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Health care providers who treat hemodialysis patients appear to be unaware of the symptoms and resulting low quality of life that their patients endure.

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Beyond Lab Data: Symptoms Matter for Hemodialysis Patients

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Context: While symptom management is integral to the treatment of many chronic diseases, for end stage renal disease being treated with maintenance hemodialysis clinical targets such as hemoglobin levels and other laboratory parameters are the primary measures of success. Indeed, symptom alleviation has not been emphasized in the treatment of end stage renal disease.

Background

Patients who receive maintenance hemodialysis report a low health related quality of life. Previous research has shown that this low quality of life was associated with the number and severity of reported physical and emotional symptoms. In addition, the symptom burden among patients receiving hemodialysis was comparable to that of patients with cancer or AIDS. Yet, although symptoms play a central role in patients' disease experiences and providers are the gateway to symptom palliation, little is known about renal provider awareness of the symptoms that their patients suffer. The aim of this study was to assess renal care provider recognition of the presence and severity of physical and emotional symptoms in maintenance hemodialysis patients.

Methods

- A total of eighteen providers were recruited from three dialysis units in Pittsburgh, Pennsylvania from February 2006 to July 2006. A little more than half the providers (56%) were from a university-affiliated dialysis unit with the remainder from community-based clinics. Nine providers were nephrologists, five were nurse practitioners or physician assistants, and four were nurse managers. Their experience varied from 1 to 27 years of treating dialysis patients with the average being 9 years.
- The patients of each of the participating providers were approached about being part of the study and a total of 75 patients were enrolled. The patients' average age was 59 years. More than half were male (67%) and more than half were white (64%). The average length of time on dialysis was a little more than four years and 21% had received a kidney transplant.

Renal care providers were largely unaware of the presence and severity of physical and emotional symptoms in their patients receiving maintenance hemodialysis.

Providers did not recognize treatable symptoms, many of which are correlated with impaired health related quality of life.

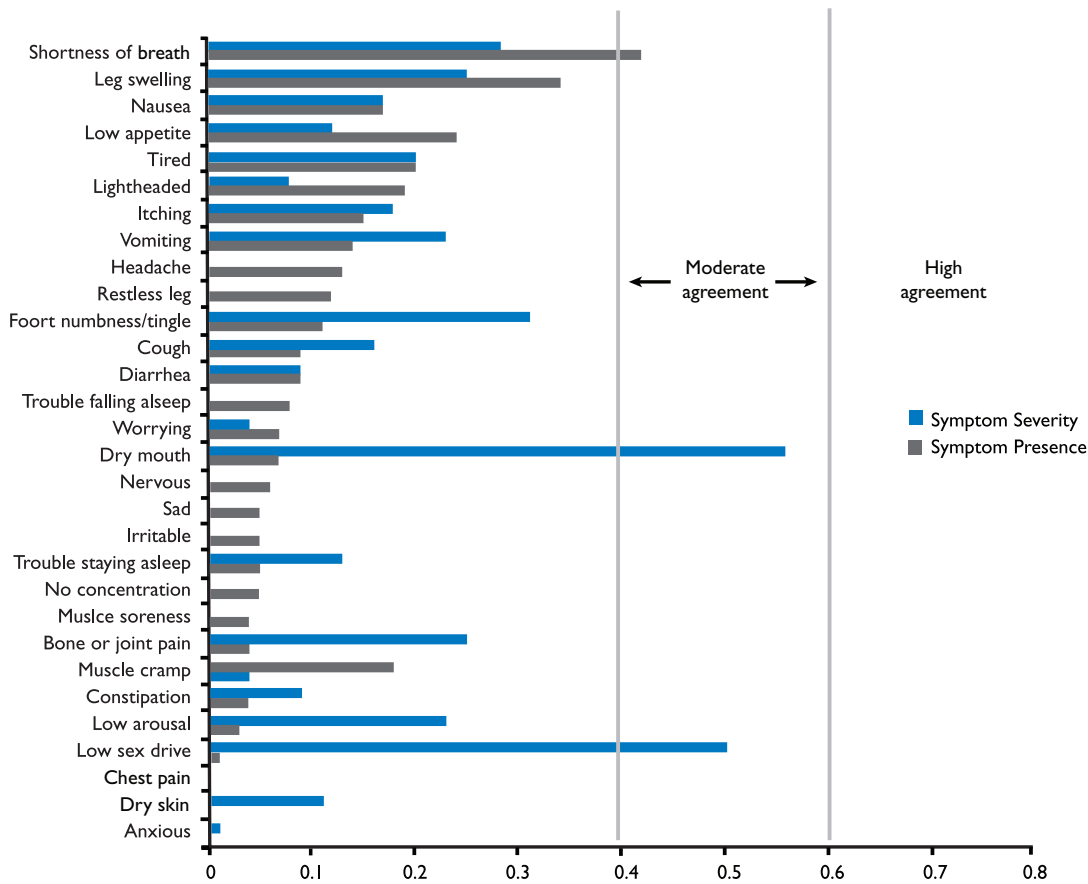
Providers with more training and/or experience tended to agree with patients more often about the presence of symptoms.

- The researchers interviewed the patients during dialysis, collecting basic demographic information and administering the Dialysis Symptom Index (DSI), a questionnaire about the presence and severity of symptoms.
- After the each patient completed his or her DSI, the patient's provider completed a similar survey. Unlike patient respondents, providers were allowed to indicate "don't know" for symptoms. The investigators also abstracted clinical and treatment-related data from patients' dialysis charts, including blood test results and information about co morbid conditions.

Results

- Providers failed to match patients' assessments for many symptoms. Overall, providers under-reported the presence of 29 of 30 symptoms (97%) and compared to patient-reported severity, underestimated the severity of 19 of 30 (63%) symptoms.
- Providers were right only about half of the time in correctly stating that patients had symptoms of shortness of breath, fatigue, and nausea. They accurately identified the presence of decreased appetite, nervousness, leg swelling, and lightheadedness between 41% and 47% of the time. Between one-quarter and one-third of the time providers agreed with the patients' surveys indicating numbness or tingling of the feet, worrying, itching, headache, vomiting and diarrhea.
- Providers also misjudged the severity of the symptoms that they identified. Agreement on the severity of individual symptoms was lowest for feeling sad and headache, and highest for dry mouth.
- Providers failed to recognize bone or joint pain, which were among the more common and severe symptoms identified by patients. Agreement between patients and providers was also low on the presence of other pain-related symptoms such as muscle cramps, muscle soreness and chest pain.
- A series of items related to psychological well-being (feeling sad, irritable or anxious), that have been found to be closely correlated with depression, were similarly unnoticed by providers.
- In addition, renal care providers failed to identify symptoms pertaining to sexual dysfunction and sleep disturbance.
- Nurse practitioners and physician assistants were less likely than nephrologists to recognize the presence of symptoms and nurse managers tended to be better at it than nephrologists. Each year of provider experience was associated with a greater likelihood of correctly identifying patient symptoms. Relative to providers at the university-affiliated dialysis unit, providers at the community clinics were less likely to recognize symptoms.

Figure 1: Low Level of Agreement between Patient and Providers on Presence and Severity of Symptoms



Note: The levels of agreement between patients and providers about symptoms and severity depicted above are derived from kappa scores. The “don’t know” responses of providers were considered disagreement. Negative kappa scores were converted to zero for clarity.

Implications

Dialysis patients commonly experience symptoms for which potentially effective therapies are available. Yet, renal care providers do not generally recognize these symptoms and therefore they remain largely undertreated.

Educating providers about the prevalence and severity of common symptoms, as well as improving their ability to recognize treatable symptoms, might improve quality of life for end stage renal disease patients.

While it is critical for those who treat patients with end stage renal disease to maintain their focus on the achievement of clinical metrics that maximize the duration of life, given the chronic nature of the condition and examples from other disease models, renal care providers might consider expanding treatment goals and standards to include targets that ensure high quality of life for these patients.

This issue of the CHERP Policy Brief was based on the following publications: 1) Weisbord SD, McGill JB, Kimmel PL. *Psychosocial factors in patients with chronic kidney disease*. Adv Chronic Kidney Dis. 2007 Oct;14(4):316-8 and 2) Weisbord SD, Fried LF, Mor MK, Resnick AL, Unruh ML, Palevsky PM, Levenson DJ, Cooksey SH, Fine MJ, Kimmel PL, Arnold RM. *Renal provider recognition of symptoms in patients on maintenance hemodialysis*. Clin J Am Soc Nephrol. 2007 Sep;2(5):960-7.

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