Published in final edited form as:

Hemodial Int. 2016 April ; 20(2): 286–292. doi:10.1111/hdi.12317.

Depressive symptom severity, contributing factors and self-management among chronic dialysis patients

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Abstract

Background—Despite the high prevalence of depressive symptoms in patients receiving chronic dialysis, there has been inadequate attention to patient-related barriers to management of depressive symptoms, such as factors identified by these patients as contributing to their symptoms, and how they responded to the symptoms.

Methods—Participants (N=210) in an ongoing longitudinal observational study of multidimensional quality of life in patients receiving chronic dialysis completed a battery of measures monthly for 12 months. For each patient at each measurement point an Event Report was generated if he/she scored outside of the normal range on the depressive symptom scale (CESD-SF 10) or expressed suicidal ideation.

Results—Of the 210 participants, 100 (47.6%) had a CESD-SF score 10 at least once resulting in 290 Event Reports. Of these 100 participants, 15 (15%) had also reported suicidal ideation in addition to having depressive symptoms. The most frequently stated contributing factors included ‘managing comorbid conditions and complications’ (56 Event Reports, 19.3%), ‘being on dialysis’ (50, 17.2%), ‘family or other personal issues’ (37, 12.8%), and ‘financial difficulties’ (31, 10.7%). On 11 Event Reports (3.8%) participants had been unaware of their depressive symptoms. On 119 Event Reports (41%) participants reported that they discussed these symptoms with their dialysis care providers or primary care providers, while on 171 Event Reports (59%) symptoms were not discussed with their healthcare providers.

Conclusions—The prevalence of depressive symptoms is high and many patients lack knowledge about effective self-management strategies.

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Conflict of Interest statement:

The results presented in this paper have not been published previously in whole or part, except in abstract format. All authors have no financial conflict of interest to disclose.

The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

Keywords

Chronic dialysis; depressive symptoms

INTRODUCTION

The presence of depressive symptoms measured by self-administered questionnaires is an independent risk factor for mortality in patients receiving chronic dialysis.^{1–3} Accordingly routine screening is emphasized to detect and manage depressive symptoms early,^{4–7} but the extent of implementing such screening in practice is largely unknown. Furthermore, a recent trial of interventions designed to assist renal care providers to evaluate and treat symptoms revealed that the interventions did not achieve improvement in the targeted outcomes, including depressive symptoms.⁸ The investigators explained that the interventions to address clinician-related barriers did not overcome patient-related barriers to symptom management (e.g., “no more pills”). These findings underscore the importance of establishing partnerships between patients and clinicians to achieve optimal management of chronic illness.^{9, 10}

Despite the extensive literature on depressive symptoms among patients with chronic kidney disease and end-stage renal disease, there has been inadequate attention to patient-related barriers to management of depressive symptoms. A study by Johnson and Dwyer,¹¹ the only study of patient-related barriers, suggests that patients’ lack of symptom recognition and lack of perceived need for help are significant barriers to depression treatment among patients receiving chronic dialysis. However, what these patients consider to have contributed to their depressive symptoms and how they manage or respond to depressive symptoms remain unknown. Improving knowledge in this area is important to develop interventions that are effective in reducing patient-related barriers. Therefore, the purposes of this study were to describe: a) depressive symptoms experienced by chronic dialysis patients on monthly assessments, b) factors identified by these patients as contributing to their symptoms, and c) how they responded to the symptoms.

METHODS**Setting and sample**

From April 2012 to April 2014, 210 participants were recruited from 12 outpatient dialysis centers in North Carolina for a longitudinal observational study on trajectories of multidimensional quality of life among patients receiving chronic dialysis (NCT01530945). Approximately 1,028 adult patients were receiving dialysis care at these 12 centers during the study period. Eligible participants were 18 years or older, had been receiving maintenance dialysis for at least one month, and were able to speak English fluently. Participants were excluded if they had hearing impairment, were too ill to participate in an hour-long data collection session, or had > 3 errors on a gross cognitive screening test, the 10-item Short Portable Mental Status Questionnaire¹² or documented advanced dementia.

Data source

Participants completed hour-long data collection sessions over the telephone that included measures of depressive symptoms and quality of life at baseline and then monthly for 12 months, for a total of 13 sessions. Per protocol for patient safety monitoring, data collectors were required to complete an Event Report to document the depressive symptom score whenever a patient scored outside of the normal range on the depressive symptom scale or expressed suicidal ideation. The study protocol was approved by the Institutional Review Board at the University of North Carolina at Chapel Hill and by the Office of Clinical Trials at the participating dialysis clinics.

Measures and data collection procedures

Depressive Symptoms—Depressive symptoms were measured using the Center for Epidemiologic Studies Depression Scale – Short Form (CESD-SF).¹³ This measure includes 10 items that tap somatic and psychological depressive symptoms each with response options of 0 (rarely or less than once a week) to 3 (frequently or 5–7 days a week). A summated score of 10 or higher is considered as abnormal: a score 10–14 suggests mild depressive symptoms, and a score 15 or higher suggests severe depressive symptoms.^{14, 15} CESD-SF psychometric properties (e.g., construct validity, sensitivity, and specificity) have been evaluated extensively in both healthy adults and in various patient populations.^{13–17} An 11th item also with response options of 0 to 3 was added at the end of the CESD-SF to assess suicidal ideation (“I had thoughts of ending my life”). This item was not scored as part of the CESD-SF, but if endorsed 1 or higher (at least 1–2 days a week), it led to the completion of an Event Report.

Event Reports—The Event Report Form documented the occurrence of either an abnormal CESD – SF score (≥ 10) or a positive response on the suicidal ideation item. The data collector asked the participant (a) “Were you aware of your mood state?” (b) “What do you think was contributing to your mood?”, and (c) “How did you respond to your mood or symptoms when you noticed?” Participant’s responses to these questions were documented in the form. The Event Report was given to the principal investigator and project manager who consulted with the participant’s clinician so that the participant could be referred to a 24-hour emergency psychiatric service or mental health clinic.

Sociodemographic and clinical characteristics—Age, gender, race/ethnicity, marital status, education, household income, and the status of having a primary care provider were collected using a Sociodemographic Profile. Clinical characteristics, including dialysis modality, years on dialysis, and current diagnosis of depression, were collected by reviewing the medical records. Comorbid conditions were also collected to compute Charlson Comorbidity Index scores to describe illness severity.¹⁸

Data analysis

Responses to the open-ended questions about contributing factors and self-management were analyzed using qualitative content analysis. Two authors (MS and JB) coded these responses, and frequently occurring codes were grouped into categories. Descriptive statistics (frequencies, percent, means and standard deviations) were used to summarize

depressive symptom severity, factors identified as contributing to the symptoms, and responses regarding self-management of depressive symptoms. Chi-square tests for categorical variables (e.g., race and gender) and t-tests for continuous variables (e.g., age and years on dialysis) were used to compare participants who did not experience depressive symptoms and those who reported mild to severe depressive symptoms at least once during their study participation. Chi-square tests were used to explore whether participants' responses to depressive symptoms differed by contributing factors to their depressive symptoms, the frequency of experiencing depressive symptoms, and the symptom severity.

RESULTS

Sample characteristics

Four hundred and forty-two potential participants were screened and 294 were determined to be eligible. Of these, 235 (80.1%) consented but 14 subsequently withdrew, ten were found to be ineligible, and one died before baseline completion, resulting in 210 participants who completed at least one data collection session (Figure 1). The mean (SD) age of the participants was 59.1 (12.4) with a range of 19 to 90. Roughly a half were women ($n = 101$, 48.1%), roughly half were married or living with a partner ($n = 91$, 43.3%), and 155 (73.8%) were African Americans. The majority of the participants ($n=199$, 94.8%) were receiving hemodialysis (Table 1). Characteristics of decliners were similar to those who joined the study.

Depressive symptom reports

The 210 participants completed at least one monthly data collection session with an average of 7.6 sessions (median, 9.5) and a range of 1 to 13 for a total of 1,600 sessions. A total of 315 sessions were incomplete; 193 sessions were due to 16 deaths (105 sessions), 8 dropouts (81 sessions), and 2 kidney transplantations (7 sessions). The reasons for the remaining 122 incomplete sessions were 'unable to reach the participant (60 sessions)', 'too busy or don't feel up to it (30 sessions)', 'hospitalization (22 sessions)', and 'time conflict (10 sessions)'.

From these 1,600 sessions, 290 Event Reports (18.1%) were generated due to a CESD-SF score ≥ 10 or because the participant had a CESD-SF score ≥ 10 as well as a positive response on the suicidal ideation item. One hundred and seventy-two Event Reports (59.3%) were due to a CESD-SF score ≥ 15 and 118 (40.7%) were due to a CESD-SF score between 10 and 14. On 28 Event Reports (9.7%) participants reported suicidal ideation in addition to having a CESD-SF score ≥ 10 .

Of the 210 participants, 100 (47.6%) had a CESD-SF score ≥ 10 at least once; of those, 15 (15%) had reported suicidal ideation in addition to having depressive symptoms. Of the 100 participants who had at least one abnormal score, 43 participants (43%) reported severe depressive symptoms (CESD-SF ≥ 15) in at least one data collection session with an average of four sessions. Participants who scored lower than 10 on CESD-SF ($n = 110$) at all data collection sessions, compared to those who scored 10 or higher in at least one monthly data collection session, were likely to be younger ($t[208] = 1.96$, $p = .05$) and were less likely to follow religious practice and customs ($t[184] = 2.06$, $p = .041$). All other sociodemographic

and clinical characteristics were similar between the two subgroups (Table 1). There was no difference in the total number of data collection sessions completed between subgroups.

Of the 100 participants who had a CESD-SF score ≥ 10 at least once, 38 had such a score once, and 62 had such a score more than once. Of the 62 who scored ≥ 10 more than once, 23 (37.1%) had such scores 2 times, 16 (25.8%) 3 times, 13 (21.0%) 4 to 6 times, 10 (16.1%) 7 to 13 times. Demographic and clinical characteristics did not differ between those who had a single CESD-SF score ≥ 10 and those who had such scores repeatedly.

Contributing factors and self-management

Table 2 presents factors that participants reported as having contributed to their depressive symptoms (CESD-SF ≥ 10) as well as how these participants responded to those symptoms. The most frequently stated contributing factors included ‘managing comorbid conditions and complications’ (56 Event Reports, 19.3%), ‘being on dialysis’ (50, 17.2%), ‘family or other personal issues’ (37, 12.8%), and ‘financial difficulties’ (31, 10.7%). On 11 Event Reports (3.8%), participants were unaware of depressive symptoms.

On 119 Event Reports (41.0%) participants reported that they had discussed these symptoms with their dialysis care providers or primary care providers while on 171 Event Reports (59%) these symptoms had not been discussed with their healthcare providers. The reasons for not seeking help or not discussing with healthcare providers were ‘they [the dialysis staff] are too busy’, ‘they do not care’, ‘they can’t do anything to make it better’, and ‘it is not too bad and I don’t see the need’. But not all participants explained the reasons for not seeking help. Whether or not participants communicated with their healthcare providers about depressive symptoms did not differ by (a) what they thought were the factors contributing to their symptoms at that time, (b) the frequency of experiencing depressive symptoms (once [$n = 38$] vs. repeatedly [$n = 62$]), and (c) the symptom severity (mild to moderate [$n = 57$] vs. severe symptoms in at least one session [$n = 43$]).

DISCUSSION

In this sample of 210 patients on chronic dialysis who were followed monthly over time, roughly half experienced mild to severe depressive symptoms in at least one data collection session. Of those, a sizable number experienced severe depressive symptoms repeatedly. Similar to a study by Weisbord et al.,² in which depressive symptoms were assessed monthly, our study confirms a high prevalence of depressive symptoms among patients receiving chronic dialysis.

Based on the contributing factors identified by participants, we suspected that depressive symptom reports might vary by certain sociodemographic (e.g., education, household income, gender) and clinical (e.g., time on dialysis, Charlson Comorbidity Index, current diagnosis of depression) characteristics. However, only age and the extent of following religious customs were found to be associated with whether or not patients experienced depressive symptoms at least once. The significant association between religious coping and psychological distress in hemodialysis patients has also been reported by others¹⁹ although their causal relationship has not been demonstrated consistently.

While Johnson and Dwyer¹¹ identified patients' lack of symptom recognition as one of the major patient-related barriers to the management of depressive symptoms, our data showed that there were only 11 Event Reports in which patients were unaware of their depressive symptoms. This difference may be due to the fact that the repeated symptom assessment in our study may have raised patients' awareness over time.

When patients recognized depressive symptoms, they reported that they shared their symptom experience with their healthcare providers roughly a half of the time. A recent study by Oakley et al.²⁰ reported that 80% of their female participants said they would not disclose depressive mood to a healthcare provider and that depression self-stigma might be associated with women's avoiding seeking treatment for depression. A national survey shows that many older African Americans with mental health disorders do not receive professional help.²¹ However, we did not find any factors (among sociodemographic and clinical characteristics, depressive symptom severity, and contributing factors) associated with how patients respond to depressive symptoms. In our study, men and women and African Americans and Caucasians were equally able to recognize depressive symptoms and similarly endorsed self-management strategies.

But the impact of communicating their symptoms to healthcare providers on improving the management of depressive symptoms is unknown since we did not collect data on how dialysis care providers responded to those symptom reports. Most care providers may try to utilize medical rounds in the dialysis clinic to address patients' care needs, but it would be very unlikely that depressive symptoms can be managed effectively during this brief interaction even if the patient is willing to communicate their symptoms to care providers. A recent study reported that the mean estimated duration of a typical interaction between nephrologists and patients during in-center hemodialysis rounds was appropriately 8 minutes.²² The irony of the current dialysis care is that there is no other patient population that spends time in a care setting as much as dialysis patients do, yet their symptoms are not adequately managed. It is clear that the current model of dialysis care is not responsive to these patients' needs.

Gitlin et al.²³ have described the complex trajectory from symptom recognition to treatment that can be affected by individuals' beliefs and symptom management strategies, response to physician diagnosis and treatment preferences. Our study was limited in that it was not designed to examine the trajectory from symptom recognition to treatment and potential factors affecting the trajectory. The sample was from one region of the U.S., and thus our findings may not be generalizable to other populations. Also, because not every participant completed all of the follow-up data collection points, our depressive symptom reports might represent an underestimate of the true magnitude of the problem. Finally, patient-reported contributing factors and self-management behaviors were from open-ended questions on the Event Reports rather than from validated questionnaires. Nonetheless, our findings suggest that the main patient-related barrier to depression management may not be patients' lack of symptom recognition but a lack of knowledge about effective self-management strategies. Future interventions to improve mental health in patients receiving chronic dialysis should target patient-related barriers in addition to provider-related barriers.

Acknowledgments

This study was supported by a grant from the National Institutes of Health (R01NR013359) to M.S.

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Figure 1.
Participants Flow

Table 1

Patient characteristics (N = 210)

Characteristic	Participants, No. (%)		
	Overall (N = 210)	No event (n = 110)	Event at least once (n = 100)
<u>Sociodemographic</u>			
Age ^a , mean (SD), y	59.1 (12.4)	60.7 (11.6)	57.3 (13.0)
Women	101 (48.1)	51 (46.4)	50 (50.0)
Race			
Black	155 (73.8)	80 (72.7)	75 (75.0)
White	49 (23.3)	27 (24.5)	22 (22.0)
Other (Hispanic, American Indian)	6 (2.9)	3 (2.7)	3 (3.0)
Marital status			
Married/living with partner	91 (43.3)	52 (47.3)	39 (39.0)
Divorced/separated/widowed	71 (33.8)	35 (31.8)	36 (36.0)
Never married	48 (22.9)	23 (20.9)	25 (25.0)
Formal education completed, mean (SD), y	12.9 (2.8)	13.2 (2.9)	12.5 (2.7)
Have a religious preference	186 (88.6)	99 (90.0)	87 (87.0)
Extent of following religious customs ^b			
Never (= 1)/sometimes (= 2)	54 (29.0)	26 (26.3)	28 (32.2)
Frequently (= 3)/always (= 4)	132 (71.0)	73 (73.7)	59 (67.8)
Importance of spirituality in life			
Not at all/somewhat important	39 (18.6)	20 (18.1)	19 (19.0)
Very/extremely important	171(81.4)	90 (82.9)	81 (81.0)
Annual income			
< \$20,000	109 (51.9)	51 (46.4)	58 (58.0)
\$20,000 – \$50,000	69 (32.9)	39 (35.5)	30 (30.0)
> \$50,000	23 (11.0)	16 (14.5)	7 (7.0)
Refused to answer	9 (4.3)	4 (3.6)	5 (5.0)
Difficulty in paying for basic needs			
Not at all/somewhat difficult	154 (73.3)	86 (78.2)	68 (68.0)
Very/extremely difficult	56 (26.7)	24 (21.8)	32 (32.0)
<u>Clinical</u>			
Hemodialysis	199 (94.8)	106 (96.4)	93 (93.0)
Vascular access type			
Arteriovenous fistula	118 (59.2)	71 (64.5)	51 (54.8)
Arteriovenous graft	48 (24.1)	26 (23.6)	22 (23.7)
Catheter	33 (16.6)	13 (11.8)	20 (21.5)
Years on dialysis, mean (SD)	4.2 (5.3)	4.4 (4.9)	3.9 (5.8)
Median (IQR)	2.9 (0.8 – 5.2)	3.4 (0.8 – 5.5)	2.0 (0.7 – 4.7)

Characteristic	Participants, No. (%)		
	Overall (N = 210)	No event (n = 110)	Event at least once (n = 100)
CCI illness severity, mean (SD)	6.8 (2.0)	6.8 (1.8)	6.9 (2.3)
Currently diagnosed with depression	35 (16.7)	14 (12.7)	21 (21.0)
Have a primary care provider	171 (81.4)	94 (85.5)	77 (77.0)

^a
p = .05

^b
p = .04

Table 2**Contributing Factors and Self-Management**

	Event Report No. (%)	Participant ^a No. (%)
<u>Contributing factor</u>		
Managing comorbid conditions and complications	56 (19.3)	49 (49.0)
'Being on dialysis', including managing vascular access issues	50 (17.2)	45 (45.0)
Family or other personal issues, including family illness	37 (12.8)	37 (37.0)
Financial difficulties	31 (10.7)	31 (31.0)
Death of family members or friends	14 (4.8)	14 (14.0)
Pain	13 (4.5)	13 (13.0)
Recent hospitalization	13 (4.5)	13 (13.0)
Nothing special, it is normal part of my life	9 (3.1)	9 (9.0)
Isolation/loneliness	8 (2.8)	8 (8.0)
Living arrangement issues	7 (2.4)	7 (7.0)
Stopped taking depression medications	6 (2.1)	6 (6.0)
Being dependent on others	2 (0.7)	2 (2.0)
Process related to kidney transplantation	3 (1.0)	3 (3.0)
Other (conflict with dialysis staff, seasonal/holidays, existential questions)	8 (2.8)	8 (8.0)
Unaware of depressive symptoms	11 (3.8)	11 (11.0)
Did not want to describe	22 (7.6)	22 (22.0)
<u>Self-management</u>		
Have not discussed with any healthcare providers	152 (52.4)	100 (100)
Have discussed with dialysis care providers or primary care providers	119 (41.0)	100 (100)
Did not act on symptoms (including unaware of symptoms)	11 (3.8)	3 (3.0)
Have talked to other non-healthcare providers (e.g., friends, family member, minister)	8 (2.8)	8 (8.0)

^a number of patients who reported the contributing factor and self-management.