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PATIENTS' EXPERIENCE OF TRANSITION ONTO HAEMODIALYSIS: A QUALITATIVE STUDY

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INTRODUCTION

Renal failure is a complex debilitating chronic illness with significant comorbidity, including diabetes, cardiovascular disorder, anaemia, hormonal and electrolyte disorders, affecting substantial and increasing numbers of the population. According to the United Kingdom (UK) Renal Registry Report, 43,901 adults received treatment (renal replacement therapy) for renal failure in the UK at the end of 2006, which represents an increase of 5% per year since 2000. (Ansell *et al.* 2007) Transplantation was the most common treatment (44.9%) closely followed by hospital-based haemodialysis (42.1%), with the remainder receiving home-based treatment. Management of renal failure, despite medical advances, places an extreme psychosocial burden upon patients and their families (Cukor *et al.* 2007a; Gilanders *et al.* 2008). Patients experience reduced quality of life compared to the healthy population, with vitality, physical and social functioning being of particular concern (Klang & Clyne 1997; Cleary & Drennan 2004). Rates of depression and anxiety amongst all patients with end-stage renal failure are between 20% and 30%, rising to over 40% in haemodialysis patients (Cukor *et al.* 2007a; Cukor *et al.* 2008).

Difficulties may be especially likely to occur during the transition onto haemodialysis (Harwood *et al.* 2005). Psychosocial difficulties have been noted at various lifespan transitions (Kralik *et al.* 2005), including adolescence (Seidman *et al.* 2003), menopause (Mishra *et al.* 2003), ageing (Cook *et al.* 1997), migration (Meleis *et al.* 2000) and retirement (Miles 2002) and in several illnesses, for example, lung cancer diagnosis (Krishnasamy 2007) and between childhood and adolescence in renal disease (Icard *et al.* 2008). Health staff may have a significant role in supporting patients at critical points through transition into critical or chronic illness (Meleis *et al.* 2000).

Despite the challenges they face, renal patients generally exhibit considerable resilience. Although rates of psychological morbidity (depression and anxiety) are high (Cukor *et al.* 2007, 2008) it is still only the minority of renal patients who experience such difficulties. It is somewhat surprising therefore that research in renal care has not yet investigated positive aspects of patients' adaptation, investigating their strengths and resilience, rather than their vulnerabilities. Studies examining resilience in other chronic illnesses have identified various factors associated with improved outcomes. Positive beliefs, finding meaning, optimism, psychological control and constructive social support have commonly been proposed as supporting resilience (Taylor & Sherman 2004). In a qualitative study of haemodialysis, patients spoke of the dialysis machine as a lifeline, existential optimism and a sense of autonomy (Hagren *et al.* 2001).

The current study adopts a qualitative positive psychology approach to examine patients' views on what helps during their transition onto haemodialysis. Positive psychology focuses on peoples' strengths and their abilities to adapt and flourish in the face of life's challenges. (Linley & Joseph 2004) The study population was restricted to haemodialysis patients (excluding those beginning other methods of renal replacement therapy) in order to keep the sample homogeneous with respect to the particular transition they experienced. Hospital-based haemodialysis patients experience the particular challenge of attending a specialist unit for treatment, usually three times a week for three to four hours.

Findings of this study may help to inform the recommended increase in the development of psychosocial interventions (British Renal Society Multiprofessional Team 2002), given that

patients' naturally occurring positive adaptations to illness and its management are often amenable to improvement (Haase 2004).

The study was overseen by a collaborative research group comprising a nurse, 2 professional researchers, 2 psychologists, a social worker and 3 patients. Two of the research group were also patients in accordance with the directive from the UK National Health Service (NHS) research governance (Department of Health 2005) that places an obligation on healthcare researchers to involve users in research wherever appropriate.

Patient influence over research may help shift away from a problem-centred approach towards investigation of people's strengths and capabilities (Baxter *et al.* 2001). This approach fits well with current moves towards partnership with patients, as stated in Standard One of the UK National Service Framework for Renal Services: a patient-centred service (Department of Health 2004). In this study, the research group oversaw all aspects of the research process, from the early stages, through face-to-face meetings and e-mail contact. Active patient involvement within the research team helped maintain the focus on patient experience within the context of their everyday lives, and reduced the tendency for the professionals to overemphasise the clinical and treatment aspects of the transition to dialysis. To ensure confidentiality, access to transcripts was not available to haemodialysis patient team members, and participant anonymity was maintained throughout.

METHOD

SETTING

The study was conducted in a medium-sized NHS Renal Unit in UK. Treatment is provided for approximately 600 renal patients (predialysis, CAPD, haemodialysis and post-transplant), of whom about 250 were receiving haemodialysis at the time of the study.

Method

A purposive sampling strategy was used to identify and recruit patients aged over 18 who had started haemodialysis within the previous six months. Selection criteria ensured that the sample reflected the diverse characteristics of the wider haemodialysis patient population with respect to age, gender, marital status, employment status, previous treatment and acute or gradual onset of kidney failure. Potential participants were excluded if they were judged to be too ill to take part, or if they had significant comorbidity such that their predominant treatment was for another illness.

Ten potential participants were identified and given an information sheet and the opportunity to ask further questions. All agreed to participate and written consent was obtained. They were then contacted personally by the interviewers who provided further time for questions, and a mutually convenient time for an interview was selected. NHS Research Ethics Committee approval for the study was granted.

PARTICIPANTS

The sample comprised five males and five females who had been on haemodialysis for between one week and six months. Background characteristics of the sample can be seen in Table 1.

DATA COLLECTION AND ANALYSIS

Practice interviews were undertaken before the actual research interviews. Individual semi-structured interviews were conducted with all participants by two interviewers sharing the

questioning to make the interview informal and conversational. The interviews were supervised by an experienced researcher, who was a member of the research group. As requested by all participants, interviews were carried out during their dialysis, in a side treatment room for privacy. The interviews covered participants' experiences of daily activities, thoughts, feelings, and social life, focussing on what, if anything, had helped them cope across these domains. The participants dictated the order and pace of the interviews, which lasted between 30 and 50 minutes.

All interviews were audio-taped and transcribed verbatim, with the influence of any pre-existing ideas held by the researchers minimised through discussion and reflection between the research team members (Patton 1990; Dey

1993; Denzin & Lincoln 1998; Mason 2002). To ensure rigour, the interpretive content analysis of the text was supported by three researchers reading all the transcripts and developing an initial categorisation with supporting quotations (Denzin & Lincoln 1998). All authors discussed and amended the categories or definitions (Patton 1990; Popay *et al.* 1998; Stiles 1999). Data analysis continued until no further modifications emerged and all relevant text was coded. In line with quality standards for qualitative research (Guba & Lincoln 1989; Mays & Pope 1995; Stiles 1993), the authors attempted to ensure that the analysis was coherent, that it accounted for all relevant data and that it usefully identified implications for clinical practice and research.

RESULTS

Analysis of the data resulted in the emergence of three main categories—'Preparation', 'Cognitive Style' and 'Social Support'—each of which consisted of several sub-categories (see Table 2). Participants who underwent an acute transition provided evidence that did not concur with the findings from those who had had preparation before treatment with respect to two of the cognitive style subcategories identified; 'Positive Reappraisal' and 'Optimism'. Furthermore, within the 'Social Support' category, participants who were older offered evidence that did not support the findings from the younger patients with respect to the 'Emotional Support' subcategory.

PREPARATION

Patients who underwent a gradual transition onto haemodialysis highlighted the benefits of preparation that had begun initially with a home visit from a nurse followed by a visit to the haemodialysis unit for the patient and family.

EDUCATION

Patients emphasised the importance of having questions addressed, with clear and honest explanations about the nature of the illness, its management, treatment and what could go wrong.

'She was very, very good because she came to my house and explained things first of all... I think it's a good idea because it doesn't come as such a shock then' (Ian).

Whilst answers to questions were generally felt to be forthcoming, participants noted that sometimes staff found it difficult to provide answers.

'...once or twice you meet a member of staff who perhaps doesn't feel secure in telling me. There is this, has always been, this sort of reluctance hasn't there, to share with the patient...' (Gina).

Such difficulty amongst some staff to answer questions perhaps led to the observation by some patients that they had to push for information.

'...unless you ask questions and unless you push, you'll get neglected for one reason and the other' (Charles).

Although the opportunity for preparation was not possible for those who underwent an acute transition onto haemodialysis, these patients recognised that a visit to the unit, before starting treatment, would have been useful.

'Make sure people get a look around first. That was one of the things I meant to tell you, and about them not telling you about what can go wrong' (Fiona).

CHOICE

Retaining a sense of personal autonomy and choice over decision making was highlighted as beneficial by all the older participants who underwent a gradual transition.

'Then [the home care nurse] said 'Well you haven't got to go on. We'll make it quite peaceful for you to pass on.' They can tell you, but it's your body. It's up to me to decide what I want to do' (Alice).

COGNITIVE STYLE

Cognitive style is a term used in psychology to describe peoples' preferred approach to explaining events and solving problems (Peterson *et al.* 1988). A range of cognitive styles—positive reappraisal, optimism, realistic expectations, acceptance, social comparisons—were demonstrated by the participants. Whilst all adopted realistic expectations and acceptance, those for whom the transition to haemodialysis was acute, tended not to use positive reappraisal and optimism, perhaps reflecting the lack of preparation that was afforded to this group.

POSITIVE REAPPRAISAL

Participants who underwent a gradual transition onto haemodialysis highlighted several ways in which they positively reappraised their future on haemodialysis, often recognising that they would be dead without haemodialysis.

'So I'm just really, really, lucky, or I could be pushing up the daisies' (Edward).

All participants who underwent a gradual transition onto haemodialysis highlighted the value of hope and an optimistic outlook towards their future:

'I never moan...Life is sweet, isn't it. There's always something to look forward to, if you look for it' (Fiona).

For some, optimism was directed towards resuming daily activities such as walking, gardening and swimming or special family events. Gina, for example, was planning a golden wedding anniversary.

'..we've got a family party one weekend and the friends the next weekend. So I've got a goal you see' (Gina).

Others additionally looked forward to receiving a possible transplant, which may or may not be forthcoming. Interestingly, sometimes, the optimism was on behalf of other patients with whom they spoke rather than for themselves directly.

'I know damn well I'm not going to get a transplant but the younger ones, the lady I talk to, she's hoping that she will be in for a transplant...' (David).

REALISTIC EXPECTATIONS

Whilst optimism following the transition to haemodialysis seems significant, it equally seems important that it is tempered within realistic expectations.

'I'm optimistic that I'm getting back — not the normal sort of life, but somewhere near it' (Bill).

For some, realistic expectations required readjustments due to the restrictions and limitations imposed by haemodialysis.

'I think you've got to be realistic...I've just got to readjust my life and do what I can' (Gina).

ACCEPTANCE

Accepting their situation was evident for all participants, whether the transition was sudden or gradual.

'I was a bit shocked at first but then you've got to put up with these things, haven't you? You've got to live with it....No good saying you won't do this and you won't do that. It's for your own good. You've just got to accept it like that' (Hazel).

Acceptance was not only directed towards the demands imposed during the transition to haemodialysis, but also associated with a growing sense of mortality. This was evident among younger as well as older participants.

'Your life doesn't go on...I'm well aware of my life expectancy but it's things you want to do and it's a fact...All the regrets, you put things into perspective' (Charles).

For some of the younger participants, however, acceptance seemed tempered by an active avoidance of more painful aspects of their situation.

'You kind of put a block to it and you just think "Oh, I'm going to get on with it" and there's all these issues you just don't go there because it's too painful to even disturb' (Charles).

SOCIAL COMPARISONS

All participants highlighted the benefit of knowing other haemodialysis patients, enabling them to make comparisons with their own situation. Some participants felt reassured by making comparisons with patients seen as coping effectively with the demands of haemodialysis.

'You only had to look at [patient], fit as a fiddle. I said, 'Well that's it for me. If it does it for him, it will do it for me' (David).

Participants were appreciative of their own state when comparing themselves with fellow patients who seemed to be in a worse situation.

'A lot of them are in a worse state than I am in, so I've got to be thankful for that too...it does help because you feel sorry for them' (Bill).

SOCIAL SUPPORT

The importance of support from a range of other people—neighbours, friends and family, staff and other patients—was highlighted by all. Instrumental support (practical help) was identified as being particularly important. Emotional support was also identified as important, especially by younger participants.

INSTRUMENTAL SUPPORT

Receiving practical help was highlighted by all participants as being particularly helpful.

'My next door neighbour, she's very good...if ever I want any help or anything, I've only got to pick up the phone' (Alice).

Surprisingly, neighbours were mentioned more often than family as a source of practical support. This arises possibly as a consequence of reluctance by patients to rely on family members, in case they become a burden.

'I don't want to start leaning on [daughter]...I don't find it easy, to be honest...I don't want to make her life a misery' (Fiona).

A fear of becoming a burden was also expressed by several participants with respect to neighbours, but this time largely with respect to talking about emotional problems rather than potentially seeking practical support.

'I don't say a lot [to neighbour]. She's got enough of her own worries' (Hazel).

EMOTIONAL SUPPORT

A marked difference of opinion arose between the younger and older participants with respect to the usefulness of emotional support. Younger participants highlighted benefits arising from having someone to talk to about their emotional difficulties.

'There's got to be people that can't talk to anyone, there definitely should be some way of giving them someone to talk, just to go on about it. Talking does help; let it all out, so basically you're out on the queries and worries that you have' (Jean).

It was not generally felt that emotional support needed to be provided by professionals, unless someone lacked friends or family to provide such support.

'I have a whole series of people that I can talk to...so I have in a way got my own counsellors haven't I,... but perhaps if I ...lived alone and didn't know which way to turn, then possibly I might have someone but it would be a professional wouldn't it' (Jean).

Older participants were wary of emotional support being provided intrusively by professionals.

'You can embarrass people by saying 'How do you feel?', we don't need any counsellors, we counsel ourselves'(Bill).

DISCUSSION

Before discussing findings and implications, it is necessary to note the study's limitations. Given the small sample sizes, caution is needed before generalising results from numerically small qualitative studies to a wider population (Denzin & Lincoln 1998). Caution is especially necessary regarding this study, in that it was conducted within a single dialysis unit. The findings may, in part, reflect specific aspects of the service provided in this unit. This is especially likely with respect to participants who partook of the preparation period, which meant these patients had received a range of services to prepare for haemodialysis.

Notwithstanding these limitations, the findings identify several factors identified as helpful in dealing with the transition onto haemodialysis. These were combined to create three main categories— preparation, cognitive style and social support. Interestingly, however, two cognitive styles—positive reappraisal and optimism—were only mentioned by participants who underwent a gradual, rather than acute, transition onto haemodialysis. Perhaps the development of these cognitive styles is facilitated through education and involvement in personal decision making during preparation for participants who underwent a gradual transition.

Across several developmental and lifespan transitions, as discussed by Mahler and Kulik (1998) and Rosenkoetter and Garris (2001), preparation has been identified as reducing psychological distress and improving general well-being (Mahler & Kulik 1998). Good-quality education and information has been identified as of central significance during patient preparation for treatment in chronic illnesses (Department of Health 2004; Ormandy 2008). Participants in this study additionally highlighted the importance of joint decision making regarding treatment. Collaborative decision making about the nature of their transition onto haemodialysis, or indeed whether to undergo the transition at all, may better enable patients to acknowledge the end of their current life stage and move onto a new one (Bridges 2004).

There are possibly opportunities to further enhance preparation for haemodialysis, in accord with participants' reports of the value of adopting realistic expectations. For example, a nurse-led short-term intervention (three times a week for four weeks) whereby patients set goals and identified strategies in preparation for haemodialysis, has been found to result in improved self-care efficacy and reduce depression (Tsay & Hung 2004).

It is possible that preparation results in increased levels of personal resourcefulness, which has been previously reported to encourage the development of a range of cognitive styles, such as positive reappraisal (Akgun & Gençöz 2004). Adaptive cognitive styles have previously been shown to be employed across a range of other medical difficulties (Kocaman *et al.* 2007) and are reported to improve well-being and resilience; in particular, seeking hope (Groopman 2005), noticing benefit and feeling gratitude (Bono *et al.* 2004) and drawing on optimism (Seligman 1991).

Learning from others who are seen as coping well (upward social comparisons) can act as a source of inspiration and hope, especially where there is clear explicit information available about what people are doing in order to function well (Cohn 2004). Making social comparisons with other patients in the same situation highlights a way to assist patients (Festinger 1954; Taylor *et al.* 1990). Constructive social comparisons are capitalised within Expert Patient Programmes, which have been designed to enable patients with chronic

illnesses to share skills in self-management (Department of Health 2006; Phillips & Cummings 2008). Such approaches could be usefully adopted for patients on haemodialysis.

Alongside preparation and the patients' own cognitive styles, social support also seems important. Receiving both instrumental (practical) and emotional social support has been identified as important in helping deal with physical illness (Uchino 2004). Across a range of chronic health conditions, social support has been associated with reduced depression and anxiety and enhanced psychological adjustment (Taylor & Sherman 2004), as well as predicting longer survival (House *et al.* 1998). For patients with chronic renal failure, social support has also been associated with increased quality of life (Cormier-Daigle & Stewart 1997). Instrumental, practical support seemed of particular significance, with neighbours being mentioned more than friends and family. In part, this seems to reflect a desire, especially amongst older participants, not to become a burden on their family. Indeed, the fact that family members were, surprisingly, not identified in the greater percentage as the main providers of support may provide some insight as to why social support interventions delivered by family members generally have small effects (Matire & Schulz 2007). Social support interventions, especially for older patients, may be more effective if they actively involve friends and neighbours. Providing the right balance between emotional and instrumental support is important, especially when taking into account the wariness of older participants, demonstrated in this study, towards emotional support from professionals.

Amongst the older-old, emotional support has been found to protect people from the negative effects of stress (Krause 2005). The challenge it is how to provide this support in acceptable ways for patients at different stages during their lives. Such support might be enhanced through efforts to maximise opportunities for patient interaction and mutual support, which could be achieved, for example, through small changes within the haemodialysis environment. Dialysis beds could be grouped in small circles rather than the more usual rows to facilitate communication between patients. Doing so may increase the sense of friendship made between patients that may not only enhance mutual support but also facilitate social comparisons (Schacter 1959). Studies have found reduced anxiety and increased function arising when potential friendships were made possible between preoperative and postoperative patients undergoing the same operation by placing them in shared rooms (Kulik *et al.* 1996)

CONCLUSION

By taking a positive psychological approach that focuses on peoples' strengths, this study has identified factors that patients find helpful in adjusting to haemodialysis. Reassuringly, several of the factors identified in this research project are supported by the findings in the literature, in particular, patients taking control of their lives, engaging in self-management and trying to focus on potential positive outcomes of their illness (de Ridder *et al.* 2008).

This study's findings illustrate the positive and active role that patients take in making their transition to life on haemodialysis, through engaging in preparation, adopting constructive cognitive strategies and drawing on social support. Renal service providers could improve the services offered through enhancing the opportunities for patients to draw on and expand their own, and one another's, positive resources and support at the times of transition.

Further quantitative research studies to identify the effectiveness of interventions proposed in this study could support their generalisation for use in the wider community.

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Name	Gender	Age Band	Treatment history	Time on haemodialysis	Onset	Marital status	Employment
Alice	F	70-80	Previous renal replacement therapy	1-3 months	Gradual	Widowed	Not employed
Bill	M	70-80	No previous dialysis	< 1 month	Acute	Married	Not employed
Charles	M	20-30	Previous renal replacement therapy	1-3 months	Gradual	Single	Not employed
David	M	>80	No previous dialysis	< 1 month	Gradual	Married	Not employed
Edward	M	30-50	No previous dialysis	1-3 months	Acute	Divorced	Employed
Fiona	F	70-80	No previous dialysis	4-6 months	Acute	Widowed	Not employed
Gina	F	70-80	No previous dialysis	1 -3 months	Gradual	Married	Not employed
Hazel	F	70-80	No previous dialysis	1- 3 months	Acute	Widowed	Not employed
Ian	M	>80	No previous dialysis	4-6 months	Gradual	Married	Not employed
Jean	F	20-30	No previous dialysis	1- 3 months	Gradual	Married	Employed

Table 1: Details of sample (names altered, and ages given in bandings, to protect confidentiality)

<i>Category</i>	<i>Definition</i>	<i>Subcategory</i>
Preparation	Perceived benefit of preparation in aiding the transition onto haemodialysis.	1. Education 2. Choice
Cognitive Style	Range of cognitive styles identified with a successful transition onto haemodialysis.	1. Positive reappraisal 2. Optimism 3. Realistic expectations 4. Acceptance 5. Social comparisons
Social Support	Extent to which instrumental and emotional support from range of people felt to support successful transition onto haemodialysis.	1. Neighbours 2. Family and friends 3. Patients

Table 2: Summary of predominant categories.