

Renal Provider Recognition of Symptoms in Patients on Maintenance Hemodialysis

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Background and Objectives: Although several studies have found that the burden of symptoms in patients who are on maintenance hemodialysis is substantial, little is known about renal providers' awareness of these symptoms. The aim of this study was to assess renal provider recognition of symptoms and their severity in hemodialysis patients.

Design, Setting, Participants, & Measurements: The Dialysis Symptom Index, a 30-item measure of symptoms and their severity, was administered to patients during a routine hemodialysis session. Immediately after surveying patients, the renal provider who evaluated the patient completed the Dialysis Symptom Index to report the symptoms that he or she believed were present in that patient. Sensitivity, specificity, and positive and negative predictive values of provider reports of symptoms were calculated using patient reports as the reference standard. Patient-provider agreement on the presence and severity of symptoms was assessed using the κ statistic.

Results: Surveys were completed by 75 patients and 18 providers. For 27 of 30 symptoms, the sensitivity of provider responses was <50%, and provider responses for 25 symptoms were characterized by positive predictive values of <75%. κ scores for 25 symptoms including those pertaining to pain, sexual dysfunction, sleep disturbance, and psychologic distress were <0.20, indicating poor provider recognition of these symptoms. Providers underestimated the severity of 19 of 30 symptoms.

Conclusions: Renal providers are largely unaware of the presence and severity of symptoms in patients who are on maintenance hemodialysis. Implementation of a standardized symptom assessment process may improve provider recognition of symptoms and promote use of symptom-alleviating treatments.

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Patients who are on maintenance hemodialysis have impaired health-related quality of life (HRQoL) compared with the general population and patients with functioning renal transplants (1–5). Although multiple factors likely contribute to these impairment in HRQoL, growing evidence suggests that physical and emotional symptoms play an important role (6–13). Parfrey *et al.* (14–16) demonstrated nearly two decades ago that physical and emotional symptoms were both common and severe in patients who were on long-term hemodialysis. More recent studies confirmed this finding and have shown that symptom burden is highly correlated with impaired HRQoL in this patient population (7–9,11). Our group recently found that physical and emotional symptom burden is associated with reduced HRQoL and higher levels of depression (8).

Despite the growing body of evidence that symptoms play an important role in the lives of patients who are on maintenance hemodialysis, there have been few efforts to examine the extent to which renal providers assess or effectively treat symptoms in these patients. Moreover, preliminary studies suggest that treatment of symptoms such as pain in patients with ESRD is suboptimal (17). Whether this is due to renal providers' underrecognition of the presence of pain or their failure to implement effective therapeutic strategies for this symptom remains unknown. The success of interventions to ameliorate pain and other bothersome symptoms and ultimately improve the overall HRQoL of dialysis patients depends in large part on the answer to this question. The aim of our study was to assess renal provider recognition of the presence and severity of physical and emotional symptoms in maintenance hemodialysis patients.

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Materials and Methods

Study Participants

We conducted a cross-sectional, observational study of long-term hemodialysis patients and their renal providers from February 2006 to

July 2006. Study patients and providers were recruited from three dialysis units in Pittsburgh, PA, including one university-affiliated and two community-based units. The university-affiliated unit provides care for a largely urban patient population and is staffed by academic nephrologists. One community-based unit serves an urban, predominantly black patient population, whereas the other services a largely suburban, white group of patients. Private practitioners treat patients at each of these community-based units. These three dialysis facilities were selected to recruit demographically diverse patients as well as a variety of renal providers from academic and community-based practice settings.

Provider and Patient Recruitment

At the initiation of the study, all physicians, physician assistants, and nurse practitioners caring for hemodialysis patients at each of the three participating dialysis units were approached and asked about their willingness to participate in a study of provider awareness of hemodialysis patients' symptoms. We also approached nurse managers at one site in which patients were seen and evaluated by nurse managers before being evaluated by the renal providers. We included only providers who had experience treating dialysis patients for at least 3 mo and who routinely evaluated patients at the study dialysis units to help ensure the enrollment of clinicians who were familiar with the care of this patient population. Informed consent was obtained from providers who were willing to participate. Standard procedure at these three dialysis units was for the nephrologist to see patients once monthly and nurse practitioners/physician assistants to evaluate patients the alternate 3 wk.

After the enrollment of all providers, patient recruitment commenced. Dialysis technicians approached patients to inquire about their willingness to participate in a study of dialysis-related symptoms during a routine hemodialysis session immediately after they had been seen by an enrolled study provider during dialysis rounds. Patients who expressed interest were approached by the study coordinator to explain the study in detail and to obtain written informed consent. To help ensure the recruitment of patients who were capable of providing reliable responses to the study survey, we administered the Mini-Cog, a combined three-word recall and clock-drawing test, and excluded patients with scores that were indicative of cognitive impairment (18,19). No data were collected from patients who did not consent to participate in the study.

Survey Administration and Data Collection

After patient enrollment, the study coordinator collected basic demographic data from the patient and administered the Dialysis Symptom Index (DSI) during the dialysis treatment. The DSI contains 30 items, each of which targets a specific physical or emotional symptom (20). Patients were asked to identify symptoms that had been present at some time during the previous 7 d by responding "yes" or "no" and to describe the severity of symptoms that had been present using a five-point Likert scale (1 = not bothersome to 5 = bothers very much). Immediately after the administration of the DSI to the patient, the same study investigator located the provider who had just examined the enrolled patient in the dialysis unit to have that provider complete the DSI and identify the symptoms that he or she believed were present in that patient during the previous 7 d and for symptoms that they believed were present, the corresponding severity. The DSI that providers were asked to complete was modified slightly to allow a response of "don't know" for symptoms that he or she was not sure were present. For providers who were unable to complete the survey immediately after rounds, we requested that the survey be completed and

returned within 24 h. This process helped ensure the temporal congruity between patient and provider completion of the DSI. Providers were not informed in advance regarding which patients would be approached for enrollment to limit the likelihood that they would alter their assessment of patients during dialysis rounds. Finally, the study investigator abstracted basic clinical and treatment-related data from the dialysis chart including hemoglobin, serum albumin, phosphorous, calcium, and intact parathyroid hormone concentrations and presence of the clinical conditions that comprise the Charlson Comorbidity Index.

Statistical Analyses

The primary analyses were based on assessing provider recognition of symptoms in their patients. To examine the accuracy and predictive value of provider responses for identifying symptoms in their patients, we calculated sensitivity, specificity, and positive (PPV) and negative predictive values (NPV) of provider responses using patient reports as the gold standard and considering provider "don't know" responses as a "no" response. Sensitivity denotes the proportion of patients who have a symptom and are correctly identified by providers as having the symptom, whereas specificity represents the proportion of patients who do not have a symptom and are identified as such by providers. PPV represents the probability that a patient has a symptom if their provider indicates its presence, whereas NPV describes the probability that a patient does not have a symptom if their provider indicates its absence. To examine agreement between patients and providers on the presence/absence of individual symptoms on the DSI, we calculated κ scores. These scores were based on agreement between patient and provider on individual symptoms and do not reflect the total number of symptoms correctly identified by the provider. The κ statistic defines the level of agreement above what is attributable to chance alone. A κ score of 0 to 0.2 signifies poor agreement, 0.2 to 0.4 indicates fair agreement, and >0.4 denotes moderate to good agreement (21). Negative κ scores represent less agreement than would be expected purely by chance. Because the DSI that was administered to patients and providers differed slightly in that providers were allowed to record "don't know" responses for the presence of symptoms, we assessed patient-provider agreement on the presence of symptoms in three different ways. The first method of calculating κ scores, which we considered to be the most clinically informative, was based on considering provider "don't know" responses as disagreement. We also calculated κ scores by considering "don't know" responses as a "no" response for providers and, last, by excluding items for which providers responded "don't know" and using only items for which providers responded "yes" or "no" to the presence of a symptom. To assess patient-provider agreement on the severity of those symptoms that both the patient and provider indicated were present, we used weighted κ scores, which give partial credit for provider responses that were close to but not identical to patients' severity rating.

Multiple logistic regression was used to explore the effects of provider type, years of experience treating dialysis patients, and dialysis unit on the outcome variable of patient-provider agreement on the presence of symptoms (considering "don't know" responses as indicating disagreement). In these analyses, we accounted for clustering of responses by providers and controlled for type of symptom and provider age. We defined statistical significance using a two-tailed $P = 0.05$. All analyses were conducted using Stata 9 (Stata Corp., College Station, TX). All study procedures were approved by the University of Pittsburgh institutional review board.

Results

Study Population

Overall, 18 of 19 providers and 75 of 79 patients were enrolled in the study; one patient did not pass the Mini-Cog test and was excluded. Ten (56%) providers were from the university-affiliated dialysis unit, and the remaining eight (44%) providers cared for patients at the community-based units. Nine providers were nephrologists, five were nurse practitioners or physician assistants, and four were nurse managers. The mean age of the providers was 41 ± 9 yr (range 27 to 56), and the mean number of years of experience treating dialysis patients was 9 ± 9 yr (range 1 to 27). The median number of surveys completed by providers was 3 (range 1 to 20). Sixteen providers were white, and two were Asian. Of the 75 patient participants, 33 (44%) were from the university-affiliated unit and the remaining 42 (56%) patients received dialysis at one of the two community-based clinics. None of the patients had been on dialysis for <6 mo. Table 1 illustrates the clinical characteristics of study patients.

Accuracy and Predictive Value of Provider Responses

The prevalence and severity of symptoms reported by patients and providers are depicted in Table 2. Providers underreported

the presence of 29 (97%) of 30 individual symptoms and, compared with patient-reported severity, underestimated the severity of 19 (63%) of 30 symptoms (Table 2). The frequency of provider "don't know" responses ranged from 3% for "shortness of breath" to 76% for "difficulty becoming sexually aroused." The sensitivity of provider responses for all symptoms other than "fatigue," "nausea," and "shortness of breath" was $<50\%$ (Table 3). The PPV of provider reports ranged from 0% for "chest pain" and "difficulty concentrating" to 100% for "dry mouth." PPV were $<75\%$ for 25 individual symptoms (Table 3).

Patient-Provider Agreement on the Presence and Severity of Symptoms

Agreement between patients and providers on the presence and severity of symptoms is displayed in Table 4. Overall, κ scores were lowest when provider "don't know" responses were considered a disagreement and slightly higher when "don't know" responses were considered as a "no" response or excluded. Considering the model in which "don't know" responses were counted as a disagreement, there was poor concordance ($\kappa < 0.2$) on the presence of 25 (83%) individual symptoms. Patient-provider agreement on the 12 symptoms that patients described as being most severe (mean severity >3.0) was universally poor ($\kappa < 0.15$). Agreement on the severity of individual symptoms was lowest for "feeling sad" ($\kappa = -0.17$) and "headache" ($\kappa = -0.15$) and highest for "dry mouth" ($\kappa = 0.56$). Weighted κ scores for the severity of five symptoms were less than zero, including those for "trouble falling asleep," "feeling sad," and "restless legs."

Associations of Provider Type, Years of Experience, and Dialysis Unit with Symptom Recognition

In the multiple logistic regression model, nurse practitioners and physician assistants were less likely than nephrologists to agree with patients on the presence of symptoms (odds ratio [OR] 0.28; $P < 0.001$), and although not statistically significant, nurse managers tended to be more likely than nephrologists to agree with patients (OR 2.8; $P = 0.21$). Each year of providers' experience was associated with a greater likelihood of agreeing with patients on the presence of symptoms (OR 1.1; $P = 0.008$). Relative to providers at the university-affiliated dialysis unit, providers at the two community-based clinics were less likely to agree with patients (OR 0.38 and 0.59 respectively; $P = 0.01$).

Discussion

In this study, renal providers were largely unaware of the presence of physical and emotional symptoms in their patients who were on maintenance hemodialysis, including symptoms that patients described as most severe. When providers did correctly identify symptoms, the severity of those symptoms was commonly underestimated by providers. Although not unexpected, these observations are novel and have potential implications for the design of interventions to improve the treatment of symptoms in this patient population.

Studies in other patient populations have also documented substantial underreporting of symptoms by providers. Using

Table 1. Baseline demographic and clinical characteristics of patients

Characteristic	Patients (n = 75)
Demographic characteristics	
age (yr; mean \pm SD)	59 ± 14
race (% white)	64
gender (% male)	67
previous transplant (%)	21
dialysis vintage (yr; mean \pm SD)	4.4 ± 5.8
Treatment variables (mean \pm SD)	
hemoglobin (g/dl)	11.9 ± 1.4
albumin (g/dl)	3.8 ± 0.4
phosphate (mg/dl)	5.1 ± 1.6
calcium (mg/dl)	8.8 ± 0.6
parathyroid hormone (pg/ml)	229 ± 199
Kt/V	1.58 ± 0.38
Comorbid conditions (%)^a	
diabetes	53
diabetes with end-organ damage	51
heart failure	21
peripheral vascular disease	15
cerebrovascular disease	15
mild liver disease	13
end-stage liver disease	8
myocardial infarction	7
obstructive lung disease	4
peptic ulcer disease	4
tumor	4
hemiplegia	1

^aNo patient had a history of dementia, connective tissue disease, leukemia, lymphoma, or HIV.

Table 2. Patient and provider reports of symptoms and their severity

Symptom	Patient-Reported Prevalence (%)	Provider-Reported Prevalence		Patient-Reported Severity ^a	Provider-Reported Severity ^a
		Yes (%)	Don't Know (%)		
Feeling tired or lack of energy	68	45	25	2.8	2.8
Dry skin	65	11	39	2.2	2.4
Dry mouth	45	5	40	2.4	2.3
Itching	45	13	36	3.0	3.7
Trouble staying asleep	45	13	39	3.1	2.8
Trouble falling asleep	44	13	40	3.5	3.4
Muscle cramps	39	17	32	3.2	2.7
Cough	39	9	29	2.3	2.1
Bone or joint pain	37	15	35	3.2	3.1
Diarrhea	33	13	29	2.7	2.9
Swelling in legs	32	19	5	2.2	2.1
Worrying	31	24	41	3.3	2.7
Muscle soreness	29	9	37	2.6	2.4
Shortness of breath	28	21	3	2.6	2.9
Difficulty becoming sexually aroused	28	7	76	3.4	3.2
Decreased appetite	25	23	12	2.1	2.9
Numbness or tingling in feet	24	12	37	3.1	2.7
Feeling sad	24	12	40	3.1	2.8
Decreased interest in sex	24	3	75	3.1	4.5
Lightheadedness or dizziness	23	20	23	3.0	2.3
Feeling anxious	23	12	41	2.5	2.6
Nausea	21	17	13	2.8	2.8
Headache	21	7	31	3.4	3.4
Restless legs or difficulty keeping legs still	21	9	33	2.6	2.3
Feeling irritable	19	4	36	3.1	2.3
Constipation	16	7	33	2.6	2.4
Difficulty concentrating	12	7	41	3.4	2.4
Vomiting	11	8	17	2.4	2.5
Feeling nervous	9	16	41	2.7	2.5
Chest pain	7	3	15	2.4	1.5
Overall	30	13	33	2.8	2.7

^aMean severity for symptoms reported as being present.

survey study techniques similar to ours, Justice *et al.* (22) compared patient- and provider-reported symptoms in a large cohort of HIV patients. The κ score for agreement on the presence of symptoms overall was 0.35 yet was found to be only 0.25 when comparing symptoms that patients had reported as at least moderately severe. These measured levels of agreement, although slightly higher than those seen in this study, were interpreted to signify considerable underrecognition of symptoms by providers. In a study of oncology patients, Grossman *et al.* (23) used a visual analog scale to compare patient and provider reports of the intensity of pain experienced by patients. In cases in which pain was reported as >4 on the 10-point analog scale, there was no statistically significant correlation between patient-described intensity of pain and the intensity reported by providers. Our findings closely mirror the results of these two studies.

Especially noteworthy in this study is provider underrecognition of specific symptoms that are amenable to treatment and are correlated with impaired HRQoL. Provider awareness of “bone or joint pain,” which was one of the more common and most severe symptoms reported by patients, was characterized by a κ score of only 0.04 and sensitivity of 18%, whereas 35% of providers recorded a response of “don’t know” for this symptom. Likewise, agreement on the presence of other pain-related symptoms, including “muscle cramps,” “muscle soreness,” and “chest pain,” were characterized by κ scores <0.05 . A series of studies found that pain affects as many as 50% of hemodialysis patients, is frequently untreated or treated inadequately, and is associated with impaired quality of life (8,11,17,24). Moreover, a recent study by Barakzoy and Moss (25) demonstrated that implementation of the World Health Organization pain treatment algorithm effectively reduced the severity of pain in he-

Table 3. Accuracy and predictive value of provider responses

Symptom	Sensitivity (%)	Specificity (%)	Positive Predictive Value (%)	Negative Predictive Value (%)
Shortness of breath	52	91	69	83
Feeling tired or lack of energy	51	67	77	39
Nausea	50	92	62	87
Decreased appetite	47	86	53	83
Feeling nervous	43	87	25	94
Swelling in legs	42	92	71	77
Lightheadedness or dizziness	41	86	47	83
Numbness or tingling in feet	33	95	67	82
Worrying	30	79	39	72
Itching	27	98	90	62
Headache	25	98	80	83
Vomiting	25	94	33	91
Diarrhea	24	92	60	71
Trouble falling asleep	21	93	70	60
Difficulty becoming sexually aroused	19	98	80	76
Restless legs or difficulty keeping legs still	19	93	43	81
Bone or joint pain	18	87	46	64
Muscle cramps	17	83	39	61
Feeling sad	17	90	33	77
Cough	17	96	71	65
Constipation	16	95	40	86
Trouble staying asleep	15	88	50	55
Dry mouth	12	100	100	58
Dry skin	10	89	63	34
Muscle soreness	9	91	29	71
Feeling irritable	7	97	33	82
Feeling anxious	6	86	11	76
Decreased interest in sex	6	98	50	77
Chest pain	0	97	0	93
Difficulty concentrating	0	92	0	87

modialysis patients. The availability of effective therapy along with the high prevalence and clinical significance of pain in hemodialysis patients underscores the importance of our finding that renal providers seem largely unaware of the presence and severity of this symptom.

A series of DSI items relate to patients' sense of psychologic well-being and have been found in previous analyses to correlate closely with depression (8). Major depression is present in nearly one in five long-term hemodialysis patients and is associated with impaired HRQoL and adverse outcomes, including mortality (26–28). Our findings suggest that renal providers are also unaware of symptoms that may signify underlying psychologic distress, which would seem to compromise their capacity to identify and intervene on this problem. Likewise, 75% of renal providers reported not knowing whether symptoms pertaining to sexual dysfunction affected their patients. Dialysis patients may feel particularly uncomfortable discussing sexual dysfunction in the setting of a dialysis unit. However, problems with sexual function are common in hemodialysis patients, and the lack of awareness among providers of their

presence and severity should serve as an impetus for the use of a standardized process of assessment of such sensitive issues (29). Last, symptoms pertaining to sleep disturbance were among the most common and severe yet were largely unrecognized by providers. Behavioral therapy may be appropriate for dialysis patients who have trouble falling and staying asleep, yet implementation of such therapy hinges on the recognition of such symptoms by providers. Providers did recognize shortness of breath and swelling with reasonable accuracy. This is likely because these symptoms are often related to extracellular volume retention, which providers routinely assess in hemodialysis patients. Efforts to increase awareness of the symptoms that are less clinically apparent on physical examination may help to improve provider assessment and treatment of such symptoms.

Our findings may be explained by the current framework for the treatment of dialysis patients in which quality of care is defined in large part by the attainment of target parameters of dialysis adequacy, anemia management, bone and mineral metabolism, and vascular access, rather than alleviation of symp-

Table 4. Patient-provider agreement on symptoms and their severity^a

Symptom	Agreement 1 ^b	Agreement 2 ^c	Agreement 3 ^d	Severity Agreement
Feeling anxious	-0.05	-0.09	-0.14	0.01
Dry skin	-0.01	-0.01	-0.02	0.11
Chest pain	0.00	-0.04	-0.04	0.00
Decreased interest in sex	0.01	0.05	0.16	0.50
Difficulty becoming sexually aroused	0.03	0.22	0.42	0.23
Constipation	0.04	0.16	0.18	0.09
Muscle cramps	0.04	0.00	0.04	0.18
Bone or joint pain	0.04	0.06	0.09	0.25
Muscle soreness	0.04	0.00	0.03	0.00
Difficulty concentrating	0.05	-0.09	-0.07	0.00
Trouble staying asleep	0.05	0.03	0.08	0.13
Feeling irritable	0.05	0.06	0.10	0.00
Feeling sad	0.05	0.07	0.13	-0.17
Feeling nervous	0.06	0.22	0.23	-0.11
Dry mouth	0.07	0.13	0.20	0.56
Worrying	0.07	0.10	0.17	0.04
Trouble falling asleep	0.08	0.15	0.22	-0.09
Diarrhea	0.09	0.19	0.22	0.09
Cough	0.09	0.15	0.20	0.16
Numbness or tingling in feet	0.11	0.34	0.38	0.31
Restless legs or difficulty keeping legs still	0.12	0.15	0.26	-0.07
Headache	0.13	0.31	0.39	-0.15
Vomiting	0.14	0.21	0.26	0.23
Itching	0.15	0.26	0.36	0.18
Lightheadedness or dizziness	0.19	0.29	0.34	0.08
Feeling tired or lack of energy	0.20	0.15	0.36	0.20
Decreased appetite	0.24	0.34	0.34	0.12
Nausea	0.27	0.45	0.42	0.17
Swelling in legs	0.34	0.38	0.39	0.25
Shortness of breath	0.42	0.47	0.46	0.28

^aLevels of agreement are reported as κ scores.^b"Don't know" responses considered disagreement.^c"Don't know" responses considered a "no" response.^d"Don't know" responses excluded.

toms or improvement in quality of life. In 2004, the Centers for Medicare and Medicaid Services changed reimbursement to nephrologists to increase the number of monthly patient evaluations and improve quality of care and outcomes. However, more frequent patient-provider interactions have not been shown to increase the proportion of patients who meet currently accepted quality metrics or improve overall quality of life or patient satisfaction with care, highlighting the need for alternative ways to improve the lives of hemodialysis patients (30). The Institute of Medicine has defined quality of care on the basis of six parameters, one of which is patient centeredness (31). Patient centeredness requires that care focus on issues that matter most to patients, including treatment of symptoms and improvement in quality of life. Our findings suggest that the current model of care for long-term hemodialysis patients is not adequately patient centered and that new systems of care that incorporate and emphasize patients' symptoms, quality of life, and satisfaction with care should be considered.

This study has important limitations. First, the sample size of patients and providers was small, which may limit the generalizability of our findings. However, our study patients were younger than the national average and seemed to have less cardiovascular comorbidity, suggesting that symptom burden may be even greater in a more ill patient group. Second, although all provider surveys were returned within 24 h of patient evaluations and all but two were returned immediately, lack of recall of symptoms may have contributed to provider responses. It is also possible that disagreement between patients and providers was due to the difficulty for providers to recall accurately which patient had a symptom, not whether they had the symptom. Third, we did not assess agreement considering provider "don't know" responses as a "yes" response. However, *post hoc* sensitivity analyses of this question did not result in different results (data not shown). Fourth, certain symptoms on the DSI may have no effective therapies, which may explain why providers are less aware of their pres-

ence. Providers did demonstrate greater awareness of symptoms such as shortness of breath and leg swelling, for which modification of the dialysis procedure might be therapeutic. This suggests that familiarity with treatment options influences providers' assessment and awareness of symptoms. Fifth, the Mini-Cog may not have detected patients with mild cognitive impairment, which could have led to the underreporting of symptoms. Finally, we did not address whether certain symptoms were addressed by patients' primary care providers, which might explain why renal providers did not accurately recognize them. Patients may not have reported certain symptoms to renal providers if they were only transiently present during the preceding 7 d, if they believed that the symptoms were being managed by nonrenal providers, or if they perceived the symptom as untreatable. However, even if other providers were administering treatment, given the severity of many symptoms, one would expect renal providers to note their presence and communicate potential undertreatment to the primary provider. We should also point out that standard practice at the university-based dialysis unit, from which nearly half of study patients and 56% of providers were recruited, is for the renal provider to assume the role of primary care provider.

Conclusions

The results of this study suggest that renal providers do not adequately recognize physical and emotional symptoms in patients who are on long-term hemodialysis and often underestimate the severity of the very symptoms that are most troubling to patients. These findings suggest that the development of a standard process of symptom assessment by renal providers, either during the dialysis procedure or apart from direct dialysis care, may be the first step toward the goal of improving recognition and treatment of symptoms in this population—processes that, in turn, could have a favorable impact on patients' overall quality of life and satisfaction with care.

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Disclosures

None.

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