmative.

TABLE I
PATIENT CHARACTERISTICS

	Patients starting dialysis (n=8)	Patients not starting dialysis (n=6)
Number of women	5 (63%)	1 (17%)
Mean age, years	72.6 ± 7.7	82.5 ± 6.0
<i>Social situations</i>		
Married / living together	7 (88%)	2 (33%)
Widow(er)	-	4 (67%)
Single	1 (12%)	-
Children		
Yes	5 (63%)	4 (67%)
No	3 (37%)	2 (33%)
<i>Time suffering from CKD</i>		
>5 years	4 (50%)	2 (33%)
1-5 years	3 (38%)	4 (67%)
<1 year	1 (13%)	-
<i>Treated by a nephrologist</i>		
>2 year	6 (75%)	3 (50%)
6 months to 2 years	2 (25%)	3 (50%)
<6 months	-	-
<i>Limitations in daily living skills</i>		
No limitations	2 (25%)	2 (33%)
Some limitations	4 (50%)	1 (17%)
Serious limitations	2 (25%)	3 (50%)
<i>Comorbidities*</i>		
None	1 (13%)	1 (17%)
Cardiovascular disease	6 (75%)	3 (50%)
Diabetes mellitus	1 (13%)	1 (17%)
Pulmonary disease	1 (13%)	3 (50%)
Other	4 (50%)	3 (50%)

CKD = chronic kidney disease. *Cardiovascular disease includes hypertension; "Other" refers to comorbidities such as peptic ulcer, thyroid disorder, back and hip pain. Total of percentages may exceed 100%, because patients might experience more than 1 comorbidity.

Other patients mentioned that they might have decided differently if they had been sick, had suffered from severe pain or had not had a partner or children.

Enjoying life

One of the most important reasons to choose in favor of dialysis is that the patient enjoys life. Patients' challenges in living with chronic kidney disease did not appear to be a limitation to appreciating the small things in life. *"I still fully enjoy life ... even though I am not able to do a whole lot anymore ... I can still intensely appreciate rather small things in life, for example relaxing in my favorite chair while overlooking our beautiful yard...."* Some patients had no problem being dependent on medical treatment and its daily consequences. These patients were able to fit the treatment into their schedules. *"The fact that such a thing as dialysis exists, and that I am offered the opportunity to use it, is just wonderful! Visiting the hospital 3 times per week is a hassle ... but, oh well ... that doesn't bother me ... weren't we used to having daily commitments during our productive years?"* A few of the patients noted that they have a good time during dialysis; they meet friendly people and appreciate the food being served.

Taking every opportunity to prolong life

Despite the burdens and limitations, most patients take every possibility to prolong life. *"We all die at some point, and we all know that. Yet, somehow it never dawned on me. It is almost as if I never realized that; I was simply living.... as if life is eternal...."* All patients who choose to start dialysis emphasized their desire for living. Some patients expressed their hope to receive a kidney transplant.

No better alternatives

A number of patients chose to accept dialysis because they felt that the alternatives were not available to them given the circumstances. *"I had no choice, or I would be dying slowly."* The choice to accept dialysis did not seem to be well-considered; rather, in the patient's perception it was the only option.

Social considerations

Care for a partner or a child being ill or disabled was for some patients the main reason to choose in favor of dialysis. The partner or children in these situations were care dependent.

Patients who declined dialysis

Patients reported enjoying life and expressed a desire to live for as long as possible, but not at any price. Remarkably, however, these patients had chosen not to start dialysis. Most of the patients who declined dialysis had made the decision before they received information on the treatment and would not have considered even the possibility. Patients indicated that they would have considered treatment when they were younger, in better health or if they had suffered from severe pain.

Loss of autonomy

Loss of autonomy was one of the most important reasons for patients to decline dialysis treatment. Patients who chose not to start dialysis seemed to have more problems with giving up their freedom and living a life dependent on medical treatment. They would rather live for a shorter time with more freedom, than longer with the limitations of a comprehensive treatment such as dialysis. *"You are going to die anyway ... and making a trip to the hospital 3 times per week, already being tired and exhausted, and while basically handing your life to others, is such a great deal of effort, I can't do that!"*

Age-associated decrease in vitality

The age-associated decrease in vitality was a reason for patients to decline dialysis. Most patients who declined dialysis mentioned that they had a good life. The discrepancy between their former life (visiting exhibitions and traveling) and present life was great. There were a lot of things they could not do anymore. Patients noted that they had already had to give up so much in life, that adding dialysis treatment would be too much. *"The ability to do things at this age is limited. In former days I could do anything I wanted, that's different now."* This group seemed to be able to face the finiteness of life. They all spoke about the good life they lived. The fact that dialysis is a serious disruption of life was reported as unacceptable. *"I am now 77, and you can twist it one way or the other, dialysis is a trouble to go through, it is just a way to postpone death. I don't see it happen to go to the hospital 3 times per week, I am already too weak, in particular physically. I am worn out!"*

A few patients indicated that, as they got older, their overall ability to plan and organize significantly deteriorated. As a result, making their doctor appointments and taking care of arrangements to get there in time, required too much energy.

Distance from dialysis center

For 1 patient the distance to the closest center (35 kilometers) was a reason to decline treatment. Most likely, this patient would have chosen to start dialysis if there had been a dialysis center that was closer.

Resistance in thinking about the future

A few patients seemed to be reluctant to think about dialysis. Some of these patients had communicated to the nephrologist that they did not want to receive dialysis. During the interview it became clear these patients had their doubts about this decision and explained that when treatment should start. Another patient preferred to live day-to-day. The frequent doctor and hospital visits affected his pleasure in life. In his view, not undergoing dialysis gives more freedom and allows the patient to live a carefree life. The patient experienced a great relief after he had made this decision to decline the treatment. *"When you commit yourself to dialysis, it pretty much occupies you everyday; one day you go to the hospital, the following day you are already anticipating your next visit. I don't like that. I even don't want to consider whether the decision is 'right' or perhaps 'wrong' since I then have to live accordingly. All I want is to continue my life, after all, I feel alive!"*

DISCUSSION

In this study we explored the considerations taken into account by elderly patients with respect to the question of whether or not to start dialysis treatment. Patients who chose to accept dialysis made this decision irrespective of their health status. In most of the cases, this decision seemed to not be a well-considered one, but in their perception, it was the only option. For those patients with relatively good health, it seemed like a natural decision. Earlier studies showed, however, that elderly dialysis patients with a higher number of comorbidities might have a worse quality of life (11) and no better survival (12-14) than patients not undergoing treatment. There is therefore a question as to what extent elderly patients with poor health status might benefit from this treatment.

For most of the patients who declined dialysis, the anticipated loss of autonomy in combination with their age-associated decrease in vitality was the most important reason for their refusal. Another reason to decline dialysis was that patient's preference to live from day to day and not wanting to be continuously confronted

with stress around illness and treatment. In this study, they were mostly men who declined dialysis treatment. Previous research on the impact of gender on the initiation of dialysis was not available. However, research on patients who withdrew once treatment was initiated proved that this was more common among women than among men (15).

Interesting, the perceived effectiveness of dialysis does not seem to be related to the outcome of the decision-making process. Patients in the current study based their decisions on their personal values, beliefs and feelings toward life, suffering and death and the expected difficulties of fitting the treatment into their life. Patients who chose to start dialysis seemed to not be ready to face the end of life and believed that everything should be done to prolong life. Patients who declined dialysis felt that the burden of dialysis would outweigh the benefits. Both findings were found previously in studies among patients who are confronted with a decision regarding life-sustaining therapy in general. Some of these studies found that even the most dependent and frail patients wanted life-sustaining therapy (16, 17). Other studies have suggested that a patient's decision regarding medical care in general is based on treatment burden and treatment outcome (health state and length of life) (18). Patients' preferences also seemed in these studies to involve a weighing of the treatment process against treatment outcomes.

It might be that the decision of the patient is influenced by the type and amount of information the physician communicates and that the decision occurs within the context of the individual patient-physician relationship. It is important for health care professionals to realize that not only is the provision of appropriate medical treatment of importance, but also sensitivity for the patient's values and beliefs. This means that the decision regarding whether or not to start dialysis treatment should not be made merely on medical grounds, but rather in close communication with the patient thereby considering his/her personal beliefs and preferences.

This study is one of the few exploring the preferences of patients who were actually confronted with the decision to either undergo treatment or not, as opposed to studies that asked healthy persons to make hypothetical treatment choices. Studies such as this one can provide important information regarding the decision-making process of patients concerning dialysis.

Our study has some limitations. A relatively small number of patients were interviewed. We do not know whether the patients who participated reflected a representative group of patients.

The participating patients were all treated by a nephrologist/multidisciplinary team, thus the results may only be generalized to patients who are under the treatment of a nephrologist and not to those who make the decision in an earlier stage (for example, in the primary care setting). It was hard to determine exactly what kind of information patients received and how well they understood this information. We also do not know to what extent the decision to start dialysis was influenced by the information and the opinion of the physician.

We obtained information about their medical conditions from the patients themselves and not from medical records. It is therefore not clear if we have given a correct representation of patients' health status. By coincidence, all patients who chose in favor of dialysis were prepared for in-center hemodialysis treatment. Patients who were offered (or chose) other types of dialysis treatment might have taken into account different considerations.

There is a great need for more research to identify the considerations upon which patients decide to either accept or decline dialysis. Also more research is needed to examine the effects of such decisions on patients' quality of life. Prospective studies from the point of the decision until death might provide this information. More insight into the considerations taken into account by patients and the effects of the decision to undergo or decline treatment, on patients' quality of life might offer doctors, nurses and other health care professionals the opportunity to guide patients in their decision-making process.

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