Choosing dialysis modality: decision making in a chronic illness context

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Abstract

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Background Patients with chronic kidney disease (CKD) are encouraged to make an informed decision about dialysis. Survival rates for dialysis are equivalent yet there is wide variation in peritoneal dialysis uptake in the adult UK population. It is unclear how much is attributable to variations in patients' preferences. Kidney function usually declines over months and years; few studies have addressed how a chronic illness context affects choice. This study describes patients' decision making about dialysis and understands how the experience of CKD is associated with treatment choice.

Method Survey employing interview methods explored 20 patients' views and experiences of making their dialysis choice. Data were analysed using thematic framework analysis to provide descriptive accounts of how patients experienced their illness and made treatment decisions.

Results Patients talked about challenges of living with CKD. Patients were provided with lots of information about treatment options in different formats. Patients did not distinguish between different types of dialysis and/or have an in-depth knowledge about options. Patients did not talk about dialysis options as a choice but rather as a treatment they were going to have.

Conclusion Most patients perceived their choice as between 'dialysis' and 'no dialysis'. They did not perceive themselves to be making an active choice. Possibly, patients feel they do not need to engage with the decision until symptomatic. Despite lots of patient information, there were more opportunities to encounter positive information about haemodialysis. A more proactive approach is required to enable patients to engage fully with the dialysis treatment options.

Introduction

Patients with chronic kidney disease (CKD) are encouraged to make an informed decision about

the type of life-sustaining dialysis treatment they wish to choose.¹ Pre-dialysis education should allow the patient to evaluate comprehensive, accurate information about the treatment

options and their consequences, evaluate this information with their own beliefs and values and make a 'trade-off' between these factors to reach an informed decision.^{2,3} There are two main types of dialysis: haemodialysis, which is conducted at home or in hospital and peritoneal dialysis, which takes place overnight at the patient's home [continuous cycling peritoneal dialysis (CCPD)] or is undertaken 4–5 times a day at home or in a convenient place, for example, at work [continuous ambulatory peritoneal dialysis (CAPD)]. Survival rates for dialysis modality are equivocal^{4–6}; choosing dialysis is therefore a 'preference-sensitive' decision,^{7,8} that is, the treatment decision tends to be based on the integration of patient's personal values and preferences, rather than being one which is the clinically correct choice.^{9–12} Each dialysis modality is delivered in different ways, and the demands of each treatment option vary considerably (see Table 1). All are intensive, invasive, physically debilitating and may impact on employment status, physical appearance, social activities and income.^{13–17} Dialysis therefore impacts on patients' lives considerably. Clinical depression is estimated to be between 12 and 45%,¹⁸ and End Stage Renal Failure (ESRF) is commonly associated with feelings of anger and hopelessness.^{19,20} Few studies have examined how patients make their treatment decisions (for reviews, see Ref. 21,22); however, what seems to be a consistent number of factors have been identified as being key to patients' choices. These include freedom to maintain current lifestyle^{10,12,23–29}; learning the opinion of others, for example, family/doctor/other patients^{12,30–36}; a need for control^{10,29,32,35,37,38}; perceived risks and consequences of dialysis^{32,36,39} and treatment-specific factors, for example, being scared of needles.⁴⁰

Despite the equivalence of dialysis treatments, uptake of peritoneal dialysis in the adult UK population is known to vary by service in terms of the quality of the resources, timing of information provision and commencement of treatment.^{21,41} It is unclear how patients make sense of these variations and how they might influence their choices.

There is little empirical research explaining decision making about dialysis from the patient's perspective. No studies have been carried out with reference to theories of how patients make choices.²² This has meant there has been little insight into the underlying processes that might explain how patients made their treatment decisions.⁴² Further, few studies have addressed how making decisions in a chronic illness context might influence treatment choice.^{10,32,43} This is despite the fact that kidney function usually declines over a period of months or years, and patients may experience peaks and troughs in their declining health. Patients therefore negotiate their treatment decision as they experience symptoms of their condition and deliberate their decision for an indefinite period of time.⁴⁴ The aim of this paper is to understand how patients with kidney failure make their dialysis treatment decision. The study objectives are:

1. To understand how the experience of CKD is associated with their treatment choice.
2. To describe how patients make their decision about dialysis.
3. To evaluate the appropriate point at which to introduce a dialysis decision aid.
4. To identify whether patients make an informed decision.

Method

Design

This study is a survey design employing qualitative methods.⁴⁵ Semi-structured in-depth interviews were employed, and patients with CKD were interviewed at different stages of their treatment decision making. The interviews were recorded using a tape recorder and audio cassette and transcribed verbatim. Data were managed using the Qualitative Software for Research (QSR) NVivo (version 7) computer program (interview schedule – see Appendix 1). Ethical approval for the research was awarded by Harrogate Ethics Committee (February, 2006).

Table 1 A decision table for the dialysis options

	CHD Haemodialysis at a specialist centre	HHD Haemodialysis at home	CAPD Continuous ambulatory peritoneal dialysis	APD Automated peritoneal dialysis (also known as continuous cycling – CCPD)
Location	At a hospital or specialist satellite unit	At home	Up to the patient. Most patients choose home or work but it can be any clean place Every day	Up to the patient. Most patients choose home but it can be any clean place Every day
Usual number of sessions a week	3 days in a week	At least 3 days a week		
Usual number of sessions per day	1 session per day	1 session per day	5 sessions per day	1 session per day
Usual length of sessions	4 h per session	About 4 h per session	About 30 min per session	About 9 h per session
How dialysis works	Automatically by a machine	Automatically by a machine	Manually by the patient – the patient drains out the used fluid and puts in a fresh supply	Automatically by a machine – the machine pumps fluid around continuously whilst the patient is asleep
Who carries out the dialysis	Staff at the hospital or haemodialysis centre unit. In some centres, patients may be trained to self-manage aspects of the dialysis session	The patient is trained to carry out HHD. In most cases, a carer (e.g. friend or nurse) is trained to help carry out HHD	The patient is trained to carry out CAPD	The patient is trained to carry out APD. In some cases, a carer (e.g. friend or nurse) is trained to help carry out APD
Equipment needed	A machine outside the body. In centres, the machines are set up next to patient beds or reclining chairs all the time	A machine outside the body and dialysate fluid. At home, the machine and supplies can be stored where convenient	Bags to take away the used dialysate and bags filled with the clean dialysate fluid At home, the bags of dialysate can be stored where convenient	A machine outside the body and dialysate fluid. At home, the machine and supplies can be stored anywhere

CCPD, continuous cycling peritoneal dialysis.

Sample

Patients attending a low clearance outpatient clinic at a large teaching hospital in the north of England were recruited between April and August, 2006. A stratified purposeful sampling technique was employed to recruit patients at different stages of decision making. This involves selecting patients based on a specific sub-sample of the population, in this case, time since referral to the 'low clearance clinic', a clinic wherein patients with advanced CKD were informed by their doctor and the nursing staff of the need for dialysis and are informed and prepared for the treatments.⁴⁶ Patients were recruited into one of four groups: newly referred patients who had received little or no treatment information (group 1); those who were deliberating their decision (group 2); those who had made their treatment decision (group 3) and patients interviewed at several time points (group 4). Understanding the process by which individuals make decision provides a measure of the quality of an informed decision.^{47–50} There is no formal analysis to estimate sample size in qualitative methods. As a guide, for this study, we estimated that five patients per group would be a reasonable sample size to generate data for these research questions. However, recruitment was discontinued when saturation was reached, that is, the author judged that no more new themes were being generated from the data.⁵¹

Inclusion and exclusion criteria

Patients were eligible for inclusion in the study if they were over the age of 18, were diagnosed with advanced renal failure, that is, had a glomerular filtration rate of <15 ,⁵² and had not previously received any form of renal replacement therapy. Eligibility for inclusion in the study was determined by referring to their medical notes and conferring with clinic staff. Patients were selected regardless of race or ethnicity, gender, religion or sexual orientation. Patients were excluded from the study if they were not cognitively capable of taking part in

an interview, for example, after speaking to the patients, the interviewer felt they were not capable of taking informed consent; were limited in their choice of dialysis owing to a pre-existing medical condition, for example, severe abdominal scarring; had chosen pre-emptive transplant, for example, were opting for a kidney transplant before commencing dialysis or had chosen conservative management, that is, palliative care.

Materials

The following materials were developed for the study and piloted with staff and authors: study information, consent forms, an interview schedule and a coding frame. The interview schedule was developed by the author to address the research questions. A renal consultant and two specialist renal nurses assessed the interview schedule and provided feedback prior to the interviews commencing. The first interview was transcribed and discussed with a co-author (HB) to reflect on the interview schedule with the aim of improvement in subsequent interviews. Minor alterations were made to the interview schedule, to include additional prompts, and data from the pilot interview were included in the analysis. Patients were asked a series of open-ended questions designed to allow the patient to provide full answers. The wording of interview questions was modified slightly to ensure they were appropriate for each of the groups. The first author carried out the interviews and used probes and prompts to encourage patients to respond to the questions as fully as possible.⁵³ Patients were asked to provide background information about their illness, their previous knowledge of ESRF and the emotional impact of the illness. Subsequent questions addressed the process with which individuals had made their decision – their thoughts about the different treatment options and the type of information they had been provided with, their preference for information and their preference for involvement in the decision-making process.

Procedure

Patients received a letter prior to their attendance at the low clearance clinic at a large teaching hospital in the north of England, to invite them to take part in the study. Patients' medical notes were inspected during the clinic under the guidance of the nursing staff, to further ensure the suitability of the patient for the study. Patients were approached in the waiting room of the low clearance clinic by the first author and were asked if they were willing to take part in an interview. The patients had the opportunity to re-read study information and ask questions; written consent was taken if they agreed to participate. Interviews were arranged at the patients' convenience; patients were interviewed in the clinic ($n = 6$) or in their home ($n = 14$).

Analysis

Data were classified using a thematic framework analysis.^{52,54} This involved the development of themes derived from the data to provide descriptive accounts of how patients experienced their illness and made treatment decisions. To ensure consistent and reliable themes were being generated from the data, the allocation of themes to the text was discussed and changed appropriately over a series of meetings with a researcher who had knowledge of renal failure and theories of decision making. The data were summarized using narratives and examples from the transcripts. Frequency counts were used to look for patterns of responses across sampling groups. Although these data cannot be meaningfully used in a quantitative way, they provide a different way to illustrate qualitative data, for example, an issue that was common or varied by sample group. All data were integrated to identify a range of views and experiences. Quotes are used to illustrate the range of experiences of patients.

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Results

A total of 18 adult patients who had not received any form of treatment previously and two patients who had previously received dialysis and kidney transplantation were recruited. This latter information was not mentioned in the patient's recent medical history and was only discovered at interview. Despite not meeting the inclusion criteria, these patients were included in the analysis as they reflected those seen in the pre-dialysis clinic, and ethical approval permitted recruitment of all those who attended the clinic.

All patients recruited were included as their experiences illustrated both new and experienced dialysis users are educated in the same manner, regardless of prior firsthand experience of dialysis. All patients were either in the process of making a dialysis treatment decision or had recently made their decision. Most patients had one interview; two patients agreed to be interviewed at different time points in their decision making. One of them died before making his choice. Thirteen were male, with a median age of 57.5 years, which is in line with the national median age for renal patients of 61.4 years⁴¹; mean, 56.9 years; SD = 14.73; $n = 18$; see Table 2).

There were no differences in the pattern of responses by sample group. This similarity in patterns suggests patients with advanced renal failure are responding to their illness in similar ways, using processes generic to individual's decision making, understanding, coping and adjustment, rather than stage of illness, 'artificial' service factors or longevity in clinic.

The following themes were identified: (i) labelling the illness, (ii) seeking medical help and receiving a diagnosis; (iii) symptoms of renal failure; (iv) perception of the cause of ill-

Table 2 Patient characteristics (*n* = 20)

Demographics	<i>n</i>
Age	
Younger than 40	2
40–49	0
50–59	9
60–69	1
70 or older	5
Missing data	2
Race	
White	18
Asian	2
Time since referral	
>6 months	8
6–12 months	2
<12 months	5
Missing data	5

ness; (v) ESRF as a chronic condition; (vi) utility of service information, (vii) usefulness of meeting dialysis patients; (viii) reasons for choosing haemodialysis; (ix) reasons for choosing peritoneal dialysis; (x) trading off between peritoneal dialysis treatment options; (xi) perceived role in choosing dialysis; (xii) perceived difficulties in choosing dialysis and (xiii) reaching a decision. These themes are reported in depth elsewhere⁵⁵ and summarized in this manuscript under three broad headings:

1. Patients' experience of living with CKD.
2. The role of information in dialysis decisions.
3. Patients' decision making about dialysis.

Patients' experience of living with ESRF

Patients had a range of experiences of ill health leading up to their diagnosis of kidney disease. For some, there was an identifiable, kidney-related cause, such as autosomal dominant polycystic kidney disease. However, for most, they were completely unaware that their kidneys were failing prior to diagnosis. When kidney failure resulted from a co-morbid condition, which led to the chronic deterioration of their kidney function, some patients referred to this long-standing condition when talking about their renal failure, for example,

polycystic kidney disease. However, most referred to a general term such as 'kidney failure' or 'kidney trouble' (*n* = 9).

I didn't even know I had a problem with my kidney to be honest with you until I came to hospital. [Interview 1; group 3]

...they came back and said 'your kidney's don't seem to be working right', so I says, 'aren't they?' [Interview 9; group 1]

Most commented that their kidney failure or kidney trouble was identified through a series of routine tests carried out by their general practitioner, often as a result of an acute bout of ill health, which led them to seek medical help.

...my head was just pounding... about an hour later I just vomited...in the sink and that was it...so I made an appointment with my GP. [Interview 3; group 2]

I felt a bit unwell and the wife says 'go to the doctors and get checked over', so I did, and...she says [the doctor], 'no, I'm not happy about this, so my brother-in-law drove us down to the hospital with an overnight bag. [Interview 3; group 2]

Central to patient's experience of CKD was the lack of specific 'kidney symptoms'. Most patients explained they had no symptoms since diagnosis. If they reported any symptom, it was being tired.

Yes, well obviously you get tired quite quick. [Interview 18; group 1]

Yes, I could be a lot better...I get tired constantly. [Interview 4; group 3].

Other symptoms were itching, swollen ankles, sleep disturbance and nausea. However, patients were unsure whether to attribute the symptoms to CKD or to normal bodily sensations.

...occasionally I get itching but that's about it. I do get cold but I don't feel bad with it. [Interview 11; group 3]

It doesn't really impact on my life... I get a bit tired and...half the time I don't know if it is due

to my medical condition or because it is because I do a lot of work. [Interview 14; group 3]

Patients held a variety of beliefs about why their kidneys had failed. For some, a clear hereditary cause was identifiable.

...my mother had it and my brother had it... because it is polycystic kidney disease. [Interview 9; group 1]

For others, the cause was more uncertain, with patients attributing their kidney disease to a number of different sources: medication, alcohol etc.

I've been taking a cocktail of tablets for 20 years erm, we know that there are side effects with tablets, so possibly that's what's caused it. [Interview 20; group 2]

I drank a lot...but I don't know about the medical side, neither my father or my mother had any problems to the best of my knowledge. [Interview 1; group 3].

Some patients did not know the cause of their CKD or it could not be identified.

Never really knew for definite why, you know, they didn't say, 'it's because you have done this'. [Interview 4; group 3]

For most patients, adjusting to kidney disease, especially one that was asymptomatic, took time.

...because at that stage I found it hard to accept. Because I thought it's not going to happen to me...it sort of took a while [to come to terms with]. [Interview 16; group 3]

I couldn't feel anything wrong with my kidneys... I just don't feel any different to how I did ten years ago. [Interview 15; group 3]

The impact on people's lives varied from monitoring the condition to moving home.

Because I've put my house up for sale, erm, because otherwise I'm not going to be able to afford to pay the mortgage or anything. I've had to make that decision. [Interview 10; group 4 (2)]

Some spoke about their experiences of having to think about dialysis choices in relation

to kidney disease, whilst being monitored and/or in an emergency,

For me it was [appropriate to discuss dialysis choices]...because to be quite honest, I knew I was poorly, but I didn't realise how poorly I was. [Interview 10; group 4 (2)]

[For the] last 18 months, 2 years, I have been going to Dr A and I have kept going and they have looked after me until they decided to do a fistula... [Interview 14; group 3]

Patients described how the illness affected their lives and how they anticipated treatment would do so, including moving home, changing jobs and holidays.

The role of information in dialysis decisions

It is clear that patients with kidney disease are exposed to a lot of information in a variety of forms: consultations with nephrologists, workshops with multidisciplinary renal staff, written and video-taped information and one-on-one visits with pre-dialysis nurses, and other patients. Patients talked about the information they received as a tool for helping them understand their illness and prepare them for dialysis rather than as an aid to their decision making.

For me it was [appropriate]...because to be quite honest, I knew I was poorly, but I didn't realise how poorly I was. [Interview 10; group 4 (2)]

I didn't realise how much it impacts, statistically, and on life expectancy. [Interview 13; group 3]

Patients talked about other patient's experiences as a source of information about specific dialysis options. Some knew an acquaintance on HD/PD, and some attended the service workshop to meet a patient.

...so I knew somebody else who was on dialysis and they went to India... and I said 'oh that seems okay, so I can have it'. [Interview 14; group 3]

Now I knew a lot of stuff because my son's girlfriend... she had three kidney transplants and she was on dialysis machine for 18 years of her life. [Interview 17; group 2]

The information patients found useful from the workshops related to the skills of carrying out dialysis and their ability to integrate dialysis into a normal life; most but not all of the patients in the study attended the workshop. Patients asked other patients about a number of different topics such as travelling abroad, hygiene regimens, dietary restrictions, benefits advice, planning the timing of the treatment, pain caused by the treatment and physical benefits of being on haemodialysis. Patients reported positively about these workshops.

...being taken through each stage and then actually talking to people that are actually had the treatment...I think that were absolutely marvellous. [Interview 20; group 2]

...it were a full day, you know what I mean?...I thought it were a very good presentation, you know, we got a sandwich and we had a cup of tea and then we come back. [Interview 8; group 3]

However, their appraisal of information seemed influenced by whether or not they liked the other patient presenting the information.

Oh there was a lad who came in a young chap, he was very repetitive...well, I, I didn't, erm, I don't know I didn't like the look of the chap. [Interview 15; group 3]

and I spoke to him and he was a former business man and [it was] very useful and he said 'if you do it, this is the way forward' and I agreed. [Interview 15; group 3]

Most commonly, first-hand experience of dialysis was seeing a patient receive haemodialysis when they visited a renal ward during the workshop.

...I mean we've all seen the patient receiving dialysis in hospital attached to this machine having their blood cleaned. [Interview 20; group 2]

Patients' decision making about dialysis

A key theme that emerged from the data was that patients perceive the 'difficult' dialysis decision to be a choice between having and not

having dialysis. Patients in this study described the choice about which dialysis option to have as being an easy decision, more in keeping with managing their kidney disease and prolonging life than making a treatment choice.

Well I suppose it's an easy decision to make because it's a decision you have to make, you know I haven't got a choice in the matter. I can't say, 'Oh I don't fancy dialysis'. [Interview 20; group 2]

Oh easy decision, I mean it has got to be done one way or the other. [Interview 5; group 3]

Patients recognised that the dialysis decision was theirs to make and they took responsibility for making it.

I haven't been told that is it you are having that, I have been given a choice and I have made my choice. [Interview 14; group 3]

Then I suddenly realised that it is only me that can make that decision, I have got to do it myself. [Interview 6; group 3]

The choice between dialysis options was seen as one between HD and PD; no differentiation was made between the different types of HD and PD.

Well I think personally myself having to do it myself at home I don't think I'd be right good at it [PD]...I'd be in the hospital [with HD] and if anything went wrong there would be somebody there who knew what to do. [Interview 11; group 3]

Patients evaluated the attributes of both options positively and negatively. Overall, more negative evaluations were generated for PD than HD (Table 3).

The key attributes of the PD and HD options were work, travel, location of treatment, support by staff, dietary changes, operation and appearance. Some of these evaluations were simple 'like/don't like' statements:

The main thing about haemo. is sticking those needles in. I don't like needles. [Interview 4; group 3]

The most common type of reasoning used to talk about the advantages or disadvantages

Table 3 Frequency of comments about each dialysis option

	Haemodialysis N (%)	Peritoneal dialysis N (%)
Positive comments	24	22
Negative comments	25	34
Total	49 (47)	56 (53)

of dialysis were as follows; for HD, the advantages were having days when the patient was not required to dialyse, support from the hospital staff and not having to have a general anaesthetic to create the arteriofistula.

I mean if you're coming for that you're coming three times in the week which leaves you four days clear. I have other things to go to...meetings to go to and what have you.... [Interview 7; group 4 (2)]

I think the biggest advantage is you are at the hospital... if things go wrong when you are at home you are sort of on your own. [Interview 12; group 2]

The advantages of PD were not only the perceived flexibility of the treatment regimen, but also fitting the regimen into existing work commitments, a lack of dietary restrictions imposed by the treatment and the perception that having treatment at the hospital would be inconvenient.

Yeah, I can eat everything I like because ...I like number one to eat you know and I cannot give up eat. [*sic*; Interview 13; group 3]

I wouldn't really have a life going to [*name of hospital*] three days per week. [Interview 10; group 4 (1)]

so I thought well peritoneal would be the easiest option where I could get up on a morning, do that first thing, take a bag with me, finish that and then carry on with my job. [Interview 3; group 2]

The disadvantages of HD were a perceived lack of flexibility in the treatment regimen; the potential side effects of receiving the treatment; having a minor operation to create an arterio-

fistula; having a dislike of needles and the visibility of the illness, that is, perceiving the patient and other people would be able to see the fistula.

...three times a week four hours a day that has the potential to be very disruptive. [Interview 2; group 2]

The disadvantage of PD was patients did not like the idea of having a catheter inserted into the abdomen.

And having something in your stomach sticking out you know, I didn't really think it would appeal to me... It is just something cosmetic. [Interview 8; group 3]

Patients also expressed concern about having an operation requiring general anaesthetic, did not know where they would store the boxes of fluid required for the treatment, did not want to be responsible for the treatment regimen and thought they might get an infection at the site of the catheter. Other non-treatment-related concerns included the following: continuing in employment, going on holiday, coping with the treatment regimen or feeling that an unrelated medical problem that would make them unsuitable for the treatment.

It was less common for patients to mention explicitly how they were able to trade off the pros and cons about HD and PD in order to make a choice. One technique used by patients was to imagine the impact of the consequences of their choice on their life, that is, would an attribute of an option enable them to maintain their life as it is now and/or flexibility in their lifestyle. However, it is not clear if all attributes were evaluated in this way and/or patients considered all aspects of their lives when trying to imagine the consequences of treatment within their daily routine.

You have got to do it at dinner time, well I work in a kitchen. So... I don't know how they would work it, I would probably have to go down to somewhere, where it would be a lot cleaner then. [Interview 9; group 1]

Discussion and conclusion

Discussion

This study described how patients with CKD made their dialysis treatment decision. These interviews provided data about how patients experienced their illness, the way patients were making dialysis decisions and whether or not they were making informed treatment decisions. The study found that kidney disease is an unusual disease context. Although a chronic and progressive illness which reduces life expectancy, most patients do not experience symptoms that can be linked obviously with the kidney's failing, for example, tiredness, itchy skin and swollen limbs. Patients were often asymptomatic until late stages of the disease, and although patients in the study were aware they had to make a decision, some expressed they felt few or no symptoms of the illness during their decision making. Dialysis impacts considerably on a patient's quality of life; however, patients expressed negative emotions upon discovering their illness rather than in their description of making their dialysis choice. At interview, patients were largely asymptomatic, were not recently diagnosed and were yet to experience any serious consequences of their illness or of their decision.

Most patients perceived their 'dialysis choice' as being one between 'dialysis' and 'no dialysis'. This contrasts with the views of clinicians who perceive the focus of the dialysis decision to be concerned with choosing *between* dialysis options.¹ Information is a key to helping patients understand their kidney disease and the need to make choices about dialysis. Evidence exists to suggest that patients often feel ill informed about all of the treatment options.^{23,24,28,33,56–58} In this study, patients reported receiving a plethora of information about the dialysis options and did not comment on being ill informed. However, they often had a simplified view of the options, that is, they did not distinguish between the different types of HD (home vs. hospital) or PD (CAPD vs. CCPD). There were a few examples

that patients were evaluating the impact of the options on their life, but they tended to evaluate the pros and cons of one option (e.g. haemodialysis) rather than by trading off the pros and cons between options (e.g. peritoneal dialysis and haemodialysis).

As kidney failure is a chronic condition, patients had time to prepare for treatment by making adaptations to their lives and consider how their lives would change as a result of the treatment in terms of their work commitments or moving home. This also meant that patients were exposed to lots of information over time. At the time of having to make decisions about dialysis options, more information was provided about HD than PD, in more accessible forms, that is, contact with patients already receiving treatment for HD in workshops, on wards and in waiting rooms.^{23,24,31,33–35} It is likely that this contact biases information seeking and the patient's assimilation of information.

Conclusion

It is unlikely that patients made an informed decision about the type of dialysis they wished to choose. This was evidenced in patient's accounts of how they sought information, that is, often through seeking the advice of others. Further, dialysis decision making often occurs over a protracted period of time, whilst this allows patients to prepare for their treatment choice, it also means that patients are exposed to more biased information about dialysis than a decision which is made in an acute context. Techniques exist that help people engage actively with information about treatment options, which enables them to evaluate the advantages and disadvantages of options in accordance with their lifestyle and values. These decision aids help 'de-bias' the information patients encounter and help them to make informed decisions.

Implications for practice

It remains an empirical question as to the optimal point at which to implement a decision aid

intervention in the context of advanced renal failure, where there is a progressive and chronic decline in kidney function, during which time patients must make their decision.

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Conflict of interest

The results presented in this paper have not been published previously in whole or in part, except in abstract format.

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1 Appendix

Interview schedule

1. Can you tell me about the history of your kidney problem?

Prompts: how did you first find out that you were ill? How old were you? What were your symptoms? What did you think it was? What action did you take/who did you talk to? When did you first find out that you had a problem

with your kidneys? Who told you? Had you heard of it before? How did you feel when you were told?

2. Had you heard about your kidney problem before your diagnosis?

Prompts: What do you know about your kidney problem? How did you know that? What do you think caused your kidney problem? Why do you think that?

3. How do you feel about your kidney problem?

Prompts: Do you feel it impacts on your life in any way?

4. Have you had any thoughts about the different types of treatment options? What do you think the good points and bad points are about each type of treatment (HD, CAPD, CAPD)?

Prompts: Do you know what the treatments are? Can you describe what you know about them? How do you know this information? Are any of these points more important to you than others? why?

5. What sources of information have you looked at?

Prompts: Have you received any written information about treatment options? How useful did you find this information? Can you remember the name of the information? How many times have you referred to it? Did it help you make up your mind? Sometimes leaflets are written very well and some aspects are not clear. What was good/bad about the information? How did it help you/friends/family? Repeat questions about DVD/video taped information

6. Have you accessed the internet or searched for information yourself?

Prompts: How useful did you find this information? Can you remember the name of the website/organisation? How many times have you referred to it? Sometimes information on the internet is very clear and sometimes it isn't so clear. What was good/bad about the infor-

mation? How did it help you/friends/family? Did it help you make up your mind?

7. Are there other sources of information that you have used that I have not covered?

8. Have you been invited to attend a workshop?

Prompts: Do you know what the days will involve? Do you think you will attend? Why/why not? Would you like to meet other dialysis patients? Why/why not?

9. When did you receive the information?

10. Would you liked to have received the information earlier or later? Why?

11. Do you think the timing of the information has influenced your decision?

12. When would you like to receive information?

13. Have you talked to other people about their kidney problem (what do they do about it?)

14. If you had NOT talked to others, could you make your decision?

15. Go through each person systematically with the prompts – partner, friends, family, other kidney patients

Prompts: How do you know this person? Can you describe them to me?

What treatment were they receiving? What did you talk about? Did you find this useful? Did it help you reach a decision? Will you be able to talk to them again? Would you like to? Would you like to talk to others who are on treatment?

16. Thinking about the information you have received is there any particular type that you prefer?

Prompts: Any particular format?

17. How do you feel about making the decision?

18. Do you want to make the decision? Do you feel angry, resentful, regretful, anxious?

19. What is your immediate reaction?

20. When you think about making the decision about which treatment to choose, what sort of things do you think about? (spouse, work, social, family, patient information)

Prompts: Is there one area of your life that is so influential in this decision? How useful did

you find this (i.e. talking to family member?) Have you found anything particularly helpful when thinking about the treatments available? Do you think about a particular place or situation or piece of information? Have you found anything unhelpful? Do you think there is any single thing that will help you make a final decision?

21. Is there anything that you can think of (any advice) that may help others make a choice?

22. Do you feel able to make a decision about which treatment you would like to have?

Prompts: Is there anything else you would like to know to help you make your decision? How do you think you will find that out? How do you feel about having to make the decision? Has it been an easy or difficult decision to make? Why? Have you had enough time to make your decision? Why/why not?

23. How much involvement would you like in your choice of treatment? Why?

24. Can you tell me about the care that you have received in this department?

Prompts: Have you been able to say what you would like to the doctors and nurses? Why has this been possible/why not? Do you think they have understood your point of view? Do you think the service could be improved in anyway to help you make a decision?

25. Have you seen the same doctor when you have visited?

Prompts: How do you feel about that? Have you received the same type of information from different people/doctors?

26. Is there anything else that you would like you say?

THANK YOU FOR TAKING PART

Would you like a summary of the report that will be produced at the end of the research?

If you would like to talk to anyone about the issues that have been raised in this interview please do so with a member of the renal team.