



ORIGINAL ARTICLE

Patient-perceived barriers to a screening program for depression: a patient opinion survey of hemodialysis patients

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Abstract

Background: Depression is a prevalent, yet underdiagnosed, psychiatric disorder among patients with end-stage renal disease. Active case identification through routine screening is suggested; however, patient-related barriers may reduce the effectiveness of screening for, and treating, depression. This study aimed to explore the perceived barriers that limit patients from participating in screening and treatment programs for depression.

Methods: In a cross-sectional study of chronic maintenance hemodialysis patients, the Perceived Barriers to Psychological Treatment questionnaire, adapted to include screening, was used to measure perceived barriers. The two-item Patient Health Questionnaire was used to identify patients with depressive symptoms.

Results: Of 160 participants, 73.1% reported at least one barrier preventing them from participation [95% confidence interval (95% CI) 66.2–80.0%]. Patients with depressive symptoms were more likely to perceive at least one barrier to a screening program for depression compared with those without depressive symptoms (96% versus 68.9%, respectively; odds ratio = 10.8; 95% CI 1.4–82.8; $P = 0.005$). The association of the barrier scores with depressive symptoms remained significant after adjustment for patient's characteristics. The most common barriers that patients expressed were concerns about the side effects of any antidepressant medications that may be prescribed (40%), concerns about having more medications (32%), feeling that the problem is not severe enough (23%) and perceiving no risk of depression (23%).

Conclusions: Negative perceptions about depression and its treatment among hemodialysis patients constitute an important barrier to identifying this condition and first need to be addressed before implementing a screening program in this population.

Key words: barriers, depression, health-care utilization, hemodialysis, screening

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Introduction

The highest rate of depression, among all chronic disorders, is seen among those patients with end-stage renal disease (ESRD) [1]. Recently we showed, in a meta-analysis [2], that patients on dialysis have a 45% increase in the risk of death when they have concomitant depression, supporting the recommendation that patients with ESRD be screened and treated for depression as part of routine care [3]. However, it appears that this recommendation is not commonly implemented. One-third of the patients on dialysis report mild to severe depressive symptoms [2, 4], and one-fifth suffer from a major depressive disorder [5, 6]. However, only a small proportion of patients on maintenance dialysis are diagnosed with depression [7], and only 16–42% have been found to have received treatment [5, 8].

In fact, the data from two studies suggest that screening and treatment programs are unsuccessful, and that despite efforts to provide better care more than half of those patients who screen positive for depressive symptoms will not get appropriate treatment [9, 10]. In one study, Wuerth *et al.* established a screening program in a peritoneal dialysis center, and showed that half of patients who did screen positive for depressive symptoms did not agree to any further assessment, thus limiting any intervention [10]. Similarly, Johnson and Dwyer surveyed patients with depressive symptoms established on hemodialysis. Their data suggested that two-thirds were unaware of symptoms or were unaware that they may need help for symptoms [9].

Based on these data, we hypothesized that there were several plausible barriers that would limit the successful introduction of screening programs targeting depression among the ESRD community. These included organizational, physician-related and patient-related barriers. We hypothesized that patients themselves had negative perceptions about depression and its treatment, and that together with social and psychological issues such as stigma, these may limit the acceptance of any sort of assessment or treatment. We therefore carried out a survey of hemodialysis patients and sought to better identify which barriers, perceived by the patients, would limit the acceptability of hypothetically participating in a screening program for depression (SPD) and determine the characteristics of those most likely to refuse participation in an SPD.

Materials and methods

Participants

Patients were recruited from two outpatient in-center hemodialysis units in Toronto. Inclusion criteria were age 18 years and older, the ability to read and comprehend English to Grade 6 level, and undergoing chronic hemodialysis treatment for at least 30 days. Patients with cognitive impairment, acute inpatient status, and inability or unwillingness to provide informed consent were excluded.

The study protocol and consent form were approved by the Research Ethic Boards of the study sites. Patients who opted not to participate in the study were asked to consent to limited data collection for comparison with participants.

Methods

Participants had two study visits during their hemodialysis sessions. On-dialysis assessment is shown to facilitate regular evaluations and increase identification of depressive symptoms [11], and thus is also a practical method for assessment of the

barriers to participating in a regular on-dialysis SPD. In the first visit, demographic and clinical data were collected and participants completed a two-item depression scale (Patient Health Questionnaire 2, PHQ-2). Data collection included age, gender, education level (years since primary school), marital status, cause of ESRD, comorbidities (Charlson Comorbidity Index) [12], time on renal replacement therapy (RRT), and history of diagnosis and treatment of depression. Within 1–2 weeks, they were visited again to fill out a questionnaire designed to measure perceived barriers to participation in an SPD.

Perceived barriers

The SPD was described as a program incorporating routine questionnaire assessments, referral and treatment for depression. Treatment was considered to be any of the currently available psychotherapy and pharmacotherapy options for depression. An adapted version of the self-report Perceived Barriers to Psychological Treatment (PBPT) questionnaire was used to measure perceived barriers [13]. In order to extend the scope of the scale for this study to include barriers to screening, we replaced 'seeing a counselor or a therapist' with taking part in an SPD. We also added 11 questions after comparing the PBPT items against a summary list of possible barriers generated through a review of the literature on reported barriers to mental health care and conceptual frameworks of health-care utilization [9, 10, 13–39].

The adapted PBPT questionnaire comprised 38 questions. Each question asked participants to rate the degree to which different kinds of problems would make it difficult to participate in an SPD. Response options were 'not difficult at all', 'slightly difficult', 'moderately difficult', 'extremely difficult' and 'impossible', rated from 0 to 4. A score ≥ 3 was considered as a positive response to the question. The 38 questions were grouped into five constructs: the presence or absence of a 'perceived threat' (the belief that there is a real risk of contracting an illness and the disease is serious in terms of its consequences); a 'perceived benefit' (the belief that the screening program can reduce the threat of the disease, and that there is little or no harm as a consequence); 'psychological barriers'; 'social barriers'; and 'practical barriers' (the patient has the perception that there are reasons to make them unwilling to participate) [24]. The overall and construct-based proportion of participants perceiving barriers to the SPD were calculated as the proportion of those with a positive response for at least one PBPT question [13].

Depression

The PHQ-2 was used to measure the two-core depressive symptoms (feeling depressed and lack of interest in doing things) [40, 41]. The PHQ-2 is validated in the primary-care setting [41], and has been used in large-scale studies on dialysis patients [42, 43]. Each item is scored between 0 and 3 and a sum of scores of 3 and higher (positive PHQ-2) serves to alert the clinician that further evaluation may be appropriate [41].

Sample size and statistical analyses

A required sample size of 159 was calculated, based on an estimated 60% of patients having one or more barriers to the SPD as defined for measurement of the primary outcome of the study, and 95% confidence intervals (95% CIs) of 15%. Basic characteristics were compared between participants and non-participants. Between-group comparisons were done using the *t*-test,

Wilcoxon rank sum test, chi-square test and Fisher's exact test, where appropriate.

Results are reported for the total score and the individual subgroups as median and quartiles. The associations between each of the five barriers construct sub-scores and the patient characteristics were examined using multiple linear regression. Explanatory variables included age, gender, education level, marital status, time on RRT, causes of ESRD, Charlson Comorbidity Score, PHQ-2 score and a known history of depression. Five models were constructed for natural logarithmic transformation of each of the barrier sub-scores. Correction for multiple testing was applied using the Benjamini-Hochberg correction procedure [44]. The final linear regression model's goodness-of-fit, normality of the residuals, influential outliers, homoscedasticity and overall significance were examined, and its findings were validated against categorical logistic model (sub-score values categorized into four groups of 1-4 based on the first quartile) and Cox proportional hazard model (sub-score values treated as time to event and assuming a value of 1 as the event for all observations, as described by Basu *et al.* [45]).

The SAS (Statistical Analysis System, version 9.2, SAS, Cary, NC, USA) was used for the statistical analyses and a P-value < 0.05 was considered significant.

Results

Participants

A total of 373 patients on hemodialysis were assessed, of whom 242 (65%) were eligible (Figure 1). Of the eligible patients, 169 consented to participate in the study (70%). Of 73 non-

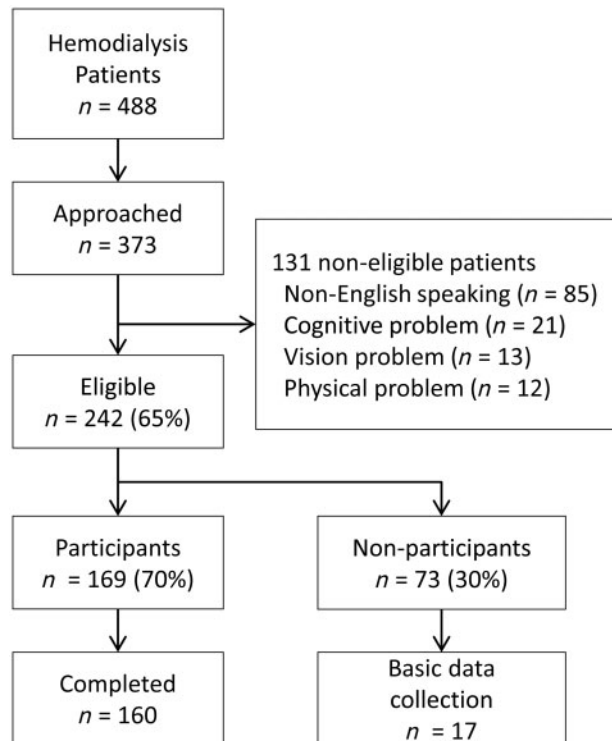


Fig. 1. Recruitment process. All of the 279 patients from the University Health Network were approached and assessed for eligibility, while 94 patients from Sunnybrook Health Sciences Centre were approached from all hemodialysis services and shifts through a convenience sampling, and 115 were not screened or approached as the target recruitment had been achieved.

participants, 17 patients (23%) consented to basic data collection (Table 1).

Barriers to screening

Of 169 participants, 160 completed the barriers questionnaire. Overall, 117 participants (73.1%; 95% CI 66.2–80.0) perceived one or more barriers to participating in an SPD, with a median of 6 barriers to the SPD (quartile range 2–10). The Cronbach's alpha coefficient was 0.95 for the questionnaire and 0.75–0.89 for the five subscales. Table 2 summarizes the barrier results. The most frequent reasons given for not being willing to participate in the SPD were concerns about anti-depressant medications (concerns about the side effects and difficulty taking additional medications) and perceiving no threat (feeling not at risk of becoming depressed or that their problem is not severe). Table 3 summarizes the frequency of perceived barriers by construct.

Depression and depressive symptoms

Twenty-seven patients (16.0%) had depressive symptoms, of whom nine (33%) had a diagnosis of depression documented in their charts and three (11%) were on treatment. Sixteen of the 27 patients with depressive symptoms (59%) had a past history of depression, of whom 13 had received treatment.

Overall, a clinical history of depression was self-reported or identified in the charts in 37 patients (21.9%), of which 21 (56.8%) had been diagnosed after the initiation of RRT. Twenty-six patients (16%) gave a prior history of treatment for depression.

Table 1. Baseline characteristics of participants and non-participants^a

Parameter	Participants	Non-participants ^b	P
Number	169	17	–
Mean age (years)	57.1 ± 17.0	52.3 ± 14.3	0.21
Male gender	103 (60.9)	12 (70.6)	0.44
Marital status			–
Married or living with partner	81 (47.9)	–	
Single, divorced or widowed	88 (42.1)	–	
Mean education level (years)	13.6 ± 3.4	–	–
Median RRT time (months)	48 (18–102)	66 (24–96)	0.48
ESRD cause			0.86
Diabetes mellitus	40 (23.7)	5 (29.4)	
Hypertension	29 (17.2)	3 (16.7)	
Glomerulonephritis	41 (24.3)	6 (35.3)	
Hereditary	27 (16.0)	2 (11.8)	
Others	20 (11.8)	1 (5.9)	
Unknown	12 (7.1)	0	
Median Charlson Score	4 (2–5)	–	–
History of depression	37 (21.9)	–	–
Treatment of depression			–
Current	6 (3.6)	–	
Previous	29 (17.2)	–	
PHQ-2			–
Median total score	0 (0–2)	–	
Positive (≥3)	27 (16.0)	–	

^aValues in parentheses are percentages for frequencies and the first and third quartiles for the median values.

^bBasic data of these patients were collected after obtaining consent. Of 242, 56 eligible patients (23%) did not participate and did not provide consent to basic data collection.

Table 2. Median subscale scores and percentage of participants with barriers (at least one barrier) for each barrier subscale

Barrier subscale	Number of questions (possible score range)	Score			Barrier positive	
		Median	First to third quartiles	Range	n	% (95% CI)
Perceiving no threat	8 (0–32)	5	1–11	0–32	69	43.1 (35.4–50.8)
Perceiving no benefit	4 (0–16)	3	1–5	0–12	68	42.5 (34.8–50.2)
Psychological barriers	11 (0–44)	7	3–14	0–40	80	50.0 (42.3–57.7)
Social barriers	5 (0–20)	3	0–7	0–20	48	30.0 (22.9–37.1)
Practical barriers	10 (0–40)	8	3–13	0–31	82	51.3 (43.5–59.0)
Overall	38 (0–152)	30	14–51	0–114	117	73.1 (66.2–80.0)

Association of depressive symptoms with barriers

Patients with depressive symptoms were more likely to perceive at least one barrier to an SPD (96% versus 68.9%; odds ratio = 10.8; 95% CI 1.4–82.8; $P = 0.005$; Figure 2).

In univariable analysis, the PHQ-2 score correlated weakly with sub-scores for perceiving no benefit ($r = 0.19$; $P = 0.01$), psychological barriers ($r = 0.26$; $P < 0.001$), social barriers ($r = 0.17$; $P = 0.03$) and practical barriers ($r = 0.38$; $P < 0.001$). Of other covariates, a history of a diagnosis of depression was associated with a higher practical barriers sub-score ($P = 0.046$). Using multiple linear regression model, no relationship was found between depressive symptoms and not perceiving any threat of depression. However, a higher depressive symptom score was a significant predictor of not perceiving any benefit from the program, and also a predictor of the total number of psychological, social and practical barriers reported, even after controlling for other covariates (Table 4). Other than depressive symptom scores, a longer time on RRT was a significant predictor of perceiving no benefit and social barriers.

In patients with depressive symptoms, the most frequent barriers were concerns about side effects of medications for depression and practical barriers related to the physical illness and costs of treatment. Concerns about medication side effects were considerably more frequent among patients with depressive symptoms as compared with those without depressive symptoms. Figure 3 compares frequency of the most common barriers between patients with and without depressive symptoms.

Discussion

This study is the first to explore the barriers to participating in a program for screening and treatment of depression from the hemodialysis patient's perspective. The data suggest a substantial proportion of ESRD patients have at least one reason that would possibly preclude them from participating in routine screening protocols that may be implemented, hence raising questions of how best to provide psychological support and care to those undergoing chronic hemodialysis.

Screening is most likely to be successful if there is a highly prevalent health-care problem that is underdiagnosed, accurate screening tools and effective treatments [46]. Based on these three factors, the implementation of screening programs aimed at early detection of depression in the dialysis population appears appropriate and necessary. It is recommended in primary-care settings and in high-risk groups such as those maintained on dialysis [47, 48]. Despite the seemingly practical benefits, there is little evidence to support the idea that screening programs are effective enough to identify most of the at-risk patients. Both pharmacological and non-pharmacological treatments, such as cognitive behavioral therapy and exercise, have

Table 3. Frequency of perceived barriers^a

Barrier	n (%)
Perceiving no threat	
My problems are not severe enough	37 (23.1)
I do not think I will get depressed ^b	36 (22.8)
Having other problems that are more important ^b	29 (18.7)
I would prefer to decide when I need help for depression on my own ^b	24 (15.3)
I would prefer to handle it on my own if I was depressed ^b	17 (10.6)
I think better treatment of the kidney problem would improve depression ^b	13 (8.2)
I think sadness is normal among people on dialysis ^b	13 (8.2)
Having treatment for depression is too self-indulgent	7 (4.4)
Perceiving no benefit	
Concerns about side effects of medications ^b	63 (39.6)
Having heard about or having had bad or unsatisfactory experiences with treatment of depression	13 (8.1)
I wouldn't expect treatment for depression to be helpful	11 (6.9)
I wouldn't expect questionnaires for depression to be helpful ^b	10 (6.3)
Psychological barriers	
Having to take more medications ^b	51 (31.9)
Anxiety about going far from my home	26 (16.3)
Distrust of mental health specialists	21 (13.1)
Having to talk to someone I do not know about personal issues	20 (12.5)
Lack of energy or motivation to make an appointment and then go	20 (12.5)
Concerns about having upsetting feelings	15 (9.4)
I feel that talking about upsetting issues makes them worse	15 (9.4)
I would be afraid of screening results for depression ^b	14 (8.8)
Discomfort with having someone see me while I am emotional	13 (8.1)
Having to fill out additional questionnaires ^b	12 (7.5)
Difficulty motivating myself to do anything at all	11 (6.9)
Social barriers	
Having a medical or insurance record of mental health services	26 (16.3)
Receiving mental health care for depression would mean I cannot solve my own problems	25 (15.6)
Having family and/or friends know I was going for mental health services	24 (15.0)
I just do not think mental health specialists would truly care about me	18 (11.3)
My concern about being judged by health-care specialists	15 (9.4)
Practical barriers	
The cost of treatment, if needed	33 (20.8)
A serious illness which requires me to stay close to home	30 (18.8)
Physical problems, such as difficulties walking or getting around	27 (16.9)
Physical symptoms (fatigue, pain, breathing difficulties, etc.)	21 (13.2)
Problems with transportation	17 (10.6)
My daily responsibilities and activities	17 (10.7)
Not knowing how to find a good mental health specialist	17 (10.8)
Getting time off work to go for mental health services	15 (9.4)
The responsibility of caring for loved ones	14 (8.8)
The lack of available mental health services in my area	13 (8.2)

^aBarriers are worded in the questionnaire as the phrases/sentences in the table following by 'would make it'/'and that would make it' and '[blank space for response options] for me to take part in a screening program for depression'.

^bQuestion present only in adapted PBPT questionnaire.

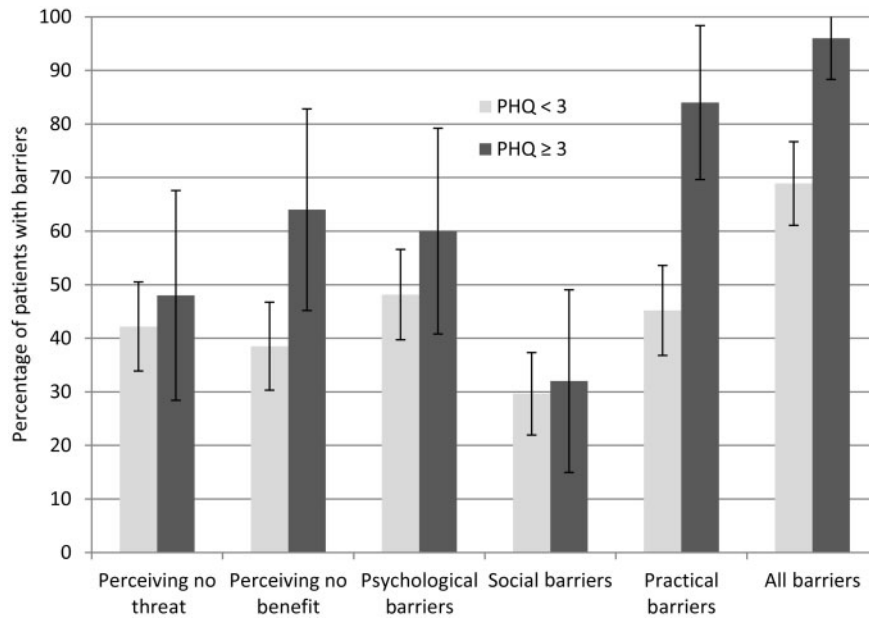


Fig. 2. Percentage of participants who perceived one barrier or more by PHQ-2 results.

Table 4. Multivariable regression model for factors associated with the log transformed sub-score of barriers^a

Independent variable	Adjusted β (95% CI)	Test statistic	R ²	P ^b
Perceiving no benefit				
PHQ-2 score	0.063 (0.025–0.102)	0.020	0.16	0.02
Time on RRT	0.001 (0.0002–0.001)	0.0003	0.16	0.03
Psychological barrier				
PHQ-2 score	0.104 (0.044–0.164)	0.030	0.19	0.01
Social barrier				
PHQ-2 score	0.065 (0.017–0.114)	0.025	0.15	0.048
Time on RRT	0.001 (0.0003–0.002)	0.0004	0.15	0.048
Practical barrier				
PHQ-2 score	0.101 (0.048, 0.154)	0.027	0.19	0.003

^aOther factors in the model: age, gender, marital status, education level, diabetes as ESRD cause, hypertension as ESRD cause, glomerulonephritis as ESRD cause, Charlson Comorbidity Score, and history of depression.

^bCorrected P-values for multiple testing.

shown promising results in dialysis patients [49–51]. Success of an SPD, however, is impeded not only by lack of evidence regarding tailored interventions for depression in dialysis patients, but also by patient-related barriers to participation. Wuerth *et al.* [10] showed that 49% of patients on peritoneal dialysis were unwilling to accept further assessment, and Johnson and Dwyer [9] reported that two-thirds of dialysis patients were unaware of their depressive symptoms or did not perceive they may need help. Our data help to identify those patient-related factors that potentially limit the effectiveness of these screening programs. Our data suggest that patient-driven concerns about the value of screening programs, as well as resistance to taking additional treatments and medications, need to be addressed prior to further implementation.

Patient-related barriers to mental health-care utilization continue to challenge physicians. More than 6% of Ontarians need treatment for a mental health problem but do not seek help [34]. In our study, we found that a significantly high

proportion of dialysis patients were at risk of depression and that most identified a number of barriers to seeking treatment. Importantly, we identified that those most at risk of depression were those with the highest number of barriers to participation in any screening protocols. The paradoxical relationship between depressive symptoms and willingness to participate in an SPD is concerning, as these are the very patients that are the most likely to benefit from an SPD, but the least likely to participate. The perception that their physical illness was more important than any psychological symptoms, along with concerns about the potential side effects of medications that may be prescribed, were the prominent barriers. Skepticism toward medication is not unusual, particularly in those with chronic disease, and is highly predictive of poor adherence with medications [22, 52, 53]. Somatization of depressive symptoms and their inherent link with poor executive function, anemia and inflammation can explain, in part, our results [54]. Although we found fewer patients with depressive symptoms who perceived not being at risk of depression as compared with those who did not have depressive symptoms, our finding that those with depressive symptoms did not consider their symptoms severe is still consistent with denial defense mechanisms against depression [55]. Denial, as a defense mechanism, is common and may exacerbate depression, when the current standards only measure the quality of care provided by dialysis programs through their ability to meet clinical and laboratory targets. Recent changes within nephrology that place an increased focus on patient symptoms and the psychological aspects of ESRD may help to alter patient and public attitudes over time.

We found patients perceived a number of practical barriers such as potential costs of the treatment and physical barriers such as time and mobility. Older adults are more likely to perceive their physical impairment as a practical barrier to access to therapy [21]. However, the number of patients who reported both time and financial costs as a barrier was surprising, particularly as, in Canada, many patients undergoing maintenance hemodialysis are entitled to subsidized or free drugs through government plans, and many spend a number of hours

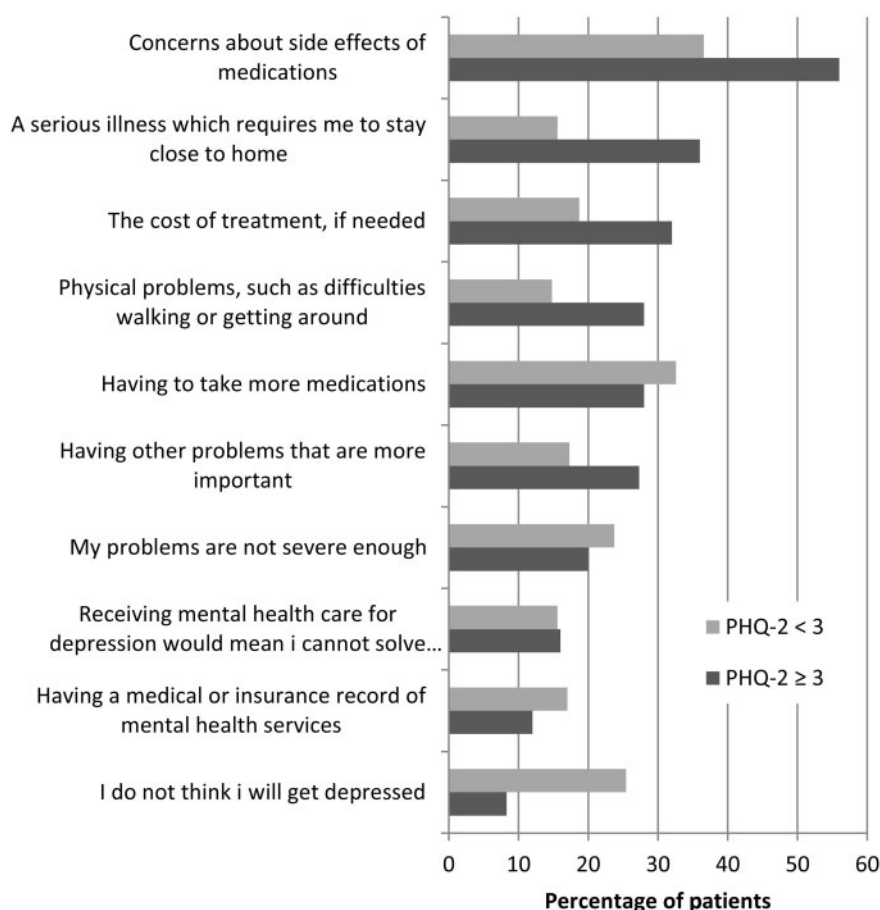


Fig. 3. Most frequently perceived barriers to screening for depression among participants without depressive symptoms (PHQ-2 < 3), as compared with those in participants with depressive symptoms (PHQ-2 ≥ 3).

undergoing dialysis treatment, time that may be used for counseling or psychological treatments.

Similar to other studies [9, 10], one-fifth of our participants considered their symptoms to be of little consequence or did not perceive themselves to be at risk of becoming depressed. In a survey of the general population in Ontario, the most common reason respondents did not seek help was the expectation that their mental health problem would get better by itself or that they could solve the problem on their own [34]. Patients with chronic conditions, including ESRD, are no different, and are more likely to prioritize physical problems and rationalize depressive symptoms as a 'normal' reaction to physical distress [22, 37].

Half of our patients perceived psychological barriers such as feeling overwhelmed with medications or a distrust of mental health specialists. Psychological barriers such as these may be underestimated as many patients who reported perceiving no threat or that there would be no benefit from a screening program may have underlying hidden emotional and/or social factors that may remain unrecognized [24]. Hemodialysis patients may present negative forms of coping and health behaviors in the form of defensive mechanisms such as denial and somatization, responses that often directly affect the physician-patient relationship [56]. Particularly in those with depressive symptoms, patients undergoing chronic maintenance dialysis are at high risk of having poor adaptive illness perception, higher emotional distress and a lack confidence that a disease can be controlled by treatment(s) [57]. They are also more likely

to have behavioral disengagement and self-blame [55]. These further add to their mistrust of health-care services and personnel.

Stigma is defined as a mark of disgrace associated with a particular circumstance, quality or person. In our study, 30% of the participants expressed concerns about the social barriers, mostly around the stigma associated with depression. Stigma is seen in 4% of the general Canadians population with psychological disorders [35]. In particular, older adults are less likely to voluntarily report depressive symptoms and may perceive depression as a character flaw [21]. Stigma is linked to several other barriers. Negative attitudes toward antidepressant use appear to be linked with perceived emotional weakness, perceived severity of illness and an inability to deal with problems [58].

Our findings highlight some important challenges of implementing an SPD in dialysis patients, but the results should be interpreted with a few limitations in mind. First, we believe it is more likely that our results underestimated the number and type of barriers facing patients at risk of depression rather than overestimated the barriers, as we speculate that non-participants were even more likely to have barriers, and those excluded because of language and comprehension barriers would not be able to participate in an SPD either. Second, we adapted the PBPT to the dialysis population and although we believe our results to be valid based on the sensitivity analysis, we acknowledge further validation is required. Third, several modifiable factors other than depressive symptoms and time on RRT may predict barriers to participating in an SPD, such as

hemoglobin and serum albumin levels and dialysis adequacy. A more comprehensive study of these conditions could help to better understand patients' behavior and to reduce non-participation in an SPD. Fourth, the PHQ-2 might lack sensitivity, but it is specific enough to identify those highly likely to be depressed [41], which aligned with our goal of assessing barriers to SPD in a subgroup of those most likely to be targets of an SPD. Finally, measurement of barriers using a self-report scale allows us to understand areas of patients' concerns, but does not necessarily provide us with the eventual reasons behind the decisions of not taking part in an SPD. One's behavior can be determined by a constellation of beliefs only when these beliefs are assumed to remain unchanged prior to, at the time of and after the behavior [33]. Surveyed patients may have conflicting ideas about depression and its treatment, and may try to alter their viewpoints and give sound reasons about their decision, which may not correspond to the reasons in a real situation [33].

Conclusions

The considerably high burden of patient-related barriers warrants a new approach to the management of depression in the hemodialysis population. This may include a more consistent or standardized approach to treating depression or a number of strategies aimed at reducing hemodialysis patients' concerns about participation in an SPD. It may be plausible to develop a number of solutions aimed at education of those delivering health care, as well as patients and their families, in order to improve awareness of the clinical significance of depressive symptoms and to encourage the routine use of interventions such as support groups or counseling. A collaborative approach requires that the physician clearly communicates with the patient about antidepressant medications and other treatment options, such as cognitive behavioral therapy, psychotherapy and exercise. There might also be a need to look at the culture of dialysis units and strategies to normalize assessment of depressive symptoms as an expectation of care from all members of the health-care team. Finally, interventions directed at changing unhelpful illness perceptions and maladaptive coping behaviors might be an effective approach in order to improve help-seeking. All such strategies would need to be studied for their effectiveness in increasing patient participation in an SPD.

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Conflict of interest statement

None declared.

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