

Support for Decision-making Regarding Continuing or Suspending Terminal-Stage Dialysis

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Abstract

【Purpose】 The aim of this study was to clarify the state of discussion regarding terminal-stage dialysis, advance directive preparation, and opinions of patients and their family members regarding terminal-stage dialysis to facilitate support for decision-making regarding terminal-stage dialysis by nurses.

【Methods】 Study design was a Mixed-method research. Study subjects comprised 948 dialysis patients who were members of the Kidney Disease Patient Association of Prefecture A, Japan. The response rate was 41.0% (n = 389), and the valid response rate was 38.8% (n = 368). We distributed questionnaires to dialysis patients, that included questions about Patient characteristics, Status of discussion regarding terminal-stage dialysis and advance directive preparation, and Free response comments regarding terminal-stage dialysis and advance directive preparation. Results were then analyzed using Pearson's chi-square test (for small-size samples, Fisher's exact test was used). K-J method was used to analyze free comments regarding terminal-stage dialysis. This study was approved by the institutional review board of Naragakuen University (approval no: 27-004)

【Result/ Consideration】 Fewer than 40% of the subjects had discussed terminal-stage dialysis with their family members, whereas <10% had discussed the issue with a healthcare provider. Moreover, only 3% of the subjects had prepared an advance directive. When offering support for decision-making regarding terminal-stage dialysis, nurses should provide necessary information while confirming the health state and current status of patients, particularly those who have received dialysis for a certain period of time and are interested in terminal-stage dialysis, as well as informing their family members. In addition, nurses should make adjustments such that patients can thoroughly discuss terminal-stage dialysis.

Key Word : Terminal-stage Dialysis, Support for Decision-making, Advance Directive

1. Introduction

As dialysis patients age, the debate over terminal-stage dialysis is increasing. Of note, in 2014, "Proposal for the Shared Decision-Making Process Regarding Initiation and Continuation of Maintenance Hemodialysis" advocated a decision-making process for terminal-stage dialysis, including advance directive preparation, by the medical team in cooperation with the patient and their family members¹⁾. In Japan, decisions regarding treatment in the terminal stage of a disease are traditionally made by the patients' family members rather than the patients themselves²⁾³⁾. Therefore, this proposal recommending support for decision-making regarding terminal-stage dialysis focusing on the patient themselves while still involving their family members and medical team is noteworthy. Moreover, the innovative advance directive referred to in this proposal honors the wishes of the patient as well as reduces the psychological burden placed on the family members, who were previously

required to make such difficult decisions.

Significant advances have been made as we entered a transitional stage in medicine and healthcare in providing support for decision-making regarding terminal-stage dialysis, which is finally being realized. However, it is unclear how patients and their family members perceive terminal-stage dialysis, to what extent they engage in discussion regarding decision-making, and how many patients make their intentions known through advance directive.

Linking support for decision-making regarding terminal-stage dialysis to clinical nursing practice requires the investigation of necessary support methods provided by nurses as a team as well as being sensitive to the patient's opinion in decision-making.

2. Study Purpose

The aim of this study was to clarify the state of discussion regarding terminal-stage dialysis, advance directive preparation, and opinions of patients and their family members regarding

terminal-stage dialysis to facilitate support for decision-making regarding terminal-stage dialysis by nurses.

3. Operational Definitions of Terms

Advance directive: A document describing the intentions of the patient regarding treatment details in advance while they are still capable of making such decisions. The advance directive protects the patient's right to self-determination in case they lose the ability to make decisions themselves in the future. The present study focused on continuing or suspending terminal-stage dialysis.

4. Study Methods

4.1 Study design

Mixed-method research

4.2 Study subjects

Subjects comprised 948 dialysis patients who were members of the Kidney Disease Patient Association of Prefecture A, Japan. The response rate was 41.0% (n = 389), and the valid response rate was 38.8% (n = 368).

4.3 Survey methods and survey period

After receiving approval from the patient association, a questionnaire, along with a request for study cooperation as well as regular paper correspondence from the association, was sent to the subjects. They were requested complete the questionnaires and directly send it to the researchers. The survey period was August 31–September 30, 2015.

4.4 Questionnaire details

To minimize the psychological burden on patients associated with answering the questionnaire, the following factors were considered. The additional content was based on repeated consultations with staff of the executive office of the patient association who were also dialysis patients.

1) Patient characteristics

Subjects were asked to answer demographic questions, such as sex, age, marital status, duration of dialysis, and subjective view of health.

2) Status of discussion regarding terminal-stage dialysis and advance directive preparation

Subjects were asked to describe the status of discussion regarding terminal-stage dialysis with healthcare providers and family members and whether they had prepared an advance directive.

3) Free response comments regarding terminal-stage dialysis and advance directive preparation

The questionnaire stated, "Please freely describe your opinion on terminal-stage dialysis and advance directive preparation."

5. Analysis Methods

We used statistical software (SPSS ver. 23) to confirm the distribution of each variable using descriptive statistics. We cross-tabulated these results according to patient characteristics, whether the subject had discussed the issue with a healthcare provider, whether they had discussed it with a family member, and whether they had prepared an advance directive. Results were then analyzed using Pearson's chi-square test (for small-size samples, Fisher's exact test was used). K-J method was used to analyze free comments regarding terminal-stage dialysis. First, the data were carefully read before identifying descriptions depending on their awareness of the question, "How does the patient/family member consider terminal-stage dialysis/advance directive preparation?" Next, these were transferred into card format. The cards containing information units were lined up and grouped according to similarity of the content shown on each card. Further, we grouped them into subcategories and further created groups on the basis of the content of the subcategories and finally named these as categories.

6. Ethical Considerations

This study was approved by the institutional review board of Naragakuen University (approval no: 27-004). A study request form was attached to the questionnaires. This request form explained that participation in the study was voluntary, subjects could withdraw their participation from the study, no disadvantages would arise in their treatment from not participating in the study, care would be taken so that individuals could not be identified from the data, the data obtained would not be used for any purpose other than research, and the results could be published in an academic journal or presented at an academic society meeting. It was also clearly indicated in the explanatory material that receipt of the completed questionnaire would be interpreted as consent to participate in the study.

7. Study results

7.1 Subject demographics

Table 1 shows the patient characteristics. The male to female ratio was 3:2, and 70% of the subjects were aged 60–70 years. Moreover, the range of duration of dialysis was 1–20 years (in maintenance phase) for >70% of the subjects. These figures are mostly consistent with the 2016 description of dialysis patients according to the Japanese Society for Dialysis Therapy (male to female ratio, 3:2; mean age, 68.15 years; and mean duration of dialysis, 7.6 years). Approximately 30% of the subjects

responded that their subjective health was poor.

7.2 Discussion regarding terminal-stage dialysis and advance directive preparation

Table 2 shows data on whether subjects had engaged in discussion with their healthcare provider and/or family members regarding terminal-stage dialysis and whether they had prepared an advance directive. Briefly, <40% of the subjects had discussed terminal-stage dialysis with a family member, whereas <10% had discussed the issue with a healthcare provider. However, only 3% of the subjects had actually prepared an advance directive and most subjects indicated that they had not prepared such a document.

7.3 Status of discussion regarding terminal-stage dialysis and advance directive preparation on the basis of patient characteristics

Table 3 shows comparisons of whether subjects had engaged in discussion regarding terminal-stage dialysis with healthcare providers and family members and whether they had prepared an advance directive on the basis of patient characteristics. In terms of discussion regarding terminal-stage dialysis with family members, more women discussed the issue with their family members than men ($p = 0.003$), subjects who had undergone dialysis for 1–20 years discussed the issue more than subjects who had undergone dialysis for less than 1 year or more than 20 years ($p = 0.03$), and subjects who self-described poor health discussed the issue with their family members more than those who did not ($p = 0.01$).

Table 1. Patient characteristics

Item	n=368	
	n	%
Sex		
Male	214	58.2
Female	154	41.8
Age		
<59 year	55	14.9
60–69 year	128	34.8
70–79 year	135	36.7
>80 year	50	13.6
Marital status		
Married	300	81.5
Unmarried	68	18.5
Duration of dialysis		
<1 year	27	7.3
1–9 years	159	43.2
10–19 years	111	30.2
≥20 years	71	19.3
Subjective health		
Healthy	26	7.1
Fairly healthy	229	62.2
Not very healthy	83	22.6
Unhealthy	30	8.2

7.4 Free response comments regarding terminal-stage dialysis and advance directive preparation

Overall, 38 subjects provided free response comments regarding their opinion on terminal-stage dialysis. We classified data into 13 subcategories regarding terminal-stage dialysis, which were subsequently grouped into five categories based on similarity. Opinions and thoughts on advance directive preparation were classified into three subcategories, which were subsequently grouped into two categories based on similarity (Table 4). Hereinafter, subcategories are shown within “<>” and categories are shown within “()”. Codes showing the data for classification are presented in italics and separated from the main text.

1) Opinions on terminal-stage dialysis

Two contrasting opinions were noted regarding terminal-stage dialysis. These were <Although I do not want other life-prolonging treatment, I want to continue with dialysis alone> and (I want to continue dialysis until the end) and (I do not want life-prolonging dialysis), which was based on observing other patients in the terminal stage and considering the burden placed on their family. Some subjects also expressed the opinion of (Wanting treatment that is not painful). Meanwhile, some subjects did not want to proactively think about the terminal stage, expressing opinions such as <I am doing everything that I can now> and (I do not want to think about it [terminal-stage dialysis] yet), and (I want more information to make a decision on terminal-stage dialysis).

2) Opinions on advance directive preparation

All subjects who described their opinion on advance directive preparation had not prepared such a directive. Some of these subjects felt “As I am the person concerned, I want to make the decision and prepare such a directive,” “I want to prepare a directive so as to not cause trouble to my family,” and (I want to prepare an advance directive), whereas other subjects wanted to leave the decision-making up to their family, i.e., (I do not want to prepare an advance directive).

Table 2. Discussion regarding terminal-stage dialysis and advance directive preparation

	n = 368	
	n	(%)
Discussion with healthcare provider		
Yes	36	9.8
No	332	90.2
Discussion with family		
Yes	139	37.8
No	229	62.2
Advance directive preparation		
Yes	11	3.0
No	357	97.0

Table 3. Comparison of whether patients discussed the issue with a healthcare provider/family and whether they had prepared an advance directive on the basis of patient characteristics

Items	Discussion with healthcare provider		Chi-squared test or Fisher's exact test	Discussion with family		Chi-squared test or Fisher's exact test	Advance directive preparation		Chi-squared test or Fisher's exact test							
	Yes (%)	No (%)		Yes (%)	No (%)		Yes (%)	No (%)								
Sex	n	n		n	n		n	n								
Male	214	16	7.5	199	93.0	n.s.	70	32.7	144	67.3	p=0.003	4	1.9	210	98.1	n.s.
Female	154	20	13.0	133	86.4		69	44.8	85	55.2		7	4.5	147	95.5	
		36	20.5	332			139		229			11		357		
Age																
<59 year	55	4	7.3	51	92.7		17	30.9	38	69.1		1	1.8	54	98.2	
60-69 year	128	11	8.6	117	91.4	n.s.	47	36.7	81	63.3	n.s.	3	2.3	125	97.7	n.s.
70-79 year	135	15	11.1	120	88.9		63	46.7	72	53.3		5	3.7	130	96.3	
>80 year	50	6	12.0	44	88.0		12	24.0	38	76.0		2	4.0	48	96.0	
Marital status																
Married	300	30	10.0	270	91.2	n.s.	116	38.7	184	61.3	n.s.	9	3.0	293	97.7	n.s.
Unmarried	68	6	8.8	62	91.2		23	33.8	45	66.2		2	2.9	66	97.1	
Duration of dialysis																
<1 year	27	2	7.4	25	92.6		10	37.0	17	63.0		1	3.7	26	96.3	
1-9 years	159	13	8.2	146	91.8	n.s.	50	31.4	109	68.6	p=0.03	4	2.5	155	97.5	n.s.
10-19 years	111	17	15.3	94	84.7		45	40.5	67	60.4		5	4.5	106	95.5	
≥20 years	71	4	5.6	67	94.4		34	47.9	36	50.7		1	1.4	70	98.6	
Subjective health																
Healthy	26	3	11.5	23	88.5		6	23.1	20	76.9		0	0.0	26	100.0	
Fairly healthy	229	20	8.7	209	91.3	n.s.	79	34.5	150	65.5	p=0.01	7	3.1	222	96.9	n.s.
Not very healthy	83	9	10.8	74	89.2		45	54.2	38	45.8		4	4.8	79	95.2	
Unhealthy	30	4	13.3	26	86.7		9	30.0	21	70.0		0	0.0	30	100.0	

n.s., No significant difference

The chi-square test and Fisher's exact test were used to compare "yes" and "no" groups for discussion with a healthcare provider/family and advance directive preparation for each item

n=368

Table 4. Opinions on terminal-stage dialysis

Category	Subcategory	Code (Illustration)
I want to continue dialysis until the end	While I do not want other life-prolonging treatment, I want to continue with dialysis alone	I do not want to undergo mechanical ventilation or gastrostomy. However, I want to continue dialysis.
	I undergo dialysis to stay alive	As I am undergoing dialysis to stay live, I want to continue with dialysis in order to live my life.
	I am scared of stopping dialysis	Thinking about before I started dialysis, I was scared just thinking about what would happen if I stopped dialysis. Therefore, I do not want to stop dialysis.
I want painless treatment	Worried about pain in terminal stage	I am worried about pain before death. That is what I want treatment for the most.
	Wanting pain reduction	As dialysis is bad enough now that I am elderly, I worry about what it will be like when I am close to death. I do not mind whether or not I undergo dialysis, I just do not want to feel pain.
I do not want life-prolonging dialysis	Because I am thinking of my family, I do not want unnecessary dialysis	For example, I do not agree with undergoing dialysis despite being unconscious or having severe dementia. I think unnecessary dialysis is simply a burden for family members.
	I do not want unnecessary dialysis as I believe it is a waste of public health costs	I have lived a sufficiently long life. I have come this far because I was blessed to have been in an environment with hardly any medical costs. I am always grateful for this. Wastefully prolonging live with dialysis is a waste of public health costs and I feel sorry about this in regards to my family and other people who require medical care.
	I want to leave things up to nature, without prolonging my life	I do not want to wastefully prolong my life—I want to die naturally. I have seen many patients suffer as they reached the terminal stage and continue to undergo dialysis despite being unconscious. I do not want to receive dialysis simply to prolong my life in that way.
I do not want to think about it yet	I do not want to think about the terminal stage yet	I cannot believe that this is happening to me and I do not want to think about it
	I am doing everything that I can now	I had never considered what would happen if I cannot judge for myself. I know that I will have to consider it eventually but I am doing everything that I can now.
I want more information to make a decision on terminal-stage dialysis	I do not have enough information about the terminal stage	Although I think it is important that I decide how I will end the terminal stage on my own, I do not know what to do about it. I am very worried about what will happen before I die. I want accurate information
	I want to consult with a healthcare provider	I want to get information from doctors and nurses. I want to receive an explanation at hospital.
	I want to consult with my family	I want to try discussing this with my family.

Table 5. Opinions on advance health directive

Category	Subcategory	Code (Illustration)
I want to prepare an advance directive	I want to display my intentions for myself	As I am the person concerned, I want to make the decision and prepare such a directive.
	I want to display my intentions for my family	I want to prepare a directive so as to not cause trouble to my family.
I do not want to prepare an advance directive	I want to value my family's intentions over my own	I have caused enough trouble to my family so far. My family can do what they wish.

8. Discussion

The aim of this study was to clarify the state of discussion regarding terminal-stage dialysis, advance directive preparation, and opinions of patients and their family members regarding terminal-stage dialysis to facilitate support for decision-making regarding terminal-stage dialysis by nurses. Our results indicated that <40% of the subjects and their family members had engaged in a family discussion regarding terminal-stage dialysis, whereas <10% of the subjects and their family members had discussed the issue with a healthcare provider. These findings indicate that although terminal-stage treatment is currently debated, there are few opportunities to proactively consider and discuss terminal-stage condition and death with dialysis patients and their family members in their daily lifestyle.

A US-based survey reported that 50% of dialysis patients stated that they “have not thought about their own death”²⁴⁾, which was consistent with our findings that <50% of the subjects had actually discussed the issue of terminal-stage dialysis. In our study, some free response comments indicated (I do not want to think about it [terminal-stage dialysis] yet), and similar to the results of the aforementioned survey, many dialysis patients in Japan do not “think about their own death,” which is the basis for discussing terminal-stage dialysis. This suggests a psychological mechanism is employed wherein patients push thoughts of the terminal stage into deep unconscious state and avoid the issue owing to their fear of death, thereby reaching some psychological stability to continue with dialysis treatment³⁵⁾.

Results of the binomial analysis indicated that patients in maintenance phase at least 1 year after starting dialysis treatment and patients with relatively poor subjective health are more likely to discuss terminal-stage dialysis with their family members than other patients. It appears that as the duration of dialysis treatment increases and patients become anxious regarding their health, they become more likely to seriously

consider their own life, including terminal-stage dialysis.

The free comment section included one such response, “I have seen many patients suffer as they reached the terminal stage and continue to undergo dialysis despite being unconscious. I do not want to receive dialysis simply to prolong my life in that way.” As patients observe other patients undergoing terminal-stage dialysis while they receive their own dialysis treatment in one of many hospital beds, it makes them anxious and scared and, thus, forces them to think about their own terminal-stage dialysis treatment. One patient was self-aware of their treatment and stated, “Although I think it is important that I decide how I will end the terminal stage on my own, I do not know what to do about it,” suggesting that patients do not have enough information to make a decision. Accordingly, patients who are interested in terminal-stage dialysis and are in the maintenance phase after a certain amount of time has passed after starting dialysis should be given necessary information. The values and wishes of each party should be considered in the repeated discussions regarding the patient’s intentions on living their life as they wish.

The present study also included patients’ opinions on advance directive preparation. We found that there were two types of patients: those who wanted to prepare an advance directive and those who did not. Moreover, while these opinions appear to be opposing, both groups are founded in the patients thinking of their family, as shown by the subcategory <I want to value my family’s intentions over my own>. This suggests that “consideration” and “reservation,” both common cultural characteristics of the Japanese, who place consideration of those around them above the consideration of their own needs, also affect decision-making on terminal-stage dialysis. To adequately support decision-making regarding terminal-stage dialysis, as a medical dialysis team, nurses must make adjustments to provide relevant information that the patient requires with understanding of the patient’s psychology. In particular, care should be taken so that patients who want to prepare an advance directive can prepare the document on the basis of appropriate discussion so

that they do not base their decision on incorrect assumptions regarding prognosis and treatment outcomes.

9. Conclusions

Fewer than 40% of the subjects had discussed terminal-stage dialysis with their family members, whereas <10% had discussed the issue with a healthcare provider. Moreover, only 3% of the subjects had prepared an advance directive. When offering support for decision-making regarding terminal-stage dialysis, nurses should provide necessary information while confirming the health state and current status of patients, particularly those who have received dialysis for a certain period of time and are interested in terminal-stage dialysis, as well as informing their family members. In addition, nurses should make adjustments such that patients can thoroughly discuss terminal-stage dialysis.

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Conflicts of interest

There are no conflicts of interest.

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