

Exploring patients' experiences of the impact of dialysis therapies on quality of life and wellbeing

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Abstract

Background: When people with chronic kidney disease reach kidney failure, renal replacement therapy is usually required to improve symptoms and maintain life. Although in-centre haemodialysis is most commonly used for this purpose, other forms of dialysis are available, including home haemodialysis and peritoneal dialysis.

Objectives: We aimed to explore the experiences of adults living with chronic kidney disease who were either approaching the need for dialysis or had reached kidney failure and were receiving a form of dialysis. In particular, we explored how different forms of dialysis affect their quality of life, wellbeing, and physical activity.

Methods: Individual semistructured interviews were conducted with 40 adults with kidney failure, comprising four groups ($n = 10$ each): those receiving in-centre haemodialysis, home haemodialysis or peritoneal dialysis, or predialysis. Interviews were transcribed verbatim, thematically analysed, and then composite vignettes were subsequently developed to present a rich narrative of the collective experiences of each group.

Findings: Compared with adults who were predialysis, quality of life and wellbeing improved upon initiation of their home haemodialysis or peritoneal dialysis. Conversely, minimal improvement was perceived by those receiving in-centre haemodialysis. Low physical activity was reported across all four groups, although those receiving home haemodialysis and peritoneal dialysis reported a greater desire and ability to be physically active than those in-centre.

Conclusion: These findings highlight that dialysis modalities not requiring regular hospital attendance (i.e., home haemodialysis and peritoneal dialysis) improve independence, quality of life, wellbeing, and can facilitate a more physically active lifestyle.

KEYWORDS

home haemodialysis, patient experience, peritoneal dialysis, quality of Life

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INTRODUCTION

Kidney failure is the fifth and final stage of chronic kidney disease. As chronic kidney disease progresses to kidney failure, renal replacement therapy is required. Currently, over 60,000 people require some form of renal replacement therapy in the UK (UK Renal Registry, 2020). Globally, the most common form of renal replacement therapy is in-centre maintenance haemodialysis (ICHD), which typically involves attending the hospital three times per week for treatments lasting ~4 h. However, alternative forms of dialysis are also available, including home haemodialysis (HHD) and peritoneal dialysis (PD). While essential, dialysis is typically associated with further negative physical and psychosocial consequences which exacerbate the notable reductions in quality of life (QoL) and wellbeing reported in those with kidney failure (Abdel-Kader et al., 2009).

LITERATURE REVIEW

ICHD, in particular, is well documented to reduce QoL (Dimova et al., 2019; Nabolsi et al., 2015) and increase symptom burden (Cruz et al., 2011; Tannor et al., 2019). Additionally, people report fluctuations in their QoL and wellbeing over the course of ICHD sessions and that the restrictions imposed on their social lives, due to dialysis schedules, as well as the heavy emotional impact of ICHD on themselves and others, negatively affect them (Jones et al., 2017). Adults receiving ICHD have also highlighted the perceived importance of maintaining physical wellbeing and social support in determining their QoL (Hall et al., 2020). Compared with ICHD, less is known regarding how HHD and PD affect the lives of people living with kidney failure. Furthering our understanding of how alternative forms of dialysis might impact the physiological and psychosocial burden on people with kidney failure, may help to inform clinical and patient decision-making. Specifically, there is a need to understand whether the perceived impact of ICHD differs from other dialysis modalities, particularly in regard to QoL, wellbeing, and the ability to maintain a physically active lifestyle.

In contrast to ICHD, HHD does not require people to travel to the hospital to dialyse and facilitates shorter dialysis sessions, which are undertaken more frequently throughout the week. The gradual and less intense nature of HHD has previously been shown to enhance the perceived physical health of people with kidney failure (Finkelstein et al., 2012), which may allow for better engagement in activities of daily living. People receiving HHD have also previously reported greater satisfaction with their clinical care than those attending for ICHD (Vos et al., 2006), with QoL reduced when individuals switch from HHD to ICHD (Eneanya et al., 2019). Although the increased freedom and lifestyle flexibility offered by dialysing at home is suggested to re-establish a sense of self and self-identity in people with kidney failure (Cases et al., 2011), further qualitative evaluation is warranted.

Whereas HHD and ICHD require blood to be pumped from their circulation into a dialysis machine for cleaning, PD requires the

patient to instil dialysis fluid into their abdominal cavity, either regularly throughout the day or using an automated machine at night. This is done in the patients' homes and, in common with HHD, frequent travel to the hospital is not required. Previous research suggests that people receiving PD are more satisfied with their treatment than those dialysing in-centre, reporting less of an impact on their lives (Juergensen et al., 2006) and higher scores in both the environment and social relationship domains of QoL (Theofilou, 2011). Despite such suggestions that people report better health outcomes and improved QoL when using PD versus ICHD (Makkar et al., 2015), further research is needed to more comprehensively compare how different dialysis modalities affect QoL and wellbeing. Since many adults living with kidney failure are physically inactive (Stack et al., 2005), which is negatively associated with QoL (Johansen et al., 2001, 2000), understanding any barriers and facilitators to physical activity imposed by different dialysis modalities is important. Therefore, the purpose of this phenomenological study was to explore the lived experience of people receiving ICHD, HHD, and PD, with a particular focus on their QoL, wellbeing, and physical activity. This study aimed to address the question, "How do the experiences of individuals pre-dialysis differ from those receiving ICHD, HHD or PD as treatment for their kidney failure?"

METHODS

This study was approved by the South Central—Berkshire Research Ethics Committee (19/SC/0302), registered on the [ClinicalTrials.gov](https://www.clinicaltrials.gov) website (NCT04427800), and adopted onto the NIHR portfolio (44737). The study methodology was designed and conducted in line with Lincoln and Guba's (1986) criteria for rigour in qualitative research and reported using the COnsolidated criteria for REporting Qualitative research checklist (Tong et al., 2007), using an empirical phenomenological approach.

Study design

A phenomenological study design, consisting of one-to-one semi-structured interviews, was used, with the data collected between October 2019 and October 2020.

Study participants

In total, 40 adults with kidney failure representing seven NHS renal units from the Wessex Kidney Centre were invited to take part in this study by a member of their primary clinical team via the telephone and advised that the researcher was not part of their direct clinical team. Participants were emailed an information sheet and, following consideration and opportunity to ask any questions, individuals provided fully informed written or verbal consent. Inclusion criteria consisted of being ≥ 18 years of age, willing and able to provide

informed consent, free from any psychiatric diagnoses at the time of interview, and, for those receiving dialysis, having been receiving dialysis for >3 months.

Data collection

Individual semistructured interviews were conducted by Joe Antoun. While these were initially face-to-face in the participants' home ($n = 10$), due to restrictions imposed by the coronavirus-2019 pandemic, the remainder ($n = 30$) were conducted via telephone. Through patient and public involvement and informal discussions with people with kidney failure, along with previous attempts to use technology within research involving this cohort, a telephone call was ranked more preferable than video conferencing. Irrespective of whether interviews were conducted face-to-face or via telephone, all were undertaken while the participant was at home, not undertaking their respective treatment session. Data collection continued until little new data emerged within interviews and concepts were well developed (data saturation), after which, several additional interviews were conducted to confirm this impression.

Interview guide

An interview guide, comprising 11 open-ended questions developed through a review of the literature, informal discussions with potential participants, and within the research team, was used to explore aspects of QoL, wellbeing, and physical activity. Participants were informed that the researcher was interested in understanding the impact of kidney failure and dialysis on aspects of their life, for example: "How would you rate your ability to keep track of day-to-day things?" and "Do you find that you now become more easily tired?" During the interviews, the topic guide was used flexibly, with prompts and probes used to encourage participants to expand and elaborate on topics when needed and participants were instructed that they could include any additional information they felt necessary. All interviews were audio-recorded and transcribed verbatim and then anonymised to protect participant identity.

Data analysis

Transcripts were analysed using the NVivo 12 software package. Coding and thematic analysis were undertaken by Joe Antoun using a systematic approach (Fereday & Muir-Cochrane, 2006). The first stage of this involved developing a code manually to organise similar and related texts to assist with the interpretation of the data. In the second stage, data were individually summarised, and any initial themes were identified. Third, initial themes were revisited, and codes applied, and then regrouped into more appropriate groups. Finally, these codes were corroborated by Daniel J. Brown and Zoe L. Saynor. An abductive approach was taken to combine codes to

generate families of ideas or similar over-arching themes. Coding was undertaken by Joe Antoun and quotes were subsequently extracted from the transcripts and linked to appropriate themes and codes.

Composite vignettes

In the second stage of data exploration, Joe Antoun moved to a position of storytelling and combined quotes from the identified themes to create composite vignettes (Bradbury-Jones et al., 2014), for each of the different treatment modalities. Each composite vignette was composed using participants' own words and the themes that were previously identified during the thematic analysis. Quotations and descriptions from within each transcript that best described the generated themes were taken and consolidated. These were then creatively weaved together to situate the narrative in the words and voices of those who experienced living with kidney failure and different dialysis modalities. The other authors were acting as critical friends reviewing and revising the drafts of vignettes several times to establish consistent and meaningful storylines. The composite vignette technique can be viewed as a form of creative analytical practice that provides a new, deeper understanding of varied experiences (Spalding & Phillips, 2007) which, to date, had not been used in people with kidney failure.

RESULTS

In total, 40 adults representing four groups with kidney failure took part in this study. The groups consisted of people preparing for dialysis in some form ($n = 10$; 70.4 ± 6.7 years; five males) as the disease control, as well as adults with kidney failure receiving ICHD ($n = 10$; 63.8 ± 12.3 years; seven males; time on dialysis: 73.4 ± 48.0 months), HHD ($n = 10$; 62.8 ± 8.9 years; eight males; time on dialysis: 16.6 ± 12.6 months), and PD ($n = 10$; 58.6 ± 13.0 years; six males; time on dialysis: 14.8 ± 11.7 months). Completed interviews ranged from 13 to 52 min (mean length: 29.1 ± 10.6 min).

Composite vignettes of adults with kidney failure

No renal replacement therapy

When you work for 50 years and you look forward to your retirement, you work hard, you save hard, you have got sufficient (money) in the bank to be able to do the things that you wanted to do and this comes up and ruins your plans, I even retired earlier than I would have done. It is also a gamble if I went on holiday. I don't want to be taken to hospital and have the emergencies and all the rest of it. It has been a bit of a change. I don't even go out for a pint anymore, which I used to, because I feel too rotten the next day. I am on a diet now too, so I have to be careful with the cooking, making sure that I have got no salt in (the food) this kind of thing. I have started to read

the labels on the boxes, you know, things like this. I am a bit slower these days than what I used to be. I'm not as quick as a walker as I used to be, but I do go out for walks if I can. If I can I like to go out every day for a walk. I would like to exercise more but, as I say, at the present moment it's not too easy – especially with my condition. I just get extremely tired very quickly, it is pretty awful. You can't even mow the lawn. You rush up the stairs – you are out of breath, plus I don't sleep as well at night. I have always been a brilliant sleeper, but now I can be awake three or four times during the night. It's rare that I actually go to bed and sleep all night and wake up at 8 o'clock. I'm awake, like I say, three or four times throughout the night. I end up falling asleep all the time everywhere. I just think the weakness and not being able to do what I want to do, that is the biggest problem, but I am hoping that will change when I start dialysis.

The first vignette represents the experience of adults living with kidney failure. A common experience described by this group was a sense of loss of control over their life, resulting in changes to their longer-term plans and reductions in their self-confidence to go out or travel anywhere. This was primarily through fear of their inevitable hospitalisation and initiation of dialysis. Our findings offer support to previous suggestions that adults living with CKD experience increased levels of anxiety (Murtagh et al., 2007; Yoong et al., 2017) and depression (Yoong et al., 2017) than the general population, with the inevitable progression towards receiving some form of dialysis intensifying this anxiety (Coulbaly et al., 2019; Rebollo Rubio et al., 2017). This vignette also described a perceived deterioration in physical function, which supports previous reports of physical impairments, specifically reduced walking speed and handgrip strength, as well as lower habitual levels of physical activity, in this group (Broers et al., 2017; Hiraki et al., 2013). Of particular importance, people living with CKD in the present study suggested that their reduced physical function impaired their ability to undertake what was previously considered typical activities of daily living which has the potential to result in reduced independence, further reductions in QoL, and exacerbated loss of sense of self.

Individuals receiving ICHD

Dialysis, they will tell you, is one day – but they don't tell you about being tired and shattered that night, or sometimes it even rolls over into the next day. It is very difficult to plan anything when you don't know how you are going to be feeling. In the early years, my partner went to a lot of parties and things which we normally would have both gone too, but I was either too tired or felt rubbish or, to a certain extent, just didn't want to mix with people. Most household tasks I find difficult to do now also, but I get on and push myself to try and get at least something done – like if I were doing something like the washing, that is a bit physical because you need to get down low to get in and out of the machine. Where I used to [before kidney disease] breeze through it, I now have to stop and think about it and take breaks. I will do the things that I need to do. I mean, I am doing as much exercise as I possibly can, like walking. I used to, let's say

with weather like today [clear blue skies], I would put a pair of walking boots on and do 20 miles a day without even thinking about it. Now, I can't even get anywhere near a quarter of a mile, let alone anything else. A lot of it is because of coming in here [the hospital to receive ICHD] three times per week. It is not so bad now that we have it [ICHD] on a Monday, Wednesday, and a Friday, but when I first started it was on a Tuesday, Thursday, and Saturday, and that is your weekend gone. I would say the dialysis drains you too. You are sitting on a bed for 4 h and then you stand up and it's tough to not fall over. They say that you should move around, but with dialysis, you can't – you have got to lay on the bed. I think, on the whole, my mood has changed – I am feeling a lot more down than I used to. It is a lot harder to pull yourself back out of it, so to a certain extent yes. I've been doing this for 16 years and it does get you down, it does really get you down. You would be amazed – you go from a person to a nonperson.

The second vignette presented the experience of adults receiving three times weekly maintenance ICHD. Many of the common difficulties (e.g., disruption to life plans and reduced physical function) experienced by people with kidney failure who were predialysis were also evidenced in this group, suggesting that they can most likely be attributed to living with kidney failure, rather than dialysis per se. However, additional problems were experienced by those requiring ICHD. First, a notable inability to plan and control time not spent on dialysis was reported in this group. This was a consequence of uncertainty regarding how days off would feel and is in line with previously reported challenges with time and lifestyle management in people receiving ICHD (Hagren et al., 2005; Ziegert et al., 2009). The feelings of anxiety and depression reported by people receiving ICHD in the present study also support and develop previous reports of an increased prevalence of anxiety and depression in adults after beginning ICHD (Cukor et al., 2008; Feroze et al., 2012; Othayq & Aqeeli, 2020). Another common experience amongst adults dialysing in-centre was perceived reductions in their physical function, which not only impacted their ability to undertake physical exercise but, perhaps more importantly, typical activities of daily living. Individuals receiving ICHD have previously exhibited impaired physical function, significant muscular atrophy, and habitual physical inactivity (Hayhurst & Ahmed, 2015; Kim et al., 2014). Of particular interest, the experience reported by those receiving ICHD only suggests modest improvements in QoL, wellbeing, and physical activity as a result of ICHD which is in line with previous findings (Broers et al., 2017) and provides further support to the need for ICHD-specific physical activity interventions (Clarkson et al., 2019).

Individuals receiving HHD

Once I had started dialysis, within a week or so I didn't need it [wheelchair] no more – I had the energy to walk. It is just unbelievable really. My husband sort of said that he has got me back. We have the relief of not commuting to the hospital three times a week. It is nice to do it [dialysis–HHD] when it suits me, so I tend to

do it at similar sorts of times most days, but it is nice that if I want to, I don't have to. I adjusted [to needing dialysis daily] quite well. I work first thing in the morning, so I used to come home from work and then I would go straight on dialysis and get it out of the way – then the rest of the day is free. However, we found it is sometimes an imposition being on dialysis, really because it seems to control your life almost – well it does. We are both retired, my partner particularly, and we had all sorts of plans to travel and do things – but that has been severely restricted of course. The problem is because I am not caring for myself as far as the blood thing, my partner is my carer and then, obviously, it affects two lives and also two lifestyles. We used to go out for breakfast quite a lot and, of course, we can't do that now. I know I can do the dialysis later in the day, but then you feel like it is hanging over you all day. I think also the thing about dialysis, or any sort of chronic condition is that it affects your confidence and self-esteem. I was certainly able to go a little bit more [leave the house] than I do now, so now I get tired a little bit more quickly – but thankfully I am still able. We normally go out regularly for 3-mile walks. I even go to the gym about three times a week and I do, primarily, strength training – but I have recently started cardio. In fact, to be honest with you, it [the ability to exercise] got better. That was the big impact of dialysis [HHD] that I found. As I say, I feel pretty well – apart from having to do dialysis all the time.

The third vignette presented the lived experiences of adults with kidney failure who were receiving HHD. Similar to those receiving ICHD, a common experience within this group was the negative impact of dialysis necessitation on everyday life. Although initially HHD may be considered a more flexible option than ICHD, people using this dialysis modality in the present study reported that they need to dialyse almost daily provided challenges in planning and a sense of guilt of not only changing their life but also their carers'. This familial guilt within the HHD population has previously been reported (Jacquet & Trinh, 2019; Nagasawa et al., 2018); however, the present findings demonstrate that, from a more positive perspective, people receiving HHD experience increased independence and control over their medical care. This is in line with previous reports that individuals receiving short daily haemodialysis had better health-related QoL than conventional haemodialysis, with specific improvements in their perceived physical health, physical functioning and satisfaction (Vos et al., 2006), as well as findings from a larger cohort where adults receiving HHD reported greater feelings of independence and QoL, when compared to ICHD. A similar population receiving HHD in China reported similar improvements in health-related QoL when compared to ICHD (Wong et al., 2019), where increases in physical aspects of health-related QoL and perceptions of their health were observed. Despite perceived reductions in the physical ability of our group of adults undergoing HHD, they did describe an increased or maintained desire to be physically active after initiating HHD and felt more able to go about their daily lives. These improved perceptions of physical health in people dialysing at home support previous reports in this population (Wong et al., 2019), as well as research showing improvements in both exercise duration and capacity when individuals switched from ICHD to nocturnal HHD (C.T. Chan et al., 2007). The

increased desire to engage in a physically active lifestyle and perceived ability to undertake activities of daily living found in adults with kidney failure undergoing HHD in the present study provides further support that, where clinically appropriate, this dialysis modality may aid in maintaining a good QoL and independence, more than ICHD.

Individuals receiving PD

Sometimes, it depends on how poorly I am feeling, but I get up and I think “oh I feel good today” and I start to do stuff, and I would normally just soldier through and get it done. But I was getting worse and worse before I started PD so, believe it or not, I now feel much better. It's not something that you would enjoy [the dialysis – PD], but you ask yourself, “do I want to suffer in pain or just get on with it?” With dialysis [PD], you are very restricted. You have got to do an exchange once every 4 h. You may be able to get away with 5 h between each one, so you have got to be very aware of the fact that, if you fancy a trip out, you have to be back for the next session. You have specific times to do things so, as I said, you have to work around it. I don't think it stops me from doing anything else, but it's one of those things where you are aware of your expectations, and you work around them. It just moves things around really. But, as I say, I and my other half have gotten used to it and, you know, it is quite important to keep yourself alive really, so you just deal with it, don't you. When I began PD, they took away all of my dietary restrictions too [compared to predialysis] and I have been on PD for 10 years now. I've always been very active and taken the kids out, with my grandkids as well – to then have all of that totally stop. I used to love them staying over and I would spend hours with them, but now I think “oh my God, I can't wait for them to go.” I don't always do as much as I like, but I do try to do as much as I can – but anything that involves an extra bit of effort, it just isn't there. I also never ever sleep through the night. I can't remember the last time that happened, so I always have a lot of broken sleep, so that probably contributes to me feeling sleepy during the day. It's up-and-down really.

The final vignette outlined the lived experience of adults with kidney failure who were dialysing using PD, and any perceived impact on their QoL, wellbeing, and physical activity of these individuals. Similar to HHD and ICHD, many of the present cohorts of people undergoing PD expressed an overwhelming impact of this treatment taking over their lives and, in particular, challenges and anxieties surrounding their time management, in line with previous findings of anxiety surrounding medical treatment in adults receiving PD (K.M. Chan et al., 2018). Despite this, people receiving PD in the present study described an increased feeling of independence and control over their medical treatment and an improved ability to care for themselves at home without the increased reliance on the medical staff, supporting previously reported increases in QoL within a PD cohort (Wong et al., 2019). The present findings also suggest improvements in physical function when compared to predialysis, supporting previous findings where individuals receiving PD were found to have greater improvements in their physical function,

particularly when compared to ICHD (Painter et al., 2017), with the main reported barriers to physical activity revolving around the timing of their PD sessions and the lack of spontaneity. When compared to those with kidney failure predialysis, individuals receiving PD reported improvements in physical function and QoL allowing a return to "normal" life and facilitating the engagement in a typical day-to-day activities.

DISCUSSION

This study aimed to explore the impact of different forms of dialysis (ICHD, HHD, and PD) on the QoL, wellbeing, and physical activity levels of adults living with kidney failure using a qualitative approach. For the first time, the lived experiences and challenges faced by adults living with kidney failure and undergoing various dialysis modalities are presented using the novel composite vignette approach. Irrespective of dialysis modality, people receiving ICHD, HHD, and PD, as well as those approaching the need for dialysis, shared similar issues surrounding a loss of their sense of self and reduced physical function. Of particular interest, however, those dialysing at home (HHD and PD) generally reported better levels of independence and QoL and a lesser extent of physical impairment than those attending hospital for ICHD, as well as a greater desire and ability to lead a more physically active lifestyle.

A particularly novel aspect of the present study was that, for the first time, the lived experiences and challenges faced by adults living with kidney failure and undergoing various dialysis modalities are presented using the novel composite vignette approach. This allows a deeper and richer understanding of not only their experiences and challenges, but particularly any perceived impact on their QoL, wellbeing, and physical activity. The present findings highlight that dialysing at home (using either HHD or PD) is linked with an improved QoL and wellbeing in adults with kidney failure, and that it may also facilitate a more physically active lifestyle than conventional maintenance ICHD. This supports similar findings of better health-related QoL in those undergoing PD and HHD, when compared to ICHD (Wong et al., 2019), as well as specifically increased levels of health-related QoL in those receiving PD when compared to ICHD (Hsu et al., 2020; Jung et al., 2019). This is important given the associations between physical activity and QoL in the renal population, particularly as ICHD is the most common form of dialysis globally. Despite improvements in certain forms of dialysis, individuals within all groups reported reductions in their own QoL compared to the earlier stages of CKD, with the overwhelming impact of their kidney failure and dialysis necessitation causing increased anxiety, depression, and reduced QoL. The present study also revealed perceived reductions in both physical function and physical activity in all of the included kidney failure groups, irrespective of whether receiving dialysis or not and, if so, irrespective of modality. Our findings do, however, also highlight a clear desire and improved ability to maintain a more physically active lifestyle when dialysing at home compared to those receiving ICHD or not yet on dialysis. This supports the need

for the promotion of home-based HD, when medically appropriate, to further promote independence in care and reduce the sedentariness that typifies most people undergoing dialysis.

The present findings need to be interpreted in the context of several methodological considerations. First, the data collection for this study was interrupted by the Covid-19 pandemic, which resulted in two-thirds of the interviews being conducted over the phone and the remainder using a more traditional face-to-face approach. Although some may consider the use of telephones to potentially reduce the quality of qualitative data obtained (Novick, 2008), it has been used successfully in the past when investigating QoL in kidney failure by both our research team (Antoun et al., 2021) and others (Ferri & Pruchno, 2009). Second, although the use of semistructured interviews allows for discussion and insight into individuals' perspectives, we must recognise that physical activity was not objectively measured in this present study. Therefore, future research objectively measuring the physical activity of people with kidney failure receiving different forms of dialysis, with measurement of the amount and intensity of any activity, would be a valuable extension of the present work. While it is recognised that member checking may typically be employed through the analysis process to support rigour (Creswell & Poth, 2017), the authors decided it would add limited value in this study due to the timing of the data collection and the interpretative analysis required which may mitigate the objectivity of the member checks (Braun & Clarke, 2013; Smith & McGannon, 2017). Finally, longitudinal follow-up of these individuals would be useful to help us further understand any potential changes to their QoL, wellbeing, and physical activity status over time.

IMPLICATIONS FOR CLINICAL PRACTICE

The findings from this study, using a novel composite vignettes approach to illuminate the lived experience of people with kidney failure, are that people receiving home-based therapies (PD and HHD) experience improved QoL, wellbeing, and habitual physical activity compared with people approaching kidney failure and those attending hospital for maintenance ICHD. As such, this study presents support that, where medically appropriate, home-based dialysis modalities facilitate self-reliance in this population by enhancing their sense of ownership of their medical problems. These findings are highly relevant to individuals approaching kidney failure who are making a decision about their favoured dialysis modality.

CONCLUSION

In conclusion, this study provides novel insight into the experiences and challenges of adults with kidney failure undergoing different forms of dialysis. Specifically, home-based modalities (HHD or PD) appear to facilitate and promote independence with their medical care, as well as improved QoL and physical function, compared to people attending hospital for maintenance ICHD. These findings

highlight the need to promote more home-based treatment modalities where appropriate and serve to provide better insight for future dialysis decision-making.

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CONFLICTS OF INTEREST

The authors declare no conflicts of interest.

AUTHOR CONTRIBUTIONS

Conceptualisation: Joe Antoun, Daniel J. W. Jones, Nicholas C. Sangala, Anthony I. Shepherd, Jo Corbett, and Zoe L. Saynor. **Data curation:** Joe Antoun, Nicholas C. Sangala, and Robert J. Lewis. **Formal analysis:** Joe Antoun, Daniel J. Brown, and Daniel J. W. Jones. **Investigation:** Joe Antoun and Zoe L. Saynor. **Methodology:** Joe Antoun, Daniel J. Brown, Daniel J. W. Jones, Beth G. Clarkson, and Zoe L. Saynor. **Project administration:** Joe Antoun and Zoe L. Saynor. **Supervision:** Anthony I. Shepherd, Jo Corbett, and Zoe L. Saynor. **Writing – original draft:** Joe Antoun. **Writing – review and editing:** Joe Antoun, Daniel J. Brown, Daniel J. W. Jones, Beth G. Clarkson, Nicholas C. Sangala, Robert J. Lewis, Anthony I. Shepherd, Melitta A. McNarry, Kelly A. Mackintosh, Laura Mason, Jo Corbett, and Zoe L. Saynor. All authors have read and agreed to the published version of the manuscript.

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REFERENCES

- Abdel-Kader, K., Unruh, M.L. & Weisbord, S.D. (2009) Symptom burden, depression, and quality of life in chronic and end-stage kidney disease. *Clinical Journal of the American Society of Nephrology*, 4(6), 1057–1064. <https://doi.org/10.2215/CJN.00430109>
- Antoun, J., Brown, D.J., Jones, D.J.W., Sangala, N.C., Lewis, R.J., Shepherd, A.I. et al. (2021) Understanding the impact of initial COVID-19 restrictions on physical activity, wellbeing and quality of life in shielding adults with end-stage renal disease in the United Kingdom dialysing at home versus in-centre and their experiences with telemedicine. *International Journal of Environmental Research and Public Health*, 18(6), 3144. <https://doi.org/10.3390/ijerph18063144>
- Bradbury-Jones, C., Taylor, J. & Herber, O.R. (2014) Vignette development and administration: a framework for protecting research participants. *International Journal of Social Research Methodology*, 17(4), 427–440. <https://doi.org/10.1080/13645579.2012.750833>
- Braun, V. & Clarke, V. (2013). successful qualitative research: student resources. <http://studysites.uk.sagepub.com/braunandclarke/study/additional.htm>
- Broers, N.J.H., Martens, R.J.H., Ornelis, T., Van Der Sande, F.M., Diederren, N.M.P., Hermans, M.M.H. et al. (2017) Physical activity in end-stage renal disease patients: the effects of starting dialysis in the first 6 months after the transition period. *Nephron*, 137(1), 47–56. <https://doi.org/10.1159/000476072>
- Cases, A., Dempster, M., Davies, M. & Gamble, G. (2011) The experience of individuals with renal failure participating in home haemodialysis: an interpretative phenomenological analysis. *Journal of Health Psychology*, 16(6), 884–894. <https://doi.org/10.1177/1359105310393541>
- Chan, K.M., Cheung, C.Y., Chan, Y.H., Chan, H.W., Chak, W.L. & Chau, K.F. (2018) Prevalence and impact of anxiety and depression in Chinese peritoneal dialysis patients: a single centre study. *Nephrology*, 23(2), 155–161. <https://doi.org/10.1111/nep.12970>
- Chan, C.T., Notarius, C.F., Merlocco, A.C. & Floras, J.S. (2007) Improvement in exercise duration and capacity after conversion to nocturnal home haemodialysis. *Nephrology Dialysis Transplantation*, 22(11), 3285–3291. <https://doi.org/10.1093/ndt/gfm368>
- Clarkson, M.J., Bennett, P.N., Fraser, S.F. & Warmington, S.A. (2019) Exercise interventions for improving objective physical function in patients with end-stage kidney disease on dialysis: a systematic review and meta-analysis. *American Journal of Physiology - Renal Physiology*, 316(5), F856–F872. <https://doi.org/10.1152/ajprenal.00317.2018>
- Coulibaly, G., Gombri, P.P., Lengani, H.Y.A., Millogo, T., Zoma, V.P., Dabilgou, A. et al. (2019) Anxiety and depression during chronic renal failure before end stage at the University Hospital Center Yalgado Ouedraogo of Ouagadougou (Burkina Faso). *Nephrologie et Therapeutique*, 15(7), 506–510. <https://doi.org/10.1016/j.nephro.2019.07.329>
- Creswell, J.W. & Poth, C.N. (2017) *Qualitative inquiry & research design: choosing among five approaches*, 4th edition. Thousand Oaks: Sage Publications Inc.
- Cruz, M.C., Andrade, C., Urrutia, M., Draibe, S., Nogueira-Martins, L.A., Sesso, R. et al. (2011) Quality of life in patients with chronic kidney disease. *Clinics*, 66(6), 991–995. <https://doi.org/10.1590/S1807-59322011000600012>
- Cukor, D., Coplan, J., Brown, C., Friedman, S., Newville, H., Safier, M. et al. (2008) Anxiety disorders in adults treated by hemodialysis: a single-center study. *American Journal of Kidney Diseases*, 52(1), 128–136. <https://doi.org/10.1053/j.ajkd.2008.02.300>
- Dimova, R., Keskinova, D., Tzekov, V. & Ginova-Noncheva, G. (2019) Health-Related quality of life in end-stage renal disease patients, using the missoula-vitas quality of life index: a multicenter study. *Medicine and Pharmacy Reports*, 92(4), 374–381. <https://doi.org/10.15386/mpr-1320>
- Eneanya, N.D., Maddux, D.W., Reviriego-Mendoza, M.M., Larkin, J.W., Usvyat, L.A., Van Der Sande, F.M. et al. (2019) Longitudinal patterns of health-related quality of life and dialysis modality: a national cohort study 11 medical and health sciences 1103 clinical sciences. *BMC Nephrology*, 20(1), <https://doi.org/10.1186/s12882-018-1198-5>
- Fereday, J. & Muir-Cochrane, E. (2006) Demonstrating rigor using thematic analysis: a hybrid approach of inductive and deductive coding and theme development. *International Journal of Qualitative Methods*, 5(1), 80–92. <https://doi.org/10.1177/160940690600500107>
- Feroze, U., Martin, D., Kalantar-Zadeh, K., Kim, J.C., Reina-Patton, A. & Kopple, J.D. (2012) Anxiety and depression in maintenance dialysis patients: preliminary data of a cross-sectional study and brief literature review. *Journal of Renal Nutrition*, 22(1), 207–210. <https://doi.org/10.1053/j.jrn.2011.10.009>

- Ferri, C.V. & Pruchno, R.A. (2009) Quality of life in end-stage renal disease patients: Differences in patient and spouse perceptions. *Aging & Mental Health*, 13(5), 706–714. <https://doi.org/10.1080/13607860902845558>
- Finkelstein, F.O., Schiller, B., Daoui, R., Gehr, T.W., Kraus, M.A., Lea, J. et al. (2012) At-home short daily hemodialysis improves the long-term health-related quality of life. *Kidney International*, 82(5), 561–569. <https://doi.org/10.1038/ki.2012.168>
- Hagen, B., Pettersen, I.M., Severinsson, E., Lützen, K. & Clyne, N. (2005) Maintenance haemodialysis: patients' experiences of their life situation. *Journal of Clinical Nursing*, 14(3), 294–300. <https://doi.org/10.1111/j.1365-2702.2004.01036.x>
- Hall, R.K., Cary, M.P., Washington, T.R. & Colón-Emeric, C.S. (2020) Quality of life in older adults receiving hemodialysis: a qualitative study. *Quality of Life Research*, 29(3), 655–663. <https://doi.org/10.1007/s11136-019-02349-9>
- Hayhurst, W.S.G. & Ahmed, A. (2015) Assessment of physical activity in patients with chronic kidney disease and renal replacement therapy. *SpringerPlus*, 4(1), 1–8. <https://doi.org/10.1186/s40064-015-1338-3>
- Hiraki, K., Yasuda, T., Hotta, C., Izawa, K.P., Morio, Y., Watanabe, S. et al. (2013) Decreased physical function in pre-dialysis patients with chronic kidney disease. *Clinical and Experimental Nephrology*, 17(2), 225–231. <https://doi.org/10.1007/s10157-012-0681-8>
- Hsu, C.-C., Huang, C.-C., Chang, Y.-C., Chen, J.-S., Tsai, W.-C. & Wang, K.-Y. (2020) A comparison of quality of life between patients treated with different dialysis modalities in Taiwan. *PLoS One*, 15(1), e0227297. <https://doi.org/10.1371/journal.pone.0227297>
- Jacquet, S. & Trinh, E. (2019) The potential burden of home dialysis on patients and caregivers: a narrative review. *Canadian Journal of Kidney Health and Disease*, 1–7. <https://doi.org/10.1177/2054358119893335>
- Johansen, K.L., Chertow, G.M., Da Silva, M., Carey, S. & Painter, P. (2001) Determinants of physical performance in ambulatory patients on hemodialysis. *Kidney International*, 60(4), 1586–1591. <https://doi.org/10.1046/j.1523-1755.2001.00972.x>
- Johansen, K.L., Chertow, G.M., Ng, A.V., Mulligan, K., Carey, S., Schoenfeld, P.Y. et al. (2000) Physical activity levels in patients on hemodialysis and healthy sedentary controls. *Kidney International*, 57(6), 2564–2570. <https://doi.org/10.1046/J.1523-1755.2000.00116.X>
- Jones, D.J., Harvey, K., John, J., Harris, P. & Butler, L.T. (2017) Understanding the impact of haemodialysis on UK National Health Service patients' well-being: a qualitative investigation. *Journal of Clinical Nursing*, 27, 193–204. <https://doi.org/10.1111/jocn.13871>
- Juergensen, E., Wuerth, D., Finkelstein, S.H., Juergensen, P.H., Bekui, A. & Finkelstein, F.O. (2006) Hemodialysis and peritoneal dialysis: patients' assessment of their satisfaction with therapy and the impact of the therapy on their lives. *Clinical Journal of the American Society of Nephrology*, 1(6), 1191–1196. <https://doi.org/10.2215/CJN.01220406>
- Jung, H.Y., Jeon, Y., Park, Y., Kim, Y.S., Kang, S.W., Yang, C.W. et al. (2019) Better quality of life of peritoneal dialysis compared to hemodialysis over a two-year period after dialysis initiation. *Scientific Reports*, 9(1), 1–10. <https://doi.org/10.1038/s41598-019-46744-1>
- Kim, J.C., Shapiro, B.B., Zhang, M., Li, Y., Porszasz, J., Bross, R. et al. (2014) Daily physical activity and physical function in adult maintenance hemodialysis patients. *Journal of Cachexia, Sarcopenia and Muscle*, 5, 209–220. <https://doi.org/10.1007/s13539-014-0131-4>
- Lincoln, Y.S. & Guba, E.G. (1986) But is it rigorous? Trustworthiness and authenticity in naturalistic evaluation. *New Directions for Program Evaluation*, 1986(30), 73–84. <https://doi.org/10.1002/ev.1427>
- Makkar, V., Kumar, M., Mahajan, R. & Khaira, N.S. (2015) Comparison of outcomes and quality of life between hemodialysis and peritoneal dialysis patients in Indian ESRD population. *Journal of Clinical and Diagnostic Research*, 9(3), 28–31. <https://doi.org/10.7860/JCDR/2015/11472.5709>
- Murtagh, F.E.M., Addington-Hall, J.M., Edmonds, P.M., Donohoe, P., Carey, I., Jenkins, K. et al. (2007) Symptoms in advanced renal disease: a cross-sectional survey of symptom prevalence in stage 5 chronic kidney disease managed without dialysis. *Journal of Palliative Medicine*, 10(6), 1266–1276. <https://doi.org/10.1089/jpm.2007.0017>
- Nabolsi, M.M., Wardam, L. & Al-Halabi, J.O. (2015) Quality of life, depression, adherence to treatment and illness perception of patients on haemodialysis. *International Journal of Nursing Practice*, 21(1), 1–10. <https://doi.org/10.1111/ijn.12205>
- Nagasawa, H., Sugita, I., Tachi, T., Esaki, H., Yoshida, A., Kanematsu, Y. et al. (2018) The relationship between dialysis patients' quality of life and caregivers' quality of life. *Frontiers in Pharmacology*, 9, 770. <https://doi.org/10.3389/fphar.2018.00770>
- Novick, G. (2008) Is there a bias against telephone interviews in qualitative research. *Research in Nursing and Health*, 31(4), 391–398. <https://doi.org/10.1002/nur.20259>
- Othayq, A. & Aqeeli, A. (2020) Prevalence of depression and associated factors among hemodialyzed patients in Jazan area, Saudi Arabia: a cross-sectional study. *Mental Illness*, 12(1), 1–5. <https://doi.org/10.1108/MIJ-02-2020-0004>
- Painter, P.L., Agarwal, A. & Drummond, M. (2017) Physical function and physical activity in peritoneal dialysis patients. *Peritoneal Dialysis International*, 37(6), 598–604. <https://doi.org/10.3747/pdi.2016.00256>
- Rebollo Rubio, A., Morales Asencio, J.M. & Eugenia Pons Raventos, M. (2017) Depression, anxiety and health-related quality of life amongst patients who are starting dialysis treatment. *Journal of Renal Care*, 43(2), 73–82. <https://doi.org/10.1111/jorc.12195>
- Smith, B. & McGannon, K.R. (2017) Developing rigor in qualitative research: problems and opportunities within sport and exercise psychology. *International Review of Sport and Exercise Psychology*, 11(1), 101–121. <https://doi.org/10.1080/1750984X.2017.1317357>
- Spalding, N.J. & Phillips, T. (2007) Exploring the use of vignettes: from validity to trustworthiness. *Qualitative Health Research*, 17, 954–962. <https://doi.org/10.1177/1049732307306187>
- Stack, A.G., Molony, D.A., Rives, T., Tyson, J. & Murthy, B.V.R. (2005) Association of physical activity with mortality in the US dialysis population. *American Journal of Kidney Diseases*, 45(4), 690–701. <https://doi.org/10.1053/j.ajkd.2004.12.013>
- Tannor, E.K., Norman, B.R., Adusei, K.K., Sarfo, F.S., Davids, M.R. & Bedu-Addo, G. (2019) Quality of life among patients with moderate to advanced chronic kidney disease in Ghana—a single centre study. *BMC Nephrology*, 20(1), 1–10. <https://doi.org/10.1186/s12882-019-1316-z>
- Theofilou, P. (2011) Quality of life in patients undergoing hemodialysis or peritoneal dialysis treatment. *Journal of Clinical Medicine Research*, 3(3), 132. <https://doi.org/10.4021/jocmr552w>
- Tong, A., Sainsbury, P. & Craig, J. (2007) Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19(6), 349–357. <https://doi.org/10.1093/intqhc/mzm042>
- UK Renal Registry. (2020) *UK Renal Registry 22nd annual report. Summary of the UKRR 22nd annual report—adults. Summary of the UKRR 22nd annual report—children and young people.* www.renalreg.org
- Vos, P.F., Zilch, O., Jennekens-Schinkel, A., Salden, M., Nuyen, J., Kooistra, M. et al. (2006) Effect of short daily home haemodialysis on quality of life, cognitive functioning and the electroencephalogram. *Nephrology Dialysis Transplantation*, 21(9), 2529–2535. <https://doi.org/10.1093/ndt/gfl256>
- Wong, C.K.H., Chen, J.Y., Fung, S.K.S., Lo, W.K., Lui, S.L., Chan, T.M. et al. (2019) Health-related quality of life and health utility of Chinese patients undergoing nocturnal home haemodialysis in comparison with other modes of dialysis. *Nephrology*, 24(6), 630–637. <https://doi.org/10.1111/nep.13429>
- Yoong, R.K., Mooppil, N., Khoo, E.Y., Newman, S.P., Lee, V.Y., Kang, A.W. et al. (2017) Prevalence and determinants of anxiety and depression in end stage renal disease (ESRD). A comparison between ESRD

patients with and without coexisting diabetes mellitus. *Journal of Psychosomatic Research*, 94, 68–72. <https://doi.org/10.1016/j.jpsychores.2017.01.009>

Ziegert, K., Fridlund, B. & Lidell, E. (2009) "Time for dialysis as time to live": experiences of time in everyday life of the Swedish next of kin of hemodialysis patients. *Nursing and Health Sciences*, 11(1), 45–50. <https://doi.org/10.1111/j.1442-2018.2009.00429.x>

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