



A survey of the psychosocial wellbeing of patients receiving haemodialysis during a pandemic: a mixed-method approach

Short report

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Evidence Brief

Why did we start?

Living with end-stage kidney disease (ESKD) and undergoing hospital haemodialysis (HD) is associated with lower quality of life (QoL) and a high prevalence of mental health problems. However, the COVID-19 pandemic has brought additional challenges for this patient population. The aim of this study was to understand the impact of COVID-19 in people receiving hospital haemodialysis by assessing factors of well-being and mental health and reporting on experiences of self-isolation.

What did we do?

This study conducted an online survey design combining validated questionnaires, demographic information and free text qualitative questions, to understand the impact of COVID-19 in patients receiving hospital HD. Two validated assessment tools of mental health distress (General Health Questionnaire-12; GHQ-12) and well-being (Personal Wellbeing Index (PWI)) were included. Free text qualitative questions were also used to investigate experiences of shielding and self-isolation in these patients. Individuals with ESKD receiving hospital HD in Northern Ireland, over 18 years of age, were recruited using an online link between July and August 2020 during the COVID-19 pandemic.

What answer did we get?

Forty-four participants were recruited. Approximately, 54% of respondents were tested for COVID-19 however, no positive results were reported by patients or associated family members. Compared to the general population during COVID-19 (April 2020), mental health distress was higher in prevalence (68.2%) and severity ($M=18.3$). Similarly, perceived quality of life ($M=37.16$, $SD=18.19$) was substantially lower compared to a pre-COVID-19 dialysis patient population. During the current pandemic, individuals receiving hospital HD have considerably poorer mental health and reduced quality of life. Qualitative data addressing the impact of shielding and self-isolation highlighted a wide range of heightened emotional and psychological burdens including anxiety and loneliness.

What should be done now?

This study has reinforced the need for appropriate psychosocial care in renal disease and an urgent need to provide supportive interventions for psychological distress in this patient population during and post COVID-19. In addition, novel interventions that maintain or improve social well-being including social support, social participation and relationships, e.g., patient-to-patient peer mentor support, should be considered to support well-being.

Background

Approximately 28,866 individuals are receiving some form of dialysis treatment in the United Kingdom (UK; 1). Haemodialysis (HD) is the most frequently used renal replacement therapy for end-stage kidney disease (ESKD; 2) with approximately 37.4% people in the United Kingdom receiving hospital HD treatment (1). Patients receiving hospital HD experience a high burden of disease arising from its chronic nature and protracted medical treatment (3). Many patients receiving HD report lower quality of life (QoL) scores in domains of environment and social relationships as well as scores for anxiety/insomnia, severe depression and overall poorer mental health (4). Several meta-analyses on the prevalence of depression in chronic kidney disease reported that approximately 39% of HD patients experience some form of depressive symptoms (5).

It has also been reported that prevalence tends to be higher in younger patients, in women and in black and minority ethnic patients (6). Overall, living with ESKD and undergoing hospital HD is extremely challenging (7).

The COVID-19 pandemic has brought additional challenges for this patient population whereby patients receiving hospital HD are considered to be at higher risk of developing severe COVID-19 due to their immunocompromised status and frail condition (8). Government guidance for the 'clinically extremely vulnerable' advised individuals such as those with ESKD, to take extra precautions during the peak of the pandemic including shielding for a period of 12 weeks (9). However, individuals attending hospital HD are unable to adhere to such strict guidelines due to twice or thrice weekly treatment., Inability to social distance during HD sessions places patients at further risk of viral transmission (10).

In addition to serious illness or death, individuals are at risk of developing post-traumatic stress disorder (PTSD) during the current pandemic. After the 2003 Severe Acute Respiratory Syndrome (SARS) epidemic it was found that poor understanding of SARS and how it spread resulted in high rates of PTSD (11). This has additional implications for patients with kidney disease during the current pandemic as mental health conditions such as depression, anxiety and PTSD are highly prevalent in renal disease patient populations (12). Poor mental health among people with kidney disease has wide-ranging implications including increased risk of treatment non-compliance, hospitalisation and death (13). Therefore, in light of the COVID-19 pandemic, patients with ESKD are likely to be at an increased risk of such outcomes.

Aims and Objectives

The aim of this study is to understand the impact by assessing factors of well-being and mental health and exploring patients' experiences of shielding.

Methods

Design: This study was carried out using a cross-sectional study design. It was conducted over six weeks between July and August 2020.

Sample: Individuals were recruited (July 2020) via an online platform during the COVID-19 pandemic. Those receiving hospital HD were included using the following inclusion criteria: Patients with ESKD receiving HD in Northern Ireland, over 18 years of age and ability to complete an online survey to capture qualitative and quantitative data. The study was approved by the Faculty of Medicine, Health and Life Sciences ethical committee (MHLS 20_77) within the host institution.

Measures: The study combined validated questionnaires, demographic information and free-text qualitative questions via a web-based survey tool. The study included author-designed binary, Likert and open-ended questions to investigate experiences and personal concerns during the pandemic. In addition, two standardised measures were included. The General Health Questionnaire-12 (GHQ-12) was used to evaluate mental health status in the present study. It is a highly reliable and validated screening instrument for mental health (14). The General Health Questionnaire-12 (GHQ-12) measures twelve psychological symptoms of psychological distress over the past few weeks. The GHQ-12 score includes factors associated with social dysfunction (items 1, 3, 4, 7, 8 and 12), anxiety and depression (items 2, 5, 6 and 9) and loss of confidence (items 10 and 11). Each item of the GHQ-12 is rated on a 4-point Likert scale (0-1-2-3) with higher scores indicating greater psychological distress (range 0-36). GHQ-12 can also be scored (using 0-0-1-1) with a cut off ≥ 4 indicating the presence of distress (15).

The Personal Wellbeing Index (PWI) investigates patient well-being which contains seven items of satisfaction, each one corresponding to a quality of life domain as: standard of living, health, achieving in life, relationships, safety, community-connectedness, and future security (16). PWI is a highly validated and reliability tool (17). Respondents were asked how satisfied participants were with their life reporting a score from zero to 10. Zero means no satisfaction at all and 10 means completely satisfied whereby higher scores indicate greater life satisfaction. All scores were transformed from a 0–10 scale to a 0–100 scale.

Analysis: Descriptive statistics were provided for demographic information including narrative description of binary and Likert responses. Mean + standard deviation (SD) scores were calculated for standardised measures of mental health (GHQ-12) and well-being (PWI). Qualitative design element adhered to a form of thematic analysis (18). The qualitative data was categorised into themes to support quantitative outcomes in a mixed-methods approach (19).

Personal and Public Involvement (PPI)

This study idea was developed in consultation with nephrology clinicians, members of the Northern Ireland Kidney Patient Association (NIKPA), Kidney Care UK and European Dialysis and Transplant Nursing Association/European Renal Care Association (EDTNA/ERCA). Mr William Johnston (Patient Advocate for Kidney Care UK and the Northern Ireland Kidney Patient Association) provided specific consultation and support on recruitment and dissemination of findings. Results have been shared (with a range of representatives from renal community (e.g., Kidney Care UK) and the wider programme of research (with renal Health Care Professionals) will be collated and disseminated collectively (e.g., 2021).

Findings

Data from both qualitative and quantitative analysis will be presented together. This includes the use of frequencies, standardised assessment scores and open-ended questions to describe a phenomenon (20). Forty-four participants who were receiving HD in Northern Ireland completed this online study (see Table 1). The sample included 26 males (59.1%) and 17 females (38.6%; n=1 not identified). The majority of respondents were ≥ 45 years old (n=32) with the largest cohort ≥ 65 years old (n=16) which is representative of UK patients (median age to start HD is 67.4; (1)). The majority of respondents were white (93.2%), married (52.3%), attending HD 3 times a week (81.8%) and not employed (68.2%).

Table 1. Sociodemographic variables

Demographic item	N	%
Gender		
Male	26	59.1%
Female	17	38.6%
Prefer not to say	1	2.3%
Marital status		
Single	12	27.3%
Married/co-habiting	23	52.3%
Widowed	9	20.4%
Employed		
Yes	14	31.8%

No	30	68.2%
Ethnicity		
White	41	93.2%
Other	3	6.8%
Age		
25-34	8	18.2%
35-44	4	9.0%
45-54	8	18.2%
55-64	8	18.2%
65+	16	36.4%
Education		
Further/university level	8	18.2%
Secondary level	28	63.6%
Primary level	8	18.2%
Caring responsibilities		
Yes	2	4.6%
No	42	95.4%
Transplant before		
Yes	10	22.7%
No	34	77.3%
Haemodialysis sessions		
4 x/ week	6	13.6%
3 x/ week	36	81.8%
≤ 2 x/ week	2	4.6%

Approximately 54% of respondents had been tested for coronavirus since the beginning of the pandemic (Table 2) however no positive tests were reported. No family members or loved ones had been tested for coronavirus. Fifteen (34%) respondents reported they had attended a facility that had cared for patients with known or suspected COVID-19 yet 31% were unsure of any positive diagnoses within their respective clinic.

Table 2. COVID-19 testing experiences

	Yes	No	Unsure
Tested for COVID-19	54%	46%	-
Loved ones tested for COVID-19	0%	100%	-
Attended a facility that cared for patients with known or suspected	34%	35%	31%

Mental Health

Table 3 shows the total average score of the GHQ-12 was 18.3. Using the assessment cut-off point (≥ 4), the majority of those attending hospital for HD treatment demonstrated mental distress (68.2%). Participants tended to have poorer responses on positive items (see supplementary table 5 for breakdown). Respondents indicated they did not feel they were 'playing a useful part' in life, 'capable of making decisions about things' or 'able to enjoy...normal day to day activities', "less than usual" or "much less than usual". Table 3 also summarises some of the associated qualitative data which highlighted shielding led to significant feelings of anxiety, whereby respondents felt "forgotten about" and "very vulnerable". Insight into respondent's ability to make decisions were burdened with "...travelling to hospital". Respondents also expressed growing symptoms of depression, "...it is making me feel more depressed", "I am fed up" and "...uneasy around other people".

Table 3. Standardised measure of General Health Questionnaire-12 (GHQ-12)

	ESKD GHQ-12 total score (95% CI)	General population GHQ-12 total score during COVID-19* (95% CI)	Qualitative data for GHQ-12 items ≥ 2
GHQ-12 total score <i>(Likert method)</i>	18.3 (15.8-20.9)	12.5 (11.5-13.5)	Playing a useful part: “feeling forgotten about”, “I feel very vulnerable”, “It has [affected] my mental health feeling down and useless...”. Capable of making decisions: “Worry about travelling to hospital”.
<i>Proportion with significant level of mental distress</i>	68.2%	28.5%	Enjoy your day-to-day activities: “I feel much safer shielding, but it is making me feel more depressed”, “I am fed up”, “...uneasy around other people”.

*Pierce et al. (2020) Northern Ireland general population sample GHQ-12 during COVID-19 pandemic recorded April 2020. CI= confident interval.

Well-being

The total average score of the PWI was 37.16 (SD=18.19; Table 4) which is considerably lower than pre- COVID-19 ESKD sample (M=64.72, SD=19.17) indicating poorer quality of life (21). All items were lower than the comparative group, in particular for personal health (M=43.18, SD=24.38), achieving in life (M=46.36, SD=26.68), community-connectedness (M=50.00, SD=33.06) and future security (M=45.91, SD=28.31) indicating the current pandemic is substantially impacting on key areas of life satisfaction. Table 4 also summarises some of the associated qualitative data. Respondents highlighted worries over disruption to their healthcare, “hospital appointments being stopped and holding things back” and “communication between hospitals regarding transplant list and what’s happening”. Many respondents expressed struggling with worries about the future, “I am worried it will have to be like this forever” and the uncertainty about their future, “not being able to go out is difficult but I despair about the future”, “not many people sticking to the guidelines in public...”. Open text responses also reported on significant social consequences, “unable to work or go out with my girlfriend”, “isolated from family” and “I am finding the loneliness difficult”.

Table 4. Standardised measure of Perceived Wellbeing Index (PWI)

Item	ESKD sample Mean (SD)	Pre-COVID19 ESKD sample* Mean (SD)	Qualitative data for items ≤ 50
Standard of Living	62.73 (28.15)	68.72 (22.42)	Personal health: “hospital appointments being stopped and holding things back”, “feel safe [when shielding]”, “communication between hospitals regarding transplant list and what’s happening” Achieving in Life: “I am worried it will have to be like this forever” Community-Connectedness “...made [patients] feel even more isolated”, “unable to work or go out with my girlfriend”, “I am finding the loneliness difficult”, “[shielding causes] sorrow”, “Not seeing people, [loneliness] is difficult”, “[Isolated] from my loved ones, feel more alone most days”, “Hospital experience made us feel even more isolated” Future Security: “not being able to go out is difficult but I despair about the future”, “not
Personal Health	43.18 (24.38)	47.67 (24.36)	
Achieving in Life	46.36 (26.68)	54.34 (26.43)	
Personal Relationships	65.45 (34.27)	74.97 (25.39)	
Personal Safety	57.95 (32.82)	73.55 (22.87)	
Community-Connectedness	50.00 (33.06)	64.85 (26.93)	

Future Security	45.91 (28.31)	63.78 (27.09)	<i>many people sticking to the guidelines in public..."</i>
Total score	37.16 (18.19)	64.72 (19.17)	

*All scores were transformed from a 0–10 scale to a 0–100 scale. *Bennett et al (2015) ESKD sample taken before COVID19.

Conclusion

The overarching aim of this study was to understand the impact of COVID-19 in renal disease by assessing factors of well-being, mental health and reporting on experiences of self-isolation in hospital HD patients. We found heightened mental health distress and reduced quality of life in this patient sample. Recently, Kidney Care UK developed and administrated a COVID-19 survey exploring the impact of the pandemic on individuals with renal disease. Their findings reported significant disruption to people's normal healthcare, negative consequences for mental health, distressing confusion over shielding and a lack of access to essential support (22). By using validated quantitative tools alongside qualitative data, our findings further help to demonstrate heightened psychological distress and reduced well-being for individuals attending hospital for dialysis during the current pandemic.

Compared to the general population in April 2020, GHQ-12 scores were worse for the patients receiving HD in this study (23). In particular, factors associated with 'social dysfunction' (e.g., able to concentrate', 'playing a useful part', 'capable of making decisions about things' and 'able to enjoy your normal day to day activities') tended to be poorer. This is not surprising as social isolation is a common difficulty in renal disease (24). In particular, patients with ESKD receiving HD, face increased social isolation and support difficulties due to the intensive and protracted nature of dialysis treatment (12), having less time for employment, hobbies and other social activities (25). Coupled with COVID-19, patients with renal disease are at an increased risk of mental health distress. Consequently, pandemic related isolation could lead to progressive withdrawal (26) and contribute to higher levels of depression and anxiety (5) in this patient population.

PWI scores highlight reduced QoL in this patient sample. Patients receiving HD tend to have significantly lower QoL compared to other renal replacement therapies however when compared to a pre- COVID-19 ESKD dialysis sample, the overall score as well as individual items on the PWI, indicate substantially lower perceived quality of life in the current study (21). In particular, lower scores for personal health, achieving in life, community-connectedness and future security provide insight into key components of life satisfaction affected for this patient sample. Additionally, qualitative data further highlights how shielding and self-isolation during the pandemic are contributing to heightened concerns of uncertainty and feelings of loneliness.

Practice and Policy Implications/Recommendations

It has been long recognised that patients receiving HD experience significantly reduced mental health and quality of life (27-29), yet little evidence currently exists relating to effective interventions for individuals receiving HD (30). Now more than ever, enhancing opportunities for psychosocial support are necessary to improve the mental health and well-being for those attending for hospital HD. The role of non-pharmacological management of mental health conditions is gaining support within renal medicine (31). In addition, recent evidence shows perceived social support is an important factor in a patient's ability to cope with their illness and also can improve QoL (32). Therefore, novel interventions that maintain or improve social well-being, including social support, social participation and relationships, should be considered. Evidence for peer mentor programs is growing. Patient-to-patient peer mentor support is associated with positive changes in patients with

kidney disease including improvements in goal-setting, better decision-making and self-management in chronic disease (33, 34). These programs provide a platform for shared experiences, emotional and educational support as well as a foundation for dedicated social activities which may provide a useful intervention for patients with kidney failure receiving hospital HD during the current pandemic and beyond (33, 34).

Pathway to Impact

This study has reinforced the need for appropriate psychosocial care in renal disease particularly during the COVID-19 pandemic. Undoubtedly, the current pandemic has fast-tracked the urgency for future research to understand psychological distress and social dysfunction in ESKD. Irrespective of this, patients with ESKD undergoing hospital dialysis should be screened regularly to assess for mental health symptoms and prompt referral and treatment must be initiated, where required. By addressing need, appropriate policies and supportive interventions that seek to prevent and reduce perceived isolation and psychological distress can be developed to monitor and manage patients at significant risk of reduced mental health and well-being. Results from this study have been submitted for publication with an international peer-reviewed journal for the multi-professional health care team caring for people with kidney disease and those who research this area.

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Supplementary info

Table 5. Standardised measure of GHQ-12 with item and frequency breakdown

General Health Questionnaire-12		Response frequencies			
		0 ☹	1	2	3 ☹
1	Able to concentrate	11.4%	31.8%	34.1%	22.7%
2	Lost much sleep	18.2%	40.9%	34.1%	6.8%
3	Playing a useful part	4.5%	0.0%	72.8%	22.7%
4	Capable of making decisions	6.8%	0.0%	75.0%	18.2%
5	Under stress	4.5%	54.6%	31.8%	9.1%
6	Could not overcome difficulties	25.0%	27.3%	34.1%	13.6%
7	Enjoy your day-to-day activities	4.5%	29.5%	31.9%	34.1%
8	Face up to problems	0.0%	61.4%	25.0%	13.6%
9	Feeling unhappy and depressed	22.7%	20.5%	47.7%	9.1%
10	Losing confidence	29.5%	31.8%	20.5%	18.2%
11	Thinking of self as worthless	56.8%	20.5%	9.1%	13.6%
12	Feeling reasonably happy	4.5%	59.2%	22.7%	13.6%