

“I didn’t have any option”: Experiences of people receiving in-centre haemodialysis during the COVID-19 pandemic

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Abstract

Background: People receiving in-centre haemodialysis (ICHD) during the COVID-19 pandemic had to adjust to more challenging treatment conditions.

Aim: To explore people’s experiences of adjustment to ICHD during the pandemic.

Methods: Thematic analysis of in-depth, semi-structured interviews with 14 adult UK ICHD patients.

Findings: Four themes were identified: ‘perceptions of the threat’, ‘impacts on treatment’, ‘impaired communication’ and ‘coping and positive adjustment’. These described participants’ experiences of vulnerability to COVID-19; the ways the pandemic affected dialysis and clinical care; the impact that measures to reduce viral transmission had on communication and interaction within dialysis units; and ways that participants coped and made positive adjustments to the adversities imposed by the pandemic.

Conclusions: The findings give insights into adjustment during extreme adversity. They also help to identify ways that support for ICHD patients could be improved as pandemic conditions recede, and ways that dialysis units could prepare for future outbreaks of infectious illness.

Keywords: COVID-19; haemodialysis; wellbeing; coping; vulnerability; communication.

Key points

- People receiving in-centre haemodialysis (ICHD) had a much more difficult and distressing experience of dialysis during the COVID-19 pandemic compared with their experience of dialysis before the pandemic.
- Participants were extremely sensitive to their vulnerability to COVID-19 within dialysis units and described anxious thoughts and feelings about attending for ICHD.
- Participants who began dialysis before the pandemic were sensitive to changes in dialysis protocols, and those who began dialysis during the pandemic found it especially difficult and stressful.
- Measures taken by dialysis units to minimise viral transmission impaired communication and interaction between patients and between staff and patients.
- Participants found ways to cope and adjust positively to the difficult circumstances.
- The experiences of ICHD patients during the pandemic can inform efforts to improve the treatment experiences of ICHD patients more generally.

CPD reflective questions

- Do dialysis patients need help to recover from the distress and anxiety they experienced during the pandemic?
- How can we use dialysis patients' experiences during the pandemic to improve coping and adjustment now that pandemic conditions have receded?
- How can we enable better communication and interaction in dialysis units despite infection control measures?
- What measures should we take to prepare dialysis units for future outbreaks of infectious illness?
- What can we learn from the experiences of dialysis patients during the pandemic that can inform nursing practice during other healthcare crises?

Introduction

Chronic kidney disease (CKD) was identified as “the disease condition conveying the highest risk for severe COVID-19” (ERA-EDTA Council and ERACODA Working Group, 2021, p. 88). The UK government classified people with stage 5 CKD as “clinically extremely vulnerable” and they were advised to shield (NHS Digital, n.d.). However, at the time of the first UK lockdown, over 24,000 adults with CKD in the UK were receiving in-centre haemodialysis (UK Renal Registry, 2020) and needed to continue attending for treatment several times a week. Contact with others using transport to and from hospital and in waiting areas and dialysis units, where people would remain for lengthy dialysis sessions, all increased the risks of COVID-19 infection (Combe et al., 2021; Ikizler, 2020; Rabb, 2020). The incidence of COVID-

19 was significantly higher among people with CKD who received dialysis than among those who did not (Chung et al., 2021).

People receiving haemodialysis were already at high risk of psychological distress and disturbance before COVID-19 (Chilcot et al., 2010; Theofilou, 2011; Wan Zukiman et al., 2017). A questionnaire survey of people receiving in-centre haemodialysis during the pandemic found that over half reported that their dialysis had been adversely impacted by staff shortages or changes, and half reported impaired interactions with staff and other patients. Over 40% were at least moderately depressed and over 30% at least moderately anxious, and depression and anxiety were higher among younger participants, those who were not married or cohabiting, and those who had tested positive for COVID-19 (Elander et al., 2022). The aims of the present study were to further explore people's experiences of in-centre haemodialysis during the pandemic and inform efforts to improve the psychological adjustment of in-centre haemodialysis patients.

Methods

The study was a qualitative exploration of participants' experiences, with data generated by individual semi-structured interviews and analysed using thematic analysis. The study protocol was approved by the University of Derby Health, Psychology and Social Care Research Ethics Committee (ETH1920-2748). The recruitment strategy aimed to achieve a sample of people with experience of in-centre haemodialysis during the pandemic at a range of treatment centres in the UK. The inclusion criteria were being over 18 years of age, having a diagnosis of end-stage CKD, and receiving in-centre haemodialysis at the time of the study. The exclusion criteria were not living in the UK and being unable to understand and speak English.

The participants were 14 adults with CKD attending for in-centre haemodialysis during the COVID-19 pandemic. Summary information about participants is given in Table 1 (some personal details have been changed to protect anonymity). Participants attended dialysis centres across almost all regions of the UK. All the participants had White British ethnic identities except for one who had a Black British ethnic identity, which means that participants with minority ethnic identities were under-represented by comparison with the national population of people receiving in-centre haemodialysis (UK Renal Registry, 2020).

Participants were recruited from respondents to a national online questionnaire survey for which invitations to participate were posted on selected online forums, discussion groups and social media including those of the UK Renal Association, the British Renal Society, Kidney Care UK, and the National Kidney Federation. Of 40 people who completed the survey and met the inclusion criteria, 22 indicated they were willing to be interviewed, of whom one changed their mind about being interviewed, 7 were not able to schedule an interview during the study period, and 14 were successfully interviewed.

After giving written consent, participants were emailed study details before being interviewed. The interviews were conducted by telephone or videocall except for one that was conducted by e-mail in order to include a participant with impaired hearing.

Table 1: Participant information

Pseudonym	Gender	Age band	Married or cohabiting	Time on dialysis	Started dialysis during pandemic	Employment	Region
Joe	Male	40s	No	20+ years	No	Employed full time	East of England
Diane	Female	50s	Yes	1 year	Yes	Employed full time	North-West England
Trevor	Male	70s	Yes	10+ years	No	Retired	Midlands
Graham	Male	70s	Yes	<1 year	Yes	Retired	Wales
Samuel	Male	70s	No	2 years	No	Retired	Midlands
Anne	Female	50s	No	20+ years	No	Unable to work due to illness	South-West England
Geoff	Male	50s	No	20+ years	No	Employed full time	Greater London
Susan	Female	70s	No	<1 year	Yes	Retired	Greater London
Lawrence	Male	70s	Yes	1 year	No	Retired	North-West England
Alfred	Male	70s	Yes	5 years	No	Retired	Midlands
Julie	Female	50s	Yes	<1 year	Yes	Employed full time	Scotland
Angela	Female	50s	Yes	5 years	No	Unable to work due to illness	Midlands
Kelly	Female	30s	No	1 year	No	Unable to work due to illness	North-East England
Thomas	Male	60s	No	<1 year	Yes	Retired	Greater London

Note: Some personal details have been changed to protect participants' anonymity.

The interview guide is given in Table 2. This was developed based on: a) the experiences of two of the authors with clinical roles in a dialysis unit during the pandemic; b) published evidence about the experiences of people with long term conditions more generally in the UK during the pandemic (Fisher et al., 2021); and c) issues identified in the questionnaire survey on which the present study built (Elander et al., 2022).

Interviews lasted 30–75 minutes and took place between January and March 2021. A written debrief with contact information and sources of further information and support was emailed to participants after the interviews.

The interviews were audio-recorded and transcribed verbatim with all personally identifying details removed. Pseudonyms were used. Transcripts were inductively coded within NVivo and themes were identified from the initial codes using reflexive thematic analysis (Braun and Clarke, 2006; 2019). The data analysis was led by the first author (ID) with other authors contributing to the identification and definition of themes, following recommendations for methodological integrity in qualitative research (Levitt et al., 2017).

Table 2: Interview guide

1	Can you tell me about your kidney disease and treatment history?
2	Can you tell me how you are finding dialysis during the pandemic?
3	How have you been since the start of the outbreak, both physically and emotionally?
4	How are you coping with having to shield or isolate yourself from others?
5	Can you tell me how managing your condition has changed since the start of the outbreak?
6	During the outbreak, what aspects of your condition and/or treatment are you most worried about?
7	Can you tell me a little bit about what it is like for you when you go in-centre to receive dialysis? <ul style="list-style-type: none"> • What are the staff like? • What is it like being around other patients? • Are you satisfied with the care you are receiving? • How are you finding having to wear PPE whilst on dialysis?
8	How has your quality of life changed since the start of the outbreak?
9	What kinds of things are you doing to reduce your exposure to the virus?
10	What kinds of help or support would make a difference to you?
11	What do you think is the best way to provide support for people on dialysis during this time?
12	Is there anything else you would like to ask us or talk about?

Results

Four themes were identified: perceptions of the threat, impacts on treatment, impaired communication, and coping and positive adjustment.

Perceptions of the threat

Participants described experiences of breaking shielding to attend for dialysis and their anxiety about their vulnerability to COVID-19 infection and the potential consequences of infection:

“There’s been a bit of the anxiety side of things, knowing that there is a virus out there that could actually ... be serious for you and stuff. And being labelled as extremely vulnerable as well. It does, you know, it kind of feels a bit strange knowing that there’s something out there that could potentially kill you.” (Joe)

Fear of being close to other patients and unit staff was a common response:

“It was fairly scary at first ... unit chairs in the waiting area weren’t socially distanced. So, I just waited outside because I didn’t want to be in a waiting area with people that were sitting close together.” (Diane)

“It frightened the life out of me, when COVID started to take hold and I knew I had to go to the dialysis unit ... going to the unit and being in close contact with other people. I mean, not just other patients, but the staff made the whole thing a bit more scary.” (Lawrence)

Participants described their uncertainty and fears about how the virus could spread within dialysis units:

“And it’s, you know, two metres or not ... once something’s actually as small droplets in an aerosol, it will move with air movements, I don’t accept that it will drop to the ground within two metres. The two-metre rule is for people who, how can I put it, are casually in the same space. But not people who are in there ... for seven hours, in exactly the same position.” (Lawrence)

“I sat and thought about this last night, that’s why I didn’t sleep a wink, I could hear someone coughing. And I thought, that’s aerosoling. And it’s going to be in the room.” (Samuel)

“I was wary about eating they brought toast around. And I didn’t have that because I felt like that was something ... that ... I wasn’t sure about. I did have a cup of tea, but I wouldn’t ... have the food.” (Diane)

Despite their vulnerability and anxiety, participants expressed a resigned acceptance because of their medical need for dialysis:

“Initially, I didn’t have any option ... that was how it was, you know, you need the treatment. So, you just go with it, I think.” (Diane)

Some participants felt that haemodialysis centres should have done more to reduce the risks of infection, and one believed they had caught COVID-19 during dialysis:

“It’s not the policy, it’s just they’re not enforcing it. I think there should be enforcement and the nurses are not even trying, not even saying to patients ‘please put your mask back on’. It’s very frustrating to be honest.” (Anne)

“I caught the COVID at hospital while I was on dialysis, that’s where I caught it. And it was me actually coming out of my bubble because I went in the afternoon ... I caught it within two, three hours of me being at dialysis.” (Geoff)

Impacts on treatment

Participants were sensitive to changes in the ways dialysis was delivered:

“... we were cut down to two days a week. That didn’t work at all. And so, a lot of us started to show fairly serious problems, mainly around potassium I use nocturnal dialysis, but I had to start going during the day for a top-up on Wednesdays. So that didn’t work. And so they put us back to three days a week. But also, we’re still sort of missing the hour, it used to be eight-hour sessions, it’s now seven-hour sessions.” (Samuel)

Participants also described the impact on dialysis unit staff and how this reduced the time available to support and interact with patients:

“I think that the staff are all doing their best. But they’re all seemingly on the run. At the start of dialysis, they’ve all got at least three patients to wire up to machines ... the amount of time they’ve got to actually interact with patients is quite limited ... I think the patients would like to spend more time actually just being able to talk to the nurses.” (Graham)

Participants who began dialysis during the pandemic described how difficult they found it. This included not being able to be comforted and supported by others, confusion about when they should attend, and being moved too quickly from the beginners’ unit:

“But the hardest part was the fact that you were going through a really traumatic time and you couldn’t be around your friends. It’s fine talking to people on the phone but there is nothing like sitting in the same room as somebody, and somebody putting their arm round you and saying it’s going to be alright.” (Julie)

“You know, the fact that I was called out to [name removed] hospital and told I would be coming for the day ... [for] dialysis... When I got there, they said, “oh we’re ever so sorry, we can't do it, come back tomorrow”. And then the next day, fortunately, I rang and checked, and they said, “Oh, sorry, we should have told you, no, it's the next day” and things like that. That went very wrong to begin with.” (Susan)

“I started at the [name removed] ‘beginners’ unit’ for six sessions. I was comfortable there and had hoped to stay for longer. But they needed the beds, for yet more beginners, and moved me as soon as possible So that was an emotional upset. Also, at [name of beginners’ unit removed], I felt much more time was being taken to explain things [After moving] it was all much more matter-of-fact, just get everything done...not unkindly, just of necessity. But it made me feel just one of many ... rather than someone new and special.” (Thomas)

Impaired communication

Many participants described how they were affected by reduced opportunities for interaction with other patients because of social distancing measures and mask-wearing:

“The beds are further apart. So that makes conversation an obstacle. And like I say we are not grouping up in the waiting area before and after shift.” (Kelly)

“We don't have much interaction now between patients. We always used to sit here and have a laugh and a joke with each other, but because we've got the mask on, we can't [do] that anymore.” (Angela)

“And then we sit. All the chairs are sort of six feet apart. It's not a social experience. We've all got masks on.” (Graham)

The lack of opportunity to talk with other patients was felt especially by participants who started dialysis during the pandemic:

“Somebody who's been through it will be very good for new people like me to talk to Because I sit there sometimes and see there's a chap who is opposite me and he's now in the position that he can use both these arms while he's on the machine Well, if I could chat to him I do understand that they normally have a buddy-buddy system, which they’re not able to do at the moment.” (Susan)

Mask-wearing also affected communication with staff, and the impact of that was felt especially acutely by participants with impaired hearing:

“It can be a bit annoying just having to wear a mask all the time in the unit ... chatting to the nurses when they're putting you on ... you can find that you can't understand them, or they can't understand you a bit as well.” (Joe)

“My hearing problem meant that what I wanted to see as a kind of team effort didn't work like that. Instead of everyone being on the ‘same side,’ each session was more like a tussle of wits. The nurses were asking me to do this-and-that, and it would have seemed to them that I was being awkward or difficult, rather than that I just hadn't properly understood the request.” (Thomas)

However, some participants welcomed reduced conversation with nurses because they saw that as reducing the risk of COVID-19 transmission:

“I don't just wear a mask, I wear my own visor as well. I find that really limits the amount of conversation I can have with the nurses. Now that suits me fine because I think, the less I talk, or they talk, the less droplets are being caused.” (Anne)

Coping and positive adjustment

Even during the pandemic, participants described experiences reflecting positive adjustment to dialysis. This included trying to lighten the mood by finding ways to mitigate the negative impact of communication difficulties:

“... they put plastic screens, heavy duty plastic screens at least four meters apart with a plastic screen between us. It doesn't stop shouting and talking to each other, which we do, or most of us do. To try and lighten the mood.” (Lawrence)

Participants appreciated the burden of the pandemic on dialysis unit staff and praised them for their work:

“They're all lovely. I think they're very much under pressure. I think members of staff shielding, obviously, if anybody tests positive, then they're off work. And you got the impression that people were covering more shifts than they would normally.” (Diane)

“The nurses are excellent. All the staff, the healthcare assistants, everyone, I mean the catering assistants. I'm sure they've got an ethos, of keeping it as jolly as they can. There's a lot of banter and good humour, which helps, it really does help. They engage with the patients.” (Lawrence)

“The staff are all very caring and trying to give us the best possible time on the machine.” (Anne)

“I didn't have a car park pass, so I couldn't park near the unit ... And when I came off, the nurse looking after me said, ‘How are you getting home’ and I said, ‘Oh I'm in my car’. ‘Where is it?’ she said, and I told her. And she walked all the way to the car with me. I mean you know that's, quite honestly, I think, beyond the call of duty.”
(Lawrence)

Participants described maintaining routines of taking personal responsibility and being actively involved in treatment:

“When we go in, we have to take our temperatures, or have our temperature taken, come in, oh we have to sanitise our hands, then come in and I re sanitize my buttonhole fistulas with a special sanitizing detergent, not detergent, sanitizing wash, and then I start prepping by myself ready to line and prime my machine and take all my obs, weight, pulse, oxygen, and blood pressure. Then I program my machine, and then I put my needles in. Or clean my arm and put my needles in. That's basically it.”
(Angela)

Participants also drew great comfort from the vaccine programme, which was in the early stages of being rolled out at the time of the study, and identified the vaccination programme as a potential relief from the pandemic:

“I think that sort of helped me a little bit because, I know I still can't go out and socialize yet properly and everything, but I think it kind of just sort of gives me a sense that I've got a bit of protection now, so I don't have to worry as much.” (Joe)

“Oh, I think it's brilliant. We've both had our first one, and we get our next in about eight weeks' time. I think the medical profession did a miracle to get it online as quickly as they did, and I'm hoping that's the salvation. And it's going to eventually get life back to something like normal.” (Lawrence)

Discussion

The findings gave insights into participants' perceptions of the threat of COVID-19 and the ways it impacted treatment and impaired communication, yet they also revealed positive aspects of adjustment to dialysis during the pandemic. These insights can inform initiatives to support and protect dialysis patients more effectively during future pandemics, and can inform initiatives to improve how people cope with and adjust to in-centre haemodialysis more generally and in the absence of pandemic conditions.

Pre-pandemic research identified staff-patient interaction and support as important in helping to reduce emotional distress and promote positive adjustment among people with end-stage renal disease (Sein et al., 2020). Social interaction with other patients within dialysis units may also be a key aspect of positive adjustment to dialysis, and the present findings reinforce this priority during periods when communication and interaction are impaired by measures to control viral transmission.

A questionnaire survey of people receiving in-centre haemodialysis during the pandemic showed that younger people and those living alone were at greater risk of depression and anxiety (Elander et al., 2022). The present findings give insights into why those groups may have been more affected; people living alone may depend more on social support within dialysis units and therefore be more affected by measures to reduce viral transmission that impair communication and interaction. Consideration of this when planning the types of mitigation needed to adapt to crisis conditions could help to minimise people's anxiety and stress about such changes.

One key clinical implication of the findings is therefore the need to maintain and extend opportunities for staff-patient communication and social interaction among patients, even during stressful periods like the COVID-19 pandemic. This means finding ways to overcome the obstacles to communication that are inevitably presented by measures to minimise viral transmission. This might be achieved by setting up online chat rooms to enable patients to communicate safely while still being able to see one another during dialysis. Considering the special impact of mask-wearing on communication for patients with hearing difficulties, as the present study highlighted, and the high prevalence of hearing impairments among people receiving renal haemodialysis (Jamaldeen et al., 2015), it is also worth offering people with hearing difficulties specific additional support with communication and interaction.

Another implication of the findings is the need to provide greater support for people who begin dialysis during pandemic or similar conditions. Beginning dialysis has been shown to be an especially stressful and difficult time even before the pandemic (Rebollo Rubio et al., 2017), and the experiences of participants in the present study suggest that COVID-19 added to the distress associated with starting dialysis.

Before the pandemic there was already a case for improving training for staff to identify and manage distress among patients with end-stage renal disease (Combes et al., 2019; Damery et al., 2019), and those initiatives might be extended with specific training on how to maintain positive communication and support despite the restrictions imposed by infection control measures. Dialysis units might also consider giving access to online mental health tools such as those designed to promote mindfulness, or they might consider offering the most severely affected patients one-to-one online sessions with renal counsellors or psychologists. However, any initiatives involving additional services or support to be provided by dialysis staff should take account of the fact that COVID-19 also severely impacted the UK renal workforce in terms of training, morale and wellbeing (Beckwith et al., 2021).

One limitation of the study was that, because participants were recruited online and the interviews were conducted by videocall, people with less online access during the pandemic were probably under-represented. The research team made active efforts to overcome obstacles to participation, including using email correspondence with a participant with impaired hearing, following good practice in using accessible formats and diverse modes of communication to collect data from participants with sensory impairments (Jaiswal et al., 2020). However, it is possible that the study findings do not fully represent the experiences of people who may have been more isolated during the pandemic, possibly including those most unwell and in need of support.

Another limitation of the study was the lack of diversity in the ethnic backgrounds of participants, with just one participant of Black British ethnicity and all others of White British ethnicity, whereas people of White ethnicity comprised only 70.4% of UK adult in-centre haemodialysis patients at the end of 2018 (UK Renal Registry, 2020, p. 107). COVID-19 had a disproportionate impact on people of non-white ethnicity in the UK (Morales & Ali, 2021), so further research on the psychological impact of CKD and COVID-19 on minority ethnic groups is needed.

Conclusions

The findings give insights into adjustment to dialysis during periods of extreme adversity, and they help us to understand the difficult and distressing experiences of people who received in-centre haemodialysis during the COVID-19 pandemic. Participants who began dialysis before the pandemic were sensitive to changes in dialysis protocols, while those who began dialysis during the pandemic found it especially difficult and stressful. Measures taken by dialysis units to minimise viral transmission impaired communication and interaction between patients and between staff and patients. However, participants found ways to cope and adjust positively to the difficult circumstances. The experiences of people receiving in-centre haemodialysis during the pandemic can inform efforts to improve the treatment experiences of in-centre haemodialysis patients more generally. They help to identify ways that support for in-centre haemodialysis patients could be improved as pandemic conditions recede, and they help to identify ways that dialysis units could prepare for future outbreaks of infectious illness.

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Authors' contributions

ID: Participated in design and coordination, transcribed interviews, led the data analysis and drafting of the manuscript and approved the final manuscript.

RK: Conceived the study, led the design and coordination, conducted the interviews, helped to analyse the data and draft the manuscript, and approved the final manuscript.

JE: Participated in design and coordination, helped to analyse the data, drafted and approved the final manuscript.

CL: Participated in design and coordination, transcribed interviews, helped to analyse the data and draft the manuscript, and approved the final manuscript.

NMS & MWT: Participated in design and coordination, helped to interpret findings and draft the manuscript, and approved the final manuscript.

CS & KM: Participated in design and coordination, helped to draft the manuscript, and approved the final manuscript.

Conflict of interest statement

The authors have no conflicts of interest to declare.

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