Improvement in Pittsburgh Symptom Score Index After Initiation of Peritoneal Dialysis

Matthew J. Novak,1 Heena Sheth,2 Filitsa H. Bender,1 Linda Fried,1,3 Beth Piraino1

The Kidney Disease Outcomes Quality Initiative (K/DOQI) 2006 recommended a minimum weekly Kt/V of 1.7 for peritoneal dialysis (PD) patients while emphasizing the importance of keeping the patient free of uremic symptoms. We examined a symptom score index [Pittsburgh Symptom Score (PSS)] designed to evaluate uremic symptoms to determine if the score improved in the first year of PD.

The PSS is a 10-symptom (fatigue, trouble sleeping, difficulty concentrating, restless legs, change in taste, loss of appetite, nausea or vomiting, pruritus, bone pain, muscle pain or weakness) questionnaire that uses a Likert scale of 0 (none) to 5 (severe). From January 1, 2003, to December 31, 2006, incident PD patients completed the PSS at 0, 3, 6, 9, and 12 months. Patients were excluded from analysis if they had been on PD for less than 6 months or on hemodialysis 6 months or more before starting PD. Prevalences of individual symptoms at 1 year and at baseline were compared using the chi-square test. Differences in PSS at the various time intervals were compared using the sign test.

The study included 45 patients [51% women; 31% African Americans; 33% with diabetes; mean age: 58.0 years (range: 30 – 89 years); mean initial Charlson Comorbidity Index: 5 (range: 2 – 11)]. Initial median total score improved to 8 from 12 (p = 0.005) by 3 months, with no further improvement. Improvements occurred in change in taste (p = 0.029 at 3 months), difficulty concentrating (p = 0.04 at 6 months), itching (p = 0.007 at 3 months), loss of appetite (p = 0.009 at 3 months), muscle pain or weakness (p = 0.002 at 3 months), sleep disturbance (p = 0.04 at 9 months), and restless legs (p = 0.026 at 9 months). Fatigue, bone pain, and nausea or vomiting scores were low at the start and did not significantly change over the first year. Significant decreases in symptom prevalence were seen in difficulty concentrating (p = 0.03), change in taste (p = 0.005), loss of appetite (p = 0.04), and muscle pain or weakness (p = 0.02) at 1 year.

Initiation of PD results in improvement in the prevalence and severity of most uremic symptoms by 3 to 9 months and is maintained at 12 months. We recommend routine checklist evaluation of symptoms at regular clinical intervals.

Key words
Symptom check list, quality of life

Introduction
Health-related quality of life (HRQoL) in patients with end-stage renal disease (ESRD) was first noted to be diminished more than two decades ago (1). Initial studies revealed lower indices of HRQoL in ESRD patients than in the general population and in transplanted patients (1,2). A more recent paper has likened the HRQoL of patients with ESRD to those with terminal malignancy (3). This is significant because some studies have shown measures of HRQoL to be an independent predictor of morbidity and mortality in dialysis patients (4). Many factors contribute to this poor HRQoL, but one of the major contributors is symptom burden. Recent studies have shown that HRQoL is strongly associated with symptom burden (5,6).

Given this correlation between HRQoL and symptom burden, the Kidney Disease Outcomes Quality Initiative (K/DOQI) has recommended greater surveillance for, and treatment of, uremic symptoms. To monitor such symptoms, multiple previous studies have used symptom checklists. We previously showed that the Pittsburgh Symptom Score (PSS) index is strongly
correlated with diminished HRQoL (7). Most prior studies on the prevalence of symptoms have been cross-sectional; whether symptoms change over time has been less well studied. What is also unknown, although assumed, is that symptoms improve with the start of dialysis.

The aims of the present study were, first, to use an easily applied symptom assessment scale—the PSS—to evaluate symptom burden in incident PD patients and, second, to longitudinally analyze symptom change over 1 year after initiation of PD.

Patients and methods

The patients included in our study were dialyzed at a single not-for-profit dialysis center run by Dialysis Clinics, Inc., in Pittsburgh. All patients were under the care of physicians in the University of Pittsburgh Medical Center, Renal and Electrolyte Division. Our retrospective analysis included all incident PD patients between January 1, 2003, and December 31, 2006, identified from the PD registry. At the start of dialysis, patients signed an institutional review board–approved consent to participate in the PD registry. Patients were excluded from the current analysis if they had been on PD for less than 6 months or on hemodialysis (HD) for 6 months or more before PD initiation. Baseline patient demographic and clinical characteristics such as diabetes status were obtained through the PD registry.

We administered a PSS questionnaire as a routine clinical evaluation before initiation of PD and at each monthly visit. The questionnaire covers a 10-symptom checklist (fatigue, trouble sleeping, difficulty concentrating, restless legs, change in taste, loss of appetite, nausea or vomiting, pruritus, bone pain, muscle pain or weakness), using a Likert scale of 0 (none) to 5 (severe). Using chart review for each patient at initiation of PD (time 0) and at intervals of approximately 3 month thereafter for 1 year. We chose to use 3-month instead of monthly intervals to minimize missing data points. Each individual symptom and the total score were included in the analysis. We also retrospectively obtained for analysis the results for each interval of the blood work [hemoglobin, calcium, phosphorus, parathyroid hormone (PTH), and albumin] routinely performed through the dialysis clinic. These laboratory results were completed by Dialysis Clinics, Inc., central laboratories. Missing data points ranged from 0% to 15%, except for PTH, for which only 19 of 45 values (58%) were available for analysis.

Statistics

Demographics and clinical characteristics are reported using descriptive statistics. Prevalences of individual uremic symptoms are reported as the percentage of patients with a score of greater than 0 for each symptom at baseline and at 12 months. Change in the prevalence of each symptom at 12 months was calculated by chi-square test. Median total PSS and individual symptom scores were used in the analysis. Change in severity of symptom scores over time was calculated by the sign test in the STATA statistical software package (StataCorp LP, College Station, TX, U.S.A.).

Results

There were 45 incident patients who met the inclusion criteria. Mean age was 58.0 ± 15.6 years (range: 30 – 89 years). Of the 45 patients, 22 (49%) were men, 14 (31%) were African American, and 15 (33%) had diabetes. At baseline, the median Charlson Comorbidity Index score was 5 (range: 2 – 11), mean albumin was 3.8 ± 0.4 g/dL, hemoglobin 11.2 ± 2.1 g/dL, Ca × P was 47.1 ± 13.3, and median PTH was 111.5 pg/mL (range: 5 – 612 pg/mL).

Median total PSS score was initially 12 (range: 1 – 45). Median total scores were higher in diabetic patients at baseline (18 vs. 12 in nondiabetic patients, \( p = 0.04 \)). Improvement in total score reached statistical significance at 6 months, with a median score of 8 \( ( p = 0.029 \), Figure 1). At 12 months as compared with baseline, 8 patients (18%) had an increased PSS (range: 4 – 26; changed by 1 – 6), 6 patients (13%) had no change (range: 1 – 16), and 31 patients (69%) had a reduced score (range: 0 – 25; changed by 1 – 29).

Table I shows the presence of each symptom, as determined by prevalence at baseline and at 12 months. Fatigue, muscle pain or weakness, and change in taste, loss of appetite, nausea or vomiting, pruritus, bone pain, muscle pain or weakness), using a Likert scale of 0 (none) to 5 (severe). Using chart review for each patient at initiation of PD (time 0) and at intervals of approximately 3 month thereafter for 1 year. We chose to use 3-month instead of monthly intervals to minimize missing data points. Each individual symptom and the total score were included in the analysis. We also retrospectively obtained for analysis the results for each interval of the blood work [hemoglobin, calcium, phosphorus, parathyroid hormone (PTH), and albumin] routinely performed through the dialysis clinic. These laboratory results were completed by Dialysis Clinics, Inc., central laboratories. Missing data points ranged from 0% to 15%, except for PTH, for which only 19 of 45 values (58%) were available for analysis.

Table I shows the presence of each symptom, as determined by prevalence at baseline and at 12 months. Fatigue, muscle pain or weakness, and change in taste, loss of appetite, nausea or vomiting, pruritus, bone pain, muscle pain or weakness, and change in taste, loss of appetite, nausea or vomiting, pruritus, bone pain, muscle pain or weakness had the highest prevalences at baseline. Fatigue, trouble sleeping, itching, and muscle pain or weakness had the highest prevalences at 12 months (>55%). A significant decline in prevalence was seen in difficulty concentrating \(( p = 0.03 \), change in taste \(( p = 0.005 \), loss of appetite \(( p = 0.04 \), and muscle pain or weakness \(( p = 0.02 \).

Table I shows the median severity at baseline and at 12 months. Fatigue, nausea or vomiting, and bone pain did not improve over the 12 months. Change in taste \(( p = 0.03 \), loss of appetite \(( p = 0.009 \), itching,
and muscle pain or weakness ($p = 0.002$) improved at 3 months. Difficulty concentrating improved at 6 months ($p = 0.04$). At 9 months, trouble sleeping ($p = 0.04$) and restless legs ($p = 0.03$) improved statistically significantly ($p < 0.05$). Hemoglobin and Ca×P did not significantly change over 12 months. Median PTH increased significantly from 115.5 pg/mL at baseline to 310 pg/mL at 12 months ($p = 0.004$). Albumin decreased from a mean of 3.81 g/dL at baseline to 3.58 g/dL at 12 months ($p = 0.001$).

**Discussion**

Many recent studies have revealed an overwhelming prevalence of symptoms in patients with ESRD (5,6,8). Many of these studies have used various forms of symptom assessment, including the Memorial Symptom Assessment Scale–Short Form (MSAS-SF), variations of the MSAS-SF, individualized questionnaires, and limited symptom assessment on HRQoL instruments (4–6,9–11). The PSS was developed at the University of Pittsburgh to assess symptom progression longitudinally in a clinical setting. It was designed for ease of use by patients, with focus on the common complaints of dialysis patients. The PSS is similar in design to other previously validated instruments including the Dialysis Symptom Index (9) and the Edmonton symptom assessment system (10,11).

Our study also demonstrates a high prevalence of symptoms in incident PD patients. The most prevalent symptoms at baseline included fatigue, muscle pain or weakness, difficulty concentrating, and loss of appetite. The prevalence of the symptoms in our study at 12 months is comparable to that of a meta-analysis by Murtagh et al. (8). However, at baseline,

---

**FIGURE 1** Total Pittsburgh Symptom Score (PSS) in incident peritoneal dialysis patients over time. The $p$ values compare median PSS at each time interval to baseline median PSS.

**TABLE I** Presence and severity of symptoms

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Baseline (%)</th>
<th>Prevalence at 12 Months (%)</th>
<th>$p$ Value</th>
<th>Baseline Median</th>
<th>Significant change achieved (months)</th>
<th>$p$ Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>80.0</td>
<td>71.8</td>
<td>0.38</td>
<td>2</td>
<td></td>
<td>0.12</td>
</tr>
<tr>
<td>Trouble sleeping</td>
<td>66.7</td>
<td>64.1</td>
<td>0.8</td>
<td>1</td>
<td>9</td>
<td>0.04c</td>
</tr>
<tr>
<td>Difficulty concentrating</td>
<td>71.1</td>
<td>54.3</td>
<td>0.03c</td>
<td>1</td>
<td>6</td>
<td>0.04c</td>
</tr>
<tr>
<td>Restless legs</td>
<td>55.6</td>
<td>43.6</td>
<td>0.27</td>
<td>1</td>
<td>9</td>
<td>0.026c</td>
</tr>
<tr>
<td>Change in taste</td>
<td>55.6</td>
<td>28.6</td>
<td>0.005c</td>
<td>1</td>
<td>3</td>
<td>0.029c</td>
</tr>
<tr>
<td>Loss of appetite</td>
<td>71.1</td>
<td>48.7</td>
<td>0.04c</td>
<td>0</td>
<td>3</td>
<td>0.009c</td>
</tr>
<tr>
<td>Nausea or vomiting</td>
<td>42.2</td>
<td>23.1</td>
<td>0.06</td>
<td>0</td>
<td></td>
<td>0.21</td>
</tr>
<tr>
<td>Itching</td>
<td>62.2</td>
<td>61.5</td>
<td>0.94</td>
<td>1</td>
<td>3</td>
<td>0.007c</td>
</tr>
<tr>
<td>Bone pain</td>
<td>24.4</td>
<td>33.3</td>
<td>0.37</td>
<td>0</td>
<td></td>
<td>0.26</td>
</tr>
<tr>
<td>Muscle pain or weakness</td>
<td>80.0</td>
<td>56.4</td>
<td>0.02c</td>
<td>2</td>
<td>3</td>
<td>0.002c</td>
</tr>
</tbody>
</table>

* Presence of symptoms was determined by prevalence, calculated as the percentage of patients with a score greater than 0 for each symptom.

* Severity was determined by median score at each interval. Month at which statistically significant change occurred is shown.

* $p < 0.05$. 

---
our population seemed to have a higher prevalence of most symptoms. That finding may be a reflection of symptom prevalence before initiation of dialysis, because the other studies focused on patients already on dialysis. Most studies of symptom burden have focused primarily on HD patients. Only Parfrey et al. (12) and Merkus et al. (5) performed analyses on both modalities.

Parfrey et al. found no significant differences between modalities; however, Merkus et al. found a statistically significant difference in lack of appetite (48% PD vs. 25% HD). Lack of appetite in our study also had a prevalence of 48% after 12 months of PD. This observation may be a result of abdominal distention related to the PD treatment or to the effect of calories received from dialysis.

We believe that our study is the first to report improvement in symptom scores after initiation of PD. As shown in Figure 1, total scores improved statistically by 6 months and maintained the improvement at 1 year. In 69% of patients, we noted improvement in symptom score; but, interestingly, 31% of patients either showed no changes or worsened scores at 1 year. Improvements in severity were seen in all symptoms except for fatigue, nausea or vomiting, and bone pain. Why these symptoms did not show improvement is unclear. The severity scores at baseline for bone pain and nausea or vomiting were relatively low, which may have limited the ability of the PSS to demonstrate statistical change. Bone pain increased in prevalence, but did not worsen statistically in severity. That finding may in part be the result of an increase in PTH over the 1-year period.

Unfortunately, in current practice, many dialysis patients continue to experience a significant symptom burden with little provider recognition. Weisbord et al. (13) recently showed that providers are unaware of the burden and severity of patient symptoms in a HD population. That finding provides further evidence for the necessity of using symptom assessment tools in routine clinical care.

Our study has several limitations. First, it was a single-center study with a small sample size—factors that may limit its generalizability to other PD populations. Second, given its retrospective nature, the study could not completely control for socioeconomic and clinical factors such as medications, infections, or hospitalizations that may have affected the symptom score. Third, some of our patients began dialysis on HD, although for less than 6 months before the change to PD. This initial treatment may have augmented their symptom scores as compared with the scores of those who began PD with no prior dialysis.

Conclusions
Our study shows that symptom burden in incident dialysis patients is extensive. It also shows that PD initiation improves the severity of most symptoms by 3 to 9 months and maintains that improvement at 12 months. Further studies directed at improving overall symptom burden are required. We recommend routine symptom assessment through a checklist during regular clinical evaluations.

References


Corresponding author:
Matthew Novak, Renal/Electrolyte Division, University of Pittsburgh School of Medicine, A919 Scaife Hall, 3550 Terrace Street, Pittsburgh, Pennsylvania 15261 U.S.A.
E-mail: novakm3@upmc.edu