PERSPECTIVES OF PATIENTS, FAMILIES, AND HEALTH CARE PROFESSIONALS ON DECISION-MAKING ABOUT DIALYSIS MODALITY—THE GOOD, THE BAD, AND THE MISUNDERSTANDINGS!

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◆ **Objectives:** This study explored the factors influencing decision-making about dialysis modality, integrating the perspectives of patients, their families, and health care professionals within an Asian population. The study further sought to understand the low penetration rate of peritoneal dialysis (PD) in Singapore.

◆ **Methods:** A sample of 59 participants comprising pre-dialysis patients, dialysis patients, caregivers, and health care professionals (HCPs) participated in semi-structured interviews to explore the decision-making process and their views about various dialysis modalities. Data were thematically analyzed using NVivo9 (QSR International, Doncaster, Australia) to explore barriers to and facilitators of various dialysis modalities and decisional support needs.

◆ **Results:** Fear of infection, daily commitment to PD, and misperceptions of PD emerged as barriers to PD. Side effects, distance to dialysis centers, and fear of needling and pain were barriers to hemodialysis (HD). The experiences of other patients, communicated informally or opportunistically, influenced the preferences and choices of patients and family members for a dialysis modality. Patients and families value input from HCPs and yet express strong needs to discuss subjective experiences of life on dialysis (PD or HD) with other patients before making a decision about dialysis modality.

◆ **Conclusions:** Pre-dialysis education should expand its focus on the family as the unit of care and should provide opportunities for interaction with dialysis patients and for peer-led learning. Barriers to PD, especially misperceptions and misunderstandings, can be targeted to improve PD uptake.

KEY WORDS: Decision-making; dialysis modality; patient education.

Dialysis is the most common renal replacement therapy for people with end-stage renal disease worldwide (1–3). The numbers of patients facing the decision about a dialysis modality are expected to rise even further with the aging of the population and the increased prevalence of diabetes (4–7).

Although the delivery of satisfactory pre-dialysis education is the subject of international guidelines, and although most patients may be medically suitable for either peritoneal dialysis (PD) or hemodialysis (HD) (8), the PD penetration rate remains low worldwide, excepting Hong Kong and Canada (1,3,7,9–12). Data from Singapore showed that, of 4169 prevalent patients on dialysis, 85.7% were on HD and only 14.3% were on PD (3). Recent data indicate that PD awareness has increased (13), and yet PD uptake rates seem to be declining. Those opposing trends are hard to place in the context of accumulating evidence that PD is associated with lower costs, better satisfaction and quality of life, and equal (if not better) clinical outcomes—at least for some subgroups (14–19). The key challenge that remains is to identify barriers to PD and to explore how the decision-making process may favor one modality over another.

The decision-making process in the context of chronic kidney disease (CKD) involves several parties [patients, families, health care professionals (HCPs)], complex organizational and socio-economic structures (for example, reimbursement or medical insurance policies), and patient preferences and clinical needs, among others. Earlier research concluded that lifestyle and psychosocial considerations are pivotal in guiding decision-making about a dialysis modality and that those factors may rank higher than medical considerations (20–22). Identified factors that may act as either facilitators or barriers for the various dialysis modalities include availability of social support or concerns about social isolation,

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preference for autonomy and control, fear of needling or infections (or both), concerns about body image, and geographic location of dialysis centers. Pre-dialysis education and care, and planned dialysis onset have also been shown to be important contextual and organizational factors that favor uptake of PD (23). Patients have a strong preference for the status quo and are reluctant to change treatments, especially in the context of emergency HD (24). Timely decisions on dialysis modality are likely to favor PD, and yet as many as 61% of CKD patients in Singapore end up on emergency dialysis (25–30).

Although previous research has unraveled aspects of the decision-making process, methodologic considerations limit the generalizability of findings. First, studies were based on Western patient samples. No data have been published on decision-making in the Asian population and in cultures traditionally viewed as more collectivistic rather than individualistic (31), which predominantly favor a family-centered model of decision-making (32). Studies have found that, for people choosing treatment, social groups such as other patients or family members play a central role in decision-making and yet perspectives on dialysis modalities have not been explored in the entire group (33,34). Patients from non-Western cultures prefer that family or significant others be largely involved in the process of receiving information and making mutually agreed choices for treatment even when patients are competent (35). This practice of family-led decision is also reinforced by policies in Singapore dictating that dialysis costs are to be borne by the children of patients and that the level of medical subsidy for dialysis is to be determined based not solely on individual means but also on immediate family (offspring) income.

Second, in most studies, the focus has been solely on prevalent dialysis patients (8,27,36,37), which may introduce recall bias into patient reports. Data on incident patients or data on how significant others (family, HCPs) implicate and influence the decision-making process are largely lacking.

The present study was designed to explore and expand on the current understanding of the decision-making process by including a mixed sample of CKD patients, incident HD and PD patients, established PD patients, family members and caregivers, and HCPs. The specific aims were

- to understand factors involved in the dialysis modality choice by integrating the perspectives of various parties (patients, families, and HCPs) involved in the process.
- to understand why patients are actively or inactively choosing or favoring HD over PD, and vice versa.

- to explore the needs of patients, their family members, and HCPs when discussing dialysis modalities and initiating onto HD or PD.

METHODS

This single-cohort cross-sectional study used a qualitative research design. A qualitative design was chosen because the research question required in-depth exploration of individual experiences of the decision-making process. Qualitative methods illuminate how people conceptualize, experience, and talk about health-related issues, and help to define the range and variability of beliefs, behaviors, and experiences of study populations without offering preconceived ideas and responses, as in questionnaire surveys.

PARTICIPANTS

The study sample comprised four groups of patients (stage 3 – 4 CKD, HD, incident PD, and established PD), family members, and renal HCPs sequentially recruited from the Singapore General Hospital Renal Medicine Department, Dialysis Center, and Peritoneal Dialysis Center from October 2010 to May 2011.

All study participants had to meet the following criteria:

- Age 21 years or older
- Able to communicate in either English or Mandarin
- No contraindications to a particular dialysis modality
- A diagnosis of CKD stage 3 or 4 [CKD (group 1)] or on PD for less than 3 months [Incident PD (group 2)], on PD for at least 6 months [Established PD (group 3)], on HD for less than 3 months [HD (group 4)], family member of a patient [Family Members (group 5)], or a HCP involved in care for any of the listed patient groups [HCPs (group 6)].

Patients who spoke only Malay or other dialects (for example, Teochew, Hokkien) and those with speech difficulties or a comorbid diagnosis of dementia or severe cognitive impairment were excluded from the study. The aim was to conduct interviews with 8 – 10 participants per group, or until saturation of themes occurred.

PROCEDURE

Participants were approached at regular clinic appointments by research coordinators with the study information sheet and consent form and were asked to consider taking part in the study.

One week later, one member of the research team contacted potential participants to answer any questions they may have had about the study, and if the participant remained willing, to organize a time and place for the study interview. One researcher, a qualified psychologist with competence in the local languages, conducted the interviews at each participant's convenience. All interviews were conducted one-to-one: that is, one interviewer for each participant, with interviews being held separately for patients and for family members from the same household.

For the purposes of the study, an interview schedule was developed (this was reviewed by an expert panel consisting of renal health professionals and piloted with 5 participants, 1 per group). Questions covered these themes:

- The process of decision-making (parties involved, procedures, and timing)—for example, “How was the decision on your dialysis treatment taken?”
- The reasons underlying choices and preferences, including treatment concerns—for example, “What were the factors you considered when you chose your current dialysis modality?”
- The participant's information and support needs—for example, “What do patients need to know to make informed choices between HD and PD?”

STATISTICAL ANALYSIS

All recorded interviews were taped and then transcribed and analyzed using thematic analysis and the NVivo9 software application (QSR International, Doncaster, Australia). Thematic analysis is a method used to identify, analyze, and report patterns within data (38). It involves searching across a dataset to find repeated patterns of meaning. Thematic analysis has 6 phases: familiarization with the data, creation of initial codes, search for themes, review of themes, definition and naming of themes, and production of a report (38). Data coded using NVivo9 were also independently audited by another researcher to ensure inter-rater agreement.

RESULTS

STUDY SAMPLE

During the study window, 76 eligible participants (including patients, family members, and renal HCPs) were approached, and 59 participants completed the interviews (response rate: 77.63%). Another 23 declined (14 CKD, 2 Family Members, 3 Incident PD, 2 Established

PD, 2 HCPs), citing lack of interest or motivation, lack of time, or reluctance to consent to recording of the interview.

The study sample consisted of 8 CKD, 8 Incident PD, 11 Established PD, 10 HD, 13 Family Member, and 9 HCP participants (Table 1). The 13 Family Member participants included 9 caregivers to PD patients, 3 caregivers to CKD patients, and 1 caregiver to a HD patient. The 9 HCP participants included 5 nurses, 2 renal coordinators, and 2 renal consultants. Of the participants, 39 were women, and 20 were men (average age: 47 years; standard deviation: 12.74 years; range: 19 – 76 years). The ethnic composition of sample closely resembled the general population, with 38 (64%) being Chinese, 14 (24%) being Malay, and 7 (12%) being Indian.

Per ethics guidelines, data were not collected for the nonparticipants (because no consent was obtained), and so it was not possible to explore potential differences between respondents and non-respondents.

BARRIERS TO HD

Data analyses revealed that one of the main barriers to uptake of HD is the fear of needling and the associated pain involved ($n = 26$, 44.06%, Table 2).

It is very painful to be shot by the needles.

—Established PD participant

Concerns about dialysis-related symptoms or side effects, and concerns related to access, were frequently reported as HD deterrents (Table 2). Hemodialysis is often accompanied by side effects both during the procedure and post dialysis; concerns about side effects were based on either previous personal or vicarious experience. Unpleasant dialysis symptoms may have been experienced firsthand by patients—that is, while on HD or as relayed by other patients. The symptoms predominantly referenced were the immediate sequelae of the HD experience rather than the long-term complications (which were rather infrequently noted).

Because I have seen HD patients after doing HD, it was quite scary. They were giddy; they had to squat down; they couldn't walk. So I felt that HD was rather terrifying.

—Established PD participant

Sometimes you might feel better; sometimes you might feel lower. So sometimes, when dialysis is concerned, it takes a lot of energy from the body away. So at times you might feel a little bit weak.

—HD participant

TABLE 1
Socio-demographics of Participants

Variable	Overall	Chronic kidney disease	Peritoneal dialysis Incident	Peritoneal dialysis Established	Hemodialysis	Family member	Health care professional
Patients (n)	59	8	8	11	10	13	9
Sex [n (%) men]	20 (33.9)	4 (50)	3 (37.5)	2 (18.2)	7 (70)	3 (23.1)	1 (11.11)
Mean age (years)	47±12.74	54.25±13.36	48±16.54	48±12.84	47.8±11.96	46.15±11.73	38±8.79
Education level [n (%)]							
Primary	6 (10.2)	2 (25)	1 (12.5)	1 (9.1)	1 (10)	1 (7.7)	0
Secondary	20 (33.9)	4 (50)	3 (37.5)	6 (54.5)	3 (30)	4 (30.8)	0
A Levels or diploma	13 (22.1)	1 (12.5)	1 (12.5)	2 (18.2)	3 (30)	6 (46.1)	0
Tertiary	11 (18.6)	1 (12.5)	1 (12.5)	0	0	0	9 (100)
Others	9 (15.2)	0	2 (25)	2 (18.2)	3 (30)	2 (15.4)	0
Employment							
Employed (full or part-time)	36 (61)	7 (62.5)	2 (12.5)	5 (45.4)	4 (30)	9 (69.2)	9 (100)
Unemployed	7 (11.9)	0	3 (37.5)	1 (9.1)	3 (30)	0	0
Retired	5 (8.5)	1 (12.5)	0	1 (9.1)	2 (20)	1 (7.7)	0
Others	11 (18.6)	0	3	4 (36.4)	1 (10)	3 (23.1)	0
Marital status							
Married	24 (64.9)	7 (87.5)	5 (62.5)	6 (54.5)	6 (60)		
Divorced	1 (2.7)	0	0	1 (9.1)	0		
Widowed	3 (8.1)	0	1 (12.5)	2 (18.2)	0		
Single	9 (24.3)	1 (12.5)	2 (25)	2 (18.2)	4 (40)		
Income [n (%)]							
S\$0–S\$2000	11 (22)	0	4 (50)	3 (27.3)	3 (30)	1 (7.7)	
S\$2001–S\$4000	22 (44)	4 (50)	2 (25)	3 (27.3)	4 (40)	9 (69.2)	
S\$4001–S\$6000	5 (10)	1 (12.5)	0	3 (27.3)	1 (10)	0	
>S\$6000	7 (14)	3 (37.5)	1 (12.5)	0	1 (10)	2 (15.4)	
Don't know/no answer	5 (10)	0	1 (12.5)	2 (18.2)	1 (10)	1 (7.7)	
Relationship with patient							
Spouse						4 (30.8)	
Child						7 (53.8)	
Others (parent/relative)						2 (15.4)	
Living with patient (% yes)						11 (84.6)	
Time caring for patient [n (%)]							
<6 Months						5 (38.5)	
7–12 Months						1 (7.7)	
13–24 Months						2 (15.4)	
>24 Months						4 (30.8)	
Not stated						1 (7.7)	
Time working as renal health care professional							
>24 Months							9 (100)

Access-related concerns reflected mainly concerns about body image. These concerns were predominantly fuelled by vicarious experience—meeting or talking to other patients or hearsay.

There will be a lot of lumps on your hands, which would be not pleasant looking. And your hand may be without any strength.

—Incident PD participant

TABLE 2
Frequency of Barriers

Factor	Response	
	(n)	(%)
Barriers to hemodialysis		
Dialysis-related side effects	29	49.15
Distance to dialysis centers	28	47.45
Fear of needling and pain	26	44.06
Access related concerns	23	38.98
Financial costs	22	37.28
Barriers to peritoneal dialysis		
Fear of infection	37	62.71
Daily commitment	32	54.23
Misunderstandings	25	42.37
Low self-efficacy	21	35.59

You see, I have seen people who have done, and their hand all very swollen. Then I look at all that, I feel so scared also.

—Established PD participant

External and organizational barriers to HD included geographic distance to dialysis centers ($n = 28$, 47.45%) and higher costs (direct costs, and indirect costs related to travelling) for HD ($n = 22$, 37.28%).

HD is more costly, PD is more cost saving. The problem lies here.

—CKD participant

It was troublesome to go to the place to do HD.

—Established PD participant

FACILITATORS OF HD

The main reasons for favoring HD were reduced time demands with an intermittent dialysis schedule ($n = 30$, 50.84%), the involvement of HCPs in dialysis procedures ($n = 29$, 49.15%), and the higher visibility of HD in Singapore ($n = 11$, 18.64%), which adds to familiarity and acceptance of HD as the norm (Table 3).

It's only three times a week. It's only four hours per session. As opposed to, you know, doing it seven times a week ten hours a day. So obviously ... it's less time consuming.

—CKD participant

The added benefit of HCPs handling all dialysis procedures can also sway patients toward HD uptake.

Going to the dialysis center, there are nurses to assist you. You don't have to do the dialysis yourself.

—CKD participant

TABLE 3
Frequency of Facilitators

Factor	Response	
	(n)	(%)
Facilitators of hemodialysis		
Intermittent dialysis schedule	30	50.84
Health care professionals	29	49.15
High visibility	11	18.64
Facilitators of peritoneal dialysis		
Convenience	33	55.93
Low cost	28	47.45

The high visibility of HD, such as the presence of dialysis centers and televised charity coverage, also encourages patients to choose HD.

I think you know the TV advertisements and NKF. When you tell patients about blood dialysis, everybody is aware of it, but when you talk to them about water dialysis, they can ask you, "Is there such a thing?"

—HCP participant

You see those on dialysis, it's normally HD. On TV, they don't introduce PD as well.

—Family Member participant

BARRIERS TO PD

One of the main drivers for low PD uptake is fear of infection ($n = 37$, 62.71%). Such fears were voiced both in relation to self-management of the dialysis exchanges and of the catheter.

Think the infection is high. The percentage is very, very high. Because your stomach is exposed when you are dialyzing. So any bacteria or germs or particles might fly in. And if you don't keep it clean then you will have problems.

—HD participant

Exaggerated fear of the infection risks seems to be driven largely by knowledge gaps and misperceptions related to PD ($n = 25$, 42.37%). Patients believe that the risk of infection is greater in PD than in HD.

And I figured out that water is basically more prone to infection rather than the blood one.

—Incident PD participant

Analysis of data showed that, relative to HD, PD is perceived as a treatment that is less safe and effective in achieving clearance. In addition, PD is seen as

an impermanent and short-lived modality, whereas HD is perceived as a modality for life. Experiences of other patients—communicated either directly or anecdotally, or witnessed by patients or family members—seem to be fuelling perception of high risk and low technique survival.

Because you used water is like you are still remaining the toxic inside. You never really remove off everything. As for blood, right, it's like you wash through machine, you turn back. I mean, it's like the toxic is so call not so call fully washed off.

—HD participant

You cannot do this until ... life.... This you doing blood dialysis until you live. But that one, no. After that, for a while, maybe your stomach spoil or something. So you have to go for blood dialysis also.

—HD participant

For peritoneal, it's not a forever process. Some people, after five years, they can't do PD anymore. Because they damage their peritoneum.

—PD participant

Water dialysis does not last for many years. Three years....

—Family Member participant

The intensive daily hassle of PD also deters patients from choosing or favoring PD. Patients discussed vividly how the every-day and self-treatment process of PD is troublesome and draining ($n = 32$, 54.23%) and how it poses restrictions to lifestyle and valued activities for patients and caregivers alike.

Every day, the four to five exchanges. Need to spend a lot of time to help with the exchanges.

—Family Member participant

A lot of times, my patients verbalize that once you tell them "every day you got to do it" and sometimes you need to do it overnight or you need to do it day-time four sessions or four cycles, they are like a bit hesitant to do it because they think hemodialysis is one shot. You go there, you dialyze, four hours later, you are a free man.

—HCP participant

Patients also mentioned that low self efficacy in personally managing the PD procedures deters them from taking up PD (21 participants mentioned this factor).

You will do it on your own, or your family. And we are not trained in that. There will be training, but I doubt we can do better than the nurse.

—HD participant

FACILITATORS OF PD

Data analyses showed that the main facilitators of PD are the (low) cost ($n = 28$, 47.45%) and convenience of PD ($n = 33$, 55.93%). References to convenience arose mainly in relation to being at home and having daytime freedom (because of automated PD) that affords patients more opportunities to pursue valued activities.

Honestly, PD is cheaper, much cheaper.

—Incident PD participant

Maybe it would be more comfortable doing the dialysis at home.

—CKD participant

For water, since I have to do it only at night, and I can do it when I am sleeping, so, like, it gives me a whole day to work with.

—Incident PD participant

DECISIONAL SUPPORT NEEDS

One common recurring theme ($n = 21$, 35.59%) was that many of the participants wanted to have a more balanced discussion about dialysis, facilitated not solely by HCPs, but with input from other patients. Patients are eager to learn and to discuss the subjective experience of life on dialysis in addition to medical and technical procedures. Although they value input from their HCPs, they expressed the need to meet and interact with current dialysis patients. Participants believe that hearing the experience of dialysis patients will give them more insight into the dialysis procedures that they or their family members will have to go through eventually.

Hospital should have social workers who have been through PD. Then, if someone wants to do PD, they should talk to them about what are PD's benefits.

—Established PD participant

Because [other patients] went through. They gone through the experiences, and they know what will happen.

—HD participant

I was hoping to hear from the other patients' opinions and queries.... Or perhaps they could gather patients' experiences and put it into a magazine. Maybe monthly they could send us the magazine. We really need to know the experiences of others.

—Family Member participant

INVOLVEMENT OF FAMILY MEMBERS

Data showed that final decisions related to dialysis are largely taken jointly with family members ($n = 24$, 40.67%) or after consultation with family members ($n = 44$, 74.57%). Patients value input from family members (spouse, children, siblings), because dialysis will affect family life and function.

I have discussed with my children. They also feel that doing HD would be better.

—CKD participant

So after that, from there, I discussed with my wife. We have discussion.... That's why we say, ultimately, we still come back to hygiene. We can't really maintain. That's why we say, "Let's go to the blood dialysis."

—HD participant

I am the person who is deciding for her. But I will discuss with my family because I am not the only one looking after her; there is still my sisters. They do take care of her, but mostly, it's me. So I will notify them what I have decided to do and so on, and my reasons for doing so.

—Family Member participant

We would be discussing with our, you know, our husbands—mainly relatives—on, perhaps, what could be the best thing for Dad at this point of time. Because his siblings are around, the family will be very much consulted.... The rest of us have to you know, consult our uncles, his brothers, and all before we decide on the best course of, you know, dialysis

—Family Member participant

DISCUSSION

The present study explored and integrated the perspectives of patients, family members, and HCPs in decision-making about dialysis modality. Patients were carefully selected to ensure that they were medically suitable for both PD and HD and to include patients with CKD as well as patients already established on either HD or PD.

Decisions on dialysis are taken in the context of family, with patients consulting members of their immediate family, and in several cases, with family members taking full responsibility for making the decision about the dialysis modality. The participants interviewed considered that discussions related to dialysis modality have not only to take the individual patient's situation into

account but also to respect family wishes. Caring for the sick is considered a family affair, especially in Chinese culture, in which duty and obligation to the family are paramount (39–41). Taking the family, rather than the individual patient, as the unit of care and education related to dialysis is therefore of paramount importance in the local setting.

Study findings showed that patients and family members evaluate modalities primarily in terms of opportunities afforded to maintain lifestyle and to handle demands on their time and the potential risks involved. But they also evaluate their own priorities and capacity in terms of acquiring skills and undertaking the crucial responsibility of care at home (20,21,24,27,36,37,42). Financial costs are also considered, but are secondary to personal convenience or preference and lifestyle considerations.

Time requirements weigh heavily in the decisions; it is often a choice between daily and intermittent treatment. The intermittent schedule of HD is clearly favored and appealing, which may explain its high penetration rates. In contrast, the daily schedule of the various PD modalities, especially continuous ambulatory PD, with its multiple manual exchanges, is perceived as more taxing for patients and families alike, despite offering autonomy and flexibility (24,37,42). Automated PD offers daytime freedom, and yet some patients are bothered by restriction of nighttime activities. It is imperative to explore how the framing of information about the time demands and scheduling of the various dialysis modalities might influence patient preference or lead to quick, misinformed decisions.

Data from the present study also show gaps in knowledge, misperceptions, and misunderstandings about PD, leading to HD being unduly favored. Because PD is perceived as less safe and effective, and also short-lived, the alternative—that is, HD—therefore becomes a more attractive option for patients eligible for either modality. These misperceptions feed exaggerated infection fears and undermine the confidence of patients and caregivers that they can undertake self-care or the crucial responsibility of managing a patient's dialysis exchanges at home. Patients and family members both discussed low confidence as one of the reasons discouraging uptake of PD.

Lack of familiarity with PD also hinders uptake of PD (12) and might also contribute to misperceptions. In Singapore, HD has a strong presence. It has been portrayed in the media, and the presence of community dialysis centers in most neighborhoods further add to its visibility. The interviewed patients and family members indicated that they preferred to go with the "norm,"

rather than opt for a less conventional treatment. That preference creates a vicious cycle in which fewer patients adopt PD, perpetuating the view of PD as the uncommon modality.

The various misconceptions of PD could stem from insufficient or total lack of exposure to pre-dialysis education sessions and biased opportunistic interactions or shared stories from other patients. Because pre-dialysis education is not a requirement of any patient curriculum within any Singapore hospital facility, and because attendance at dialysis orientation sessions with renal coordinators is not mandatory, many patients might forgo such consultations or minimize attendance (coming to just a single session) for the sake of saving time and money. (The consultations are held in the hospital and are not free.) In this context, patients might lack information and therefore rely on stories from other patients or friends, which may or may not portray an accurate picture of dialysis (43). Previous work has similarly shown that treatment decisions by patients for dialysis or transplantation were influenced by the experiences of other patients (20,24,42–45). Interview data indicated that the dialysis preference or choice of patients and family members might be reinforced by knowing of successful or unsuccessful experiences of others with either PD or HD. Data showed that witnessing or hearing stories of peritoneal infection or technique failure leading to conversion to HD constituted living proof for other patients that PD is unsafe and does not work as efficiently as HD. This form of communication can endure, potentially biasing patients against PD.

Carefully planned and timed pre-dialysis education is therefore critical in clarifying the misconceptions (46–51). It is imperative to revisit or review how to best cater for the decisional support needs of patients and then to design patient resources and pre-dialysis programs that are sufficiently proactive to engage patients in making informed decisions about dialysis modality, while eliciting and targeting misperceptions and misunderstandings. However, simply providing information may not suffice. Pre-dialysis programs should also include structured and paced peer learning. Patients value direct interactions or having access to stories from other patients, because that information provides them with emotional support, information, reassurance, and practical advice. Our data reaffirm that information about the subjective experience of life on dialysis is as important as information on the procedural aspects of the various dialysis modalities—the primary agenda of the patients being what it feels like to live on HD or PD rather than what PD or HD is about. Literature on preparation for stressful medical procedures (for example, surgery)

has similarly shown that patients value both procedural and sensory information about the procedures (52).

Physicians need to be aware that their patients and their patients' families seek out opportunities to obtain input from other patients or might hear anecdotal stories of experiences with a particular modality. More carefully planned and timely opportunities to meet with other patients should therefore be organized as part of formal pre-dialysis patient education, and those opportunities should be followed by consultations with renal coordinators. That sort of approach would allow patients and family members to receive adequate information and to make informed decisions about a dialysis modality. Further work is needed to delineate the optimal balance between education about the subjective experience on dialysis (including sensory information on dialysis modalities) and clinical education to facilitate decision-making.

Furthermore, structured decision aids developed to support provision of (individually tailored) information about dialysis modalities and to facilitate consideration of personal values and effective communication of the questions, concerns, and preferences of patients to renal health care providers may be a valuable addition to renal consultations and general educational materials, reducing misunderstandings and hence improving the quality of decision-making.

Providing a real choice of modality also requires supportive financial structures and reimbursement policies with respect to pre-dialysis education (14). It is likely that the system in Singapore—in which most medical services, including pre-dialysis education, are mostly fee-for-service, with only limited financial support from the government—may be hindering well-informed decisions. As shown in other settings, implementation of reimbursement is likely to improve patient knowledge of dialysis, thus helping to achieve an informed patient decision for a dialysis modality, which is linked to improved rates of PD uptake (14,47,49,50,53). However, more work is needed to document pre-dialysis education utilization rates in relation to PD uptake and penetration rates.

The present study has several limitations. Participants were recruited from a single hospital facility, and participation hinged on language spoken (patients fluent only in Malay or dialects were excluded because of staff availability). Future research should look to breach communication barriers and include patients from multiple facilities to ensure greater generalizability of findings. Another limitation was the low participation in the CKD and Incident PD groups. Future research would benefit from collecting more data about those two patient categories, because their dialysis modality decisions are either imminent or recent.

Our study sample represented the national dialysis population well (3), but more work is nevertheless needed. Generalizability in other settings has to be explored, because variations in the patterns of medical practice and financial reimbursement or policies related to end-stage renal disease, dialysis modality utilization, and models of service delivery preclude drawing conclusions on the wider international level without replication.

CONCLUSIONS

Results from our study provide insight into dialysis modality decision-making in an Asian context. The identified factors illustrate the need for improvements in the Singapore health care system with regard to the care of kidney disease patients. Based on findings from the present study, it is evident that compulsory and reimbursed or free pre-dialysis education has to be provided for kidney disease patients so that they can make a comprehensive decision on the treatment needed and also so that misperceptions and misunderstandings of treatment, especially PD, can be dispelled.

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DISCLOSURES

The authors have no financial conflicts of interest in this study to declare.

REFERENCES

1. United States, Department of Health and Human Services, Public Health Service, National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, U.S. Renal Data System (USRDS). *2009 Annual Data Report*. 2 vols. Bethesda, MD: USRDS; 2009.
2. Stel VS, van de Luijngaarden MW, Wanner C, Jager KJ on behalf of the European Renal Registry Investigators. The 2008 ERA-EDTA registry annual report—a précis. *NDT Plus* 2011; 4:1–13.
3. Choog HL, ed. *Seventh Report of the Singapore Renal Registry 2007/2008*. Singapore: Health Promotion Board; 2010.
4. Ramirez SP. Chronic kidney disease prevention in Singapore. *Clin J Am Soc Nephrol* 2008; 3:610–15.
5. Tan CC, Chan CM, Ho CK, Wong KS, Lee EJ, Woo KT. Health economics of renal replacement therapy: perspectives from Singapore. *Kidney Int Suppl* 2005; (94):S19–22.
6. Gilbertson DT, Liu J, Xue JL, Louis TA, Solid CA, Ebben JP, *et al.* Projecting the number of patients with end-stage renal disease in the United States to the year 2015. *J Am Soc Nephrol* 2005; 16:3736–41.
7. Kuriyama S. Peritoneal dialysis in patients with diabetes: are the benefits greater than the disadvantages? *Perit Dial Int* 2007; 27(Suppl 2):S190–5.
8. Jager KJ, Korevaar JC, Dekker FW, Krediet RT, Boeschoten EW on behalf of the Netherlands Cooperative Study on the Adequacy of Dialysis (NECOSAD) Study Group. The effect of contraindications and patient preference on dialysis modality selection in ESRD patients in the Netherlands. *Am J Kidney Dis* 2004; 43:891–9.
9. Lameire N, Van Biesen W. Epidemiology of peritoneal dialysis: a story of believers and nonbelievers. *Nat Rev Nephrol* 2010; 6:75–82.
10. Nayak KS. Asia, a melting pot for peritoneal dialysis practices: redefining and expanding peritoneal dialysis horizons in Asia. *Perit Dial Int* 2004; 24:422–3.
11. Schaubel DE, Morrison HI, Desmeules M, Parsons DA, Fenton SS. End-stage renal disease in Canada: prevalence projections to 2005. *CMAJ* 1999; 160:1557–63.
12. Mahajan S, Tiwari SC, Kalra V, Bhowmik DM, Agarwal SK. Factors affecting the use of peritoneal dialysis among the ESRD population in India: a single-center study. *Perit Dial Int* 2004; 24:538–41.
13. Kutner NG, Zhang R, Huang Y, Wasse H. Patient awareness and initiation of peritoneal dialysis. *Arch Intern Med* 2011; 171:119–24.
14. Just PM, de Charro FT, Tschosik EA, Noe LL, Bhattacharyya SK, Riella MC. Reimbursement and economic factors influencing dialysis modality choice around the world. *Nephrol Dial Transplant* 2008; 23:2365–73.
15. Rubin HR, Fink NE, Plantinga LC, Sadler JH, Kliger AS, Powe NR. Patient ratings of dialysis care with peritoneal dialysis vs hemodialysis. *JAMA* 2004; 291:697–703.
16. Harris SA, Lamping DL, Brown EA, Constantinovici N on behalf of the North Thames Dialysis Study (NTDS) Group. Clinical outcomes and quality of life in elderly patients on peritoneal dialysis versus hemodialysis. *Perit Dial Int* 2002; 22:463–70.
17. Brown EA, Johansson L, Farrington K, Gallagher H, Sensky T, Gordon F, *et al.* Broadening Options for Long-Term Dialysis in the Elderly (BOLDE): differences in quality of life on peritoneal dialysis compared to haemodialysis for older patients. *Nephrol Dial Transplant* 2010; 25:3755–63.
18. Sennfalt K, Magnusson M, Carlsson P. Comparison of hemodialysis and peritoneal dialysis—a cost–utility analysis. *Perit Dial Int* 2002; 22:39–47.
19. Gokal R, Figueras M, Ollé A, Rovira J, Badia X. Outcomes in peritoneal dialysis and haemodialysis—a comparative assessment of survival and quality of life. *Nephrol Dial Transplant* 1999; 14(Suppl 6):24–30.
20. Morton RL, Tong A, Howard K, Snelling P, Webster AC. The views of patients and carers in treatment decision making for chronic kidney disease: systematic review and thematic synthesis of qualitative studies. *BMJ* 2010; 340:c112.

21. Murray MA, Brunier G, Chung JO, Craig LA, Mills C, Thomas A, *et al.* A systematic review of factors influencing decision making in adults living with chronic kidney disease. *Patient Educ Couns* 2009; 76:149–58.
22. Kelly–Powell ML. Personalizing choices: patient's experiences with making treatment decisions. *Res Nurs Health* 1997; 20:219–27.
23. Chanouzas D, Ng KP, Fallouh B, Baharani J. What influences patient choice of treatment modality at the pre-dialysis stage. *Nephrol Dial Transplant* 2012; 27:1542–7.
24. Morton RL, Devitt J, Howard K, Anderson K, Snelling P, Cass A. Patient views about treatment of stage 5 CKD: a qualitative analysis of semistructured interviews. *Am J Kidney Dis* 2010; 55:431–40.
25. Piccoli GB, Mezza E, Burdese M, Consiglio V, Vaggione S, Mastella C, *et al.* Dialysis choice in the context of an early referral policy: there is room for self care. *J Nephrol* 2005; 18:267–75.
26. Gokal R. Peritoneal dialysis in the 21st century: an analysis of current problems and future developments. *J Am Soc Nephrol* 2002; 13(Suppl 1):S104–16.
27. Stack AG. Determinants of modality selection among incident US dialysis patients: results from a national study. *J Am Soc Nephrol* 2002; 13:1279–87.
28. Little J, Irwin A, Marshall T, Rayner H, Smith S. Predicting a patient's choice of dialysis modality: experience in a United Kingdom renal department. *Am J Kidney Dis* 2001; 37:981–6.
29. Lameire N, Van Biesen W. The pattern of referral of patients with end-stage renal disease to the nephrologist—a European survey. *Nephrol Dial Transplant* 1999; 14(Suppl 6):16–23.
30. Teo BW, Ma V, Xu H, Li J, Lee EJ on behalf of the Nephrology Clinical Research Group. Profile of hospitalisation and death in the first year after diagnosis of end-stage renal disease in a multi-ethnic Asian population. *Ann Acad Med Singapore* 2010; 39:79–87.
31. Aronson E, Wilson TD, Akert RM. *Social Psychology*. 6th ed. Upper Saddle River, NJ: Pearson Prentice Hall; 2007.
32. Hines SC, Glover JJ, Holley JL, Babrow AS, Badzek LA, Moss AH. Dialysis patients' preferences for family-based advance care planning. *Ann Intern Med* 1999; 130:825–8.
33. Charles C, Whelan T, Gafni A, Reyno L, Redko C. Doing nothing is no choice: lay constructions of treatment decision-making among women with early-stage breast cancer. *Sociol Health Illn* 1998; 20:71–95.
34. Orona CJ, Koenig BA, Davis AJ. Cultural aspects of non-disclosure. *Camb Q Healthc Ethics* 1994; 3:338–46.
35. Kaufert JM, Putsch RW, Lavallée M. End-of-life decision making among Aboriginal Canadians: interpretation, mediation, and discord in the communication of "bad news". *J Palliat Care* 1999; 15:31–8.
36. Whittaker AA, Albee BJ. Factors influencing patient selection of dialysis treatment modality. *ANNA J* 1996; 23:369–75.
37. Wuerth DB, Finkelstein SH, Schwetz O, Carey H, Kliger AS, Finkelstein FO. Patients' descriptions of specific factors leading to modality selection of chronic peritoneal dialysis or hemodialysis. *Perit Dial Int* 2002; 22:184–90.
38. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006; 3:77–101.
39. Holroyd E, Cheung YK, Cheung SW, Luk FS, Wong WW. A Chinese cultural perspective of nursing care behaviours in an acute setting. *J Adv Nurs* 1998; 28:1289–94.
40. Chao YM. Nursing's values from a Confucian perspective. *Int Nurs Rev* 1995; 42:147–9.
41. Shih FJ. Concepts related to Chinese patients' perceptions of health, illness and person: issues of conceptual clarity. *Accid Emerg Nurs* 1996; 4:208–15.
42. Lee A, Gudex C, Povlsen JV, Bonnevie B, Nielsen CP. Patients' views regarding choice of dialysis modality. *Nephrol Dial Transplant* 2008; 23:3953–9.
43. Winterbottom AE, Bekker HL, Conner M, Mooney AF. Patient stories about their dialysis experience biases others' choices regardless of doctor's advice: an experimental study. *Nephrol Dial Transplant* 2012; 27:325–31.
44. Holley JL, McCauley C, Doherty B, Stackiewicz L, Johnson JP. Patients' views in the choice of renal transplant. *Kidney Int* 1996; 49:494–8.
45. Gordon EJ. Patients' decisions for treatment of end-stage renal disease and their implications for access to transplantation. *Soc Sci Med* 2001; 53:971–87.
46. Thodis E, Passadakis P, Vargemezis V, Oreopoulos DG. Peritoneal dialysis: better than, equal to, or worse than hemodialysis? Data worth knowing before choosing a dialysis modality. *Perit Dial Int* 2001; 21:25–35.
47. Manns BJ, Taub K, Vanderstraeten C, Jones H, Mills C, Visser M, *et al.* The impact of education on chronic kidney disease patients' plans to initiate dialysis with self-care dialysis: a randomized trial. *Kidney Int* 2005; 68:1777–83.
48. Goovaerts T, Jadoul M, Goffin E. Influence of a pre-dialysis education programme (PDEP) on the mode of renal replacement therapy. *Nephrol Dial Transplant* 2005; 20:1842–7.
49. Marrón B, Martínez Ocaña JC, Salgueira M, Barril G, Lamas JM, Martín M, *et al.* Analysis of patient flow into dialysis: role of education in choice of dialysis modality. *Perit Dial Int* 2005; 25(Suppl 3):S56–9.
50. Klang B, Björvell H, Clyne N. Predialysis education helps patients choose dialysis modality and increases disease-specific knowledge. *J Adv Nurs* 1999; 29:869–76.
51. Chidambaram M, Bargman JM, Quinn RR, Austin PC, Hux JE, Laupacis A. Patient and physician predictors of peritoneal dialysis technique failure: a population based, retrospective cohort study. *Perit Dial Int* 2011; 31:565–73.
52. Johnston M. Dimensions of recovery from surgery. *Int Rev Appl Psychol* 1984; 33:505–20.
53. Motiwala SS, McFarlane PA. Standardized preplanned patient education to encourage transfer from hospital hemodialysis to home dialysis. *Perit Dial Int* 2008; 28:403–7.