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An exploration of successful psychosocial adjustment to long-term in-centre haemodialysis

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ABSTRACT

Objectives: Haemodialysis extends life for people with end-stage kidney disease (ESKD) worldwide, but it imposes significant psychosocial burdens and there is little evidence about successful adjustment. This study aimed to improve understanding of successful psychosocial adjustment to in-centre haemodialysis (ICHHD; dialysis in a hospital or satellite unit).

Methods: Individual semi-structured interviews were conducted with a purposive sample of 18 people with ESKD who had all received in-centre haemodialysis in the UK for at least 90 days in the last two years. An inductive thematic analysis was employed to identify themes from the verbatim interview transcripts.

Results: There were four themes: 1) *reaching a state of acceptance*, which described the importance of accepting the necessity of dialysis; 2) *taking an active role in treatment*, which described how being actively involved in treatment gave participants greater feelings of autonomy and control; 3) *utilising social support networks*, which described the benefits of instrumental and emotional support; and 4) *building emotional resilience*, which described the importance of optimism and positivity.

Conclusions: The themes demonstrated elements of successful adjustment that could be targeted by interventions to promote psychological flexibility and positive adjustment among people receiving in-centre haemodialysis worldwide.

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End-stage kidney disease; haemodialysis; positive adjustment; qualitative

Introduction

End-stage kidney disease (ESKD) is a global health problem that affects between 4.9 and 9.7 million people worldwide, of whom over 2.6 million received kidney replacement

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therapy (KRT) (Liyanaage et al., 2015; see also Thurlow et al., 2021). Worldwide, haemodialysis is the predominant form of KRT (Himmelfarb et al., 2020; Lee et al., 2021) and in-centre haemodialysis (ICHD; haemodialysis at a hospital or satellite clinic) is the most common KRT worldwide (Robinson et al., 2016; Thurlow et al., 2021). With some exceptions, the most common duration and frequency of haemodialysis worldwide is 3-4h of dialysis, 2-3 times per week (Lee et al., 2021). In the UK, over 24,000 adults received ICHD in 2019, most commonly for 4-5h, 3 times per week (UK Renal Registry, 2021).

Haemodialysis is a burdensome, invasive treatment (NHS Inform, 2020) that prolongs lives but causes significant cardiovascular morbidity and reduced quality of life (Yusop et al., 2013). Treatment often begins immediately after ESKD is diagnosed and continues without respite (Evans & Taal, 2015); therefore the first 3 months are critical in terms of health outcomes and mortality (Lai et al., 2012; Noordzij & Jager, 2014). People receiving in-centre haemodialysis must make ongoing psychosocial adjustments as they integrate the potentially lifelong treatment into their lives and cope with side effects and complications. Poor adjustment to haemodialysis can involve treatment nonadherence, depression, ineffective coping, and impaired social functioning and quality of life (Chilcot et al., 2008; Cukor et al., 2007). These adjustment difficulties are relatively common and can have serious adverse clinical implications, especially when they include treatment nonadherence (Clark et al., 2014). People receiving dialysis therefore need help to develop more successful adjustment and coping mechanisms.

Stanton et al. (2007) defined psychological adjustment to chronic disease generally as preserving functional status and managing affect in the face of illness. They argued that adjustment should be multi-dimensional and relate to psychological, social and physical aspects, consistent with biopsychosocial models of chronic illness. In response to this, Moss-Morris (2013) proposed a working model of adjustment incorporating personal background, illness characteristics, social and environmental factors and ongoing illness stressors. The interplay between these factors can disrupt emotional equilibrium and reduce quality of life, leading to various coping strategies causing either successful or hindered adjustment.

The Stress and Coping Model (Lazarus & Folkman, 1984) suggests that adjustment would be influenced by a person's appraisal of stressors, their coping strategies for managing stressors and their appraisal of the efficacy of those strategies. Crisis theory distinguishes between appraisal-focused coping, problem-focused coping and emotion-focused coping, and suggests several categories of adaptive tasks that are central to adjustment (Moos & Schaefer, 1984). An alternative to coping-based approaches to adjustment are acceptance-based approaches, as acceptance and psychological flexibility can also lead to successful adjustment (Esteve et al., 2007). Psychological flexibility is conceptualised as the ability to fully contact the present moment and change or persist in behaviours based on personal values (Kashdan & Rottenberg, 2010), and has been found to help with adjustment to other chronic conditions (Hulbert-Williams et al., 2015). These models and theories provide a useful framework for understanding the adjustment process and the factors that influence it. However, there is no recognised measure of adjustment. In many studies, adjustment is assessed by measuring depression, anxiety, optimism or wellbeing (e.g. Billington et al., 2008; Symister & Friend, 2003).

Adjustment can be viewed as an outcome or goal to be achieved, or as a process. In one major review, adjustment was conceptualised as an outcome and studies were

included in the review only if they included adjustment to illness as an outcome (Stanton et al., 2007). Treating adjustment as a goal or outcome can be useful if one is concerned with efforts to help those affected achieve better adjustment. However, adjustment is always an ongoing process, and in most chronic illnesses and medical processes there are always new things to encounter and adjust to, so conceptualising adjustment as a process can also be useful for efforts to help people adjust more successfully to their circumstances.

Whether as an outcome or a process, adjusting to dialysis is complex and challenging, and initiatives to improve people's adjustment to dialysis need to be guided by those affected to result in meaningful innovations that support high-quality care (Himmelfarb et al., 2020). It is therefore important to explore people's first-hand experiences of successful adjustment to long-term in-centre haemodialysis (Noordzij & Jager, 2014), in order to better understand how we can help people engage more effectively with dialysis and improve their experience of treatment.

In a qualitative study conducted in the USA over 40 years ago, adjustment to long-term haemodialysis was associated with religious faith, interactional behaviour and low degrees of alienation (O'Brien, 1982). In a qualitative study of 20 people with diabetic renal disease in the UK (of whom only three were on dialysis, and only one on haemodialysis), the authors concluded that participants constructed a 'good adaptation' by adopting a stance of stoicism and uncertainty (King et al., 2002).

A phenomenological study examining the lived experience of women with end-stage-kidney disease (ESKD) undergoing haemodialysis in the USA found that adjustment appeared to follow a trajectory of three phases: initiation, appreciation and grappling, although the process was cyclical rather than linear (Tanyi & Werner, 2008). However, this adjustment process seemed to focus more on the challenges of dialysis rather than giving insights into the nature of positive adjustment to dialysis.

A more recent qualitative exploration of emotional distress and adjustment among people with ESKD in the UK found that those with strong support networks and long-standing positive relationships with staff at their dialysis unit, and those who described feeling in control of their condition, reported being better able to manage their distress and develop effective coping strategies that enabled better adjustment to treatment (Sein et al., 2020). However, that study utilised a varied sample including pre-dialysis and transplant patients, so the findings may not help to explain long-term adjustment to dialysis.

Existing research has therefore focused more on negative adjustment, with samples that included people with less chance to adjust or those having adjustment difficulties. Hence, there is a need to explore more successful adjustment among people purposively selected for their experience of in-centre haemodialysis over extended periods of time. The purpose of this study was therefore to understand successful psychosocial adjustment by exploring the experiences of people receiving in-centre haemodialysis from the National Health Service in the UK.

Availability and use of kidney replacement therapy is comparable across Northern and Western European countries including the UK, as well as in Australia and New Zealand (Liyanage et al., 2015), and in-centre-haemodialysis (IHD) is the most common treatment modality worldwide (Robinson et al., 2016; Thurlow et al., 2021). As noted earlier, in terms of dialysis duration and frequency, IHD in the UK is

comparable to the most common worldwide pattern of dialysis delivery. The experience of dialysis and the challenges of adjustment to ICHD in the UK should therefore be comparable to the experiences and challenges faced by people with ESKD in many other countries, so the ultimate aim was to inform care and support for people receiving in-centre haemodialysis more generally.

Methods

Study design

For this qualitative study, the data were collected by one-to-one semi-structured interviews that were designed to facilitate comparisons across interviews on key topics whilst giving participants the freedom to share views and delve deeply into their personal experiences (Low, 2013). The verbatim interview transcripts were analysed using thematic analysis.

The study protocol was approved by the NHS North East—Newcastle and North Tyneside 2 Research Ethics Committee (REC reference: 19/NE/0218). This study is reported in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines for interviews (Tong et al., 2007) and the APA Style Journal Article Reporting Standards for Qualitative Research (JARS-Qual) (Levitt, 2020).

Participants and recruitment

The participants were 18 people with end-stage kidney disease (ESKD) who were aged over 18 years, had received in-centre haemodialysis for at least 90 days in the last 2 years (including people presently on home haemodialysis who previously received in-centre haemodialysis) and could converse in English. People with active infection or malignancy or whose medical condition made participation in an interview difficult were excluded. The study utilised purposive sampling and focused on people with sufficient experience of in-centre haemodialysis to have had the opportunity for successful adjustment.

Participants were recruited through referrals from the Renal Unit at an NHS Hospital and *via* brief invitations to participate posted on the Kidney Care UK and British Renal Society online support groups, as well as Kidney Research UK, Dialysis Network UK and Chronic Kidney Disease UK Facebook groups. There were 27 individuals who initially expressed interest: 16 at the Renal Unit and 11 in response to online invitations. Of these, one person declined to be interviewed, three could not arrange a convenient date/time for an interview, five did not answer the telephone or Teams call at the time arranged, and 18 were interviewed.

Commensurate with Braun and Clarke (2013) recommended sample size for qualitative studies, a sample of 18 was considered large enough to represent a range of experiences, whilst allowing for in-depth exploration of participants' views. There was no relationship established between researchers and participants prior to the study. Recruitment and data collection took place between April and September 2020, during the COVID-19 pandemic. Key features of study participants are presented in Table 1.

Table 1. Participant information.¹

Pseudonym	Age band	Gender	Married or cohabiting ²	Region of England	Employed ³	Current type of haemodialysis	Approx. time on dialysis	Interview method
Dean	60s	Male	No	Midlands	No	In-centre	5-10 years	Telephone
Paul	50s	Male	No	North	No	In-centre	5-10 years	Microsoft Teams
James	70s	Male	No	Midlands	No	In-centre	20+ years	Microsoft Teams
Jessica	50s	Female	Yes	Midlands	No	In-centre	5-10 years	Telephone
John	70s	Male	No	Midlands	Yes	In-centre	10-20 years	Telephone
David	60s	Male	Yes	North	No	In-centre	1-5 years	Telephone
Peter	70s	Male	No	Midlands	No	In-centre	5-10 years	Telephone
Harry	30s	Male	Yes	Midlands	No	Home	1-5 years	Telephone
Ashley	<25	Female	No	Midlands	No	In-centre	<1 year	Microsoft Teams
William	80s	Male	No	Midlands	No	In-centre	1-5 years	Telephone
Justin	70s	Male	No	Midlands	No	In-centre	<1 year	Telephone
Kumar	50s	Male	Yes	South-west	Yes	Home	1-5 years	Microsoft Teams
Claudia	50s	Female	No	Midlands	No	In-centre	5-10 years	Telephone
Vikesh	70s	Male	No	Midlands	No	In-centre	5-10 years	Telephone
Emily	68	Female	No	Midlands	No	In-centre	1-5 years	Telephone
Gary	40s	Male	No	East	Yes	In-centre	10-20 years	Microsoft Teams
Stephen	70s	Male	No	Midlands	No	In-centre	5-10 years	Telephone
Dwaine	50s	Male	Yes	Midlands	No	In-centre	5-10 years	Telephone

Notes to Table 1:

1. Certain details have been changed to protect participants' anonymity.
2. Yes = married, civil partnership or cohabiting; no = single, divorced or separated.
3. Yes = full-time or part-time; no = retired or not working because of illness.

Procedure

Participants who were personally recruited in hospital were given a standardised participant information sheet that explained the aims of the research, why it was being conducted and what it involved at least 48 h before asking for written consent, after which a convenient time for a videocall or telephone interview was arranged. Participants recruited online were directed to a brief Qualtrics survey where they viewed standardised participant information, confirmed informed consent and provided contact details to arrange a convenient time for an interview *via* telephone or videocall, allowing at least 48 h between recruitment and interview.

An interview guide was used as suggested by Willig (2013), which involved exploring participants' kidney disease and treatment history and their own experiences of life on haemodialysis. The prompts included:

- Could you tell me a bit about your kidney disease and treatment history?
- What type of dialysis are you on? (If on home dialysis, when were you last on hospital dialysis?)
- Can you tell me how you are finding dialysis?
- What sorts of things have helped you to live better on dialysis?
- Or helped you get used to the idea of being on dialysis?
- What advice would you give to someone preparing to start dialysis, or in the early stages of dialysis?
- Is there anything you would like to ask us or talk about?

Additional questions were asked as appropriate to further explore participants' experiences. All interviews were conducted by the first author (RK), a researcher of Asian British origin with Masters level research training, employed as a research assistant in health psychology and undertaking doctoral training in health psychology at the time of the study. RK had academic knowledge of ESKD and prior experience of conducting research with those living with chronic conditions but had no personal lived experience of ESKD and did not know any of the participants personally or professionally. The interviews lasted from 15 to 90 min, though most lasted between 35 and 60 min. Only participants and RK were present at the interviews. Only one interview was conducted with each participant. Following the interviews, participants were signposted towards support services and debriefed on the purpose of the study and their right to withdraw. After each interview, reflexive notes were written to aid the analysis. The interviews were audio-recorded and transcribed verbatim. The transcripts were anonymised, so they contained no personally identifying information and participants were given pseudonyms.

Analytic approach

The anonymised transcripts were analysed using reflexive thematic analysis, a systematic qualitative method allowing detailed description of themes within data and interpretation of the wider topic (Braun & Clarke, 2006, 2021). Themes were identified using the guidelines for thematic analysis outlined by Braun and Clarke (2013): (1) familiarisation with the data through repeatedly listening to and reading the transcribed interviews, (2) generation of initial codes, (3) searching for themes, (4) reviewing potential themes, (5) defining and naming themes, and (6) producing the report. Coding and analysis of the data was primarily led by RK, although other members of the research team were involved in discussions around data analysis and the identification of themes. The analysis was conducted without the use of specific qualitative data analysis software. Potential themes were reviewed against the transcripts to ensure they were established in the data and were then discussed iteratively amongst the wider team, but not with participants, before being finalised. The analysis was positioned within critical realism (Willig, 1999), and an inductive approach was adopted, whereby the analysis was driven by the data rather than pre-existing concepts (Braun & Clarke, 2013). Identification of themes continued until the researchers felt the depth and detail of the data and the analysis were sufficient to explain the phenomena (Braun & Clarke, 2021).

Results

The analysis generated four themes that gave insights into experiences of successful psychosocial adjustment to long-term in-centre haemodialysis: (1) reaching a state of acceptance, (2) taking an active role in treatment, (3) utilising social support networks and (4) building emotional resilience. In the analysis presented below, we present selected quotations to illustrate the themes. In some cases, more than one quotation is used to illustrate a point, which is to illustrate different aspects of

themes and subtle variations in participants' experiences and does not mean that only those participants made that point. Quotations are accompanied by participants' pseudonyms.

Theme 1. Reaching a state of acceptance: 'You live with it, it's as simple as that'. (Justin)

Participants described how, over time, they had reached a level of acceptance of their treatment because they realised there was no alternative. They had come to the realisation that dialysis was essential for survival and that they had no choice but to accept the treatment or give up altogether:

I've got to have it or else I'll die so I don't really have a choice, you know I have to go for the treatment ... I don't have any problems going for the treatment and I've got no issues in my head about, you know, I can't go today... I know I have to go and I know if I miss sessions it's my life I'm playing with. (Emily)

Emily expressed the importance of persevering with treatment and described how she had become accepting of her inner thoughts and feelings about dialysis, which appeared to have matured over the course of her illness. This seemed a kind of resigned acceptance. Important elements in this theme were the need to psychologically accept dialysis rather than fighting against it, which William described, or feeling sorry for oneself, which David described:

You can't fight it you've got to accept it and how it's going to keep you alive. (William)

There's no point feeling sorry for yourself you have to accept all of this and just get on with it as positive as you can otherwise, you know, I think it's very easy to get very depressed. (David)

This theme also highlighted the importance of learning to live alongside dialysis and incorporate it in daily life:

I think it's [dialysis] just something you got to learn to live with ... I'm just learning to live with it, it's something I've got to do. (Jessica)

Similarly, Peter and Vikash described how they had accepted dialysis without objection and indicated their lack of choice as adherence to treatment was a matter of life or death, with Vikash comparing dialysis to a lifeline. Though both participants acknowledged their dependence on dialysis, they emphasised different aspects of acceptance in their descriptions, with Peter describing how he tried to treat dialysis as a normal part of life and Vikash describing having to adjust to it:

I've just got to lead as normal life as possible ... I've got to take dialysis for granted now, and I'll be on dialysis till I die. (Peter)

There's no struggling, we get used to it because, you know, dialysis is our lifeline. Yeah, whether you like it or not, you have to get adjusted to it. (Vikash)

Emily described how she had normalised dialysis and accepted that the treatment had become a mundane part of life that she no longer thought about. She also highlighted that dwelling on the past and having unhelpful thoughts about life before

dialysis was of no benefit. Reaching a state of acceptance, although forced, was therefore a useful strategy to avoid being caught up in a negative spiral of thoughts:

No point trying to go back trying to live my life how it was before I started having problems because it just wouldn't work, and I don't have mean thoughts about 'oh why me?' or anything like that or 'why did it have to be me?', 'why did I have to have it?' you know it just doesn't come into it, like I say it's just part of life. (Emily)

Theme 2. Taking an active role in treatment: 'Being in control of your own treatment is very liberating'. (Paul)

Participants valued opportunities to be responsible for their own treatment and emphasised that self-management of their condition and its treatment allowed them to regain some of the control that had been lost. They also believed that being involved in the treatment process was beneficial both physically and psychologically, as they were able to establish methods that worked well for them and maintain a positive attitude:

I do actually put my needles in myself as well ... that does help with the experience as well as being a little bit more in control of the dialysis rather than relying on the nurses all the time. (Gary)

I think one of the best outcomes you can have on dialysis is if you do everything yourself ... even though it's something that you've got to do, if you're reliant on everyone else you just feel like you're left apart and there's nothing you can do whereas if you promote self-care, then at least, I mean I go in every morning knowing that my treatment is my responsibility ... Erm and also it means that the staff aren't having to do everything for you, because you become more independent ... And even if you're not going to needle yourself ... just coming in and lining your machine up and getting everything ready is an element of control that makes life a lot easier. (Paul)

Gary and Paul additionally highlighted the benefits that taking an active role in their treatment had for healthcare professionals by minimising their reliance on nurses, consequently reducing staff pressure and workload. Paul's narrative also illustrated his desire to feel useful rather than feeling 'left apart' in the treatment process. Moreover, Paul pointed out that adopting problem-focused coping strategies such as engaging in self-cannulation or self-care procedures allowed him to feel more productive and reduced the stress associated with dialysis. The theme highlighted how self-care was an important strategy to gain autonomy and independence:

I am the kind of person who wants to be involved in it, so literally after a few weeks I turned round and said, why do you have to stick needles in me why can't I stick needles in me? ... I'm quite happy because I'm part of the process and I can be left on my own most of the time ... The more you involve yourself in the process, time goes by quicker, you have more control. (James)

James mentioned his yearning to be actively involved in his treatment from a very early stage and essentially to be left to get on with it. He also put forward the notion that by engaging in the treatment process, the burdensome and laborious nature of dialysis was minimised somewhat. Stephen similarly described how he values his independence and the importance of being autonomous whilst on dialysis. He

explained that the benefits of taking more responsibility for treatment also extended to being able to get himself to and from the dialysis centre rather than relying on others, which eliminated some of his frustration about in-centre haemodialysis:

I do, I drive myself now, I use my own transport which takes a lot of the frustration out ... Make sure you have your own transport, I would say that's essential. Don't rely on other people, try and be as independent as you can be. (Stephen)

Stephen's narrative also highlighted how, by taking control of his dialysis, he was able to move away from being a patient and having a 'sick role,' towards being in control of his health and working in collaboration with healthcare staff to make shared decisions about his treatment and care, almost alluding to a sense of empowerment:

You get comfortable, you know what you can do, you know you don't just sit there and be told what to do you know what you have to do, you know what you don't have to do. So if anyone's telling you you've got to do this, that and the other and you don't have to do it, you can tell them. (Stephen)

Theme 3. Utilising social support networks: 'Your support network is what will get you through'. (Kumar)

This theme captured the benefits of utilising practical and emotional support from loved ones, healthcare professionals and other patients to help participants adjust. One aspect of this theme was the use of existing social networks as a means of support to share experiences of dialysis. Participants described the benefits of getting existing friends, family and colleagues involved in the treatment process and looking to them for emotional support:

I mean it's great to get people along and people do get involved, so getting people to come and visit you in dialysis and all that is great and it does help, so that side of it is really good and does work. (Paul)

Paul touched upon the value of having others accompany him during dialysis, whilst Emily stressed the importance of ensuring that friends, family and colleagues are appropriately educated about ESKD and its treatment so that they are well-equipped to provide support. She also acknowledged the benefit of having people to confide in regardless of their proximity:

Make sure that you pass information to work colleagues, family, friends so that they can understand what you're going through and support you... I may not have anybody in the house that I can speak to, but I've still got you know, friends and family who I can speak to on a regular basis, and um if I'm ever feeling a bit low or a bit sorry for myself, I just ring somebody up and have a chat and I'm fine again. (Emily)

Another aspect of this theme was the development of friendships and connections with others on the dialysis unit. Participants mentioned positive effects of meeting other patients and interacting with them during dialysis, forming almost a new dialysis 'family'. They emphasised the ability to learn from others and provide and receive informational support:

You get to chat while you're on dialysis and then you learn from each other, that's one positive ... The social side and the fact that you do learn from other people. (Claudia)

The theme included support networks within dialysis units, which can provide support and help with coping, and gave insights into how fellow patients can be like an extended family who are there to turn to in times of need and can act as buffers against the adversity of dialysis:

You're all in the same sort of boat and you can discuss each other's problems you know, and you do help each other through it really ... so it's nice when you get into a bay where you've got that, but it is like a family up here don't get me wrong because we all help each other in our own way. (Dwayne)

In contrast, Gary described how the high mortality rate associated with ESKD meant that support from other patients can be lost at any time and relationships can be broken:

I've actually met some of my best best friends through dialysis ... I mean unfortunately though, some of my friends have passed away through dialysis, which is always sad if that happens, um, but yeah so you can make good connections through dialysis. (Gary)

Support from healthcare professionals was also of significance, with James describing them as allies who were a part of his 'team' working collectively to achieve good health, whilst David highlighted the value of having invested professionals around for instrumental and psychological support. Moreover, David indicated the immense effect of dialysis on temperament and gave prominence to averting feelings of forlornness:

I see my nephrologists as, not err, well I am a friend of his, not in that sense because we don't socialise, but as a friend who's part of my team and that's my attitude to it. It's my team and if I do things correctly my team will function. (James)

I think help from other people is very, very important ... So that you're not dealing with this yourself, and whether that help is in the form of therapy or psychologist or dietitian or somebody that knows your situation, because going on to dialysis is such a life changer that it can affect your whole mood. (David)

Theme 4. Building emotional resilience: 'Don't let it get you down'. (Stephen)

This theme encapsulates participants' articulated ability to be resilient, adapt to adversity and handle the stressors of dialysis. Most participants fostered an optimistic outlook on the prognosis of their condition and the treatment. They demonstrated high levels of emotional control, preventing them from becoming overwhelmed by dialysis or letting it affect their lives, and this in turn allowed them to maintain functional status:

I do dialysis on the basis it keeps me alive. I don't let dialysis take over my life, that's what's allowed me to work and keep me going. I've made sure that I work, that dialysis is just another treatment and it's not going to overtake my mind. (Kumar)

Kumar articulated his ability to compartmentalise and mentioned his use of this coping strategy to avoid unhelpful thoughts about dialysis, whilst Harry and Dean emphasised positivity as a vital element of adapting to life on long-term dialysis. Additionally, Dean demonstrated a level of psychological flexibility by not merely grudgingly tolerating dialysis, but actively embracing it without protest and continuing to live in line with his values of optimism and positivity:

I think the most important key point would be just try to stay as positive as you can, because it is so, so easy to get depressed and get down about things. (Harry)

I always take most of it [dialysis] in my stride, but I always try and see the good ... I have had low points, but I do just try and remain positive, and I try and make light of everything if I can, and that's what's got me through it really. (Dean)

Ashley looked upon dialysis as protected time that was reserved for her to undertake educational activities and do things that she enjoyed. Her resilience was motivated by the opportunity to accomplish things during treatment, enabling her to move towards academic and personal goals:

I actually quite enjoy going [to dialysis], I know it sounds like such a bad thing to say, but it's like me time if you understand what I mean...I'm like a student at the minute and I don't get a lot of time like for myself, so when I go there either I study or you know, I do something that I like to do. (Ashley)

Part of emotional resilience was an almost relaxed approach to dialysis that seemed to resemble psychological flexibility, taking it 'as it comes' and not reflecting too much:

I just, well, just take it as it comes quite honestly. (Justin)

I think the people who find it [dialysis] easier perhaps are the ones who don't reflect very much. (John)

William illustrated how his life experience has enabled him to remain unfazed by dialysis and accept the treatment into his lifestyle. His resilience seemed to have stemmed from his hardiness, positive attitude and high levels of self-awareness:

It's sort of a way of life for me now ... I just go with the flow ... I mean if you think about it, I'm a pretty good age and I've had a lot of experience and you know nothing seems to faze me ... Some people worry about these things, I don't worry about anything I just get on with it and yeah take every day as it comes. (William)

Discussion

The study aimed to explore the successful psychosocial adjustment experiences of people with end-stage kidney disease (ESKD) on long-term in-centre haemodialysis. The findings give insights into ways that social support, acceptance of treatment, feelings of control and resilience all play a part in the multi-dimensional process of adjustment to haemodialysis. One point to note is that there are no themes illustrating experiences of not adjusting or not coping. Participants had all been on dialysis for long enough to have time to adjust and the interview questions focused on positive adjustment. Previous studies have described adjustment to dialysis mainly in terms of emotional distress (Sein et al., 2020) and 'grappling' (Tanyi & Werner, 2008), whereas this study aimed to provide a clearer picture of positive, successful adjustment.

The first theme demonstrated participants' need to psychologically accept that they had no choice but to live with the treatment. Some participants articulated a resigned acceptance of dialysis, and resigned acceptance was one of the themes in an analysis of 10 people's experiences of coping with automated peritoneal dialysis in Australia (Duncanson et al., 2022). However, other participants were more

psychologically flexible and able to embrace their need for dialysis in a more positive way.

The importance of acceptance is consistent with quantitative studies of people with end-stage kidney disease that identified acceptance of treatment as crucial in the adjustment process (Symister & Friend, 2003), and with conceptual analyses of the different forms that acceptance of chronic kidney disease and dialysis might take (Chan, 2013; Stalker et al., 2018). The present findings add to these by showing how acceptance of treatment was constructed from participants' perceptions and beliefs about their treatment, and how acceptance was experienced by participants.

The second theme highlighted participants' need for a sense of autonomy and control in a situation which would otherwise make them dependent. Participants described a lack of choice over treatment, so some chose to engage in self-care practices instead. This allowed them to feel less of a burden on healthcare staff, de-emphasised their sick role and enabled shared decision-making, contributing to a greater sense of empowerment. These findings are consistent with previous insights that control perceptions can improve the adjustment process (Sein et al., 2020), and with Crisis Theory, which suggests that people affected by chronic illness undertake adaptive tasks to preserve a sense of competence and control, particularly when they feel their bodies are 'out of control' (Moos & Schaefer, 1984).

In the third theme, participants detailed the benefits of receiving instrumental and emotional support from healthcare professionals and loved ones. The importance of social support from loved ones and renal staff for adjustment to dialysis was also recognised by Sein et al. (2020), and there is an abundance of literature advocating social support for individuals living with chronic illness (Petrie & Jones, 2019). The present findings contribute insights into the practical and quite intimate forms this took within dialysis units. Participants described befriending patients on the dialysis unit to exchange expertise, and due to seeing them on a regular basis saw them as extended family, illustrating the strength of feeling towards them and noting the impact that loss of fellow patients could cause.

The final theme illustrated participants' optimism and positivity. There is general literature on the benefits of building emotional resilience to promote health (Davis, 2009), but the present participants' experiences of resilience seemed to involve being able to remain psychologically flexible despite the adversity of dialysis.

The concept of psychological flexibility was involved in both the first and last themes, and this suggests an aspect of successful adjustment that could be a target for interventions with a more positive focus. Psychological interventions such as mindfulness, and acceptance and commitment therapy (ACT), which aims to increase psychological flexibility, could potentially help people become more resilient and accepting of dialysis, and thus better adjusted to it.

Some of the findings imply a conceptualisation of adjustment as an outcome or state to be achieved, and they give insights into factors that can lead to successful adjustment. However, it is important not to treat adjustment just as an end point, as noted in the introduction, and some of the insights gained, especially in relation to acceptance and psychological flexibility, support a conceptualisation of adjustment as a process rather than an outcome.

The findings have a number of implications for clinical practice and should have potential for translating into improved care well beyond the immediate UK context of the study, for the essential features of in-centre haemodialysis are broadly similar around the world. As noted in the introduction, availability and use of kidney replacement therapy is comparable across northern and western European countries, including the UK, as well as in Australia and New Zealand (Liyanage et al., 2015), and the pattern of receiving haemodialysis for several hours a day, several days a week, is similar across the world, including in the UK (Lee et al., 2021; UK Renal Registry, 2021).

The findings suggest that dialysis centres should actively support patients to choose whether to engage in self-care behaviours, and they should ensure that those with less well developed support networks are provided with adequate social support. This might be achieved by having experienced 'expert' patients as role models or 'buddies' to provide advice and support to new patients. Additionally, psychological interventions such as ACT or Mindfulness, if shown to be effective, could be incorporated into routine care for this patient population, particularly those new to dialysis or in the pre-dialysis stage, to increase acceptance of the treatment and foster emotional resilience.

A strength of this study was its participant sample, allowing for an in-depth exploration of the experiences of people with considerable experience of dialysis, who had achieved successful adjustment. The study was conducted during the COVID-19 pandemic, when dialysis was more anxiety-provoking than usual (Danton et al., 2022; Elander et al., 2022), which makes participants' positive adjustment and resilience seem more striking. However, the methods used do have some constraints and limitations. Firstly, 13 of the 18 participants (72%) were recruited at a single clinical centre, so their experiences might reflect local factors. Also, only two out of 18 participants (11%) were from minority ethnic backgrounds, whereas people from Black, Asian or other minority ethnic groups comprise 29.7% of people receiving in-centre haemodialysis (UK Renal Registry, 2021). This means that participants from minority ethnic groups were under-represented in the study sample despite being over-represented in the national population of people receiving in-centre haemodialysis.

In conclusion, the study gave insights into the process of successful psychosocial adjustment to long-term in-centre haemodialysis, which involved an integration of becoming actively involved in one's own treatment, using cognitive strategies to build a sense of resilience and reach a state of acceptance, and effectively seeking practical and emotional support from others. The results support the use of psychological models and interventions that target those factors to improve the adjustment process among this population.

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Author contributions

Romaana Kapadi (lead researcher) conceived and designed the study, recruited participants, conducted and transcribed the interviews, led the data analysis and wrote and prepared the manuscript. James Elander, Amy E. Burton and Jennifer Taylor contributed to the study design, data analysis, reading of drafts and assisted with writing and preparing the manuscript. Emma Coyne, Nicholas M. Selby, Maarten W. Taal, Kathryn Mitchell and Carol Stalker contributed to accessing services, interpretation of the data analysis, reading of drafts and preparation of the manuscript. All the authors approved the submitted manuscript.

Disclosure statement

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Data availability statement

The data that support the findings of this study are available from the corresponding author upon reasonable request. The data are not publicly available due to privacy or ethical restrictions.

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