

Factors that Prevent Extensive Deceased-donor Kidney Transplantation among Japanese Women on Hemodialysis: Analysis of Patient Interviews

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Abstract

This study aimed to clarify the factors that have hindered the progress of deceased-donor kidney transplantation in Japan from the perspective of the patients. A semi-structured questionnaire was used to conduct interviews with adult female hemodialysis patients treated at the University Hospital. Data were collected regarding all of the treatment options presented at the time of dialysis initiation and patient opinions about the deceased-donor kidney transplant registry. Narrative data obtained during the interviews were analyzed using content analysis. Three female hemodialysis patients, aged 54–67 years, participated in this study. By performing content analysis of the interview data, four themes, 13 categories, and 24 subcategories were identified that may influence the low utilization of deceased-donor kidney transplantation among female hemodialysis patients in Japan. This study revealed the following main reasons for the low utilization of deceased-donor kidney transplantation among Japanese women on hemodialysis: 1) high satisfaction with hemodialysis, 2) deceased-donor kidney transplant not being a realistic treatment option, 3) low interest in kidney transplant, and 4) costs associated with deceased-donor kidney transplant (risks, physical and psychological burdens).

Introduction

The number of patients undergoing dialysis has been steadily increasing. In 2020, the number of dialysis patients was 2,754 per million people, or approximately one in every 363 persons in Japan [1]. In 2018, Japan had the second highest prevalence of patients undergoing dialysis in the world after Taiwan [2, 3]. According to the United States Renal Data System, Japan has one of the highest prevalence rates of end-stage renal disease (ESRD) worldwide [4]. Treatment options for ESRD include dialysis therapy (hemodialysis and peritoneal dialysis) and renal transplantation [5]. Although the number of dialysis patients in Japan is approximately 340,000, only 12,505 of them had been registered with the Japan Organ Transplant Network at the end of 2019 for deceased-donor kidney transplantation [6]. Furthermore, the sex ratio of registrants was tilted towards men: 67% men versus 33% women registered with the transplant network. In 2020, the sex ratio for recipients was 141 men (61.3%) versus 89 women (38.7%) for donated kidney transplants in Japan [6].

Although there are about 12,000 people seeking kidney transplants in Japan, the supply and demand for kidney transplants is not balanced, with only 2,057 kidney transplantations carried out in 2019 (1,827 living donor transplants and 230 deceased-donor kidney transplants) [6]. In 2022, according to the United States Renal Data System, more than 33.3% of ESRD cases worldwide received a kidney transplant, the notable examples being Iceland (70.5%), Norway (67.5%), the Netherlands (65%), Estonia (62.9%), and Finland (62.7%) [4]. In contrast, only 2.4% of patients with ESRD in Japan received a kidney transplant [4]. Due to the small number of kidney donors available, almost 90% of kidney transplants carried out in Japan each year are living donor kidney transplants [6,7].

It is hoped that the social and economic benefits of kidney transplantation will help to make kidney transplantation more widespread in Japan. Hemodialysis patients inevitably face time constraints and dietary restrictions, whereas kidney transplantation

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reduces the risk of death and improves the quality of life [6, 8-15]. In addition, kidney transplantation is superior to dialysis in terms of long-term cost-effectiveness [10, 15-17]. An overall break-even point of 3.1 years (3.2 years for deceased-donor and 2.8 years for living donor kidney transplantation) has been reported for Medicare reimbursement costs for kidney transplantation and dialysis [18]. The number of dialysis patients is increasing year by year, but the number of patients with ESRD registered in the Japan Organ Transplant Network for deceased-donor kidney transplantation has remained stagnant [6]. Deceased-donor kidney transplants are much more widespread in other countries compared to Japan [4], and the following factors may account for transplantation refusal in the Japanese population: patients doing well on dialysis [19], or not finding dialysis burdensome [20], patient misperceptions, inadequate information, and misinformation about kidney transplantation [19, 21-23], perceived risks of renal rejection and death from surgery [19, 21], being influenced by the experiences of other patients with failed transplants [21, 22], the requirement of several time-consuming appointments and tests prior to transplantation [19, 20], not wanting an organ from another individual in their body for personal or religious reasons [19], and advanced age [19, 21, 22], among others.

Although more female hemodialysis patients in Japan should be encouraged to undergo deceased-donor kidney transplantation, the number of research articles addressing this problem is limited.

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Therefore, this study aimed to clarify the factors hindering increased utilization of deceased-donor kidney transplants among female hemodialysis patients in Japan.

Materials and Methods

Participants

Adult female hemodialysis patients undergoing treatment at the University Hospital were recruited in this study; nurses referred the prospective patients to the researchers. To avoid any pressure from the medical staff on the patients to participate in the study, the aim of the study was explained by a researcher (H.H.), and the patients were asked to participate voluntarily. The study population included all female hemodialysis patients treated in the unit regardless of the duration of dialysis or the primary disease for which dialysis was initiated.

Data collection

Semi-structured interviews were conducted by one researcher (H.H.) in September 2013. For all interviews, the researcher used a newly developed interview guide. The following questions were asked: 1) Were you aware of the three treatment options (hemodialysis, peritoneal dialysis, and kidney transplant) at the time of dialysis induction? 2) Has your doctor ever explained the option of deceased-donor kidney transplant to you? 3) Were you able to make your own choice of treatment option (hemodialysis, peritoneal dialysis, or kidney transplant) at the time of dialysis initiation? 4) Have you ever considered receiving a deceased-donor kidney transplant? 5) What is your registration status with the Japan Organ Transplant Network?

During the interview, if ambiguous expressions were found in the statements of the participant, the interviewer rephrased the statements to confirm their intentions. Furthermore, follow-up questions such as "What did you feel in that scenario or context?" were asked during the course of the interview. We also asked about the level of satisfaction with the hemodialysis treatment on a five-point ordinal scale of: "1. Very dissatisfied", "2. Somewhat dissatisfied", "3. Neither satisfied nor dissatisfied", "4. Somewhat satisfied", and "5. Very satisfied". The interviews were completed within 30 minutes to avoid any inconvenience to the patients and were conducted in a place where the patient could talk freely and yet, privacy could be maintained. The responses were recorded on an IC recorder with the consent of the patient.

Analytical methods

All audio recordings were transcribed verbatim by the researcher (H.H.) who conducted the interviews. The verbatim transcripts were checked against the audio recordings to ensure the authenticity of each recording. Two independent researchers (H.H. and Y.M.) separately read the verbatim transcripts frequently to immerse themselves in the data and share their perceptions of patient intentions to ensure consistency in the findings. The interviews, transcription, and data analysis were conducted in Japanese. The results of the analysis were translated into English by the first researcher (Y.M.), and the second researcher (M.S.Y.) checked the accuracy of the translation. Narrative data from the interviews were analyzed using standard qualitative content analysis methods, with reference to Belerson's method of content analysis [24]. We created a verbatim transcript of the information obtained and extracted, and coded the contexts in which thoughts and influences on the deceased-donor kidney transplant registry were discussed. Subcategories were created based on similarities in semantic content. The contents of the subcategories were further classified and named into categories based on their

similarity in meaning. In addition, data such as age and period of hemodialysis treatment are presented as mean \pm standard deviation (SD).

Trustworthiness

To examine the reliability of the categorization strategy, Scott's formula [25] was used. Specifically, two researchers (H.H. and M.S.Y.), other than the one who was in charge of the original analysis (Y.M.), performed the categorization work separately, and their concordance rates were calculated based on Scott's formula (also known as the kappa coefficient). The standard for reliability assurance was set at a concordance rate of 70% or higher, according to the previous literature [26].

Ethical considerations

This study was conducted with the approval of the Niigata University Ethics Committee. Participation in this study was voluntary, and the data were anonymized. All participants were informed in advance of the purpose of the study, the methods of data collection, their voluntary participation, and that they will not be at a disadvantage by refusing to participate in the study and can withdraw their consent at any time. Finally, verbal and written informed consents were obtained from all participants in accordance with the Declaration of Helsinki [27]. Patient privacy was fully protected throughout the study.

Results

Characteristics of participants

Table 1 lists the characteristics of study participants and their registration status with the Japan Organ Transplant Network. Three female hemodialysis patients, aged between 54 to 67 years (mean age 62.3 ± 7.2 years), participated in this study. The primary disease that led to hemodialysis induction differed for each participant, and the duration of treatment before hemodialysis induction also varied widely, ranging from 0.7 to 28 years (14.9 ± 13.7 years). Hemodialysis history ranged from 6 to 14 years (8.7 ± 4.6 years), and all patients had three dialysis sessions per week that was similar to the average frequency of dialysis in Japan. Regarding the satisfaction level of hemodialysis treatment, two patients answered, "somewhat satisfied" (the top 2 out of 5) and one patient answered, "somewhat dissatisfied" (the bottom 2 out of 5).

Patient choice for renal replacement therapy

All participants were on dialysis, and were asked about their choice of treatment upon starting renal replacement therapy for ESRD. All three patients were aware of the three treatment modalities (hemodialysis, peritoneal dialysis, and kidney transplantation) at the time of dialysis initiation, but only one patient had received an explanation of the deceased-donor kidney transplant procedure from her physician (Table 2). Similarly, only one of them was able to voluntarily choose one of the three treatment options at the time of dialysis initiation. Also, none of them were registered with the Japan Organ Transplant Network.

Qualitative content analysis of interview text

Among the factors that prevent hemodialysis patients from seeking deceased-donor kidney transplantation, we extracted 24 subcategories that were further grouped into 13 categories and four themes during data analysis (Table 3). Here, the categories are indicated by square brackets ([]), subcategories by angle

Table 1: Demographic profiles of participants and their hemodialysis status.

Participant	A	B	C
Age	66 years old	67 years old	54 years old
Sex	Female	Female	Female
Living arrangement	Alone	Husband	Husband, son, mother-in-law
Employment status	Unemployed	Employed	Unemployed
Primary disease	Hepatorenal syndrome	Chronic glomerulonephritis	Nephrosclerosis
Duration from diagnosis to start of hemodialysis	0.7 year	16 years	28 years
Period on hemodialysis	6 years	14 years	6 years
Number of hemodialysis sessions	3 sessions / week	3 sessions / week	3 sessions / week
Satisfaction level with in-center hemodialysis	Somewhat satisfied	Somewhat satisfied	Somewhat dissatisfied

Table 2: Patient awareness of the option of a deceased-donor kidney transplant and registration status with the Japan Organ Transplant Network.

Participant	A	B	C
Were you aware of the three treatment options (hemodialysis, peritoneal dialysis, kidney transplant) at the time of dialysis induction?	Yes	Yes	Yes
Has your doctor ever explained to you about deceased-donor kidney transplants?	No	Yes	No
Were you able to make your own choice of treatment options (hemodialysis, peritoneal dialysis, kidney transplant) at the time of dialysis induction?	Yes	No	No
Have you ever considered receiving a deceased-donor kidney transplant?	No	No	Yes
What is your registration status with the Japan Organ Transplant Network?	Unregistered	Unregistered	Unregistered

brackets (< >), and patient statements by quotation marks (“ ”). The reliability of the categorization was confirmed by a Scott’s agreement rate of 0.864 (checked by H.H.) and 0.864 (checked by M.S.Y.), respectively. Therefore, there was almost perfect agreement for reliability of the categorization between the researchers analyzing these data.

Theme 1: High satisfaction with hemodialysis

This theme consisted of three categories and six subcategories, representing 25.0% of the total subcategories. This theme supported the participant response of "somewhat satisfied" satisfaction level with hemodialysis shown in Table 1. Three categories were extracted from the patient narratives: [Doing well on hemodialysis], [Trust in hemodialysis], and [Convinced to initiation of hemodialysis]. The following are representative quotes from the patients:

“I am satisfied with my dialysis therapy and would like to continue with hemodialysis.”

“It is hard to stay on dialysis, but I have heard that dialysis is getting better, and patients can survive as long as 20 or 25 years.”

“Except for not being able to travel for a few days, I am very happy with my hemodialysis.”

“I don’t think I would want to get a kidney from someone else because dialysis keeps me alive.”

Theme 2: Deceased-donor kidney transplant is not A realistic treatment option

This theme consisted of four categories and seven subcategories, representing 29.2% of the total subcategories. Four categories were extracted from the patient narratives: [Less likely to receive deceased-donor kidney transplant], [Medical staff did not present the option of deceased-donor kidney transplant], [Misconceptions about deceased-donor kidney transplant], and [Refusing deceased-donor kidney transplant option due to advanced age]. The following are typical narratives:

“I learned on TV that deceased donor kidney transplants have long waiting lists and few kidneys available.”

“Because of my advanced age, I have never considered undergoing a deceased-donor kidney transplant.”

“At the time of starting renal replacement therapy, the doctor only explained hemodialysis. Therefore, I thought that other treatments were not my therapeutic options.”

“I thought that deceased-donor kidney transplant was a treatment for those who could not sustain life on dialysis.”

“To date, I have not received any explanation from my doctor regarding a deceased-donor kidney transplant.”

Theme 3: Low Interest In Kidney Transplant

This theme consisted of three categories and six subcategories, representing 25.0% of the total subcategories. Three categories were extracted from the patient narratives: [Passive attitude toward deceased-donor kidney transplant], [External circumstances leading to disinterest in deceased-donor kidney transplant], and [Unfamiliar with deceased-donor kidney transplant option for ESRD patients]. The main narratives are as follows:

“I did not voluntarily ask my doctor any questions about donated kidney transplants.”

“At the time of my introduction to dialysis, I had no interest in a kidney transplant.”

“I thought my kidney function was not so bad, so I thought kidney transplant was something else.”

“I don’t know what to prepare for a deceased-donor kidney transplant. I don’t think about getting half of that person’s kidney and living a long life.”

Theme 4: Costs associated with deceased-donor kidney transplant (Risks, Physical And Psychological Burden)

This theme consisted of three categories and five subcategories,

Table 3: Factors that prevent hemodialysis patients from seeking deceased-donor kidney transplant.

Theme (4)	Category (13)	Subcategory (24)
High satisfaction with hemodialysis	Doing well on hemodialysis	Very satisfied with hemodialysis
		No serious dialysis complications
		No fatigue after dialysis
	Trust in hemodialysis	Believing that hemodialysis works well
		Good outcomes and long-term survival on hemodialysis therapy
	Convinced to initiation of hemodialysis	Understanding and acceptance of informed consent for starting hemodialysis
Deceased-donor kidney transplant is not a realistic treatment option	Less likely to receive deceased-donor kidney transplant	Few people are willing to donate their organs
		Long waiting period for deceased-donor kidney transplants
	Medical staff do not present the option of deceased-donor kidney transplant	When patient initiated renal replacement therapy, doctor only explained hemodialysis option to the patient
		Medical staff did not discuss the deceased-donor kidney transplant option once hemodialysis was initiated
	Misperceptions about deceased-donor kidney transplant	Recognition that donated kidney transplantation is a treatment for patients who cannot sustain life on dialysis
	Refusing deceased-donor kidney transplant option due to advanced age	Not able to consider a deceased-donor kidney transplant due to advanced age
		No need to get a deceased-kidney transplant because I have already lived long enough
	Low interest in kidney transplant	Passive attitude toward deceased-donor kidney transplant
Not talking to someone about a deceased-donor kidney transplant option		
Only passive media (TV, magazines, posters) mention deceased-donor kidney transplants		
External circumstances leading to disinterest in deceased-donor kidney transplant		No opportunity to have a conversation about deceased-donor kidney transplants with someone close to patient
Unfamiliar with deceased-donor kidney transplant option for ESRD patients		Feel that deceased-donor kidney transplant is someone else's problem
		Not interested in deceased-donor kidney transplant option at the time of initiation of dialysis
Costs associated with deceased-donor kidney transplant (risks, physical and psychological burdens)	Uncertainty about deceased-donor kidney transplant outcome	There is no guarantee that the transplanted kidney will be accepted by the recipient's body
	Procedural and social burden of registering for deceased-donor kidney transplant	Perception of hardship to endure in testing associated with registering for donated kidney transplant
		Apologies to family members; for having to be transported to and from the hospital for kidney transplant testing
	Ethical and psychological burdens of deceased-donor kidney transplant	Guilt of waiting for the donor to die
		Guilt of getting a kidney from a dead person

ESRD, end-stage renal disease.

representing 20.8% of the total subcategories. Three categories were extracted from the patient narratives: [Uncertainty about deceased-donor kidney transplant outcome], [Procedural and social burden of registering for deceased-donor kidney transplant], and [Ethical and psychological burdens of deceased-donor kidney transplant]. The major narratives are as follows:

“Recently, my husband and I talked about how we should have registered for a donor kidney transplant and decided to ask the nurse about it. However, a few weeks ago, the nurse told us that there would be a lot of tests to go through, so I gave up on the idea of a deceased-donor kidney transplant. The only reason I did not register for a donor kidney transplant was because of the difficulty of the tests.”

“If I were to get a kidney transplant from a donor, I don't know if the kidney would fit without being rejected.”

“I have heard that there are many tests to register for a donor kidney transplant wish list and I am not keen on registering.”

“I feel that I should not receive a kidney from a deceased person.”

“The kidney is donated after the donor has died. I felt that I should not expect that to happen.”

“I have heard that there are many tests required to register with the Japan Organ Transplant Network. I would like to register if the tests were simple.”

“My elderly mother drives me for hours to and from the dialysis room for each dialysis session. Therefore, I do not want to put an additional

burden on my mother by having to undergo the necessary tests related to my transplant."

Discussion

This study aimed to identify factors hindering the progress of deceased-donor kidney transplantation in Japan from the perspective of the patient. The results of semi-structured interviews with three adult female hemodialysis patients revealed four main themes: 1) high satisfaction with hemodialysis, 2) deceased-donor kidney transplant is not a realistic treatment option (due to long wait times), 3) low interest in kidney transplant, and 4) costs associated with deceased-donor kidney transplant (medical risks, physical and psychological burdens).

The study participants had a mean age of 62.3 ± 7.2 years and a mean dialysis duration of 8.7 years that is typical of the general patient population (Table 1). The Japanese Society for Dialysis Therapy has been surveying the status of chronic dialysis therapy in Japan at the end of every year since 1968 [28]. According to this registry, the average age of chronic dialysis patients at the end of 2013 was 69.4 years, with an average dialysis duration of 7.4 years (6.8 years for men and 8.4 years for women). The average age of such patients has been slowly increasing since the 1980s, and in 2013 was approximately 67 years [1]. In our study, all three patients had three weekly dialysis sessions, and this is the typical number of sessions for hemodialysis in Japan. Among the three participants, two patients chose "somewhat satisfied" (the top 2 out of 5) and one patient opted for "somewhat dissatisfied" (the bottom 2 out of 5) in the satisfaction level of hemodialysis treatment (Table 1). According to the Dialysis Outcomes and Practice Patterns Study, a multi-country prospective cohort study of hemodialysis patients, Japanese hemodialysis patients have a longer life expectancy [29, 30]. At the end of 2020 in Japan, the longest time spent on dialysis was 52 years and 4 months, and 8.5% patients had been dialyzed for more than 20 years [1]. Since dialyzers are disposable and the dialysate is extremely clean [1], in the authors' experience, no patient in Japan has suffered from endotoxin contamination. Although some patients complain of discomfort due to low blood pressure during dialysis, many patients are relatively satisfied with their treatment, and very few suffer from serious complications of hemodialysis. Hemodialysis patients often complain of physical restraints during dialysis and inconveniences such as fluid and food restrictions. However, as long as patients are self-managed and receive appropriate dialysis treatment three times a week, they can survive for a long time and have little need for a kidney transplant. The categories [Doing well on hemodialysis] and [Trust in hemodialysis] were derived from this study, but similar findings have been reported in surveys done in the US: 83% of patients who did not want a transplant stated that they were doing well on dialysis [19]. Similarly, some patients do not wish to undergo transplantation because they do not find dialysis particularly burdensome [20].

All participants were asked how they chose their treatment when they had to initiate renal replacement therapy due to ESRD (Table 2). All participants were aware of the three treatment options (hemodialysis, peritoneal dialysis, and renal transplantation) at the time of dialysis initiation, but only one indicated that she was able to choose her own treatment option. One participant sought an explanation from her physician about deceased-donor kidney transplant after 12 years of hemodialysis. However, at the initiation of renal replacement therapy, none of the participants were told about the deceased-donor kidney transplant option by their physicians.

In other countries, the majority of patients with ESRD do not have the option of chronic peritoneal dialysis, home hemodialysis or kidney transplantation [31]. In a previous survey [31], 30% of patients claimed that they were not offered treatment options until dialysis had begun, and 48% of patients reported that they were offered treatment options less than one month before or only after their first dialysis session. These findings, taken together with our survey results, imply that patients are not being informed adequately of the available treatment options. However, considering the overwhelming acceptance of hemodialysis for treating ESRD in Japan, it seems natural for the attending physician to recommend hemodialysis as the first treatment choice. In 2020, of the 40,744 new dialysis patients, 93.9% were started on hemodialysis or hemodiafiltration and 6.1% on peritoneal dialysis [1]. The efficacy of pre-emptive kidney transplantation without dialysis has been verified [32, 33], and patients can request preemptive kidney transplantation when they register with the Japan Organ Transplant Network [5]. However, in Japan, the average wait time for a deceased-donor kidney transplant for patients aged 16 years or older is approximately 5,400 days (~15 years) [5, 6, 15] [34], and therefore, it is very difficult to receive a deceased-donor kidney transplant at the beginning of renal replacement therapy. Therefore, it is possible that deceased-donor kidney transplantation may not have been explained to our participants at the initiation of hemodialysis. In other words, since patients with ESRD usually make treatment decisions regarding transplantation only after starting hemodialysis, it is important to not confuse their default treatment status of being on dialysis with their future choices regarding transplantation [19]. Nevertheless, ESRD patients have the right to be informed about all available treatment options, including deceased-donor kidney transplant [15].

Our data show that only one of the three participants responded that she was able to choose her own treatment. This may indicate that participants did not feel that they had sufficient information to discuss this option with the medical staff at the time of treatment selection. Indeed, the subcategories <When patient initiated renal replacement therapy, the doctor only explained the hemodialysis option to the patient> and <Medical staff did not discuss the deceased-donor kidney transplant option once hemodialysis was initiated> were derived from the analysis of the interviews with the participants (Table 3). Furthermore, these subcategories led to the category [Lack of information from medical staff to patients regarding deceased-donor kidney transplant] as a factor that prevented the patients from considering a kidney transplant. This category would be indirectly related to [Unfamiliar with deceased-donor kidney transplant option for ESRD patients]. Since patients do not consider deceased-donor kidney transplantation as relevant to them, they may form a [Passive attitude toward deceased-donor kidney transplant] and their information sources may be limited to passive sources from the media. According to the perceptions of the participants of this study, medical staff at the dialysis unit see hemodialysis patients three times a week, but still do not actively provide information to the patients. In a previous study, 24.8% of patients reported never having heard about kidney transplantation from their physicians [21], and 56% of participants had inadequate information about transplantation [21]. The explanation given by the physician about the treatment plan was only for hemodialysis, and this may have contributed to the patient perception of [Unfamiliar with deceased-donor kidney transplant option for ESRD patients]. The subcategory <Recognition that donated kidney transplantation is a treatment for patients who cannot sustain life on dialysis> indicates patient misconceptions about deceased-donor kidney transplantation, but the lack of explanation

from medical staff may also have contributed to these misconceptions. Surveys in other countries have reported that many patients have incorrect knowledge of the basic facts about kidney transplantation [21, 31, 35]. Patient misperceptions, inadequate information, and misinformation about kidney transplantation are possible factors reducing access to kidney transplantation for dialysis patients [19, 21-23], highlighting the need for the provision of correct information from medical staff and its discussion with patients [20].

Patient misconceptions about transplantation may lead them to overestimate the risks of kidney transplantation. The psychology of risk aversion is manifested in the subcategory <There is no guarantee that the transplanted kidney will be accepted by the body of the recipient>. However, in Japan, the 5-year graft survival rate for living donor renal transplants was 94.3% from 2010 to 2016, while that for deceased-donor kidney transplant was 88.0% [5]. The 10-year graft survival rate for living donor kidney transplants is 90% [5]. In the long term, graft loss may result in a return to dialysis. However, patients who receive kidney transplants have a longer life expectancy and a better quality of life than those on hemodialysis [6, 8-15] and this should be considered by patients. Previous studies have reported on patient-perceived risks of renal rejection and death from surgery [19, 21]. In addition, observing the experiences of other patients with failed transplants may negatively impact patient perceptions of transplantation [21, 22]. However, this is not necessarily a misconception since studies have shown that ESRD patients who return to dialysis after a failed transplant have a lower quality of life than similar patients who did not receive a transplant [36-38].

The participants in this study perceived <Perception of hardship to endure in testing associated with registering for donated kidney transplant> as a barrier to deceased-donor kidney transplantation. Furthermore, patients also perceive the numerous time-consuming appointments and tests prior to transplantation as an obstacle [19, 20]. In fact, transplant recipients undergo several and varied tests such as screening for cancer, electrocardiogram, echocardiogram, fecal occult blood, and evaluation of dialysis complications such as dialysis amyloidosis [5, 15], and therefore, there is a need for prioritizing patient education. The subcategories <Guilt of waiting for the donor to die> and <Guilt of getting a kidney from a dead person> were also extracted in our study. This is consistent with the opinion stated by participants in the previous study [20], namely *"I figure if there's a transplant, give it to somebody young. Give them an opportunity to have a longer life."* Moreover, 43% of the participants did not want a transplant because they did not want an organ from another person in their own body due to personal or religious reasons [19]. The ethical and psychological burden felt by the patient must be fully considered, keeping in mind individual religious and cultural backgrounds.

As the category [Refusing deceased-donor kidney transplant option due to advanced age] was extracted in this study, age was often mentioned as a barrier to kidney transplantation during interviews. Increasing age is associated with a decreased probability of seeking a kidney transplant [19,21,22]. In contrast, some patients express altruistic sentiments and want younger people to receive transplants [19]. This may be due to a longer history of dialysis and familiarity with dialysis-related self-management as one gets older, an unwillingness to take the risk of trying new treatments, increased surgical risk with age, or a longer average wait time before transplantation, considering life expectancy at the time of transplantation [22]. In Japan, the waiting period for deceased-donor kidney transplant is approximately 15 years [34]. Since the duration of the waiting period is an important

factor in selecting candidates for deceased-donor kidney transplant, patients with a longer duration of dialysis therapy are often selected [34,39]. At the time of this study, 75% of deceased-donor kidney transplant recipients had waited more than 10 years for a transplant [34]. Despite the efforts of the Japan Organ Transplant Network and other agencies, a major challenge that remains is the strengthening of the system to increase the number of donated kidney transplants in Japan.

This study has some limitations. As a pilot study, it was necessary to select appropriate participants within a few months of ethical review approval. Therefore, a small, single-center study was conducted. However, the analyzed interviews presented rich and detailed narratives of individual participants, providing a substantial amount of data for analysis. The fact that patient testimonies are based on their memories of dialysis initiation six or 16 years ago can be another limiting factor in accuracy. Thus, further research is needed to generalize these results, but the conclusions drawn from this study can serve as a useful starting point for other studies on similar topics.

Conclusions

In summary, this study revealed that the main reasons for the low utilization of deceased-donor kidney transplants among Japanese women on hemodialysis are as follows: 1) high satisfaction with hemodialysis, 2) deceased-donor kidney transplant not perceived as a realistic treatment option, 3) low interest in kidney transplant, and 4) costs associated with deceased-donor kidney transplant (fiscal cost, medical risks, physical and psychological burdens). In addition, access to transplantation has been difficult in Japan due to the current situation where deceased-donor kidney transplantation is not offered as a treatment option to most patients who are being initiated into maintenance dialysis. Our present findings support the need to promote shared decision making by educating patients with ESRD via medical staff in parallel with the incentivization of deceased-donor kidney transplantation by the Japan Organ Transplant Network.

Competing Interests

The authors declare that they have no competing interests.

Author Contributions

Conceptualization, H.H., Y.M.; investigation, H.H.; data curation, H.H., Y.M.; analysis, H.H., M.S.Y., Y.M.; writing-original draft preparation, Y.M.; writing-review and editing, M.S.Y., H.H.; project administration, Y.M. All authors have read and agreed to the published version of the manuscript.

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Data Availability Statement

The interview guide can be found in the Materials and Methods section of the manuscript. To protect the privacy of participants, records containing personal, confidential data will not be released to the public. Anonymized data are available upon reasonable request by contacting the corresponding author.

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