Original Clinical Research Quantitative

How Are Albertans "Adjusting to and Coping With" Dialysis? A Cross-Sectional Survey

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Abstract

Background: Depression and anxiety are commonly reported (40% and 11%-52%) among adults receiving dialysis, compared with ~10% among all Canadians. Mental health in dialysis care is underrecognized and undertreated.

Objective: (1) To describe preferences for mental health support reported by Albertans receiving dialysis; (2) to compare depression, anxiety, and quality-of-life (QOL) domains for people who would or would not engage in support for mental health; and (3) to explore sociodemographic, mental health, and QOL domains that explain whether people would or would not engage in support for mental health.

Design: A cross-sectional survey.

Setting: Alberta, Canada.

Patients: Adults receiving all modalities of dialysis (N = 2972).

Measurements: An online survey with questions about preferences for mental health support and patient-reported outcome measures (Patient Health Questionnaire–9 [PHQ-9], Generalized Anxiety Disorder–7 [GAD-7], and Kidney Disease QOL Instrument–36 [KDQOL-36]).

Methods: To address objectives 1 and 2, we conducted chi-square tests (for discrete variables) and t tests (for continuous variables) to compare the distributions of the above measures for two groups: Albertans receiving dialysis who would engage or would not engage in support for mental health. We subsequently conducted a series of binary logistic regressions guided by the purposeful variable selection approach to identify a subset of the most relevant explanatory variables for determining whether or not people are more likely to engage in support for mental health (objective 3). To further explain differences between the two groups, we analyzed open-text comments following a summative content analysis approach.

Results: Among 384 respondents, 72 did not provide a dialysis modality or answer the PHQ-9. The final data set included responses from 312 participants. Of these, 59.6% would consider engaging in support, including discussing medication with a family doctor (72.1%) or nephrologist (62.9%), peer support groups (64.9%), and talk therapy (60%). Phone was slightly favored (73%) over in person at dialysis (67.6%), outpatient (67.2%), or video (59.4%). Moderate to severe depressive symptoms (PHQ-9 score ≥10) was reported by 33.4%, and most respondents (63.9%) reported minimal anxiety symptoms; 36.1% reported mild to severe anxiety symptoms (GAD-7 score ≥5). The mean (SD) PHQ-9 score was 8.9 (6.4) for those who would engage in support, and lower at 5.8 (4.8) for those who would not. The mean (SD) GAD-7 score was 5.2 (5.6) for those who would engage in support and 2.8 (4.1) for those who would not. In the final logistic regression model, people who were unable to work had 2 times the odds of engaging in support than people who are able to work. People were also more likely to engage in support if they had been on dialysis for fewer years and had lower (worse) mental health scores (odds ratios = 1.06 and 1.38, respectively). The final model explained 15.5% (Nagelkerke R^2) of the variance and with 66.6% correct classification. We analyzed 146 comments in response to the question, "Is there anything else you like to tell us." The top 2 categories for both groups were QOL and impact of dialysis environment. The third category differed: those who would engage wrote about support, whereas those who would not engage wrote about "dialysis is the least of my worries."

Limitations: A low response rate of 12.9% limits representativeness; people who chose not to participate may have different experiences of mental health.

Conclusions: Incorporating patients' preferences and willingness to engage in support for mental health will inform future visioning for person-centered mental health care in dialysis.

Abrégé

Contexte: La dépression et l'anxiété sont plus fréquemment signalées chez les adultes traités par dialyse (dépression: 40 %; anxiété: 11 à 52 %) comparativement à la population canadienne (environ 10 %). Les problèmes de santé mentale sont insuffisamment reconnus et traités dans les soins de dialyse.

Objectifs: (1) décrire les préférences en matière de soutien en santé mentale des Albertans traités par dialyse; (2) comparer les domaines de la dépression, de l'anxiété et de la qualité de vie (QV) pour les personnes désirant obtenir ou non du soutien en santé mentale; (3) explorer les domaines sociodémographiques, de santé mentale et de QV qui expliquent pourquoi une personne désirerait obtenir ou non du soutien en santé mentale.

Conception: Sondage transversal.

Cadre: Alberta, Canada.

Sujets: Adultes recevant toutes les modalités de dialyse (N=2972).

Mesures: Un sondage en ligne comportant des questions sur les préférences en matière de soutien en santé mentale. Les mesures des résultats rapportés par les patients à trois questionnaires (questionnaire-9 sur la santé des patients [PHQ-9], questionnaire-7 sur les troubles anxieux généralisés [GAD-7] et l'instrument QOL-36 pour l'insuffisance rénale [KDQOL-36]).

Méthodologie: Pour répondre aux objectifs 1 et 2, nous avons effectué des tests chi-carrés (pour les variables discrètes) et des tests t (pour les variables continues) pour comparer les distributions des mesures ci-dessus pour deux groupes: les Albertains sous dialyse désirant obtenir ou non du soutien en santé mentale. Une série de régressions logistiques binaires guidées par une approche de sélection ciblée des variables a ensuite été effectuée pour identifier un sous-ensemble des plus pertinentes variables explicatives permettant de déterminer si les gens sont plus susceptibles de vouloir obtenir du soutien en santé mentale (objectif 3). Pour expliquer plus précisément les différences entre les deux groupes, nous avons analysé les commentaires en texte ouvert en suivant une approche d'analyse de contenu sommative.

Résultats: Des 384 répondants, 72 n'ont pas indiqué de modalité de dialyse ni répondu au questionnaire PHQ-9. L'ensemble de données final comprend les réponses de 312 patients. De ce nombre, 59,6 % envisageraient d'obtenir du soutien, notamment une discussion sur les médicaments avec un médecin de famille (72,1 %) ou un néphrologue (62,9 %), une participation à des groupes de soutien par les pairs (64,9 %) ou une psychothérapie (60 %). Les répondants préféraient le téléphone (73 %) plutôt qu'une visite en personne pendant la dialyse (67,6 %), qu'une consultation externe (67,2 %) ou qu'une consultation vidéo (59,4 %). Des symptômes dépressifs modérés à graves (score PHQ-9 $\geq$10) ont été rapportés par 33,4 % des répondants. La plupart des répondants (63,9 %) a signalé des symptômes minimes d'anxiété et 36,1 % ont signalé des symptômes d'anxiété légers à graves (score GAD-7 $\geq$5). Le score moyen (É-T) au PHQ-9 était de 8,9 (6,4) pour les sujets qui désiraient obtenir du soutien et de 5,8 (4,8) pour ceux qui n'en désiraient pas. Le score moyen (É-T) au GAD-7 était de 5,2 (5,6) pour les sujets qui désiraient obtenir du soutien et de 2,8 (4,1) pour ceux qui n'en désiraient pas. Dans le modèle final de régression logistique, les personnes qui ne pouvaient pas travailler étaient deux fois plus susceptibles de vouloir chercher du soutien que celles qui pouvaient travailler. Les répondants étaient également plus susceptibles de se faire aider s'ils étaient sous dialyse depuis moins longtemps et avaient des scores de santé mentale inférieurs (les plus faibles) (rapports de cotes respectifs: 1,06 et 1,38). Le modèle final expliquait 15,5 % (Nagelkerke R^2) de la variance avec 66,6 % de classification correcte. Nous avons analysé 146 réponses à la question: *«Y a-t-il autre chose que vous souhaiteriez nous dire?»* Dans les deux groupes, les deux principales catégories étaient la QV et l'impact de l'environnement de dialyse. La troisième catégorie différait: ceux qui en obtenaient écrivaient sur le soutien, alors que ceux qui n'en obtenaient pas ont indiqué que la *«dialyse était le moindre de leurs soucis».*

Limites: Le faible taux de réponse (12,9 %) limite la représentativité; les personnes qui ont choisi de ne pas participer pourraient avoir des expériences différentes en matière de santé mentale.

Conclusion: L'intégration des préférences des patients et de leur volonté d'obtenir du soutien en santé mentale permettra d'éclairer la vision future des soins de santé mentale axés sur les patients traités par dialyse.

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What Was Known Before

- Mental health concerns, especially depression and anxiety, experienced by people receiving dialysis are higher than in the general public.
- The perspectives of people receiving dialysis regarding mental health supports have rarely been addressed.
- Canadians receiving dialysis have resoundingly said that their mental health is a priority.

What This Adds

- Most people with worse scores for depression, anxiety, and quality of life would consider engaging in mental health supports.
- Phone (73%), in person during dialysis (67.6%), outpatient (67.2%), and real-time video (59.4%) were all acceptable modes of mental health support.
- People receiving dialysis were more likely to engage in support if they were unable to work (due to disability or health status), had been on dialysis for fewer years, and had lower (worse) mental health scores (odds ratios [ORs] = 1.99, 1.06, and 1.38, respectively).

Introduction

> Coping with kidney disease is a mental milestone, it's self-consuming. Dealing with anxiety and depression is always there, and is always at the forefront. It feels like there's nothing I can do about it, or anything there to help me.
>
> —Survey participant

People receiving dialysis are more likely to suffer from mental health symptoms but less likely to receive treatment than the general population.[1] The most common mental health symptoms reported by people receiving dialysis are depression and anxiety (40%[2] and 11%-52%[1]), significantly higher than 5% and 3%, respectively, reported by all Canadians.[3] Mental health symptoms are underdiagnosed and undertreated among Canadians on dialysis and deserve attention;[4-7] the need for support is now greater.

For the >40 000 Canadians receiving dialysis,[8] depressive symptoms remain.[4-6] While clinicians may be reluctant to prescribe antidepressants due to inconclusive medication trials,[9] kidney function affecting effectiveness, and medication contraindications,[4,9-11] people receiving dialysis are also reluctant to take antidepressants due to side effects, medication interactions, or stigma.[4,9] But pharmaceutical interventions are only one form of potential support; psychosocial interventions may be more preferable,[9] with cognitive-behavioral therapy supported with the strongest evidence of efficacy and effectiveness.[12,13] Anxiety often coexists with depression for people receiving dialysis treatment.[14] Yet the literature and evidence base on prevalence of anxiety is scant despite its frequent presentation.[15] Both depression and anxiety are associated with devastating consequences for the people who are living with these symptoms, including but certainly not limited to increased mortality[14-17] and poor quality of life (QOL).[14-16,18,19]

Patients and clinicians first alerted us to this need: We identified that mental health symptoms experienced by Canadians receiving dialysis are not routinely assessed and inadequately addressed.[6,20-24] This was confirmed in our realist synthesis on patient-reported outcome use in kidney care[25-27] and by some of our community advisors in a kidney patient-led Patient and Community Engagement Research (PaCER) study on mental wellness[28] who wrote, "the most glaring gap in care is the lack of psychosocial support available to patients" (p. 3). However, the perspectives of people receiving dialysis regarding mental health supports have rarely been addressed.

Would people experiencing mental health challenges while receiving dialysis treatment be willing to engage in mental health support? An assumption may be that due to the natures of these challenges, no, they would most often not be willing. But have we asked people with this lived experience? Wuerth et al[29] found that people receiving peritoneal dialysis frequently refused assessment and treatment for depressive symptoms, despite discussions involving the health care team and patient about potential benefits. In Canada, Farrokhi et al[30] surveyed people receiving hemodialysis about their perceived barriers to participating in screening and treatment for depression. The most common perceived barriers were side effects from prescribed antidepressants (40%), more medications (32%), not seeing the problem as severe (23%), and not perceiving risk of depression (23%). The global Standardized Outcomes in Nephrology (SONG) hemodialysis and peritoneal dialysis initiatives conducted a secondary analysis of 26 focus groups from 6 countries with 644 patients and caregivers to describe their perspectives on mental health in dialysis.[31] Participants highlighted the need for mental health supports, especially when considering either to continue or withdraw from dialysis. Given that we now understand mental health symptoms are often not addressed, would people receiving dialysis treatment be willing to engage in support for mental health?

In collaboration with Alberta Kidney Care North and South, our objectives were as follows:

1. To describe preferences for mental health support reported by Albertans receiving dialysis.
2. To compare depression, anxiety, and QOL domains for people who would or would not engage in support for mental health.
3. To explore sociodemographic, mental health, and QOL domains that explain whether people would or would not engage in support for mental health.

Methods

Study design

We conducted a cross-sectional survey. We undertook this patient-oriented research in collaboration with (1) an

International Methods Advisory Committee, (2) a Community Advisory Committee, (3) the Medicine Strategic Clinical Network—Kidney Health Section, and (4) Alberta Kidney Care North and South. The Community Advisory Committee included people on dialysis, a family caregiver of a person on dialysis, kidney transplant recipients, renal cancer survivors, and kidney community members.

The study received ethics approval from the University of Alberta (No. Pro00102704), the University of Calgary (No. REB20-1585), and Northern Alberta Clinical Trials and Research Center (No. PRJ37694).

Survey content

We developed a survey that included a demographic section, preferences for mental health treatment, validated patient-reported outcome measures, including the Patient Health Questionnaire–9 (PHQ-9),[32,33] the Generalized Anxiety Disorder–7 (GAD-7),[34] and the Kidney Disease QOL Instrument–36 (KDQOL-36),[35,36] and an open comment box (see Supplemental File 1). The survey was provided only in English because the project did not have the funds to cover the costs for required translational work into the top 3 to 5 languages used by Albertans receiving dialysis treatment (Arabic, simplified Chinese, traditional Chinese, Punjabi, and Vietnamese). Following the advice of our Community Advisors, throughout the survey we used the term "adjusting to and coping with dialysis" instead of "mental health." For example, in the introduction, we wrote: "Imagine that you are having some challenges adjusting to or coping with dialysis. This could include experiencing depression, anxiety, ongoing sadness, persistent trouble sleeping, frequent mood changes, and so on." A listing of free resources was provided at the end of the survey, including peer support, mental health, and kidney supports (see https://www.healthyqol.com/kidney).

Survey Pretest

The survey was pretested with people receiving dialysis in December 2020 to assess duration and feasibility. Participants for the pretest were recruited through Community Advisory Committee members and people who participated in a previous study and had provided consent to contact for future research. In total, 5 people provided feedback on the draft survey. Two pretest protocols were used. In one protocol, we asked people to record how long it took them to complete the survey, and then engage in a discussion about the survey. In the other protocol, we asked people to provide live feedback while on the phone during their completion of the survey. Changes were made to survey content based on their feedback. The survey was then programmed into the platform REDCap,[37,38] and members of the research team and the Community Advisory Committee provided feedback on the online format.

Participant Recruitment

During the COVID pandemic, on January 8, 2021, an invitation letter was mailed to the homes of all adult Albertans receiving all forms of dialysis (n = 2972). The URL for the survey link was provided only in the mailed letter of invitation. This approach was selected to ensure that only people receiving dialysis had access to the survey link. Recruitment posters were also displayed in all Albertan dialysis clinics. The Kidney Foundation of Canada (KFOC), Northern Alberta & the Territories Branch, and the Southern Alberta Branch, also invited people to participate through their newsletters, Facebook posts, and tweets. People were invited to complete the survey online, through phone or paper. Upon completing the survey, all participants could enter a draw for a previously used tablet or one of 10 grocery gift cards for Can$25.

With the support of Alberta Kidney Care North and South, additional recruitment measures to boost the response rate were added from February 22 to March 7, 2021. Poster handouts were given to all patients arriving for in-center dialysis, and home dialysis managers were asked to share the survey link and/or phone number with patients during telehealth appointments. Another round of social media posts through Facebook and Twitter were distributed by KFOC. These efforts had minimal impact: 12 new paper survey requests and 55 participants entered the online survey. In retrospect, mailing invitation letters to peoples' homes was significantly more effective than handing out posters and promptings by clinicians.

Data Analysis

We performed analyses using SPSS Statistics for Windows, Version IBM SPSS 27 (SPSS Inc., Chicago, Ilinois). To address objectives 1 and 2, we calculated proportions and conducted chi-square tests to describe and compare the distributions of the discrete variables for two groups: Albertans receiving dialysis who would engage and those who would not engage in support for mental health. We calculated means and standard deviations to describe the distributions of the continuous variables (objective 1), and obtained unadjusted odds ratios (ORs) with confidence intervals to compare differences across the two groups (objective 2). To address objective 3, we conducted a series of binary logistic regressions and were guided by the purposeful variable selection approach (by Hosmer, Lemeshow, and Sturdivant)[39] to identify a sub set of the most relevant explanatory variables for determining whether or not people are more likely to engage in support for mental health. We first included all variables with a univariate *P* value of .25 and then iteratively reentered and removed variables to arrive at a final model that includes all variables that had parameter estimate *P* values of <.05 as well as potential confounders that influenced parameter estimates for one or more of the other variables by more than

20% (regardless of statistical significance). We examined missing data patterns. To avoid inconsistent exclusions of respondents and biased estimates in the multivariable regression analysis due to missing responses, we applied multiple imputation, using chained equations, to impute 20 data sets for the multivariable regression analysis (2.65% imputed data). To further explain differences between the two groups, we analyzed open text comments following a summative content analysis approach.[40] Two team members worked together to develop a list of categories and subcategories of participants' statements regarding depression, anxiety, and QOL. QOL categories were informed by the five domains of the KDQOL-36. After all open texts were categorized, the team members compared and contrasted responses for people who would or would not engage in support for mental health.

Results

Response Rate and Demographics of Participants

Of the 2972 Albertans receiving dialysis who were invited to participate, 384 completed the survey for a response rate of 13%. Out of the 384, we excluded 72 who did not provide a dialysis modality and completed the PHQ-9. The final data set for the quantitative analysis consisted of responses from 312 participants. Their characteristics are shown in Table 1. To address representation, at the time of the survey, Alberta Kidney Care reported 2050 people (70%) receiving facility-based hemodialysis (our sample had 59.9%), 199 (7%) receiving home hemodialysis (our sample had 18.3%), and 679 (23%) receiving peritoneal dialysis (our sample had 21.8%). Two thirds of survey participants were male (65%), the mean age was 62.5 (SD = 13.86) years, and the mean number of years on dialysis was 3.79 (SD = 4.33 years). Most participants reported "white" as their ethnic background (75.2%).

Those who would consider engaging in mental health support (n = 186; 59.6%) had a mean age of 60.8 years and an average time on dialysis of 3.4 years. In comparison, individuals who would not consider engaging in support (n = 126) tended to be older, with a mean age of 65.0 years, and had been on dialysis longer with an average of 4.4 years (see Table 1).

Preferences for Mental Health Support

To address our first objective, in this section, we report on preferences for mental health support from the 186 patients who would consider engaging in support. Not surprisingly, 171 patients (93.4%) considered mental health support to be somewhat to very important. More than a third had previously received treatment for mental health concerns (36.6%; n = 68/186) or talk therapy (36%; n = 67/186). A fifth of participants (20.4%; n = 38/186) had past experience with peer support, either one-on-one or in groups.

We asked people to comment on the care, support, or treatment options for mental health support they would be willing to try. The majority were willing to try having a *medication discussion with a family doctor* (72.1%; however, 4.5% said they do not have one) or a *nephrologist* (62.9%), and *talk therapy* (60.0%). People were asked, "*If you were to engage in one-on-one care, who would be your preferred care provider?*" with rank options limited to family doctor or GP, psychiatrist, psychologist, registered nurse, social worker or counselor. A *family doctor or GP* was most frequently identified as the most preferred (41.8%; n = 61/146). The most frequently identified second preference was a *registered nurse* (33.1%; n = 50/151), third was a *social worker or counselor* (27.2%; n = 41/151), and fourth was a *psychologist* (31.4%; n = 44/140). *Psychiatrists* were most frequently identified as least preferred (33.8%; n = 45/133). Regarding preferences for support, participants most frequently identified *talk therapy* (29.8%; n = 37/124) and *medication discussion with a nephrologist* (27.3%; n = 35/128), whereas *referral to a psychiatrist* was most frequently identified as the least preferred option (27.6%; n = 34/123). Participants were also willing to try both peer support groups (64.9%) and one-on-one peer support (58.2%). However, 50% of them were only willing to try peer support in addition to treatment provided by a trained care provider (see Figure 1).

We asked people to comment on the mode ("places or ways") of support for mental health they would be willing to try. Participants had a similar willingness to try receiving support, but phone call was slightly preferred (73.0%) over in person at dialysis (67.6%), outpatient (67.2%), or video (59.4%; see Figure 1). When asked to rank modes of support, they could imagine them all. People preferred support *in person during in-center dialysis* (43.4%; n = 69/159), but 26.4% (n = 42/159) also ranked this as "least preferred." A similar pattern existed for support during *outpatient visits*: 29.6% (n = 40/135) ranked it as "most preferred"; on the contrary, and with minimal difference, 28.1% (n = 38/135) ranked it "least preferred." *Video call* and *phone call* ranked in the middle. Participants' preferred frequency of receiving support was *as needed* (53%; n = 96/181), once a month (26.5%; n = 48/181), or once a week (17.1%; n = 31/181).

Across all 312 respondents, the majority had access to home internet (91.6%; n = 283/312). The most common type of technology available to participants at home was a cell phone including a camera and microphone (69.9%). Two participants (0.6%) reported that they did not have access to any technology (see Table 2). Many had experience using video calls (74.8%; n = 231/312), and 70% (n = 216/312) had received care through telehealth. In addition, the majority of participants reported having a safe space to talk and receive mental health support (95.1%; n = 294/312); however, 3.9% (n = 12/312) did not have access to a safe space and 1.0% (n = 3/312) were unsure about access to a safe space.

Table 1. Characteristics of Participants.

Self-reported characteristic	Total Sample Total (n = 312) %	Would engage in support Total (n = 186) %	Would not engage in support Total (n = 126) %	P value[a]
Gender	(n = 312)	(n = 186)	(n = 126)	.812
Male	65.1	65.6	64.3	
Female	34.9	34.4	35.7	
Age	(n = 301)	(n = 178)	(n = 123)	.009
Mean years (SD)	62.54 (13.86)	60.81 (14.29)	65.05 (12.85)	
Range (min-max)	22-89	22-88	22-89	
Marital status	(n = 310)	(n = 185)	(n = 125)	.467
Married and common law	63.2	64.9	60.8	
Widowed, separated but still legally married, divorced, single never married	36.5	35.1	39.2	
Home address	(n = 305)	(n = 182)	(n = 123)	.861
Rural (less than 10 000 people)	24.9	25.3	24.4	
Urban (more than 10 000 people)	75.1	74.7	75.6	
Highest educational level	(n = 309)	(n = 186)	(n = 123)	.342
Elementary and high school[b]	35.9	32.8	40.7	
College/trade school/CÉGEP and undergraduate degree	55.3	57.5	52.0	
Postgraduate degree and other	8.7	9.7	7.3	
Employment status[b]	(n = 310)	(n = 186)	(n = 124)	
Retired (% yes)[c]	53.5	47.3	37.1	.007
Unable to work (disability/health; % yes)[c]	35.5	43.5	23.4	<.001
Working (full-time or part-time; % yes)[c]	14.2	14.5	13.5	.842
Other (% yes)[c,d]	9.7	11.3	7.3	.352
Ethnic background[b]	(n = 306)	(n = 183)	(n = 123)	
White (Caucasian; % yes)	75.2	71.6	80.5	.077
First Nations (North American Indian) and Metis (% yes)	7.5	8.2	6.5	.582
Other (% yes)[e]	17.6	20.8	13.0	.081
Missing (% yes)	2.3	1.1	4.1	.088
Current dialysis modality	(n = 312)	(n = 186)	(n = 126)	.175
Peritoneal dialysis	21.8	25.3	16.7	
Home hemodialysis and nocturnal dialysis	18.3	18.3	18.3	
In-center hemodialysis (hospital/community)	59.9	56.5	65.1	
Total numbers of years on dialysis	(n = 303)	(n = 180)	(n = 123)	.074
Mean years (SD)	3.79 (4.33)	3.40 (3.64)	4.37 (5.15)	
Range (min-max)	0-28	0-26	0-28	

[a]Based on chi-square test for categorical variables and *t* test for continuous variables.
[b]Answer categories were "select all that apply."
[c]The variables are not mutually exclusive; participants were able to "select all that apply"; for example, some people chose retired and working part-time.
[d]"Other" employment status includes homemaker, student, and unemployed.
[e]"Other" ethnic groups include Latin American, Southeast Asian (eg, Vietnamese, Cambodian, Malaysian, and Laotian), Arab, West Asian (eg, Iranian, Afghan), Korean, Japanese, South Asian, Chinese, Black, and Filipino.

Compare Depression, Anxiety, and QOL Domains

To address our second objective, in this section, we report and compare 312 dialysis patients' reports of depressive symptoms, anxiety symptoms, and QOL both for those who would or would not engage in support for mental health. Moderate to severe depressive symptoms (PHQ-9 score ≥10) were reported by 33.4% of all participants. The mean

(SD) PHQ-9 score was 7.7 (6.0) for all, 8.9 (6.4) for those who would engage in support, and lower at 5.8 (4.8) for those who would not. People with mild depressive symptoms were 1.78 times more likely to be willing to engage in support (compared with those with minimal depressive symptoms), people with moderate depressive symptoms were 3.36 times more likely to be willing to engage in support
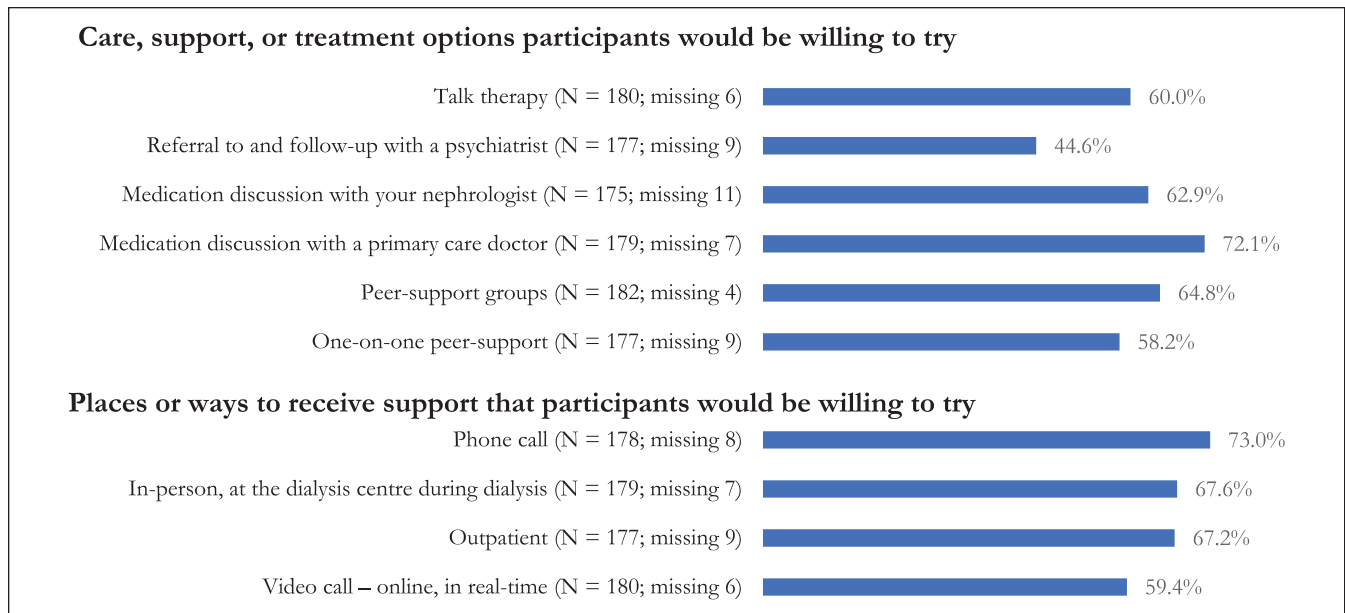
Care, support, or treatment options participants would be willing to try

Talk therapy (N = 180; missing 6)	60.0%
Referral to and follow-up with a psychiatrist (N = 177; missing 9)	44.6%
Medication discussion with your nephrologist (N = 175; missing 11)	62.9%
Medication discussion with a primary care doctor (N = 179; missing 7)	72.1%
Peer-support groups (N = 182; missing 4)	64.8%
One-on-one peer-support (N = 177; missing 9)	58.2%

Places or ways to receive support that participants would be willing to try

Phone call (N = 178; missing 8)	73.0%
In-person, at the dialysis centre during dialysis (N = 179; missing 7)	67.6%
Outpatient (N = 177; missing 9)	67.2%
Video call – online, in real-time (N = 180; missing 6)	59.4%

Figure 1. Supports, and modes of support, participants were willing to try.

Table 2. Technology Available at Home.

Technology available at home	Yes Total (n = 309; 3 missing) (%)
Internet	91.6
Cell phone including camera and microphone	69.9
Laptop or desktop computer including camera and microphone	57.9
Home phone	46.6
Tablet including camera and microphone	42.1
Laptop or desktop computer without a camera and microphone	16.5
Cell phone without camera and microphone	8.7
Tablet without a camera and microphone	3.9
None of the above	0.6

(compared with mild), and people with moderately severe depressive symptoms were 4.44 times more likely to be willing to engage in support (compared with moderate). In other words, those experiencing greater depressive symptoms were more willing to engage in support for mental health (see Table 3).

The majority (63.9%) reported minimal anxiety symptoms; 36.1% reported mild to severe anxiety symptoms (GAD-7 score ≥5). The mean (SD) GAD-7 score was 4.24 (5.2) for all, 5.2 (5.6) for those who would engage in support, and 2.8 (4.1) for those who would not. Similar to those experiencing depressive symptoms, people with greater anxiety symptoms were more willing to engage in support for mental health. People with mild anxiety symptoms were 2.29 times more likely to be willing to engage in support (compared with those with minimal anxiety symptoms), people with

moderate anxiety symptoms were 3.68 times more likely to be willing to engage in support (compared with mild), and people with severe anxiety symptoms were 3.88 times more likely to be willing to engage in support (compared with moderate; see Table 3).

The KDQOL-36 has 5 domains, and higher scores mean better QOL. In all 5 domains, people with lower QOL were more willing to engage in support. With respect to the 5 KDQOL-36 domains, engaging in support is predominantly associated with self-reported mental health (OR = 1.66 for every 10-unit decrease in SF-12 mental component summary score) and, to a lesser extent, symptoms/problems, effects, and burden of kidney disease (ORs = 1.37, 1.25, and 1.18, respectively; see Table 3). Overall, individuals with worse depressive symptoms, anxiety symptoms, and QOL domain scores for mental health, symptoms, effects,

Table 3. Distributions of Patient-Reported Outcomes.

Self-reported characteristic	Total sample (n = 312)	Would engage in support (n = 186)	Would not engage in support (n = 126)	Unadjusted ORs [95% CI]
Mental health	n (%)	n (%)	n (%)	
PHQ-9 (n = 312)				
Minimal (0-4; referent)	121 (38.8)	55 (29.6)	66 (52.4)	—
Mild (5-9)	87 (27.9)	52 (28.0)	35 (27.8)	1.78 [3.12-1.02]
Moderate (10-14)	57 (18.3)	42 (22.6)	15 (11.9)	3.36 [6.71-1.69]
Moderately severe (15-19)	47 (15.1)	37 (19.9)	10 (7.9)	4.44 [9.71-2.02]
Severe (20-27)	0 (0)	0 (0)	0 (0)	0 [0-0]
GAD-7 (n = 299)				
Minimal (0-4; referent)	191 (63.9)	97 (54.8)	94 (77.0)	—
Mild (5-9)	64 (21.4)	45 (25.4)	19 (15.6)	2.29 [4.20-1.25]
Moderate (10-14)	24 (8.0)	19 (10.7)	5 (4.1)	3.68 [10.31-1.32]
Severe (15-21)	20 (6.7)	16 (9.0)	4 (3.3)	3.88 [12.05-1.25]
QOL domains	Mean (SD)	Mean (SD)	Mean (SD)	
Symptoms/problems of kidney disease (n = 303)	72.6 (16.5)	68.9 (17.1)	78.2 (13.9)	1.47 [1.25-1.73][a]
Effects of kidney disease (n = 303)	62.4 (23.4)	57.9 (23.3)	69.0 (21.8)	1.25 [1.12-1.39][a]
Burden of kidney disease (n = 304)	41.5 (28.5)	36.3 (28.2)	49.4 (27.3)	1.18 [1.09-1.28][a]
SF-12 physical component summary (n = 285)	35.8 (10.8)	35.0 (10.7)	36.8 (10.9)	1.17 [0.94-1.46][a]
SF-12 mental component summary (n = 285)	46.4 (11.4)	43.8 (11.6)	50.4 (10.0)	1.74 [1.38-2.20][a]

OR = odds ratio; CI = confidence interval; PHQ-9 = Patient Health Questionnaire-9; GAD-7 = Generalized Anxiety Disorder; QOL = quality of life; SF = short form.
[a]ORs are for every 10 unit *decrease* in scores, where lower values reflect worse health.

and burden were more likely to consider engaging in support for mental health.

Explore Sociodemographic, Mental Health, and QOL Domains

To address our third objective, in this section, we explore sociodemographic, mental health, and QOL domains that explain whether people would or would not engage in support for mental health. Age, employment status, ethnicity, dialysis modality, number of years of dialysis, and all of the patient-reported outcome measures (GAD-7, PHQ-9, and each of the KDQOL-36 domains) had univariate (unadjusted) P values of <.25 and were therefore initially included in the multivariable logistic regression. In addition, gender was included as a potentially confounding covariate for theoretical purposes, although there was no gender difference between the two groups.

When applying purposeful variable selection, only "unable to work" (due to disability or health status), "years on dialysis," and "mental health" (as measured by the KDQOL-36 SF-12 mental component summary), were retained as explanatory variables in a main effect model. When each of the excluded variables was reentered one-by-one, "symptoms/problems" (domain measured by the KDQOL-36) were retained as an additional confounder in the final model. Although people who would engage in

support were found to be younger and more likely to be retired in the univariate analysis (see Table 1), these variables did not contribute to explaining the likelihood of engaging in support after accounting for the ability to work and years on dialysis. Similarly, although people who would engage in support were more likely to have higher scores on most KDQOL domains in the univariate analysis (see Table 3), only the mental health and symptoms/problems domains were retained in the final multivariable model. Finally, the PHQ-9 and GAD-7 measures of mental health did not contribute to the final model over and above mental health as measured by KDQOL-36 SF-12 mental component summary. In the final model, people who are unable to work had 2 times the odds of engaging in support than people who are able to work. People were also more likely to engage in support if they have been on dialysis for fewer years and have lower (worse) mental health scores (ORs = 1.06 and 1.38, respectively; see Table 4). The final model explained 15.5% (median Nagelkerke R^2) of the variance and correctly classified 66.6% of cases (77.7% for "would engage in support," and 50.3% for "would not engage in support").

Of the 384 participants, 163 provided open-text comments in response to the question: "Is there anything else you would like to tell us." We excluded 17 responses that did not address mental health or QOL. For example, these comments included statements about COVID vaccines or

Table 4. Variables Explaining Whether People Would Engage in Support.

Explanatory variables	Coefficient	*P* value	Adj. OR [95% CI]
Unable to work (disability/health)	0.69	.278	1.99 [1.15-3.43]
Total numbers of years on dialysis[a]	0.06	.029	1.06 [1.00-1.12]
Symptoms/Problems of Kidney Disease[b]	0.17	.092	1.18 [0.99-1.80]
SF-12 Mental Component Summary[b]	0.32	.137	1.38 [1.05-1.80]

Adj. OR = adjusted odds ratio; CI = confidence interval; SF = short form.
Note. The model explains "Would engage in support." Model fit: $\chi^2(4) = 38.0$, $P = .000$. Nagelkerke $R^2 = 15.5\%$.
[a]ORs are for each one-year *decrease* in years.
[b]ORs are for every 10 units *decrease* in scores, where lower values reflect worse health.

saying "Thank you." The eight categories, in descending order, for all respondents were QOL, impact of dialysis environment, hopes for future, support, "dialysis is the least of my worries," coping strategies, depression, and anxiety. Exploring between participants who would or would not engage in support for mental health, the top 2 categories for both groups were QOL and impact of dialysis environment. The third category differed: those who would engage wrote more about support, whereas those would who not engage wrote about "dialysis is the least of my worries" (see Table 5).

When we explore the two groups by subcategories, we see more granularity. Those who would engage most often addressed the importance of the care team (subcategory 4.2/19.6%). For example, one participant wrote, "Renal nurses at the [unit] are for the most part rude, uncaring, mean, and DO NOT LISTEN." Meanwhile, those who would not engage talked more about dialysis being the least of their worries (8.0/16.6%). One person wrote, "My other physical problems compound my kidney disease and dialysis." The next four top subcategories for those who would engage were as follows: effects of kidney disease (3.2/18.5%—"Life sucks. I dialyze every second night for 8 hours. Feel crappy all the time but worse the day after dialysis. I am weak, tired, no energy and don't give a crap about anything. I keep doing this 'cause my family wants me to ☺"), burden of kidney disease (3.3/16.3%—"Dialysis 'eats up your life' . . . My entire life is about kidney disease—my whole life revolves around it. I'm a different person now"), physical issues (3.4/9.8%), and transplant (6.1/9.8%). For participants who would not engage, the next 4 top subcategories were as follows: effects of kidney disease (3.2 / 13%), burden of kidney disease (3.3 / 13%), physical issues (3.4 / 11.1%—"After dailyzis filing very bad" [sic]), and the care team (4.2/13%—"'I feel that the health care system is not listening to me. No one cares about my concerns. I feel that health care members do not care about me because they know I have to be here. I feel that people are not actually answering my questions. I feel sometimes I'm treated as less than human. I want participants [sic] to actually listen to me.").

Discussion

We found that 59.6% of Albertan respondents receiving dialysis were willing to engage in mental health support and the majority were willing to try having a medication discussion with a family doctor (72.1%) or a nephrologist (62.9%) and engaging in talk therapy (60.0%). Individuals with worse depressive symptoms, anxiety symptoms, and QOL domain scores for mental health, symptoms, effects, and burden were more likely to consider engaging in support for mental health. This is counter culture and perhaps challenges what we assume. It tells us that people receiving dialysis treatment who need mental health support would be willing to engage. This was confirmed in our third objective: people receiving dialysis were more likely to engage in support if they were unable to work (due to disability or health status), had been on dialysis for fewer years, and had lower (worse) mental health scores (ORs = 1.99, 1.06, and 1.38, respectively). These results, from each of our 3 objectives, will now be discussed in relation to other people's findings.

Considering our first objective and description of preferences for mental health support: By rank order, Albertans receiving dialysis treatment identified that their most preferred health care provider for support was a family doctor or GP, followed by a registered nurse, a social worker or counselor, a psychologist, and least preferred was a psychiatrist. Respondents' most preferred mode was phone call, which could be delivered by a family doctor. Lehecka et al[41] sent a survey to Canadian Society of Nephrology members seeking their attitudes of psychosocial care in hemodialysis units. Thirty nephrologists responded. While 94% agreed with the patient respondents in our study that focusing on psychosocial care improved patient outcomes, they had a different perspective of who would be the ideal health care provider: 97% believed social workers were best suited. However, 89% believed the ratio of social workers to patients was too high, and 47% disagreed with the statement "in [their] hemodialysis unit, social workers are able to provide personalized and sufficient psychosocial care" (p.3). When we presented this finding to our Community Advisory Committee, they were not familiar with what dialysis social workers "do," nor how they could support mental health concerns. While patients might prefer to speak with their family doctor (if

Table 5. Content Analysis of Open-Text Responses.

Category	Subcategory	Total Sample (n = 146)ᵃ n (%)	Would engage in support (n = 92) n (%)	Would not engage in support (n = 54) n (%)
1. Depression	(1.1) Feeling down, depressed, or hopeless	8 (5.5)	6 (6.5)	2 (3.7)
	(1.2) Sleep issues (trouble falling or staying asleep or sleep too much)	2 (1.4)	2 (2.2)	
2. Anxiety	(2.1) Feeling nervous, anxious, or on edge	3 (2.1)	2 (2.2)	1 (1.9)
	(2.2) Not being able to stop or control worrying	1 (0.7)	1 (1.1)	
	(2.3) Worrying too much about different things	1 (0.7)	1 (1.1)	
	(2.4) Trouble relaxing	1 (0.7)	1 (1.1)	
3. Quality of Life	(3.1) QOL symptoms/problems of kidney disease	13 (8.9)	6 (6.5)	7 (13.0)
	(3.2) QOL effects of kidney disease	24 (16.4)	17 (18.5)	7 (13.0)
	(3.3) QOL burden of kidney disease	22 (15.1)	15 (16.3)	7 (13.0)
	(3.4) QOL physical issues	15 (10.3)	9 (9.8)	6 (11.1)
	(3.5) Mental issues	8 (5.5)	7 (7.6)	1 (1.9)
4. Impact of dialysis environment	(4.1) Dialysis clinic setup	11 (7.5)	7 (7.6)	4 (7.4)
	(4.2) Care team	25 (17.1)	18 (19.6)	7 (13.0)
	(4.3) Importance of dialysis modality	8 (5.5)	6 (3.7)	2 (3.7)
5. Support	(5.1) Family care giver is a resource	9 (6.2)	7 (7.6)	2 (3.7)
	(5.2) Peer support	4 (2.7)	4 (4.3)	
	(5.3) Lack of support in rural areas	3 (2.1)	2 (2.2)	1 (1.9)
	(5.4) Support person needed during dialysis runs	1 (0.7)	1 (1.1)	
	(5.5) MH support needed for (new) patients	2 (1.4)	2 (2.2)	
	(5.6) Support needed for family caregivers	1 (0.7)	1 (1.1)	
6. Hopes for future	(6.1) Transplant	13 (8.9)	9 (9.8)	4 (7.4)
	(6.2) More portable options for hemodialysis	1 (0.7)	1 (1.1)	
	(6.3) Travel options	3 (2.1)	1 (1.1)	2 (3.7)
	(6.4) Future treatment	4 (2.7)	2 (2.2)	2 (3.7)
7. Coping strategies	(7.1) Spirituality	2 (1.4)	1 (1.1)	1 (1.9)
	(7.2) Being organized	1 (0.7)		1 (1.9)
	(7.3) Don't dwell on illness	2 (1.4)	2 (2.2)	
	(7.4) Engaged in health and self-care	9 (6.2)	4 (4.3)	5 (9.3)
8. "Dialysis is the least of my worries"		15 (10.3)	6 (6.5)	9 (16.6)

ᵃWhere applicable, more than one category or subcategory may have been assigned to a participant's open-text responses.

they have one), and nephrologists may be referring to overworked social workers, participants' reports of mental health symptoms tell us that they nevertheless persist and are inadequately addressed.

Albertan respondents reported that, by rank order, 43.4% could imagine receiving mental health support in person during in-center dialysis. Dialysis "chairside" support has been often used in practice or research in this field,[42,43] perhaps because patients appreciate not having to come for a separate appointment. But Albertans in a different study investigating use of patient-reported outcomes in in-center dialysis also voiced their concerns about privacy for chairside mental health support.[20] Patients' perspectives spanned the spectrum from feeling like they needed a private environment to feeling like all manner of their health was already discussed in a non-private environment, so why should mental health be

any different? Nurse participants in this study held similar views spanning this continuum.[20] We do not have the qualitative data from this study to be able to explain patients' perspectives, but we do know that they closely ranked mental health support during outpatient visits, through video or phone calls. These findings remind us that many internal and external factors, including, but certainly not limited to, stigma[20,29-31] influence both patient and multidisciplinary kidney practitioners' comfort level regarding the location or ways in which mental health may be addressed.

Regarding our second objective and comparison of depression, anxiety, and QOL domains for people who would or would not engage in support for mental health, Albertan respondents who participated in our study during COVID had somewhat elevated depression and anxiety symptoms compared with pre-COVID reports in the EMPATHY project

pre-COVID in Northern Alberta. In our study, 33% reported moderate to severe depressive symptoms (PHQ ≥10); in EMPATHY, 29.2% of 408 patients reported a PHQ-2 ≥3 (range = 0-6, representing presence of depressive symptoms warranting further discussion).[20] In our study, 36% reported mild to severe anxiety symptoms (GAD-7 ≥5); in the EMPATHY project pre-COVID in Northern Alberta, 21.1% of 408 patients reported a GAD-2 ≥3 (range = 0-6, representing presence of anxiety symptoms warranting further discussion).[20] This aligns with international reports of the impact of COVID on people receiving dialysis,[44-49] but a more fulsome comparison within Alberta may be warranted as further data become available.

We found that Albertans receiving dialysis who were living with worse depressive symptoms, anxiety symptoms, and QOL were more willing to engage in mental health support. This finding is novel because we might assume that, as symptoms increase, people may be more reserved and less willing to engage. For example, Gregg et al[50] reviewed pharmacologic and non-pharmacologic interventions for treatment of depression in people with chronic kidney disease and end-stage kidney disease. They wrote,

> While psychological interventions such as cognitive behavioral therapy [CBT] avoid some of the pitfalls of pharmacologic therapy, the primary limitation to their implementation is wide access to such treatments *and willingness to participate* [italics added]. In the absence of these barriers, this is a promising therapeutic option. (p. 461)

Our findings contribute to this field with evidence that people receiving dialysis who need mental health support are willing to engage. Furthermore, 60% were willing to engage in talk therapy, which includes CBT.

Regarding our third objective and exploration of sociodemographic, mental health, and QOL domains to explain whether people would or would not engage in support for mental health, our "take away" message is that if you want to know whether people receiving dialysis treatment want to engage or not in mental health support, at a minimum, you should look at and ask about their mental health (e.g. using KDQOL-36 SF-12 mental component summary), inability to work (due to disability or health status), and total years on dialysis. Notably, the KDQOL-36 SF-12 mental component summary was a stronger explanatory variable regarding willingness to engage in mental health support compared with the PHQ-9 and GAD-7. Furthermore, of the employment status variables (Table 1), inability to work consistently remained in the model, but being retired or working (full-time or part-time) did not provide an explanation. This sociodemographic information about inability to work is rarely collected or included as a part of health information requested from a person receiving dialysis treatment. Furthermore, it is a contribution to the literature and an unusual finding because it is not assumed to influence

willingness to engage in mental health support. Aggarwall et al[51] found that, among 200 people in India with CKD stages III-V-D, anxiety, depression, and sleep quality were found to be significantly correlated to unemployment. Although they do not define reasons for unemployment, the authors acknowledge that discrimination and social stigma linked to mental illness are substantial barriers to peoples' health and employment. Kutner et al[52] also discovered that, for 585 people receiving dialysis in the United States, and using a PHQ-2 score ≥3, those no longer working had higher depression (12.1% for those who were employed compared with 32.8% for those who were no longer employed.) What our findings add is that those who are not working due to disability or health status may be more willing to engage in support for mental health.

The content analysis confirms our final model, while adding further explanatory insights. Broadly, QOL was the top category both for those willing or not willing to engage in support. While the KDQOL-36 SF-12 mental component summary was a strong explanatory variable in our model, people's open text comments more often addressed other elements of QOL, particularly the effects and burden of kidney disease. In our final model, symptoms/problems domain was a confounding variable, but it was only addressed in 8.9% of all comments by respondents. Our finding from the content analysis of the importance of the care team (a subcategory under the "impact of dialysis environment" category) to all respondents is an important contribution to the literature; it was also the most highly discussed subcategory (17.1% for all, 19.6% for those willing to engage, and 13% for those not willing to engage).

The strengths of our study include development with a community advisory committee, collaboration with kidney care across Alberta, and investigation of patients' perspectives previously not explored. Nevertheless, there are some limitations. Despite strategies to boost engagement, the response rate was only 13%, which limits our capacity to address representation or draw conclusions. Certainly, responses are subject to selection bias. While Canadians receiving dialysis have prioritized mental health,[7,20,28] our low response rate may indicate that people who chose not to answer the survey may have different experiences of mental health or willingness to engage in supports. While phone and mail options were available to complete the survey, sending a URL in the letter of invitation may have been a deterrent. Because we did not require responses to any items in the survey, there was higher missingness in some sections. Willingness to engage in support for mental health is not the same as engaging in support, thus future work is needed to examine uptake of support when it is offered or available. Future work in the field may also consider translating the survey into the top 3 to 5 languages of Albertans receiving dialysis, employing monetary incentivization if finances are in place,[53] mailing paper copies of the survey with the

invitation letter, or recruiting onsite with clinician champions or collaborators.

While we do not claim that our study findings are representative, they illuminate the high mental health symptom burden experienced by Albertans' receiving dialysis. These findings will be used to inform this work to develop a pathway for mental health care for Albertans receiving dialysis.[54] Future work is urgently needed in Canada to support both patients and multidisciplinary kidney practitioners[6,7,28] toward recognition of mental health concerns and follow-up in ways that uphold person-centered principles[55] in kidney care.[56] Research is needed to explore implementation and access of non-pharmacologic mental health supports for Canadians receiving dialysis.[6] This future work will be a part of a culture shift toward recognition of mental health burden that so often accompanies dialysis treatment but has long been left ignored.

Conclusions

Kidney care has excelled in treating the physical body affected by dialysis, but has overlooked the interconnections with the psychosocial. In the global movement toward patient-oriented research, Canadians receiving dialysis have resoundingly said that their mental health is a priority.[7,20,28] Of the Albertan respondents to our survey, the majority confirmed that addressing their mental health was an integral part of addressing their overall health; 59.6% were willing to engage in mental health support. Individuals with worse depressive symptoms, anxiety symptoms, and QOL were more likely to consider engaging in support for mental health. This tells us that many who need mental health support, would be willing to engage. People receiving dialysis were also more likely to engage in support if they were unable to work (due to disability or health status), had been on dialysis for fewer years, and had lower (worse) mental health scores. Incorporating patients' preferences and willingness to engage in support for mental health will inform future visioning for person-centered mental health care in dialysis.

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Data Sharing

Ethical approval was not attained for the purposes of public sharing of the data. Scientists who are interested in using the data may contact the corresponding author for further information.

Supplemental Material

Supplemental material for this article is available online.

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