

Patient and caregiver values, beliefs and experiences when considering home dialysis as a treatment option: a semi-structured interview study

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ABSTRACT

Background. Home dialysis can offer improved quality of life and economic benefits compared with facility dialysis. Yet the uptake of home dialysis remains low around the world, which may be partly due to patients' lack of knowledge and barriers to shared and informed decision-making. We aimed to describe patient and caregiver values, beliefs and experiences when considering home dialysis, to inform strategies to align policy and practice with patients' needs.

Methods. Semi-structured interviews with adult patients with chronic kidney disease Stage 4–5D (on dialysis <1 year) and their caregivers, recruited from three nephrology centres in New Zealand. Transcripts were analysed thematically.

Results. In total, 43 patients [pre-dialysis ($n = 18$), peritoneal dialysis ($n = 13$), home haemodialysis ($n = 4$) and facility haemodialysis ($n = 9$)] and 9 caregivers participated. We identified five themes related to home dialysis: lacking decisional power (complexity of information, limited exposure to home dialysis, feeling disempowered, deprived of choice, pressure to choose), sustaining relationships (maintaining cultural involvement, family influence, trusting clinicians, minimizing social isolation), reducing lifestyle disruption (sustaining employment, avoiding relocation, considering additional expenses, seeking flexible schedules, creating free time), gaining confidence in choice (guarantee of safety, depending on professional certainty, reassurance from peers, overcoming fears) and maximizing survival.

Conclusions. To engage and empower patients and caregivers to consider home dialysis, a stronger emphasis on the development

of patient-focused educational programmes and resources is suggested. Pre-dialysis and home dialysis programmes that address health literacy and focus on cultural and social values may reduce fears and build confidence around decisions to undertake home dialysis. Financial burdens may be minimized through provision of reimbursement programmes, employment support and additional assistance for patients, particularly those residing in remote areas.

Keywords: haemodialysis, home haemodialysis, patients, peritoneal dialysis, qualitative research

INTRODUCTION

Patients on home dialysis experience greater autonomy, independence and treatment-related flexibility than patients receiving facility dialysis [1–3]. Home haemodialysis (HD) is associated with longer survival [4–6], while extended hour HD improves quality of life and mortality [7–9]. Home dialysis is also more cost-effective than facility dialysis [10, 11]. Despite the advantages of home dialysis to both patients and healthcare providers, the global prevalence of home dialysis remains very low, ranging from 11% in the US to 18% in the UK [12], while countries with historically higher rates such as New Zealand and Australia have demonstrated a recent decline in numbers [13, 14]. In 2012, home HD was provided to 19 and 9.2% of all dialysis patients in New Zealand and Australia, respectively, whereas Canada, Denmark, Finland, Scotland, Singapore, Turkey and the UK reported rates between 3.0 and 5.7%. In some regions of Europe, there were much lower rates of home HD or this treatment was not available

[15]. The low uptake of home dialysis is often attributed to a lack of clinician experience and reimbursements for home HD, and centralization of services [16]. In addition, global disparities in access to renal replacement therapy (RRT) have recently been quantified, showing limited access to RRT internationally, particularly within low-income countries [17]. This has driven a priority to develop and implement low-cost and innovative health service solutions such as home dialysis.

Barriers to home dialysis include sufficient social and physical supports at home, age, impaired dexterity, insufficient space to store equipment and supplies, and the need for home modifications to make home dialysis possible (e.g. plumbing, electricity) [18, 19]. Many of these barriers, however, are surmountable with adequate pre-dialysis education and planning. Pre-dialysis education about home dialysis in addition to standard multidisciplinary care is associated with an increase in the proportion of patients commencing with home dialysis [16, 20]. International guidelines recommend that all suitable patients are offered a choice of dialysis modality including home dialysis [21]. Previous research regarding treatment decision-making has identified factors that influence patient and caregiver treatment decisions [1], but it did not specifically explore perspectives when considering home versus facility dialysis. This study aims to describe patient and caregiver values, beliefs and experiences when considering home dialysis modalities as a treatment option, to inform patient education strategies, clinical care and ongoing support of home dialysis programmes and align policy and practice with patients' needs.

MATERIALS AND METHODS

We used the consolidated criteria for reporting qualitative health research (COREQ) [22].

Context

This study was conducted in New Zealand, where home dialysis rates are 51%, among the highest in the world [12]. Participants were recruited from three dialysis units: Counties Manukau, Hawke's Bay or Capital Coast District Health Board. All units have established pre-dialysis education programmes and offer all forms of dialysis modality [facility HD (hospital, satellite), home HD and continuous ambulatory and automated peritoneal dialysis (CAPD and APD)]. 'Community houses' were offered by two units where patients can independently dialyse in an unstaffed homelike setting [23].

Participant selection

Participants were eligible if they were adults aged 18 years and over, had chronic kidney disease (CKD) Stage 4–5D, had received formal education about dialysis treatment options or had commenced dialysis within the previous 12 months; or were an informal caregiver for a family member or close friend on dialysis. Participants were purposively selected by recruiting nephrologists and nurse specialists to include a diverse range of age, gender, ethnicity, geographical remoteness, socioeconomic status and clinical characteristics (CKD stage and dialysis

modality). The study was approved by the ethics committees of each participating hospital.

Data collection

A preliminary interview guide was developed based on recent systematic reviews of patients and caregiver perspectives of dialysis [2, 24] and discussion among the research team (Supplementary data, File S1). Author R.C.W., a nurse practitioner, conducted a single semi-structured interview with each participant in the patient's choice of either their home or a clinic room at the hospital between July 2014 and January 2015. R.C.W. was known to some patients from one participating dialysis centre. Translators were used for three participants with limited English. Participant recruitment ceased when data saturation was achieved, that is, when no new concepts emerged in subsequent interviews. All interviews were digitally recorded and transcribed. Field notes were taken during all interviews.

Data analysis

The transcripts were entered into the software HyperRESEARCH, version 3.7.2 (ResearchWare, Inc.) for qualitative data management. We also drew from the principles of grounded theory to guide our data analysis; we used memoing to identify preliminary concepts. We then clustered these concepts into descriptive categories using constant comparisons of data. During this process, we re-evaluated these concepts by examining, comparing, conceptualizing and contextualizing the data [25]. We used thematic analysis concurrently to inductively identify and organize related concepts into overarching themes [26]. In the first round of coding, R.C.W. coded the transcripts line by line, identified concepts inductively and grouped similar concepts relating to patient and caregiver perceptions of pre-dialysis education and decision-making about dialysis modalities. R.L.M. and A.T. also read the transcripts independently, to ensure that the themes reflected the full scope of the data collected (investigator triangulation). This preliminary thematic framework was reviewed by all authors. In subsequent iterations, the coding schema was refined through a series of discussions among the investigator team.

RESULTS

Forty-three patients and nine caregivers participated (total $n = 52$; 83% of those approached by study investigators agreed to participate). Participant characteristics are presented in Table 1. The age of the participants ranged from 22 to 79 years (mean 55 years), and 25 (48%) were men. Eighteen (42%) of 43 patients were at CKD Stage 4–5 who had received formal pre-dialysis education, 13 (30%) were treated with peritoneal dialysis [CAPD ($n = 9$), APD ($n = 4$)], 4 (9%) were treated with home HD and 9 (21%) were treated with facility HD.

We identified five major themes that described participant's experiences and beliefs when considering home dialysis: lacking decisional power, sustaining relationships, reducing lifestyle disruption, gaining confidence in choice and maximizing survival. Illustrative quotations are provided in Table 2. A thematic

Table 1. Patient and caregiver characteristics

Characteristics	Patients no. (%)	Caregivers no. (%)
Age category (years)		
20–30	3 (7)	
31–40	4 (9)	3 (33)
41–50	8 (19)	
51–60	10 (23)	1 (11)
61–70	13 (30)	4 (44)
71–80	13 (30)	1 (11)
Male	23 (53)	2 (22)
Modality		
Pre-dialysis	18 (42)	2 (22)
CAPD	9 (21)	3 (33)
APD	4 (9)	2 (22)
HHD	4 (9)	1 (11)
Hospital/satellite	8 (19)	1 (11)
Ethnicity		
European	10 (23)	4 (44)
Māori	15 (35)	3 (33)
Pacific Islander	13 (30)	1 (11)
Other	5 (12)	
Marital status		
Married/de facto	25 (58)	6 (66)
Divorced/separated	3 (7)	1 (11)
Single	10 (23)	2 (22)
Widowed	5 (12)	
Highest level education		
Completed primary school	12 (28)	3 (33)
Completed secondary qualification	12 (28)	3 (33)
Completed certificate or diploma	11 (26)	1 (11)
Completed degree/higher	8 (19)	2 (22)
Employment status		
Full time	9 (21)	
Part time/casual	3 (7)	2 (22)
Not employed	6 (14)	2 (22)
Beneficiary	18 (42)	3 (33)
Retired	7 (16)	2 (22)
Estimated gross household annual income (NZ\$)		
10–20 000	7 (16)	
21–30 000	4 (9)	2 (22)
31–40 000	11 (26)	3 (33)
41–50 000	1 (2)	
51–60 000	7 (16)	2 (22)
61–70 000	7 (16)	
71–100 000	2 (5)	1 (11)
>101 000	4 (9)	1 (11)
Time to dialysis unit (travelled one way) (min)		
0–10	10 (23)	2 (22)
11–20	11 (26)	3 (33)
21–40	16 (37)	1 (11)
41–80	1 (2)	
>81	5 (12)	3 (33)

CAPD, continuous ambulatory peritoneal dialysis; APD, automated peritoneal dialysis; HHD, home haemodialysis; NZ, New Zealand.

schema illustrating the key conceptual links among these themes is presented in Figure 1.

Lacking decisional power

Complexity of information. Many participants found it difficult to understand information about home dialysis modalities. They were overwhelmed by medical jargon and found that the written information was not easily assimilated or understood. Participants suggested the need for simpler and

more visual information as they could not imagine the ‘bags inside me’ or ‘actually see the machine for home’. Specifically, they suggested clearer information about the practical aspects and benefits of home dialysis. Participants who were illiterate or for whom English was a second language felt lost and embarrassed about being unable to read and understand the information given. As such, they indicated to clinicians that they understood the information.

Limited exposure to home dialysis. Some participants felt that they were not sufficiently informed to make a decision about their dialysis modality because they had no previous experience or knowledge of dialysis and had only been offered one dialysis education session. Home HD, particularly, was confronting, and they did not feel confident in their ability to manage independently. Instead, they chose in-centre HD regarding this as the ‘safest option’ under the supervision of the clinical staff. Participants believed that the more ‘time to come in and familiarize with the home dialysis machine, the more exposure the better, the more relaxed you feel’ about going home.

Feeling disempowered. During clinical consultations to discuss modality preferences, some felt powerless to articulate their concerns particularly if they perceived that their doctor was ‘sitting up on a ladder’ talking to them. They felt unable to ask questions or believed that they were expected to immediately comprehend and understand the information regarding each modality. Some participants felt so disempowered during clinical encounters that they instinctively chose the safest option, facility dialysis.

Pressure to choose home dialysis. Some participants felt pressure to choose a home dialysis modality after being told that facility units were already at full capacity. Some speculated that physicians insisted on home dialysis because it was ‘cheaper for the unit’. For this reason, some were reluctant to attend further routine appointments. Others acknowledged that they needed some pressure from clinicians to overcome their initial fears and hesitancy towards home dialysis.

Deprived of choice. Participants who wanted to choose a particular dialysis modality sometimes felt that there was no such opportunity. Some requested overnight modality options, such as APD and nocturnal home HD, but felt that they were refused this option without a reasonable explanation. Others were unaware of the reasons they did not commence dialysis on their chosen modality and were ‘waiting for someone’ to discuss changing to a home modality with them. Some participants believed that home HD was deliberately portrayed by doctors and nurses as a more ‘complex, harder to learn’ option, and they concluded that these clinicians thought it was beyond their capabilities.

Sustaining relationships

Maintaining cultural involvement. Particularly for Māori and Pacific Island participants, the choice of home dialysis was largely dependent on their ability to maintain involvement in their community. This included attending community

Table 2. Illustrative quotations for each identified theme

Theme	Quotations
Lacking decisional power	
Complexity of information	<p>'They might be telling you all this stuff but you can't hear anything else, you're just freaking out'. (C5)</p> <p>'Sometimes it's easy to overwhelm people with too much information, if you get too much information you just don't know where to start'. (HHD3)</p> <p>'I have a degree and I don't understand most of the stuff in the pamphlets and books, no wonder they all just go to the hospital and have it done, they probably don't understand why it's better to go home or they don't have enough information or understanding for them to feel ok to try or confident to try even'. (ICHHD7)</p>
Limited exposure to home	<p>'It's all technical it's all written for doctors or nurses it's not written for the uneducated or the people that it effects'. (PD6)</p> <p>'I don't really remember her educating me about it at all, I really don't think you do get enough information'. (HHD1)</p> <p>'The fact that there isn't a companion DVD or even on the same DVD a section on home haemodialysis, it's kind of a bit lopsided, there wasn't the same presence for home hemodialysis'. (HHD3)</p>
Feeling disempowered	<p>'I've actually never seen the bag be done, I've only ever seen the machine once at hospital. So I don't know it'. (Pred8)</p> <p>'It's good just to go to someone like [clinician] that actually sits down and talks with you and not actually at you'. (HH2)</p> <p>'It's more the way they educate, their manner, talking in normal words, rather than using all the medical jargon and abbreviations'. (HHD1)</p>
Pressure to choose	<p>'There are some people I can't talk to. I had this bad time with my doctor, and I just walked out, he just didn't know how to talk to me and so I just said nothing and said I had to go'. (Pred3)</p> <p>'The only thing really holding you back is either fear or laziness, being a little bit pressured to that decision is a good thing'. (HHD3)</p>
Deprived of choice	<p>'I was just thinking you guys just want to get everyone on home dialysis, and I just wasn't even listening, it was making me angrier cause they didn't understand me, they weren't helping me get there by shoving it in my face'. (ICHHD5)</p> <p>'To me it still felt like someone had their foot in my back and were pushing me along'. (PD11)</p> <p>'I have not even thought about that [home HD]. And yet I've seen people coming through the corridor to do the home training unit. No, I've never even been told'. (C6)</p> <p>'There are so many people that are doing it [nocturnal home HD] overseas, it's just sad that it wasn't even a consideration'. (C2)</p> <p>'They put the tube in my stomach for PD when I was in hospital, they thought that was better'. (PD1)</p> <p>'I haven't heard about that, like a machine at home, like at the hospital?'. (Pred10)</p>
Sustaining relationships	
Maintaining community involvement	<p>'Our culture is our life, things like birthdays, tangi (funerals) celebrations, meetings, we need to be able to attend, as that is what makes us us, that is a huge consideration when we were thinking about dialysis, we didn't want to be tied to something and not be able to do those things'. (C5)</p> <p>'We go to a lot of hui (meetings), to the marae (cultural meeting house). That was a lot of the reason why I wanted to go home too. I can work around it. I don't have to miss it'. (HH4)</p> <p>'Being able to attend hui (meetings) and tangi (funerals) and unveilings, home is the treatment that allows me to do that, not hospital'. (Pred13)</p>
Family influence	<p>'My aunty is on haemo, she told me that that was the way to go, I choose hospital haemo initially, cause that was her recommendation'. (C3)</p> <p>'I thought my family and my boy and what was best for us, my family doesn't do well when I have to come into hospital, that was also a big consideration'. (PD8)</p>
Trusting clinicians	<p>'I selected the PD, because I wanted a chance to go to my country, to my see my family'. (PD9)</p> <p>'For us, trust is very important. How they approach us is another factor, to reduce barriers, to form trust'. (C4)</p> <p>'People from your own culture. You can see they see your reality there, they know what it's like for you, what's important. Then you learn a lot better'. (IC6)</p> <p>'We have to go and meet the people, we have to have that same person, so we think then I have to go and see that person again, I know them, they know me, that's what will work'. (PD1)</p>
Minimizing social isolation	<p>'I just want the company of the other patients ... I can see myself doing the home one, in the community house'. (ICHHD5)</p> <p>'I think there's a strong community advantage in if there were community houses, you make new friends, but it's not just that, people are in the same boat, and you can learn and get strength from that'. (Pred7)</p> <p>'People can come and see me still at home, cause that's me, that's what I live for, so I can't give that away'. (Pred3)</p>
Reducing lifestyle disruption	
Sustaining employment	<p>'With home dialysis, I can work more and support my family and that's really important cause they are reliant on me financially'. (PD7)</p> <p>'For me the main thing is being able to work a bit more on the power bill is nothing if I can work'. (PD6)</p> <p>'If I couldn't keep my job, that would have a major impact, so if it was hospital, that would have a major impact'. (Pred1)</p>
Avoiding relocation	<p>'Moving away from family is important, we've got family at home that rely on us a lot with the grandchildren and we lose that too and we're letting them down'. (C2)</p> <p>'The hospital one, that's a lot of travelling and I'm not moving'. (Pred6)</p> <p>'With hemo, you have to move to [city] to learn for 3 months, that's not really fair'. (Pre12)</p>
Considering additional expenses	<p>'She was afraid of the machine using lots of power. She was worrying it would be too expensive to run it'. (HHD4)</p> <p>'We have such a tight budget now, to add anything extra even five dollars of power, that could tip us over, so that meant the machine at home was out'. (Pred3)</p>
Seeking flexible schedules	<p>It's just too much out of my life, going to the hospital you know three times a week, when they tell me to'. (Pred3)</p> <p>'I'm not going to go Tuesday, Thursday and Saturday for the rest of my life, not when I can do it when I want at home'. (IC6)</p>

Continued

Table 2. Continued

Theme	Quotations
Creating free time	'Home seemed a little scary but more convenient ... In the end it was more of a lifestyle compromise, having the days free and being able to travel ... and the night time bags that seemed heaps better than the day time bags'. (C9) 'With home hemo, I thought I could come home from work, dialyse and then just continue with whatever I was doing and so that seemed to fit in better for me'. (HH1) 'Definitely lifestyle for me trumped the health benefits'. (PD8)
Gaining confidence in choice	
Guarantee of safety	'Knowing we had 24 h support if anything went wrong was such a huge relief, just to have that safety blanket'. (C5) 'When you have no idea, someone saying to you, that's a really good decision is suddenly the biggest reassurance you can ever get'. (C5) 'I think it would be helpful to have a support person with you, just at the start, just for the first few times'. (Pred4)
Depending on professional certainty	'It would have been better if they had of helped me decide, it is your choice but also you don't have a clue what it's going to be like, so you do need some guidance with that'. (PD 8) 'If the doctor said that I should do something for mum, that would be the strongest influence, as a patient you always look to the doctor, you know he's got the certificate to say he know what will be best'. (C3) 'The recommendation didn't really make us decide home but reinforced what we were thinking and took away the doubt that we might be making a bad decision'. (C5)
Reassurance from peers	'The best thing would have been coming in and watching and hearing from other patients, you get a much better understanding and more idea about the practical things'. (HH2) 'I talked to this one lady about needling herself and she said it was quite easy, she told me to have a go'. (IC4) 'She was saying it took her a while to learn how to hook it up, but now it's like second nature to her, that was good, hearing it from people like you that you can relate to'. (Pred12)
Overcoming fears	'They did say at home you have less chance of infection, that immediately clicked with us, that you've got to have it at home, just that'. (C9) 'I'm fine to do the dialysis at home, if they offered someone to come in and put the needles in and then take them out maybe, although maybe with time I'd get better and be able to take them out, that is the only thing stopping me from going home'. (IC4) 'I just felt I didn't have the confidence to be doing it at home alone, I thought if something went wrong, I did something wrong I'd panic terribly'. (Pred2)
Maximizing survival	'The health benefits of home, that made the biggest difference over everything else'. (C3) 'I wanted to know which one was better, which one would work better and make me feel better, in the long term what is going to make me as well as possible for as long as possible'. (HH2) 'People should be telling you about which one's going to make you well and live longer, that would make you decide'. (Pred6)

Quotations are from study participants; the codebook containing the themes and sections from each participant coded to the respective themes are available on request. C, caregiver; Pred, pre-dialysis patient; IC, in-centre haemodialysis patient; PD, peritoneal dialysis patient; HH, home haemodialysis patient.

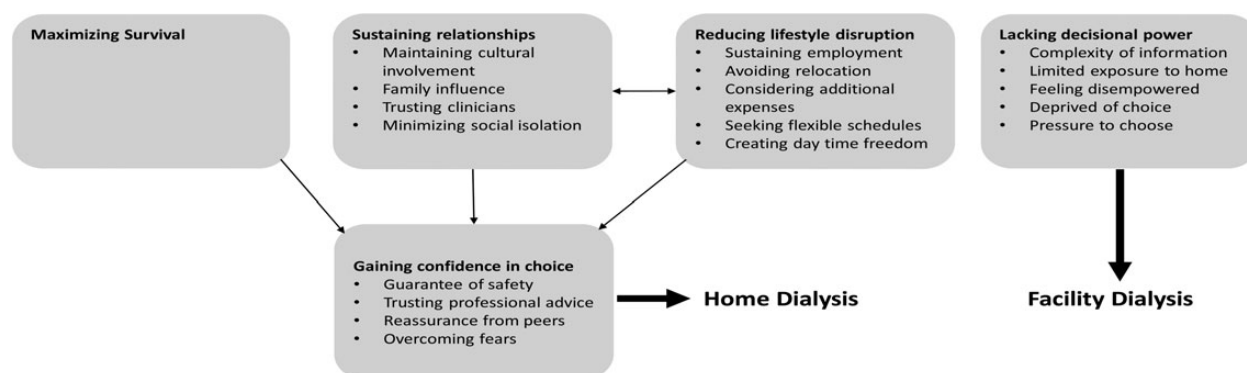


FIGURE 1: Thematic schema of patient and caregiver values, beliefs and experiences when considering home dialysis as a treatment option. Lacking decisional power was a barrier to home dialysis. Being unable to comprehend information, unfamiliarity with home dialysis, disempowerment or feeling pressured to choose home dialysis caused participants to feel hesitant and apprehensive of home dialysis. Therefore, some participants choose hospital dialysis, which they regarded as the safest option. The ability to sustain relationships, reduce lifestyle disruptions and maximize survival encouraged patients to be more confident in their decision-making to choose home dialysis. The themes Sustaining relationships and Reducing lifestyle disruption are linked with a bidirectional arrow as they were often described by participants as interconnected and impacting on each other.

meetings, funerals, family functions, and cultural and church activities. These participants opted for the home dialysis modality (PD or HD) that would allow them to retain their own

identity and standing within the community and often took the advice of others of the same ethnic group as to the treatment which would enable this.

Family influence. The influence of family members during the choice of home dialysis was stronger among participants whose family members had previous experience with home dialysis. Although advice from family members regarding the perceived risk of home dialysis created uncertainty and fear for some participants, many participants discussed ‘filtering’ this advice with that obtained from doctors and nurses. In contrast, participants with family members who had experienced home dialysis felt more comfortable and confident with home dialysis, particularly for those considering home HD.

Trusting clinicians. Participants emphasized the need to develop and maintain trust with clinicians, particularly when they were being advised to consider home dialysis. Clinicians who were seen as trustworthy helped participants to overcome feeling vulnerable at home, particularly if they did not have strong support networks. Participants who perceived their physician to be talking to them ‘as though they were clueless’ did not trust their recommendations or rationale and did not feel that they would be adequately supported at home. Māori and Pacific Island participants valued the clinicians who demonstrated an understanding of their cultural values, particularly through the use of their language. When clinicians delivered information in a way that showed they understood them in the context of their lives, this enabled them to trust their recommendation for home dialysis.

Minimizing social isolation. Some participants enjoyed the social connectedness in dialysis units and described facility dialysis sessions as a ‘free social outing’, which they did not want to relinquish. However, younger participants often considered home dialysis as an opportunity for more contact with their family and their already well-established social networks. Participants who had the option of independent HD in a community house believed that this gave them the benefits of home dialysis, in terms of flexibility of scheduling and ability to maintain employment, but also allowed for frequent social contact with others.

Reducing lifestyle disruption

Sustaining employment. Being able to dialyse outside of work hours was viewed by young and working-age participants as a key advantage of home dialysis as this minimized disruption to work and enabled them to continue their employment. Being able to dialyse when it was convenient for them allowed participants to maintain financial security for themselves and their family; this was particularly important if they were the sole provider.

Avoiding relocation. Home dialysis was preferred by participants who lived in rural areas as it enabled them to avoid relocation or regular commutes to a city. Commuting or having to relocate in order to access dialysis was expected to incur additional expenses. Additionally, moving away from their land (which for indigenous people holds significant cultural value), family and friends would cause emotional upheaval to themselves and their families. Many participants considered these attributes of home dialysis more important than any

potential survival benefits, ‘I know the machine would be better, but I am not me if I move, my life, everything important to me is gone, the bags [PD] mean I can stay and be alive’ (PD5).

Considering additional expenses. Participants considered additional expenses of home dialysis and how these would impact on their lifestyle and the trade-offs they may need to make with increased out-of-pocket costs. Home HD, in particular, was expected to incur higher consumable costs such as power and water. This was particularly relevant for participants who were already struggling financially due to decreased earning capacity and were concerned that they could not cope with any additional costs even if only very small.

Seeking flexible schedules. Some participants preferred home dialysis to avoid restrictive dialysis schedules of facility dialysis. In contrast, some patients who had commenced on facility dialysis felt disadvantaged by the inconvenience of having their dialysis schedule changed by the hospital at short notice. These participants considered an advantage of home dialysis was the ability to plan their dialysis schedule.

Creating free time. The ability of participants to ‘fit the treatment in around me’ encouraged them to choose home dialysis. PD was often chosen as it allowed freedom to travel, particularly for those participants who had family living overseas, especially Pacific Island people. The ability to maintain daytime freedom was also noted among patients’ preferences for nocturnal home dialysis (particularly APD). However, facility HD offered greater free time for caregivers, particularly if the patient required a high level of medical support.

Gaining confidence in choice

Guarantee of safety. Participants initially felt anxious about dialysing alone at home as they expected to ‘get something wrong’; however, they overcame their initial fears with reassurance from clinicians and ongoing education and experience. They gained confidence when their clinician supported their choice for home dialysis early in their decision-making, as this reinforced that home dialysis was a safe and suitable decision. Also, access to on-call nurses, close supervision during the commencement phase of home dialysis and regular follow-up clinic appointments helped participants to overcome their apprehension.

Depending on professional certainty. Participants felt that a strong treatment recommendation from a trusted doctor or nurse allowed them to be more confident in their decision to choose home dialysis. Caregivers felt that the doctor recommending or supporting their decision relieved some of the burden of responsibility in making that choice. Some participants felt that they were left unsure about their choice and would have appreciated advice about which treatment was the most clinically advantageous as this would have given them more confidence and certainty in their decision.

Reassurance from peers. Having the opportunity to discuss home modalities with other patients and caregivers who were experienced in doing home dialysis normalized these

treatments and made them less confronting. Participants felt that hearing of other patients who had gone through similar feelings of apprehension and fear made them confident that they too would overcome these concerns. Participants developed a better appreciation of the practicalities of home dialysis from their peers including aspects that they had not previously considered, such as being able to dialyse while helping with their children's homework, and how much storage space for supplies was needed. Others felt more comfortable asking personal questions, for example, regarding relationships and whether there was any pain involved in needling.

Overcoming fears. The fear of developing an infection discouraged some participants from choosing PD, while others who dreaded self-cannulation were averse to home HD. Although the fear of needling was perceived as an important consideration, some participants felt that they could overcome this with adequate support, particularly if the participants valued the potential benefits of home HD.

Maximizing survival

Some participants learned from clinicians that home dialysis was associated with increased survival compared with facility dialysis and thus opted to do dialysis at home. Others felt that an increased knowledge of survival benefits, particularly of home HD, may have helped them to make a more informed decision and also motivate them to overcome some of their fears regarding home dialysis.

DISCUSSION

The capacity of patients and caregivers to engage in decision-making about home dialysis was strengthened by increased education and information, understanding the benefits of home dialysis and confidence gained through the support and reassurance of clinicians, peers and family. However, some perceived that they lacked power to make decisions, which was identified as a barrier to choosing home dialysis as they cognitively defaulted to facility dialysis as it was deemed as the safe and familiar treatment option. Being unable to comprehend information, unfamiliarity with home dialysis, disempowerment of decision-making or feeling pressured to choose home dialysis caused participants to feel hesitant and apprehensive of home dialysis. The ability to sustain relationships, reduce lifestyle disruption and maximize survival encouraged participants to gain confidence in their decision-making and to choose home dialysis.

The findings of our research help to address one of the central research priorities in this area of identifying ways to enhance communication and maximizing patient participation in modality decision-making [27, 28]. Our research provides new insights about patients' and caregivers' decision-making specific to home dialysis. Despite all participating units having established pre-dialysis programmes, the educational needs of the patients were not always being met and participants struggled with the complexity and delivery of information they were receiving. Patients' perceptions of their own knowledge has been shown to increase with more frequent nephrology clinic visits

[29], and lack of time to educate patients has been previously identified by pre-dialysis nurses as a barrier to empowering patients and families [30]. Other studies support this finding, indicating that despite receiving information through pre-dialysis education, a large proportion of patients did not feel that they had sufficient knowledge and choice of all modalities [19, 29, 31].

Participants urged the need for pre-dialysis information to be more balanced, with advantages and disadvantages of each option presented, and without pressure to choose home dialysis. The pressure to choose home has previously not been identified and raises an important issue for further discussion as some countries try to increase home dialysis numbers by setting targets [32]. It is strongly advocated that patients take the lead in choosing their dialysis modality, after being given neutral information about each option [33], yet research suggests there are a number of influences on this choice, including physician bias [34] and peer influence [35]. Complicating this further, our findings also suggest that some patients value a clinical recommendation and not all people want to be actively involved in dialysis decision-making. These findings support the need to improve the process of shared decision-making when patients choose a dialysis modality. The timing, quantity and depth of information that patients and caregivers receive during the decision process need to be tailored to individual preferences.

The lack of exposure, familiarity, visibility and the perceived complexity of home HD to patients and caregivers may account for its low rates internationally [12], as participants were less likely to feel comfortable to choose this modality, a finding concordant with a study of patient and caregivers with no previous exposure to home HD [36]. Home HD was also often portrayed by clinicians and educators as more complex, difficult to learn and was considered more expensive, resulting in apprehension towards this modality.

Finally, concerns of sustaining employment, considering out-of-pocket costs and avoiding relocation raise the issue of public policy to ensure equitable access to all dialysis modalities. As end stage kidney disease is more common in those living in remote areas [37–39], and the impact of relocation for treatment has been identified among indigenous Australians [40], financial considerations for patients, particularly those already those financially disadvantaged requires further exploration.

In order to address patients' unmet educational needs, further emphasis on development of pre-dialysis educational material may be warranted, ensuring their suitability for people with low literacy, and facilitating understanding. Increased training of clinicians in the process of shared decision-making, patient engagement [41] and providing greater access to patient decision-aid tools [42], which focus on individual patient priorities, may also assist in better meeting educational needs. The development of culturally appropriate education programmes and resources, which better meet the cultural needs of indigenous and ethnic groups, may also aid in addressing some of the identified issues around unequal access to home dialysis.

Exploring potential solutions for those living in rural areas and those with financial concerns might identify ways to reduce the burden of home dialysis on these groups. As patients are often reluctant to relocate, additional support for these

populations, which has proved successful in other studies [43–45], may reduce financial and cultural stressors of relocating. Governmental policy may also address this and the issue of retaining employment while patients train for home HD and explore reimbursement for out-of-pocket costs.

We plan to conduct discrete choice experiments based on the findings of this study that will determine the trade-offs patients and their families make when considering home dialysis as a treatment option [46]. There are also a number of potential pre-dialysis interventions that could be explored to test their effectiveness in improving patient knowledge and understanding: the development of culturally specific education sessions and programmes incorporating peer support from other patients dialysing at home. A comparison study that compares more frequent and targeted education to specific patient groups and compares home dialysis rates may also provide useful information into the aspects of education delivery, which are more effective.

A strength of our study was the inclusion of participants who have home dialysis as an option when choosing dialysis treatment as well as the inclusion of under-researched populations, participants from ethnic minority groups and participants with English as a second language. However, our study also included a number of potential limitations. The study was conducted in New Zealand, a country that has a strong culture of home dialysis, and, therefore, the transferability of the findings to countries without home dialysis may be limited. However, our findings could inform pre-dialysis programmes and strategies to better align practice and policy with patient preferences and needs. The interviewer was known to participants from one dialysis centre, and this relationship may have resulted in self-censoring of responses, although when compared with participants from other centres, similar themes were identified. The use of translators for three participants is an additional limitation as the interviews were not conducted in these participants' first language, and thus there is a degree of uncertainty about whether the linguistic and cultural nuances of their data were sufficiently captured.

To effectively engage and empower patients and caregivers to consider home dialysis, a stronger emphasis needs to be placed on the development of patient-focused educational programmes and resources, which meet their individual needs. Developing pre-dialysis and home dialysis programmes that meet the health literacy and cultural needs of patients and caregivers may increase the acceptance and decrease the fears of home dialysis. Financial burdens may be minimized through provision of reimbursement programmes, employment support and additional assistance for patients, particularly those residing in remote areas.

SUPPLEMENTARY DATA

Supplementary data are available online at <http://ndt.oxfordjournals.org>.

AUTHORS' CONTRIBUTIONS

R.C.W., K.H., R.L.M. and A.T. were involved in the research idea and study design. Data acquisition was done by R.C.W.

and data analysis by R.C.W. and A.T. Data interpretation was done by R.C.W., A.T., K.H., R.L.M. and S.C.P., and supervision or mentorship by A.T., K.H., R.L.M., S.C.P. and M.R.M. R.C.W. drafted the manuscript, and all other authors contributed to writing and revision of the manuscript.

ACKNOWLEDGEMENTS

R.C.W. is supported by a University of Sydney APA Scholarship, Baxter Clinical Evidence Council research programme, New Zealand Lotteries Health Research Grant and the Hawke's Bay Medical Research Fund. R.L.M. is supported by an Australian National Health & Medical Research Council Early Career Researcher Fellowship (ID1054216). S.C.P. is supported by a Rutherford Discovery Fellowship from the Royal Society of New Zealand. M.R.M. is supported by a Jacquot Research Establishment Fellowship of the Royal Australasian College of Physicians. A.T. is supported by a National Health and Medical Research Council Fellowship (ID1037162).

CONFLICT OF INTEREST STATEMENT

None declared.

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Received for publication: 10.7.2015; Accepted in revised form: 12.8.2015