

## Characteristics of dialysis important to patients and family caregivers: a mixed methods approach

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### Abstract

**Background.** Little is known about pre-dialysis patients' or family caregivers' preferences for dialysis modality and the reasons underlying their decisions. The aim of this study was to rank the most important characteristics of dialysis on which patients and caregivers make decisions about treatment.

**Methods.** A mixed methods approach was used with groups of pre-dialysis patients (chronic kidney disease Stage 4/5), dialysis patients and family caregivers. Characteristics of dialysis were identified and ranked individually and then consensus of the most important characteristics was determined within each group. Purposive sampling was used to recruit participants until data saturation was achieved. Transcripts of focus groups were coded and analysed to examine the rationale behind the ranking.

**Results.** Thirty-four participants from two Australian hospitals attended six 'nominal group' focus groups between September 2009 and February 2010. Two groups involved pre-dialysis patients (total  $n = 8$ ), two involved peritoneal and haemodialysis patients, respectively ( $n = 9$ ) and two involved caregivers of dialysis patients ( $n = 17$ ). We identified 28 characteristics of dialysis important to patients and caregivers. Patient groups agreed that the most important characteristics were (i) survival, (ii) convenience of dialysis at home and (iii) dialysis-free days. For caregivers, the most important were (i) convenience of dialysis at home, (ii) respite and (iii) the ability to travel.

**Conclusions.** Patients and family caregivers highly value treatment that enhances survival and can be performed at home. Future planning of dialysis services could better reflect these priorities through provision of increased home dialysis support services and planned respite for caregivers.

**Keywords:** chronic kidney disease; dialysis; dialysis caregivers; patient preferences; treatment decision making

### Introduction

In the UK, estimated costs for home-based dialysis modalities such as peritoneal dialysis (PD) are almost £20 000 per patient per year less than centre-based haemodialysis (HD) [1]. With no evidence of a significant difference in terms of survival or quality of life between the two modalities [2–4], it would seem economically advantageous to increase the proportion of Stage 5 chronic kidney disease (CKD) patients managed on a home-based therapy. While it is acknowledged that in the absence of contraindications to either modality, patient preference is the most important deciding factor [4–7], few studies have published the factors that influence dialysis choice from the perspective of CKD patients [7–10]. In fact, most prior studies have presented a list of characteristics or themes central to dialysis modality choice, without an attempt to prioritize or rank them. Additionally, most studies report characteristics nominated by patients who had already commenced dialysis, many of whom presented acutely and had limited choice in their modality. The findings from these studies may reflect a preference for the decision that has already been made or a preference for the modality the patient knows best. There are scarce data on the characteristics important to pre-dialysis patients who do not have the benefit of experience with one or more dialysis modalities and no studies to our knowledge that make comparisons between characteristics important to pre-dialysis and dialysis patients.

Family support has been identified as an important factor in the uptake of both PD and home HD [11, 12], with more patients commencing PD if family caregivers were present, and in-centre HD chosen more frequently by older patients without family support. The National Kidney Foundation/Kidney Disease Outcomes Quality Initiative guidelines recommend pre-dialysis education be given to all individuals including family caregivers who are likely to influence patient decisions about modality choice [13]; however, few studies have examined the modality preferences of family caregivers particularly when interviewed separately from the patient [14]. To date, no studies have reported

individual or group prioritization of characteristics important in modality decision making from the perspective of pre-dialysis patients or caregivers.

Knowledge of the most important characteristics of dialysis from a patient and caregiver perspective could enable the optimization of pre-dialysis patient education and support for informed decision making. This is particularly important as increased patient autonomy in CKD treatment decision making has been linked to improved survival and quality of life [15, 16]. The aim of this study was to rank the characteristics of dialysis upon which pre-dialysis patients, current dialysis patients and caregivers make decisions about treatment and the reasons underpinning their decisions.

**Materials and methods**

We used a ‘mixed methods’ approach, which involves both quantitative and qualitative components in a single research project [17]. Using a nominal group technique, we obtained individual and group rankings of dialysis characteristics (the quantitative component) and then analysed the narrative text from transcribed focus groups using qualitative methods to better understand the rationale for the ranking. The nominal group technique uses a highly structured focus group to gather information from relevant participants about a given issue. It consists of several steps in which participants rank, discuss and then re-rank a series of items or questions [18]. Nominal group techniques have been successfully applied to various areas of health research [19, 20] and have specifically been used in prioritizing patient preferences for treatment in palliative care [21, 22]. As the purpose of this study was to reach group consensus over priority characteristics for dialysis treatment, we also performed a group ranking exercise. The steps taken are outlined in Figure 1. This study was approved by the Human Research Ethics Committee of the Sydney South West Area Health Service, Australia.

*Recruitment and data collection*

Participants for each nominal group (dialysis, pre-dialysis and caregiver) were recruited from Royal Prince Alfred and Concord hospitals in New South Wales, Australia using purposive sampling [23]. The composition of each focus group was designed to strike a balance between participant homogeneity (e.g. personal experience with CKD or being on dialysis) and participant diversity (e.g. age, sex). We deliberately combined dialysis sub-modalities (i.e. continuous ambulatory PD with automated PD in the PD group; and home HD with satellite HD in the HD group) to

encourage expression of divergent views and experiences. Others have found that some divergence in participant experience results in more animated and enthusiastic discussion with clearer articulation of beliefs and attitudes [24, 25].

The optimal number of participants for a nominal group process is considered to be between five and eight [18], with a minimum of three required. Purposive sample sizes are usually determined on the basis of theoretical saturation (the point in data collection when new data no longer bring additional insights to the research question). Participants were identified by their treating clinician and contacted by the facilitator (R.L.M) who discussed the purpose and conduct of the focus groups in detail. Participants unable to rank numerically or write in English were excluded. All participating pre-dialysis patients had received education through a multidisciplinary seminar where they were exposed to home HD, PD, satellite HD, transplantation and conservative care treatment options. In addition, they had all discussed treatment options with their nephrologist or one of two pre-dialysis coordinators. The 3 hour nominal groups were conducted in a hotel conference room. Each group was facilitated by R.L.M., while A.T. recorded field notes, both of whom had prior experience conducting focus groups with dialysis patients. All groups were audio-recorded and transcribed verbatim. Written informed consent was obtained from each participant and recruitment continued until concurrent analysis revealed data saturation.

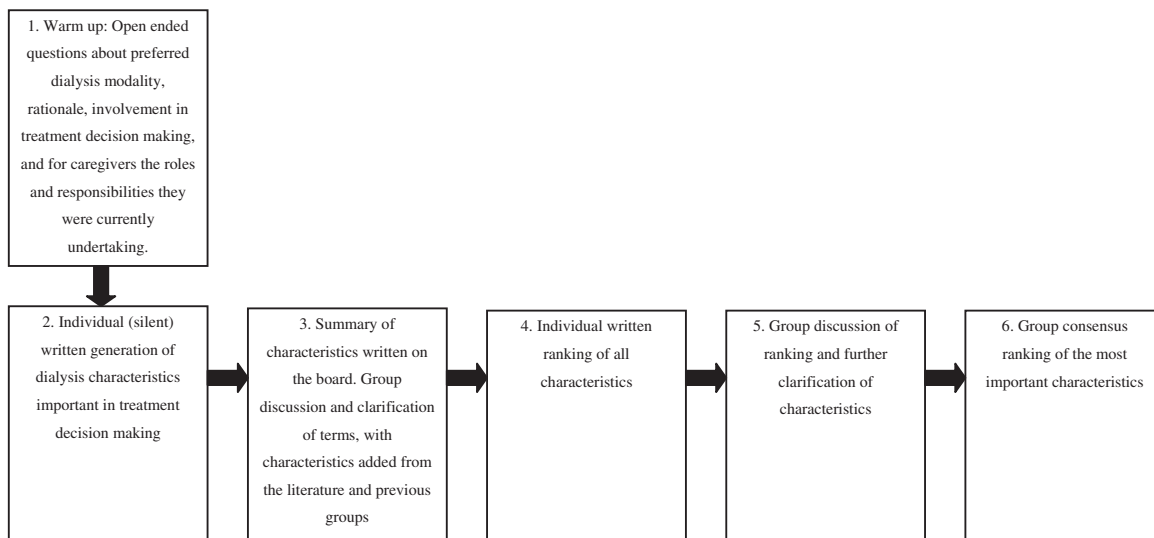
*Data analysis*

*Quantitative ranking.* We analysed the individual written rankings for all participants. A maximum priority score [19] was calculated from the dialysis characteristics prioritized by individual patients and caregivers in their top five (first = 5 points, second = 4 points, third = 3 points, etc.) and summed across all patient or caregiver groups. Data were presented as a percentage of the maximum possible priority score (number of participants completing ranking multiplied by 5 points).

For the qualitative data, we conducted thematic analysis of the transcripts according to a method described by Boyatzis [26, 27], to identify reasons underpinning the participants’ ranking decisions. We specifically explored the similarities and differences in themes around treatment decision making between pre-dialysis patients and current dialysis patients. We used NVivo v8.0 software ([www.qsrinternational.com](http://www.qsrinternational.com)) to code and analyse the data. Data saturation was achieved when no new characteristics or themes were mentioned by the dialysis patients, the pre-dialysis patients or the caregiver groups when combined with our previous findings from a systematic review of qualitative studies and an analysis of 97 dialysis patient interviews [9, 10].

*Use of field notes*

The field notes served two purposes in the analysis. The first was to record observations of participants such as their seating positions around the



**Fig. 1.** Flow chart for ranking procedure using a modified nominal group technique.

table: the pattern of conversation; non-verbal body language and facial expressions; mood and emotions (e.g. grief, humour, frustration) and informal dialogue during the tea breaks. These data were added to the written transcripts to highlight important themes for the analysis. The second purpose was to keep track of all the dialysis characteristics mentioned by participants, so that they could be grouped, clarified and ranked during each focus group session.

## Results

### Participant demographics

Of the 79 participants approached, 34 (43%) participated in the study (Table 1). Reasons for non-participation included work or conflicting family and social commitments and inpatient hospitalizations. The six nominal groups involved a total of 17 patients (32% response rate) and 17 adult caregivers (65% response rate). (Figure 2) The median number of participants per group was 6 (range 3–9). There were two groups of pre-dialysis patients (three and five in each group), two groups of dialysis patients (one HD group with six participants and one PD group with three participants) and two groups of family caregivers of patients receiving home dialysis (eight and nine participants, respectively). The roles and responsibilities reported by the caregivers are presented in Appendix 1 (supplementary material). Of note, seven of the nine dialysis patients had experienced other dialysis modalities and all the HD participants had experienced satellite dialysis. Home HD typically involved longer treatment hours than satellite HD and was performed solely by patients or their caregivers. None of the pre-dialysis patients reported medical contraindications to either dialysis modality.

### Ranking

Twenty-eight separate characteristics (25 for patients and 19 for caregivers) were nominated as important in dialysis decision making. (Table 2) Survival, convenience of dialysis at home, a flexible dialysis schedule, the presence of a dialysis fistula/needles and the ability to travel were the characteristics given the highest priority by individual patients. For caregivers, the highest ranked characteristics were convenience of dialysis at home, ability to travel, a flexible dialysis schedule, respite and staff support (including after-hours phone support). The similarities of ranked characteristics between patients and caregivers are depicted in Figure 3.

Characteristics ranked highly by caregivers but not mentioned by patients included caregiver ability to work or socialize and out of pocket costs. The characteristics ranked proportionally higher by caregivers than by patients were the ability to travel, staff support and the independence achieved through self-management of dialysis treatment. (Table 2) Survival was not specifically identified by caregivers as a decision making characteristic; however, it was implied through discussion. The impact of the fistula and insertion of dialysis needles was less of a consideration for caregivers than for patients.

Group consensus was recorded after discussion, clarification and justification. Each group agreed on the top three

characteristics with dissent from only one participant in the HD group. (Table 3) Across all four patient groups, (i) survival, (ii) convenience of dialysis at home and (iii) dialysis-free days were most important. For caregivers, it was (i) convenience, (ii) respite and (iii) the ability to travel. Participant quotations to illustrate these characteristics are presented in Table 4.

### Thematic analysis

Overall, decisions about preferred dialysis modality were considered with reference to the patient's prospects for kidney transplantation. Both patients and caregivers talked about eligibility for the waiting list, length of time already spent waiting, the progress of transplant work-up and who

**Table 1.** Characteristics of nominal group participants

Participant characteristics	Patients <i>n</i> = 17 (%)	Caregivers <i>n</i> = 17 (%)
Mean age years (range)	59 (40 to 81)	61 (30 to 86)
Males	11 (64.7)	6 (35.3)
Females	6 (35.3)	11 (64.7)
Ethnicity		
Anglo Celtic	8 (47)	8 (47)
Asian	4 (24)	4 (24)
Eastern European	3 (17)	3 (17)
Pacific Islander	2 (12)	1 (6)
African American	0 (0)	1 (6)
Self reported comorbidities		
Diabetes	10 (59)	4 (24)
Cardiovascular disease	7 (41)	4 (24)
Cancer	1 (6)	2 (12)
Depression	1 (6)	1 (6)
Employment status		
Employed	4 (23.5)	4 (23.5)
Unemployed	5 (29.4)	3 (17.6)
Retired	8 (47.1)	10 (58.8)
Education level		
Primary school ± high school	9 (52.9)	10 (58.8)
Tertiary	8 (47.1)	7 (41.2)
Distance from home to renal unit		
0 to 10 km	14 (82.4)	8 (47.1)
11 to 20 km	2 (11.8)	1 (5.9)
>20 km	1 (5.9)	8 (47.1)
Has a dialysis caregiver		
Yes	10 (58.8)	n/a
No	7 (41.2)	n/a
Relationship to dialysis patient		
Spouse/partner	n/a	13 (76.5)
Parent	n/a	1 (5.9)
Child	n/a	1 (5.9)
Other family, e.g. sibling	n/a	2 (11.8)
Current treatment		
Satellite HD (~15 h/week)	3 (17.6)	n/a
Home HD (~21 h/week)	3 (17.6)	n/a
PD (APD × 2, CAPD × 1) <sup>a</sup>	3 (17.6)	n/a
Pre-dialysis	8 (47.1)	n/a
Caregiver support for current treatment		
Home haemodialysis	n/a	12 (70.6)
PD	n/a	5 (29.4)
Mean dialysis duration years, <i>n</i> = 9 (range)3.34 (1 to 7)		n/a
Caregiver's mean dialysis support duration years (range)	n/a	4.67 (1 to 11)

<sup>a</sup>APD, automated peritoneal dialysis; CAPD, continuous ambulatory peritoneal dialysis. n/a, Not applicable.

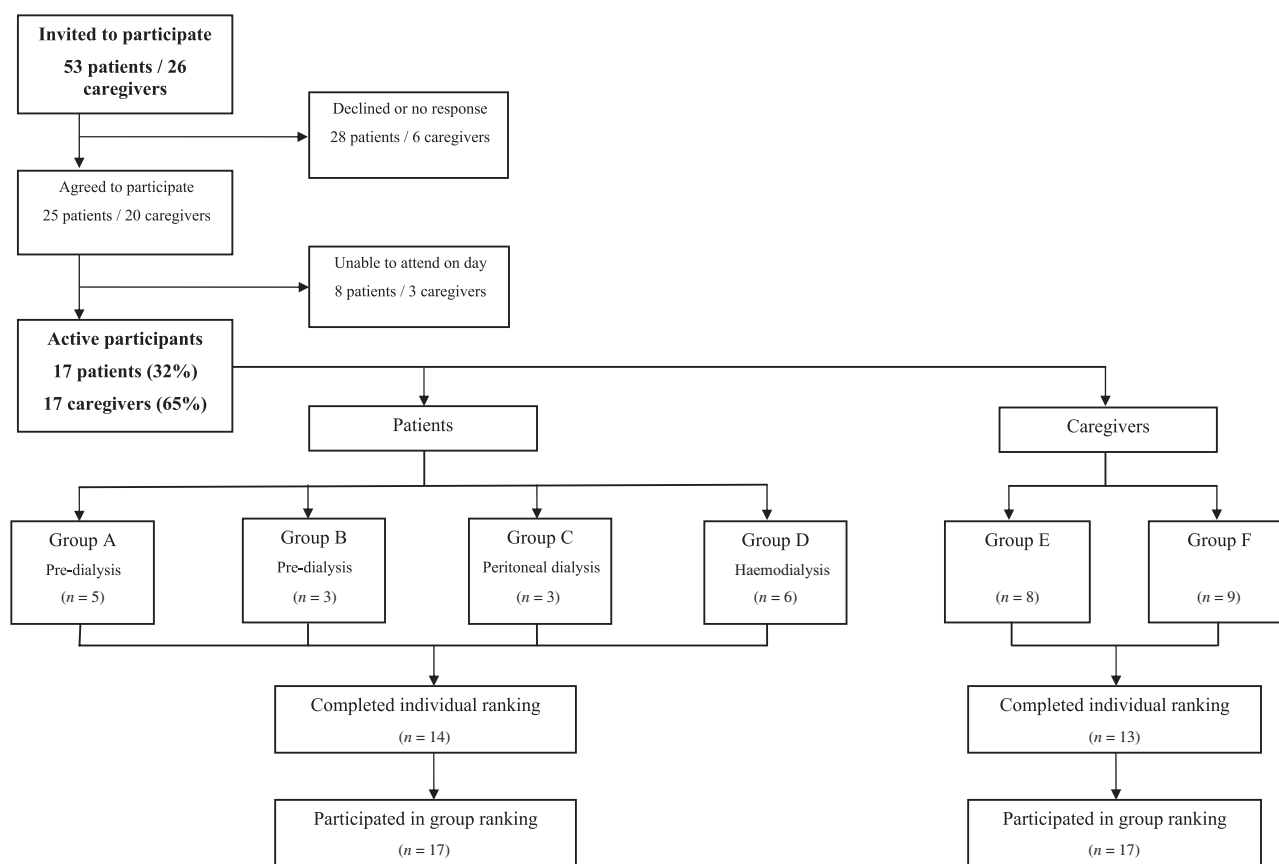


Fig. 2. Recruitment of participants into nominal groups.

in their family had offered to be a living donor. Some patients would accept home dialysis in the short-term while they waited for their living donor to be assessed. This was based not only on their own perceived ability for self care but also the consideration of burden put on their caregivers. A few patients felt that PD, compared with HD, allowed them to live life more fully, while waiting for a transplant, however, dialysis was still only perceived as an interim measure. Some patients were ineligible for transplantation due to medical contraindications and consequently, dialysis was viewed as the second-best alternative.

*Comparison of characteristics between pre-dialysis patients and current dialysis patients*

There were eight characteristics in common to current dialysis and pre-dialysis patients, five raised only by current dialysis patients and four other characteristics raised only by pre-dialysis patients. (Figure 4) Of note, the characteristics for pre-dialysis patients were privacy, staff or family support, perceived quality of life and the side effects of treatment. Examples of these are presented in Table 5. Current dialysis patients were more concerned about flexibility with their treatment schedule and effectiveness of dialysis over the longer term. This was particularly apparent in patients who had been taken off the transplant waiting list for medical reasons.

For most focus group participants, survival was their number one priority. Two pre-dialysis patients mentioned a non-dialysis or conservative care option. One of these patients was not convinced that she wanted any form of dialysis and the other indicated he would stop treatment if he could not dialyse himself at home. We found that group discussion of conservative management and palliative care as a treatment alternative was not encouraged by the other pre-dialysis group participants.

**Discussion**

Six nominal groups identified and ranked 28 characteristics of dialysis important to patients and caregivers. Group consensus of the most important characteristics for patients was survival, convenience of dialysis at home and dialysis-free days; and for caregivers was convenience of dialysis at home, respite and the ability to travel. Most participants framed the considerations of dialysis modality within the context of their access to transplantation. Pre-dialysis patients wanted a modality that maintained a ‘normal’ life that kept dialysis private, minimized side effects and provided reasonable quality of life. They were apprehensive about the impending treatment and wanted reassurance from professional staff and their family. Current dialysis patients were more concerned about their ability to change their treatment schedule and the effectiveness of their modality over the longer term.

**Table 2.** Individual ranking of all characteristics important to patients and caregivers about choice of treatment

Characteristics	Patients			Caregivers		
	Patient rank	Max priority score <sup>a</sup>	Number ranking this factor in the top 5 ( <i>n</i> = 14)	Caregiver rank	Max priority score <sup>a</sup>	Number ranking this factor in the top 5 ( <i>n</i> = 13)
Keeps patient alive (survival)	1	49.4%	12	n/m <sup>b</sup>	n/m <sup>b</sup>	n/m <sup>b</sup>
Convenience (dialysis at home)	2	27.1%	8	1	70.8%	13
Flexible schedule	3	23.5%	7	3	35.4%	8
Treatment involves cannulation or presence of a fistula	4	21.2%	6	15	4.6%	1
Ability to travel	5	20.0%	7	2	40.0%	9
Dialysis-free days	6	20.0%	7	11	10.8%	3
Ability to work or socialize (patient)	7	17.6%	5	10	13.8%	4
Hours 'on' dialysis	8	15.3%	6	8	15.4%	4
Better health (patient)	9	15.3%	6	14	7.7%	1
Staff support—including after hours phone support	10	10.6%	4	5	23.1%	6
Self-management (independence)	11	8.2%	3	7	20.0%	5
Side effects of treatment, e.g. distended abdomen	12	4.7%	1	n/m	n/m	n/m
Risk of peritonitis or presence of PD catheter	13	3.5%	3	n/m	n/m	n/m
Continuous dialysis (patient stability/no fluctuations)	14	3.5%	1	18	0.0%	0
No fluid or diet restrictions	15	2.4%	2	19	0.0%	0
Freedom	16	2.4%	1	n/m	n/m	n/m
Clean (blood-free dialysis)	17	2.4%	1	n/m	n/m	n/m
Training time and simplicity of learning treatment	18	1.2%	1	n/m	n/m	n/m
Travel time to attend hospital dialysis	19	1.2%	1	12	9.2%	5
Storage and home modification	20	0.0%	0	n/m	n/m	n/m
Having a caregiver	21	0.0%	0	n/m	n/m	n/m
Pain or discomfort	22	0.0%	0	n/m	n/m	n/m
Cooking requirements for a renal diet	23	0.0%	0	16	4.6%	4
Number of visits per week to hospital	24	0.0%	0	6	23.1%	6
Waiting at hospital for dialysis to commence	25	0.0%	0	17	1.5%	1
Respite	n/m	n/m	n/m	4	29.2%	8
Ability to work or socialize (caregiver)	n/m	n/m	n/m	9	15.4%	4
Out of pocket costs	n/m	n/m	n/m	13	9.2%	4

<sup>a</sup>Priority scores were calculated from the characteristics prioritized by individual patients and caregivers in their top 5 (first = 5 points, second = 4 points, third = 3 points, etc.) and summed across all patient or caregiver groups. Data are presented as a percentage of the maximum possible priority score (number of participants completing ranking × 5 points). When score = 0.0%, the characteristic was mentioned as important but not ranked in the top 5. Rows with a 'n/m' denote characteristics not mentioned by participants.

<sup>b</sup>Although survival was not mentioned specifically, caregivers implied that keeping the patient alive was important.

Our study identified survival as the most important consideration to pre-dialysis patients and current dialysis patients when selecting a treatment modality, a finding that has not been specifically identified by previous studies [7, 10]. It may be that in previous studies, increased survival as a rationale for choosing dialysis was implied and not explicitly stated by patients; however, we deliberately considered survival in the patient ranking exercises because we wanted to determine its relative importance when grouped with other quality of life characteristics. There is no evidence from randomized controlled trials that patient survival is superior with one dialysis modality compared to another.

Registry data suggest that survival is longer in patients treated with home HD; however, these studies are subject to patient selection bias [28]. Recent matched cohort analyses indicate a survival advantage in the short-term with PD [29, 30] and longer-term survival comparable to deceased donor transplantation with nocturnal home HD [31].

We found consistency in the ranking of characteristics independent of the type of dialysis. For example, 'survival' was the most important consideration regardless of the patient's current modality type and prior experience. We found the characteristic 'convenience of dialysis at home' to be equally desirable between home and satellite patients,



as well as the ‘flexibility’ of treatments. Home patients emphasized the benefit of flexibility in their home dialysis schedule and satellite patients lamented the lack of flexibility in their treatment schedules. Although the reason underpinning the importance of the characteristic reflected the patients’ experience, the top ranked characteristics were the same.

The convenience of dialysis at home was ranked very highly by both patients and caregivers; yet home dialysis still represents a small proportion of dialysis treatment in most developed countries [32]. Our results suggest that barriers for dialysis at home from a patient’s perspective were concerns about self-cannulation and the provision of staff support, particularly overnight and at weekends. Many studies have found detailed pre-dialysis patient education results in a higher proportion of patients choosing home HD or PD [33, 34]. Pre-dialysis patients who received multifaceted education were more likely to perceive freedom and control as advantages and consequently chose self-care dialysis [34].

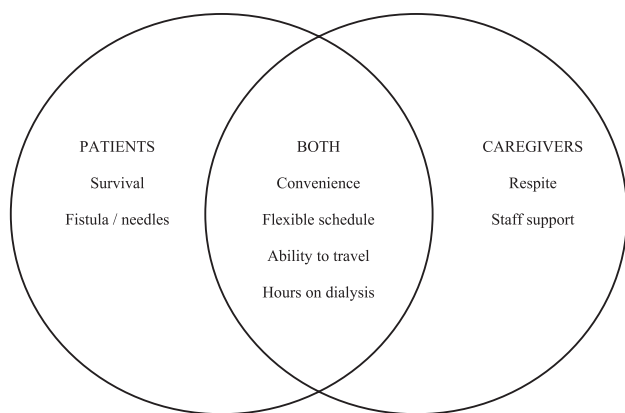
There appeared to be a divergence between the caregivers’ desire to have their family member dialysing at home and their own need for respite. When each characteristic was ranked, the convenience of dialysis at home was the most important factor. Many caregivers mentioned benefits such as a ‘happier’ patient, less waiting

around and less driving to hospital. The need for respite was ranked fourth. Although caregivers preferred home dialysis, they felt caregiver respite was needed for long-term home dialysis to be sustainable. Caregiver burden has also been reported as an important consideration to patients. An Australian review of home HD found home patients themselves may request a permanent transfer to satellite HD to give the family respite [28]. Upfront discussions to plan for temporary but regular respite, as well as strategies to enable travel may help future caregivers with this role.

This study was limited to English-literate patients and caregivers from two Australian renal units where home dialysis is encouraged. Our participants may have been more highly educated than the broader dialysis population; however, less than one-quarter were employed and many were living on sickness benefits. The findings may not be transferable to patients and caregivers with low literacy or to regions without access to home HD or PD training units. We did not formally collect data on participants’ income and therefore cannot draw any conclusions about the influence of income on individual ranking of characteristics. In addition, our findings with respect to caregivers are limited to those caring for family members on home-based dialysis and may not be transferable to the caregivers of pre-dialysis or satellite-based dialysis patients. Although the number of nominal groups was relatively small, we reached data saturation relatively quickly when combined with the findings from our previous studies [9, 10] and believe additional groups would not have identified new characteristics or changed the group consensus rankings.

The strengths of this study included a mixed methods design allowing both ranking of characteristics and exploration of the rationale behind the ranking as well as comparison between groups. The nominal group technique was well suited to obtaining individual ranking of characteristics prior to group consensus in a single sitting. We included patients with no prior experience of dialysis and patients with extensive experience of dialysis representing each modality. The caregivers in this study had many years experience of supporting home HD or PD.

Our study identified many important characteristics that were not confined to the dialysis treatment itself. This is in contrast to a study by Hornberger *et al.* [35], who identified a minimum dataset on patient preferences for accurate



**Fig. 3.** Differences in the highest ranked characteristics nominated by patients (includes pre-dialysis and current dialysis patients) and caregivers.

**Table 3.** Group ranking (consensus) of the most important characteristics to patients and caregivers about choice of treatment

Rank	Patients				Caregivers	
	Pre-dialysis	Pre-dialysis	PD	HD		
1	Keeps patient alive (survival)	Keeps patient alive (survival)	Convenience (dialysis at home)	Keeps patient alive (survival)	Convenience (dialysis at home)	Convenience (dialysis at home)
2	Dialysis-free days	Flexible schedule	Keeps patient alive (survival)	Better health (patient)	Better health (patient)	Respite
3	Convenience (dialysis at home)	Ability to travel	Self-management (independence)	Dialysis-free days	Respite	Ability to travel

**Table 4.** Rationale for group consensus of characteristics—description and participant quotations

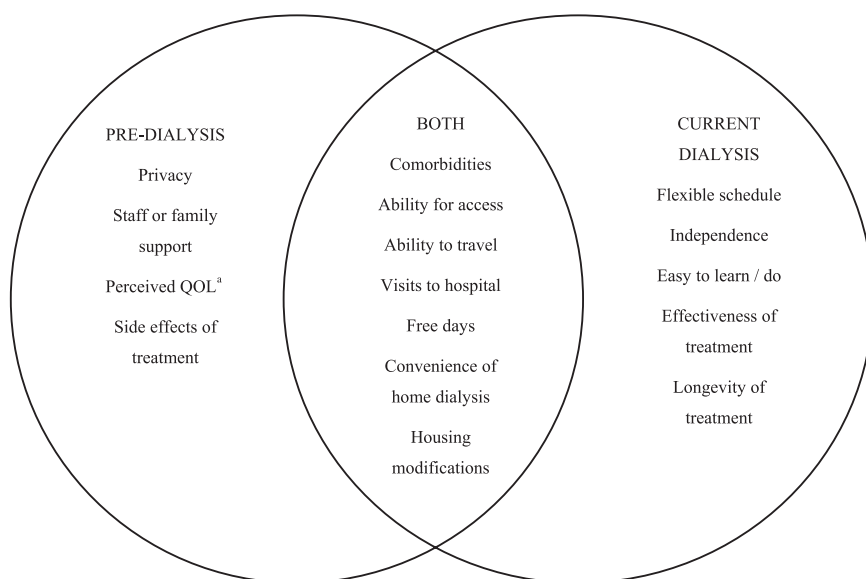
Characteristic	Description	Participant quotations
Survival	Maximizing survival was not a conscious thought that required ranking on the board—it was considered as a ‘given’. Dialysis was thought of as extending or prolonging survival until a cure was found or transplantation occurred. Not all dialysis modalities were considered worth living for. Some pre-dialysis patients considered centre HD as ‘worse than death,’ due to the perceived loss of individual autonomy.	<i>“I’d be tempted to put survival on the top of the list. I sort of, see that as being self explanatory really.” (Man, 60s, pre-dialysis)</i> <i>“Because the reality is there . . . Okay, when I’m on the transplant list, I’ve still got to be on the PD until that (transplant) happens.” (Man, 50s, PD)</i> <i>“And being able to self manage I think enables me to maintain and retain a high degree of control over my life and lifestyle . . . I mean the other end of the scale is going into hospital on a regular basis, so I wouldn’t . . . I’d pull the plug.” (Man, 60s, pre-dialysis)</i>
Convenience of dialysis at home	The convenience of dialysis at home enabled patients to change the duration of their treatments (both shorten and lengthen) and change their scheduled days. In this sense, home dialysis was attractive because of the perceived autonomy. Compared to dialysis in a hospital or satellite centre, home was thought to be quieter, more relaxing and inclusive of family members. Dialysis at home avoided frequent trips to the hospital which meant less commuting, less early morning starts, and less reliance on a friend or family member as a driver.	<i>“The good thing is that you’ve got the freedom to do what you want, like you can do longer hours, shorter hours or, you know, swap your days around, things like that. That’s the most important thing. That’s the good part of it and like, doing it in the satellite centre, you don’t have that freedom, you know, you’re restricted. But at home it’s a lot easier. (Man, 60s, home HD)</i> <i>“But I prefer dialysis at home. . . because I can manage, and not have anyone to take me back and forward. It would be difficult because both of my children are working. . . and I wouldn’t have the time to or be able to be back and forward for all the time. Very, very hard and I get very tired.” (Woman, 80s, pre-dialysis)</i>
Dialysis-free days	Nocturnal home HD and nocturnal PD (on a cyclor) were perceived to provide every day free of dialysis. Likewise, conventional HD provided four dialysis-free days per week. Pre-dialysis patients perceived the benefit of dialysis-free days as the ability to have a normal routine, to work and to be socially active.	<i>“Yeah, I’m considering peritoneal dialysis because it interferes with your life less. You can do it at night. And it doesn’t interfere with your day. . . If you do it overnight, all your days are free.” (Woman, 50s, pre-dialysis)</i> <i>“And have my day free to do what I like to do. . . I’ll go out or stay home and do what I like to do, cook or do my own thing.” (Woman, 80s, pre-dialysis)</i>
Respite	Caregivers felt respite would make home dialysis a more manageable and attractive option for the long term.	<i>“So I think a carer must have some (respite) because otherwise they’re just going to slowly buckle under the load.” (Man, 80s, caregiver)</i>
Ability to travel	Many overseas-born patients and their caregivers chose a dialysis modality that would allow them to travel ‘home’ to visit their family. PD was chosen for easy access to relatives in Asia, the Pacific Islands and the northern states of Australia. Caregivers of patients on home haemodialysis talked about the need for private health insurance in order to access holiday dialysis ‘spots’ in satellite facilities. Caregivers felt very restricted in both the length of time they could go away and also the locations they could travel to with the patient.	<i>“My mother um, she got all her friends in Hong Kong, because she wants to travel. (The doctor) said that peritoneal is the best, because it’s the best one, and she can have the fluids dropped off anywhere she wants.” (Woman, 60s, caregiver)</i> <i>“Yeah, home haemo isn’t (portable) . . . There’s one house in the state that I know of, that’s the only place you can go (laughs). And I’ve been going there since 1985, since my husband got sick” (Woman, 50s, caregiver)</i>

decisions about dialysis care. The dataset included mortality, uraemic symptoms, hospital days per year, the inconvenience associated with long dialysis treatment duration, presence of hypotension during dialysis and presence of other symptoms during dialysis. No consideration was given to broader patient-important characteristics of dialysis such as independence, a flexible treatment schedule, the ability to work or socialize or the ability to travel.

Our study also identified many characteristics important to caregivers that were different to those important to patients. This finding not only confirms previous results of differences in spousal caregiver preferences for continuation or withdrawal of dialysis treatment [14] but also reflects the specific roles and responsibilities of caregivers. Informal caregivers play a vital role in facilitating the self-management of chronically ill patients; however, adequate support for this role is still lacking.

This study highlights the important characteristics of dialysis to patients and family caregivers in treatment decision making. These characteristics could inform specific pre-dialysis patient education modules for new patients and their caregivers and potentially assess patients for suitability to home dialysis modalities. Knowledge of these characteristics could also inform policy and planning for dialysis services to support patients and their caregivers at home. The characteristics of dialysis that are important to patients and caregivers could also be used to inform the design of a patient decision aid or a discrete choice experiment to elicit preferences for treatment.

Patients and family caregivers highly value treatment that enhances survival and can be performed at home. Future planning of dialysis services could better reflect these priorities through provision of increased home dialysis support services and planned respite for caregivers.



<sup>a</sup>QOL = quality of life

**Fig. 4.** Differences in characteristics discussed by pre-dialysis patients and current dialysis patients.

**Table 5.** Themes around important considerations for pre-dialysis patients: description and participant quotations

Themes	Description	Participant quotations
Privacy	Some patients described their CKD as visible only to themselves and were conscious when they started dialysis treatment their illness would become more visible to work colleagues, friends and family. There was a reluctance to disclose the disease and impending dialysis to other family members in order to shield them from the full effects of the prognosis. Interestingly, the desire for privacy was also the rationale for choosing HD in a satellite centre, which could be kept out of sight of family members. PD was favoured by some because the catheter could be hidden away inside clothing, and dialysis could be done in the privacy of their bedroom overnight.	<i>(Discussion between two pre-dialysis patients)</i> “How is your family handling it all? How do they, how do they ah . . . How are they reacting?(Man, 70s, pre-dialysis) “Well they haven’t had the, the impact of . . . I keep telling them that, oh my kidneys, nothing, nothing really bad, so . . . ”(Man, 40s, pre-dialysis) “You’re not telling them too much?” (Man, 70s, pre-dialysis) “No.” (Man, 40s, pre-dialysis) “With PD . . . You can still go to the beach, and no-one would know” (Woman 50s, pre-dialysis)
Staff or family support	Some patients without family support discussed a preference for dialysis in a hospital with nursing staff present rather than dialysis on their own at home. In particular, patients with comorbid conditions that were complex to manage were more likely to request HD in a satellite centre.	“To choose this particular dialysis, I want to be in the hands of medical people here in satellite . . . but because I have a fear that I might develop problem which is connected to diabetes . . . any of the other dialysis would have been okay if I had a wife or someone who lives in the house with me, I would be fine.”(Man, 70s, pre-dialysis)
Perceived quality of life	Pre-dialysis patients articulated the benefit of dialysis was to keep themselves alive—but with an acceptable quality of life. Patients wanted to have the freedom to do the things that were important to them, such as work or social activities. For some patients, the prospect of being hooked up to a haemodialysis machine was thought of as equal to death.	“Um, the whole thing comes down to lifestyle really, but . . . being able to, ah, to do, to ah, to ah have fairly normal physical activities is pretty important to me. I don’t wish to be . . . I just want to remain as active as possible.” (Man, 50s, pre-dialysis) “To be honest, it (hospital haemodialysis) looked like a room full of people who were all about to die.” (Woman, 50s, pre-dialysis)
Side effects of treatment	Commonly discussed side effects included abdominal distention associated with PD and a stiff and sore fistula arm with HD. Some individuals were acutely aware of peritonitis as a potential complication of PD and were concerned about commencing this treatment due to a real or perceived inability to maintain the necessary hygiene. Others were concerned about ‘blood stream infections’ from a temporary vascular access catheter.	“The fistula is the one that you have in your hand you see? And it makes your hand stiff and uncomfortable.” (Woman 80’s, pre-dialysis) “I’m just inclined to think it’s probably a lower infection rate for haemodialysis, which means at swimming and stuff like that it’s probably better” (Man 60s, pre-dialysis)



## Supplementary data

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

**Acknowledgements.** The authors gratefully acknowledge the participation of nominal group participants. We also thank Jacqui Moustakas, Samantha Sherwood, Kim Grimley, Liz Haberecht and Mohamed Zuhair from the Sydney South West Area Health Service for their assistance with recruitment.

**Funding.** R.L.M is supported through National Health and Medical Research Council grants #457281 and #571372.

**Conflict of interest statement.** None declared.

## References

- Baboolal K, McEwan P, Sondhi S *et al.* The cost of renal dialysis in a UK setting—a multicentre study. *Nephrol Dial Transplant* 2008; 23: 1982–1989
- Korevaar JC, Feith Gw, Dekker FW *et al.* Effect of starting with hemodialysis compared with peritoneal dialysis in patients new on dialysis treatment: a randomized controlled trial. *Kidney Int* 2003; 64: 2222–2228
- Vale L, Cody J, Wallace S *et al.* Continuous ambulatory peritoneal dialysis (CAPD) versus hospital or home haemodialysis for end-stage renal disease in adults. *Cochrane Database Syst Rev* 2004;(4):CD003963
- Covic A, Bammens B, Lobbedez T *et al.* Educating end-stage renal disease patients on dialysis modality selection: clinical advice from the European Renal Best Practice (ERBP) Advisory Board. *Nephrol Dial Transplant* 2010; 25: 1757–1759
- Couchoud C, Savoye E, Frimat L *et al.* Variability in case mix and peritoneal dialysis selection in fifty-nine French districts. *Perit Dial Int* 2008; 28: 509–517
- Jassal SV, Krishna G, Mallick NP *et al.* Attitudes of British Isles nephrologists towards dialysis modality selection: a questionnaire study. *Nephrol Dial Transplant* 2002; 17: 474–477
- Lee A, Gudex C, Povlsen JV *et al.* Patients' views regarding choice of dialysis modality. *Nephrol Dial Transplant* 2008; 23: 3953–3959
- Wuerth DB, Finkelstein SH, Schwetz O *et al.* Patients' descriptions of specific factors leading to modality selection of chronic peritoneal dialysis or hemodialysis. *Perit Dial Int* 2002; 22: 184–190
- Morton RL, Tong A, Howard K *et al.* The views of patients and carers in treatment decision making for chronic kidney disease: a systematic review and thematic synthesis of qualitative studies. *Br Med J* 2010; 340 c112
- Morton RL, Devitt J, Anderson K *et al.* Patient views about treatment of stage 5 CKD: a qualitative analysis of semistructured interviews. *Am J Kidney Dis* 2010; 55: 431–440
- Oliver MJ, Garg AX, Blake PG *et al.* Impact of contraindications, barriers to self-care and support on incident peritoneal dialysis utilization. *Nephrol Dial Transplant* 2010; 25: 2737–2744
- Jager KJ, Korevaar JC, Dekker FW *et al.* The effect of contraindications and patient preference on dialysis modality selection in ESRD patients in The Netherlands. *Am J Kidney Dis* 2004; 43: 891–899
- National Kidney Foundation. Kidney Disease Outcomes Quality Initiative (K-DOQI). *Clinical Practice Guidelines for Hemodialysis Adequacy. Guideline 1. Initiation of Dialysis. 1.1 Preparation for Kidney Failure.* New York: National Kidney Foundation, Inc, 2006
- Pruchno RA, Lemay EP Jr, Feild L *et al.* Spouse as health care proxy for dialysis patients: whose preferences matter? *Gerontologist* 2005; 45: 812–819
- Stack AG, Martin DR. Association of patient autonomy with increased transplantation and survival among new dialysis patients in the United States. *Am J Kidney Dis* 2005; 45: 730–742
- Szabo E, Moody H, Hamilton T *et al.* Choice of treatment improves quality of life. A study on patients undergoing dialysis. *Arch Intern Med* 1997; 157: 1352–1356
- Bergman MM. *Advances in Mixed Methods Research.* Thousand Oaks, CA: Sage, 2008
- Delbecq AL, Gustafson DH, Van de Ven AH. *Group Techniques for Program Planning: A Guide to Nominal Group and Delphi Processes.* Glenview, IL: Scott, Foresman, 1975
- Sanderson T, Morris M, Calnan M *et al.* Patient perspective of measuring treatment efficacy: the rheumatoid arthritis patient priorities for pharmacologic interventions outcomes. *Arthritis Care Res* 2010; 62: 647–656
- Corner J, Wright J, Hopkinson J *et al.* The research priorities of patients attending UK cancer treatment centres: findings from a modified nominal group study. *Br J Cancer* 2007; 96: 875–881
- Tuffrey-Wijne I, Bernal J, Butler G *et al.* Using Nominal Group Technique to investigate the views of people with intellectual disabilities on end-of-life care provision. *J Adv Nurs* 2007; 58: 80–89
- Aspinal F, Hughes R, Duncleley M *et al.* What is important to measure in the last months and weeks of life?: A modified nominal group study. *Int J Nurs Stud* 2006; 43: 393–403
- Teddlie C, Tashakkori A. *Foundations of Mixed Methods Research: Integrating Quantitative and Qualitative Approaches in the Social and Behavioral Sciences.* Thousand Oaks, CA: Sage, 2009
- Leask J, Hawe P, Chapman S. Focus group composition: a comparison between natural and constructed groups. *Aust N Z J Public Health* 2001; 25: 152–154
- Kitzinger J. Qualitative Research: Introducing focus groups. *BMJ* 1995; 311: 299–302
- Boyatzis RE. *Transforming Qualitative Information: Thematic Analysis and Code Development.* Thousand Oaks, CA: Sage Publications Inc, 1998
- Barnett-Page E, Thomas J. Methods for the synthesis of qualitative research: a critical review. *BMC Med Res Methodol* 2009; 9: 59
- Kerr P, Polkinghorne KR, McDonald SP. Home hemodialysis in Australia: current perspective. *Hemodial Int* 2008; 12: S6–S10
- Weinhandl ED, Foley RN, Gilbertson DT *et al.* Propensity-matched mortality comparison of incident hemodialysis and peritoneal dialysis patients. *J Am Soc Nephrol* 2010; 21: 499–506
- McDonald SP, Marshall MR, Johnson DW *et al.* Relationship between dialysis modality and mortality. *J Am Soc Nephrol* 2009; 20: 155–163
- Pauly RP, Gill JS, Rose CL *et al.* Survival among nocturnal home haemodialysis patients compared to kidney transplant recipients. *Nephrol Dial Transplant* 2009; 24: 2915–2919
- U.S. Renal Data System. *USRDS 2008 Annual Data Report: Atlas of Chronic Kidney Disease and End-Stage Renal Disease in the United States.* Bethesda, MD: Chapter 12 International comparisons. 2008
- Marron B, Martinez Ocana JC, Salgueira 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–S59
- McLaughlin K, Jones H, VanderStraeten C *et al.* Why do patients choose self-care dialysis? *Nephrol Dial Transplant* 2008; 23: 3972–3976
- Hornberger JC, Habraken H, Bloch DA. Minimum data needed on patient preferences for accurate, efficient medical decision making. *Med Care* 1995; 33: 297–310

Received for publication: 14.1.11; Accepted in revised form: 11.3.11