



# Consumer values, perspectives and experiences of psychological health when living with dialysis at home: An in-depth interview study

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## Abstract

**Background:** People treated with home dialysis report social and emotional isolation, fear of catastrophic events and concern about being a burden. There is a paucity of research exploring psychological well-being among consumers dialysing at home. We aimed to explore the psychological health issues related to home dialysis, and how these issues may impact on sustaining home-based treatment.

**Methods:** We conducted a qualitative interview study with 36 consumers. We included patients with experience of home dialysis and caregivers. Thirteen participants had experienced peritoneal dialysis, seven home haemodialysis, seven had experienced both and nine caregivers. Data were analysed inductively to generate themes and a conceptual framework.

**Results:** We identified four themes and subthemes: overwhelming isolation and disconnection (devastating isolation of home dialysis; abandoned from support; escalating anxiety; compounding impact of feeling like a burden); importance of support systems (impact on relationships; need for emotional support; reassurance through shared experiences; valuing trustworthy and committed clinicians); burden of distress (individualised feelings of low mood; grappling with stigma surrounding diagnosis; contemplating treatment withdrawal and suicide); seeking mental health support (normalising mental health support as a distinct entity in dialysis care; overcoming barriers to seeking mental health support; additional tools for mental health support and connection).

**Conclusion:** Consumers may experience intense psychological distress during home-based dialysis care. Increasing clinician and health services literacy about the management of psychological impacts of home-based dialysis may improve consumer safety, quality of life and sustainability of home treatment.

## Keywords

Depression, end-stage kidney disease, home dialysis, home haemodialysis, peritoneal dialysis, qualitative

## Introduction

Home-based dialysis is promoted globally to alleviate demand for, and costs of, facility-based dialysis care. Home dialysis prevalence varies across health systems from 71% of dialysis patients in Hong Kong to 14% in the United States,<sup>1</sup> in part due to practice norms, clinical infrastructure and service design and healthcare funding and reimbursements.<sup>2</sup>

One-third of people treated with long-term dialysis experience depressive symptoms,<sup>3</sup> and many report severe psychological distress.<sup>3,4</sup> Anxiety is also common among those treated with dialysis.<sup>5</sup> Both anxiety and depression

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are associated with reduced quality of life.<sup>6</sup> Although patients doing home dialysis report freedom to maintain employment and improved flexibility and quality of life, they also experience social and emotional isolation, fear of catastrophic events and concern about being a burden to their family.<sup>7,8</sup>

In the recently published ‘Kidney Disease: Improving Global Outcomes (KDIGO) Home Dialysis Controversies Conference’, it was identified that emotional preparedness and support is as important as educational preparedness for those looking to dialyse at home.<sup>2</sup> Despite this, however, there is little research that explores and documents the severity and impacts of home dialysis on psychological health and family and physical health. Providing safe and effective patient-centred care is a pillar of healthcare quality requiring understanding of all aspects of the consumer experience. Understanding these specific factors may be fundamental to providing high-quality care that supports patients’ confidence and agency to choose and sustain home dialysis.<sup>9</sup>

Psychological and somatic effects of depression and stress can lead to the development of several complications in patients with kidney disease including lower quality of life and motivation to self-care, increased hospitalisation rates and increased cardiovascular risk and mortality.<sup>10,11</sup> We therefore conducted a qualitative interview study with consumers (patients and caregivers) to explore consumer psychological values, perspectives and experiences related to home dialysis.

## Methods

We conducted an in-depth interview study according to the Consolidated criteria for REporting Qualitative research (COREQ)<sup>12</sup> and the consolidated criteria for strengthening reporting of health research involving indigenous peoples (CONSIDER) statement.<sup>13</sup>

### *Participant recruitment and selection*

We recruited consumers who are currently or have previously utilised home dialysis therapies. We invited consumers to participate via established peak patient support/advocacy groups (Kidney Health New Zealand [KHNZ] and the Auckland Dialysis Kidney Society) and dialysis services in Te Whatu Ora (the national health service of New Zealand) in Canterbury and the Hawke’s Bay. Participants were purposively sampled to include diverse demographic characteristics (age, sex and geographical remoteness) and modality of home dialysis (peritoneal dialysis and home haemodialysis). Of those who initially enquired about participation or were invited into the study, nine were not interviewed (one due to time constraints, three declined and the remainder were not able to be further contacted).

Two researchers conducted in-depth interviews until data saturation occurred. Data saturation was confirmed

by regular discussion of the research team during the interview and recruitment process, and six further interviews were conducted to ensure diversity of age, sex and rurality. Participant recruitment began, and interviews were conducted between 16 March and 1 November 2022. The study was approved by the Eastern Institute of Technology Research and Ethics Committee (EA08260721). The participating hospital sites provided locality authorisation.

### *Design and setting*

Due to restrictions and safety concerns related to the SARS-CoV2 pandemic, most interviews were conducted using videoconferencing or by telephone, based on participants’ preferences. The interview schedule contained open-ended questions exploring the participants’ psychological experiences of home dialysis (item S1).

Two authors conducted the interviews (RH and SH). Both are female and experienced and trained in qualitative research. RH is a social science researcher with formal training in clinical psychology. SH is a kidney nurse specialist with considerable previous experience in qualitative interviewing and home dialysis care. CW is an indigenous nephrologist and researcher who was involved in study design, conduct analysis and reporting. Initial interviews were conducted by RH and SH together to increase consistency of interviewing. The majority of the interviews were conducted by RH. All interviews were conducted in English. Interpreters and cultural support workers were offered to all participants but were not requested.

Interview length varied from 37 min to 132 min. Field notes were taken during each interview. All interviews were recorded and transcribed verbatim. Member checking of transcripts and draft themes was offered to participants to enable review and revision of the interpretation of findings. Of the eight participants who requested this, two replied with additional comments to add to transcripts and confirmed draft themes.

### *Data analysis*

Transcribed interviews were imported into NVivo (QSR International Pty Ltd, version 11) and analysed using thematic analysis.<sup>11,12</sup> RCW developed a list of initial codes, then SCP trialled the codes on two transcripts, they then compared the application of coding and clarified before developing a codebook. The codebook was also discussed with the two interviewers, and consensus on the coding application was achieved. RCW and SCP then independently coded all transcripts, meeting regularly to discuss emerging patterns. Together, RCW and SP developed a preliminary thematic framework, which was reviewed and discussed by all other authors. The coding schema was refined through iterative discussions among all authors. CW provided indigenous cultural oversight during study conduct.

**Table 1.** Patient participant characteristics.

Sex	n (%)
Female	13 (48)
Male	14 (52)
Marital status	
Married/de facto	19 (70)
Single/separated/divorced	7 (26)
Widowed	1 (4)
Age (years)	
18–30	1 (4)
31–40	6 (22)
41–50	2 (7)
51–60	5 (19)
61–70	6 (22)
>70	6 (22)
Not specified	1 (4)
	Av age 58
Ethnicity	
New Zealand European	14 (52)
Māori	5 (18)
Pasifika	2 (7)
Chinese	1 (4)
Indian	1 (4)
Other	3 (11)
Not specified	1 (4)
Dialysis experience	
Shortest time	4 months
Longest time	20 years
Average	5 years
Dialysis modality	
PD	13 (48)
HHD	7 (26)
Both	7 (26)
Employment	
Beneficiary or not in paid work	12 (45)
Full time	2 (7)
Part time	3 (11)
Retired	9 (33)
Not specified	1 (4)
Highest qualification	
High school	13 (48)
Trade certificate	3 (11)
Post-graduate	9 (37)
Not specified	1 (4)
Interview beneficiary/unemployed	
Video call	12 (45)
Phone	12 (45)
Face to face	3 (10)

PD: peritoneal dialysis; HHD: home haemodialysis.

## Results

Thirty-six consumers participated (aged from 24 years to 70+ years), including nine caregivers/partners. Table 1 provides the demographic characteristics of the 27 patient participants. Six couples were interviewed together, and an additional three people were interviewed on behalf of their partners who had experienced home dialysis. Of these three patient partners, one had dementia and two did not want to be interviewed. Twenty participants identified as female and 16 as male. Of the 27 patients interviewed, 13 had

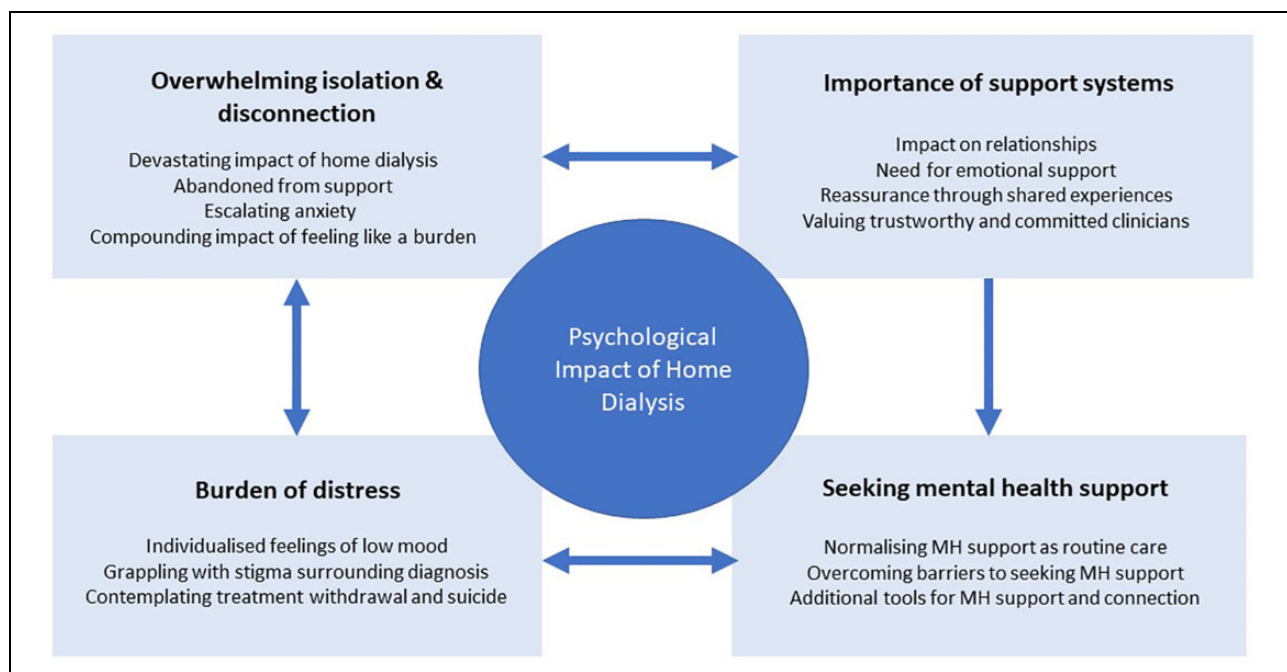
experienced peritoneal dialysis, 7 home haemodialysis and 7 had experienced both. Of the caregivers/partners interviewed, seven were female and two male, the average age was 60 and five of the nine were currently in paid employment. Four participants were interviewed face to face, 15 via videoconferencing and 7 via telephone.

Four themes and related subthemes were identified: overwhelming isolation and disconnection (devastating isolation of home dialysis; abandoned from support; escalating anxiety; compounding impact of feeling like a burden); importance of support systems (impact on relationships; need for emotional support; reassurance through shared experiences; valuing trustworthy and committed clinicians); burden of distress (individualised feelings of low mood; grappling with stigma surrounding diagnosis; contemplating treatment withdrawal and suicide); seeking mental health support (normalising mental health support as a distinct entity in dialysis care; overcoming barriers of seeking mental health support; additional tools for mental health support and connection). These themes are shown within a conceptual framework (Figure 1). All themes and subthemes were discussed by both patients and caregivers/partners. Although caregivers did not discuss their own burden of distress, they did describe those of their partner. Themes and subthemes therefore represent both patients and caregivers, and if there were findings specific to either group, it is stated. Selected participant quotations representing each subtheme are detailed in Table 2.

### *Overwhelming isolation and disconnection*

*Devastating isolation of home dialysis.* Patients described an overwhelming sense of isolation on home dialysis. For some, this was based on being confined within their home. Caregivers also often felt left out from ‘normal activities’ and restricted in their social connections. Disconnection further exacerbated anxiety and ‘dark thoughts’ (*participant 10*). For those who had also experienced facility haemodialysis, the contrast of this with home dialysis and having no one to talk to while on dialysis was unrelenting. Participants who had been on home dialysis during Covid-19 discussed how periods of restrictions and lockdowns compounded their isolation from family, friends and peers, ‘the hardest part I think for me was “cause it was during Covid . . .” cause I wasn’t there to go and talk to some of the patients because of Covid and restrictions’ (*participant 25*).

*Abandoned from support.* Many participants felt abandoned by family, friends and healthcare staff, describing ‘being forgotten’ (*participant 24*) over time. Some felt that because others didn’t understand the emotional toll of home dialysis, it was difficult to talk about their emotions and ask for support, and when they did talk about their experiences, their friendships became strained and they



**Figure 1.** Participants identified the overwhelming isolation and disconnection arising from dialysis treatment at home. This isolation was exacerbated by feeling abandoned by clinical staff and support systems, which in turn led to escalating and poorly controlled anxiety. Patients felt like a burden to family and carers and avoided discussing their psychological concerns. Unsupported and unspoken psychological distress further strained their support systems and directly impacted trust within their close relationships. Consumers additionally lost trust in their healthcare professionals and felt neglected by the health system. Conversely, support systems were central to emotional support and included peer support and trusted clinicians. Psychological experiences were sometimes constant and unrelenting and also could be a variable leading patients to doubt whether they had a problem or needed support. The burden of psychological and emotional distress was so severe that many patients contemplated ending their life or withdrawing from treatment. Stigma prevented patients from seeking mental health care and delivery of psychological care to dialysis patients was poor.

‘lost contact’ (*participant 26a*). Some participants discussed Covid-19 restrictions as further exacerbating this feeling of being abandoned as restrictions limited nurses and other supports from visiting them at home, ‘obviously with Covid there hasn’t been much of that calling in lately’ (*participant 13*).

**Escalating anxiety.** Home dialysis created ‘a lot of those little doubts and anxieties’ (*participant 8*). As this anxiety was not addressed, it escalated resulting in feeling ‘stressed about everything and always on edge’ (*participant 5*). This often resulted in a change in personality and how this ‘underlying pressure’ (*participant 18*) impacted their lives. For some, anxiety also resulted in panic attacks or out of character outbursts of anger ‘he’d get angry and start throwing things around that he could reach’ (*participant 15a*).

**Compounding impact of feeling like a burden.** Many patients felt guilty of being a burden to their friends, family and partner. This resulted in them not ‘making space for my own needs’ (*participant 22*). They felt home dialysis was ‘putting a lot of pressure on other people’ (*participant 23a*), and they didn’t want to add to this by being an emotional burden. In contrast, the caregivers being interviewed felt

upset that their (patient) partner wasn’t being open about their emotions.

### Importance of support systems

**Impact on relationships.** Home dialysis caused tension in relationships. For some caregivers, they resented their partner being on dialysis because they were unable to contribute to parenting or social activities. Dialysis at home also resulted in changed roles within relationships and reduced intimacy ‘he has his own room and I have my own room. Obviously, that’s affected our relationship’ (*carer 10b*).

**Need for emotional support.** The importance of having family to ‘share the mental load’ (*participant 19*) was a key factor in dealing with the psychological impacts of home dialysis. Many described the need for emotional support and to have someone ‘being there’ (*participant 8*). Some described how discussing their feelings with someone they were already close to was better than seeing a trained professional. ‘I don’t really need to talk to someone external about it. We just deal with it together’ (*carer 10b*).

**Reassurance through shared experiences.** Patients found peer support from other people on dialysis who they could relate to, be honest with and reciprocate support. Those who

**Table 2.** Selected participant quotations.

Overwhelming isolation and disconnection	
Devastating isolation of home dialysis	'Dialysis has really taken a toll on XX in terms of the isolation. To have him separated from us. He goes to bed early and so he misses out on quite a lot of time at the end of night and he's in his room' (Female carer); 'To be aware of mental health, just watch yourself . . . That would be my golden piece of advice just watch yourself cause it's gonna be hard, you're on your own and it's really hard' (Male patient); 'I don't know what is going to come because I don't want to continue like this, taking care of him all the time. It's making me crazy' (Female carer); 'I do feel stressed about it sometimes. I feel like I manage it pretty well, but just even talking about it with you now, I feel myself tearing up about it' (Male patient)
Abandoned from support	'It was so scary and always stressed. My health was deteriorating. I had to keep talking to the doctor'(Male patient); 'when you've suddenly lost all your friends, you've lost all your family, you've lost everything cause they're able to go out and do whatever and for ourselves there's nothing spontaneous there anymore'(Female patient); 'In the unit you have the nurses there all the time, and you can talk to them, but at home, you're on your own, you hardly get a visit and you just are you, by yourself' (Male patient); 'At home on dialysis, you're pretty much abandoned from support, you don't think about the emotional and mental health support you are getting by having those daily conversations with the nurses until they stop, and you wonder why it got so bad' (Female patient)
Escalating anxiety	'You're always sort of on edge, not knowing what's coming' (Female patient); 'my anxiety blew out pretty bad and I had to be . . . Well, I'm medicated now, because I was just spinning out. If I had to go out to do something, just fricking nightmare' (Male patient); 'of late my major concern is night times. The anxiety that accompanies night time not sleeping, and the anxiety of having to take yet another pill. I have the spectre of dialysis hovering over me all the time. So my quality of life at the moment I would say is about as bad as you can get' (Male patient); 'My husband used to be very relaxed and easy going but it's not the case, things upset him more than they used to because of the pressure of it I think. Last Thursday night we had a power cut and he just lost the plot where normally it wouldn't even bother him. It has more of an underlying pressure on your life than you realise at times' (Female carer)
Compounding impact of feeling like a burden	'I would always hold back when I was talking to family, not be fully open the extent of how tired I was' (Female patient); 'I struggle now even with making space for my own needs where I perceive those needs to be a burden for someone else. Like there's a lot of trying to make myself take up the least amount of space possible in someone else's life . . . I would feel bad if I was to bug someone with my feelings' (Female patient); 'When you are on dialysis, you already feel like a burden, you are so restricted in what you can do, the last thing you want to do is then start telling people about how mentally hard it is, and down you are, you'd have no one left, so you don't, and then it gets worse, and worse' (Female patient)
Importance of support systems	
Impact on relationships	'My mum and dad get affected by it quite a lot I think. And my brothers' (Male patient); 'it's created quite a bit of tension in our relationship . . . Just really the resentment of him not being around to help . . . every now and then when things get really stressful with the kids and he's not around here, I do tend to snap at him' (Female carer); 'And it's important for their support people to be aware of signals, and be kind because the frustration is not focused at them, it's just frustration' (Male patient); 'I'm probably not the most outward going person where that's concerned. I'm old school and I tend to keep it up, bottle it up inside and sometimes unfortunately for XX I do take it out on XX. I try not to but, you know' (Male patient)
Need for emotional support	'It's good to talk to other people . . . I certainly know when we've talked about it we wished we'd had more support before X gone on it' (Female carer); 'you know if you can talk it through with family, friends, if you have that option to be honest about your mental health then you share the mental load, it's not as hard' (Male patient)
Reassurance through shared experiences	'what would be great if you know knowing other dialysis patients in this area like there's no support groups, I don't know anyone else doing dialysis so I can't even message someone and say I'm having a shit day this is how I'm feeling, what do you, you know because they, I don't have anyone' (Female patient)
Valuing trustworthy and committed clinicians	'I have a really good dialysis nurse . . . really supportive and everything. I'm thankful for that' (Female patient); 'They [nurses] are all absolutely wonderful. And that makes a hell of a difference . . . , they've been there for a long time and you just feel so comfortable. Well I feel so comfortable with any of them' (Male patient); 'the doctor picked up on it and said you know do you get depressed and things. That was the first time we had that conversation. Just every so often it just gets him down' (Female carer)

(continued)

**Table 2.** (continued)

Burden of distress	
Individualised feelings of low mood	'I did have some pills to take you know some, you know happy pills . . . my friend told me XX take them. You'll feel so much better (Female patient); 'well I'd had moments you know like you get a little bit frustrated. But I don't think I've actually had depression as such. I usually sort of work things through myself if sometimes I've been down a little, but I've always sort of come back' (Male patient); 'You wouldn't be a kidney failure person without stroking the black dog every now and then. You just wouldn't. I just can't see how you could travel this path and not need help, mental help because it's a tough path' (Male patient)
Grappling with stigma surrounding diagnosis	'I wouldn't say I've ever had issues with depression. Which is good. My dad has pushed me numerous times to take anti-depressants but I said no I don't need those' (Female patient); 'It's sad really. Not really depressed. I don't know, it might be the same thing Yeah, I think XX has depression. I just think he does really good at masking it' (Female carer); 'I don't think so, not the clinical version of it. Sure, I have days where I feel down about it, but I don't think I'm a depression kind of person. I don't know, the whole situation's depressing' (Female patient); 'I was just like yeah I'm tired of being depressed you know. I mean but at the same time I was kind of sort of like I'm not depressed, what are you talking about. I'm fine you know. But I've noticed that yeah no I was very depressed. I've still got it, but I wouldn't say clinically' (Male patient)
Contemplating treatment withdrawal and suicide	'I have quite extensive conversations with terminating life, what are they called end life process. I've contacted the end life team, in other words euthanasia team' (Male patient); 'for me, my depression was so deep that I did try to end it. That was just because at the time there were so many different things happening with my health and I just felt I've had enough' (Female patient); 'I did have some suicidal ideation during that phase of my spiritual health was real bad' (Female patient)
Seeking mental health support	
Normalising mental health support as a distinct entity in dialysis care	'The nurse needs to be able to refer me on for this'(Female patient); 'there's not enough support on the true journey of it . . . nothing to help with the emotional side of it'(Male patient); 'I feel like if they had counselling just maybe once or twice during their training process, or just even when they're getting used to . . . even after they get their initial diagnosis, I think that would be really helpful to just have someone to talk to about how you're feeling' (Female patient); 'they have to address the mental AND physical health' (Male patient)
Overcoming barriers to seeking mental health support	'I don't get any (support). . . I've tried numerous times to get support from our social worker. Absolutely no help whatsoever. Like no help. Nothing. So yeah, I've just given up to be honest' (Female patient); 'I won't get well physically without getting mentally well. So back when I first started and I realised that I was really low, low I said to my nurse I'm, you know this is, I'm feeling, I'm bad and he said you need to get a, go to your GP and get a referral and that's the way to have to do it, like he's got, he can't do it, you have to go through your GP and it's silly. . . . I was just at breaking point' (Female patient); 'I don't have any money so I don't pay for, I can't pay for counselling. So, it had to be a pathway, so you have to go through your GP, it's really hard to go and tell someone that you're feeling like you want to kill yourself you know that's huge' (Female patient)
Additional tools for mental health support and connection	'There is so much technology around, so many apps and things, but none are used' (Male patient); 'if we had something like a mood indicator on our machine, you could do that remotely everyday, then someone would see that the last two days there's a crying face and call you, instead of you having to try and ring and tell someone how you feel' (Female patient); 'it's hard to start a mental health conversation, easier if there's a cue for your nurse or doc to bring it up with you' (Male patient)

didn't have peer support discussed how this would have provided them with reassurance and help to normalise their feelings. 'I would have just loved for somebody in my age group say, that went through the same thing that rang me up and said hey you're going to be okay' (*participant 6*).

**Valuing trustworthy and committed clinicians.** Many participants felt supported by a trusting relationship with their dialysis nurse or doctor. They could talk openly with them about their emotional and mental health and seek appropriate support when needed. Many appreciated their clinician knowing them so well that they initiated a conversation

about the patient's mental health having deteriorated: 'With my consultant, he reached out to mental health for me, and I got an acute team to sort me out' (*participant 12*).

### **Burden of distress**

**Individualised feelings of low mood.** Participants openly discussed their struggles with low mood and their experience that feeling low was normal and acceptable. Many described 'a sliding scale' (*participant 20*) of mood, where certain challenges and changes led to a lower mood, while some days were better.

**Grappling with stigma surrounding diagnosis.** Patients described being on a spectrum of sadness and debated within themselves about whether sadness or ‘down’ days were normal considering the ‘situation’s depressing’ (*participant 13a*) or whether they were clinically depressed. Some didn’t consider themselves depressed as they hadn’t received a clinical assessment and been given a diagnosis. ‘I don’t think I’ve had depression. But yes, I get depressed, but no, I don’t have depression’ (*participant 13a*). Others also discussed that their family members considered them depressed and needing antidepressants, but they themselves knew that this would be a passing phase. Others found it difficult that other people didn’t ‘see’ that they were depressed even when they told them.

**Contemplating treatment withdrawal and suicide.** Several patients discussed that they had seriously contemplating ending their lives. Some had discussed suicidal thoughts openly with their medical team and sought help for this, understanding that they needed immediate help. Others had ‘quite extensive conversations about terminating life, I’ve contacted the end-of-life team, in other words euthanasia team’ (*participant 16*).

### Seeking mental health support

**Normalising mental health support as a distinct entity in dialysis care.** Participants felt mental health support was not valued the same as physical support. Those who had tried to access mental health support had given up asking as they had ‘tried numerous times. . . Absolutely no help whatsoever’ (*participant 11*). Wait times were perceived as too long, and during this delay, there was no ‘platform where I feel I can voice out my concerns’ (*participant 1*). They felt frustrated that the system did not ‘work for the patient’ (*participant 5*), as they then had to tell more than one person that they weren’t coping and ‘it’s really hard to go and tell someone that you’re feeling like you want to kill yourself’ (*participant 5*).

**Overcoming barriers to seeking mental health support.** The stigma of seeking counselling or mental health support created challenges, particularly as there was a lack of understanding within their families and communities about depression and anxiety. For some, this meant that they were ‘putting on a happy face’ (*participant 10b*). For others who were diagnosed with depression, they spoke of how this was not acknowledged or validated by others ‘it’s really hard for people to see that when you don’t present as someone who’s literally on the edge of topping yourself’ (*participant 20*). For some seeking mental health support made them feel like they were ‘weak’ or ‘crazy’ (*participant 19*).

**Additional tools for mental health support and connection.** Telemedicine, information technology or digital apps were seen as potential ways to improve access to mental health support for home patients. Tools such as these would enable

contact with health services for ‘a question or a worry or a concern that can be answered. You know just in a quick message would be so, so good’ (*participant 11*). Others saw potential in being able to report quickly and easily a ‘mood indicator’ (*participant 17*) so that it helped clinical staff to monitor changes in mood. There was also a perceived benefit in being able to reach out and ‘remain anonymous’ (*participant 1*).

## Discussion

This in-depth interview study with consumers experiencing home-based dialysis identified overwhelming isolation and disconnection arising from dialysis treatment at home. This isolation was exacerbated by feeling abandoned by clinical staff and support systems, which in turn led to escalating and poorly controlled anxiety. Patients felt like a burden and avoided discussing their psychological concerns. Unsupported and unspoken psychological distress further strained their support systems and directly impacted trust within their close relationships.

Conversely, support systems of family and friends were central to emotional support. Patients also received reassurance through connecting with peers with kidney disease, which enabled their experiences to be validated and enabled them to offer reciprocated care. They particularly valued clinicians whom they could trust and who identified their mental health needs spontaneously and routinely. The psychological experiences were sometimes a constant and unrelenting struggle, and also could be variable and changing often, leading patients to doubt whether they had a problem or needed support. The burden of psychological and emotional distress was so severe that many patients contemplated ending their life or withdrawing from treatment. Stigma prevented patients from seeking mental health care, and delivery of psychological care to dialysis patients was poor. Patients wanted mental health care to be routinely provided in dialysis services and also remotely accessible and non-judgemental.

In this study, consumers reported that clinicians who routinely considered the psychological aspects of home dialysis provided consumers with early access to care, identified symptoms promptly, discussed and treated symptoms and provided early referral to additional services. Other studies have also associated strong clinician support with enabling effective management of distress<sup>14</sup> and continuity of care and good clinician communication with enabling smooth transitions between health providers.<sup>15</sup> Similarly, research in cancer care has demonstrated that poor clinician communication was associated with high levels of psychological distress for consumers.<sup>16</sup> Likewise, enhanced and routinely delivered psychosocial support can significantly reduce caregiver burden and anxiety.<sup>17</sup> This emphasises the importance of clinician literacy and effective communication related to psychological well-being, which has been effective in advanced care planning in kidney patients<sup>18</sup>

and similarly may have benefits in identifying and supporting consumer mental health for home dialysis.

Our study also identified the stigma of a mental health diagnosis for patients and the challenges this added to seeking and accessing mental health support. To limit the requirement for consumers to access care in the context of stigma and poorly designed services, these consumer-based perspectives indicate that delivering mental health services routinely in home dialysis care is recommended, particularly given the high prevalence of both depression and anxiety in this group of patients.<sup>3</sup> Similar studies of patients and caregivers of those receiving facility dialysis have also identified the huge hidden burden of depressive symptoms and depressive illness in patients with CKD<sup>19</sup> and the lack of support services.<sup>20</sup> Training staff to support patients dialysing at home in psychological care is important, particularly given that patients in our study preferred talking to trusted clinical staff over specialty mental health clinicians who they didn't know. In a previous study, brief low-intensity psychological therapy delivered in partnership with nurses already involved in the patients' care, reduced depression.<sup>21</sup>

The experiences of patients and caregivers in our study support the implementation and evaluation of routine mental health support for consumers of home dialysis, particularly among those at risk of low adherence, suicidality and withdrawal from care. Given the feelings of isolation and abandonment discussed by participants, increasing nursing support and home contacts may be an important quality improvement for home dialysis care. Other studies in cancer care have identified patients perceive nurses as their primary point of contact for health-related issues and emotional support.<sup>15</sup> Participants in our study identified solutions to increase support and mental health well-being in the form of peer support. Peer support is already identified in research as important in supporting patients on home dialysis.<sup>22–26</sup> Alternative models of care that support patient well-being on home dialysis include community home dialysis where patients reported positive effects of 'home' dialysis in a community environment on their emotional and psychological well-being.<sup>22</sup>

The strengths of this study include interviewing a diverse range of consumers at a national level and member checking of transcripts by participants. Participants were offered the opportunity to review both their transcripts and the final interpretation of findings.

A limitation of the study may be the self-identification of participants. Although generalisability is not recognised as a limitation of qualitative studies, it could be postulated that New Zealand might be different from other health jurisdictions in that services, accessibility of psychological support may be more accessible in other countries, and access to mental health services may be different across regional areas and between units. We also only interviewed consumers, and there may be additional benefits to understanding clinician viewpoints on this topic. Our study was

conducted over the time of Covid-19 social restrictions, and these may have exacerbated feelings of isolation and loneliness for participants.

In conclusion, consumers may experience intense psychological distress during home-based dialysis care. Increasing clinician and health services literacy about the management of psychological impacts of home-based dialysis may improve consumer safety, quality of life and sustainability of home treatment.

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### **Author contributions**

Research idea and study design: RCW, SCP, CW; data acquisition: RCW, SH, RH; data analysis/interpretation: RCW, SCP, CW, SH, RH, AR. Each author contributed important intellectual content during manuscript drafting or revision and accepts accountability for the overall work by ensuring that questions pertaining to the accuracy or integrity of any portion of the work are appropriately investigated and resolved.

### **Declaration of conflicting interests**

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### **Informed consent to participate**

All participants provided written informed consent to participate in this study.

### **Informed consent to publish**

None.

### **Supplemental material**

Supplemental material for this article is available online.



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