Original Article

Monitoring Symptoms in Patients with Advanced Illness in Long-Term Care: A Pilot Study

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Abstract

The Edmonton Symptom Assessment Scale (ESAS) was administered daily by nursing staff in a long-term care facility (LTCF) to monitor symptoms. Scores greater than or equal to 5 on a 0–10 scale were considered moderate-to-severe and triggered prompt treatment. One hundred and eight patients with advanced illness and perceived prognosis of less than 6 months were identified for rapid symptom management over a 7-month period. Forty-six (43%) of these patients had at least one episode of moderate-to-severe symptoms during the follow-up period. Thirty-one of these patients (67%) had a primary diagnosis of advanced AIDS and 12 (26%) had advanced cancer. Pain was the most frequent of the 15 symptoms measured, occurring in 29 patients. In the case of pain (P = 0.001), tiredness (P = 0.004), and well-being (P = 0.003), rapid symptom management led to significantly improved distress scores within 48 hours. These data suggest that it is feasible for nurses in an LTCF to use the ESAS on a daily basis to assess patients and obtain prompt treatment for distressful symptoms. Rapid treatment of symptoms can be an important quality indicator in nursing home patients with advanced illness. J Pain Symptom Manage 2006;32:168–174. © 2006 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words

Advanced illness, ESAS, long-term care, symptom distress, quality improvement, end-of-life care, symptom assessment

Introduction

Recent guidelines for end-of-life care in nursing homes promote the use of evidence-based protocols in assessment, planning, and evaluation of all aspects of care. The control and prevention of symptoms, such as pain, depression, and fatigue, is dependent upon a comprehensive assessment and early patient identification, and such protocols may achieve these outcomes. Studies demonstrate significant correlations among depression, fatigue, pain, and other symptoms in patients with advanced illness, and recommendations include incorporating multidimensional scales...
and algorithms that concurrently address and guide treatment of the most common symptoms.5

Terence Cardinal Cooke Health Care Center (Center) is a 729-bed long-term care facility (LTCF) in New York City that provides care for diverse populations that include advanced AIDS, geriatric, and cancer patients. There are 156 geographic beds dedicated to patients with advanced AIDS, structured on a full-time medical staff model. The Center recognized the special needs of these patients and developed a pilot protocol to identify those with unmet symptom management needs, provide adequate pain and symptom control in a timely manner, and monitor patient care outcomes. Although standards for the quality management of pain are widely promulgated in LTCFs, standards for the assessment and prompt treatment of symptoms that may be highly prevalent and distressful in the final stages of life are less common. If feasibility and improvement goals could be reached in the pilot test of the Center’s protocol, findings could serve as a justification for a larger palliative care program.

The impetus for this initiative coincided and was motivated by collaboration with the United Hospital Fund and Institute for Healthcare Improvement (IHI), which provided support and expertise in quality improvement techniques.6 During the 9-month collaboration, authors applied the IHI rapid cycle testing methodology to pilot a protocol to improve symptom distress in a subpopulation at the Center. The study sought to 1) determine the feasibility of using a daily nursing assessment/reassessment protocol to prompt early treatment of symptoms using a standardized tool, 2) determine the frequency of moderate-to-severe symptom distress in patients with advanced illness, and 3) determine whether a system for rapid treatment could improve symptoms within 48 hours after identification.

The Edmonton Symptom Assessment Scale (ESAS) is widely recognized as a reliable and valid instrument in both research and clinical arenas.5 We assessed the feasibility of daily ESAS administration by staff to identify a subgroup of patients with high symptom distress. It was not the purpose of this pilot to study treatment interventions and their specific effects on outcomes, nor was it intended to study symptom distress over periods of time longer than the 48-hour window set as the standard for control of distressing symptoms.

Methods

Approval to conduct the study was given by the Center’s Institutional Review Board. Requirement for consent was waived. The database was secured and confidentiality assured by using patient identification numbers.

Sample and Setting

The pilot study was conducted between November, 2001 and June, 2002. Following an initial start-up period to in-service physicians and nursing staff about the study and method for using the ESAS, a 7-month data collection period began. Potentially eligible patients were first identified by one of the authors (JB) according to diagnosis and disease condition. Verbal patients with advanced illness were discussed with the primary physician.7–10 No primary physician refused to participate in the study. Chronic diseases included late stage AIDS, cirrhosis, dementia, and cerebral vascular disease.

A total of 108 patients were identified as potentially eligible for the pilot, representing approximately 3% of the Center’s daily census. Thirty-two (30%) of these patients were non-verbal and unable to participate in the ESAS evaluation. Another 30 (28%) patients were verbal but never registered ESAS scores equal to or greater than 5, and were, therefore, excluded. The remaining 46 (43%) patients had at least one or multiple experiences of moderate-to-severe symptoms at some time during their course and comprise the study group.

Instrument

The ESAS is a validated patient-report instrument widely used in Canada in palliative care and hospice settings. Although there have been reports of its use in the United States in acute care settings, no reports of its use in LTCFs were identified.11

The ESAS uses a numerical scale from 0 to 10 to measure the intensity of each of eight symptoms (pain, tiredness, appetite, deceased sense of well-being, depression, drowsiness,
anxiety, and shortness of breath), with 10 re-
representing the most severe symptom distress.
Seven additional symptoms frequently en-
countered by Center staff were added to the “other”
category of the tool (i.e., insomnia, pruritis,
nausea/vomiting, diarrhea, constipation, stom-
atitis, and hiccups) by the study team.

Procedure
After potentially eligible patients were iden-
tified, the primary physician was asked “Would
you be surprised if your patient expired during
the next six months?” If they answered “no,”
the patient was designated as appropriate
for the pilot and the protocol of “routine”
monitoring and recording of symptom experi-
ences by nursing staff was initiated.
The day shift nurse placed an ESAS form in
the patient’s record after obtaining their initial
responses to the 15 symptoms. Verbal patients
who were able to respond underwent an inter-
view by nurses three times daily (8-hour shifts)
to complete the ESAS. Although proxy assess-
ments have been used in prior studies with
consistent caregivers, nonverbal patients were
not included for the initial pilot phase to max-
imize feasibility and acceptance of the new
method, and to learn the frequency and
resources needed to administer the tool. The
patient’s ability to participate was determined
by the nurse and primary physician. Some
patients were identified and interviewed near
the time of admission. Others were inpatients
at the Center for some time whose conditions
had worsened. Actual lengths of stay were not
recorded.

To assess the feasibility of using the ESAS,
several parameters were examined: the propor-
tion of patients with completed assessments,
the time taken to carry out the assessments,
the acceptability of the questionnaire to the
patient and nurse, and the training required
to learn how to use of the ESAS. The four areas
were assessed at weekly meetings with Nurse
Managers, selected nursing staff, and the pro-
ject staff. All ESAS interviews were performed
by staff and maintained in a logbook on each
unit. Symptom distress was defined as moder-
te-to-severe if it received a score equal to or
greater than 5 on the ESAS. If a patient scored
a symptom(s) at this level, the primary physi-
cian was notified and treatments prescribed
in all cases. ESAS scores at symptom onset
and 48 hours later were entered into a secured
database for analysis. The 48-hour time inter-
val was chosen because of the nature of some
symptoms to produce high distress, i.e., pain
and anxiety, and it allowed a reasonable time
for treatments to have an effect. With symp-
toms, such as depression and fatigue, more
time was anticipated for change to occur. All
scores pertaining to episodes of any symptom
observed in each patient during the study
period were entered into the database.

Statistical Analysis
At weekly meetings with nursing manage-
ment and project staff, issues relating to imple-
mentation and acceptance by patients and staff
were recorded. This included the proportion
of patients with completed assessments; the
time needed to carry out assessments and calls
to physicians for treatment; the acceptability
of the questionnaire to the patient and nurse;
and the training/education needed to develop
competency in using ESAS.
The extent of moderate-to-severe symptoms
was calculated. Mean ± standard deviation
was used to describe normally distributed
data, median (minimum, maximum) was
used for skewed data, and percent was used
for categorical data. Symptom improvement
within the same patient was analyzed by com-
paring the ESAS score at 48 hours (Post)
with the patient’s ESAS score at the onset of
each episode (Pre). A generalized linear
model approach was used to include all obser-
vations in patients with more than one episode
of a particular symptom. Since symptom scores
tended to be skewed, a gamma distribution was
assumed for the underlying probability
distribution.

To measure symptom change over the
course of episodes, the order of the episode
within each patient (i.e., first episode = 1, sec-
ond episode = 2, etc.) was added as a covariate
along with an episode × pre/post interaction
term to determine whether the magnitude of
ESAS scores changed with subsequent epi-
sodes within a patient. Since estimates from
generalized linear models tend to be unreli-
able with very small sample sizes, results are re-
ported only for comparisons involving at least
10 patients. A Bonferroni-Holm level of signif-
ificance was used to control for the number of
comparisons. All analyses were carried out using SAS 9.0 (SAS Inc., Cary, NC).

Results

Basic characteristics of the patient sample in the study are shown in Table 1. The majority of patients (67%) were diagnosed with advanced AIDS, which resulted in a sample that was relatively young (median = 47.1 years) and male (63%). Since the remaining patients were older, with diagnoses of either cancer or geriatric end-stage chronic illness, there was also a wide range of ages in the sample (minimum = 30 years, maximum = 85 years). Twenty-three patients were African-American (50%), fourteen (30%) were Hispanic, and nine (20%) were Caucasian.

Feasibility

The completion rate was determined by measuring the proportion of patients with completed assessments. By week four of the pilot, nurses’ adherence to the protocol was >90%. Time to complete ESAS was under 5 minutes on average. Nurses initially reported that completion of the ESAS was burdensome when completed each shift. This was especially problematic when symptoms had not changed, or patients were not available because of visitors, being asleep, or away from their room. The protocol was changed to a daily rather than shift assessment. Acceptability to the patient and nurse was recorded. A few patients refused to complete the ESAS, especially when they reported low symptom distress or were too fatigued. Once daily assessments began, fewer patient’s and staff complaints were heard. Training time, to learn how to administer and complete the ESAS, was short. Nurses were asked to query patients verbatim using the 15-symptom tool and to place forms in a logbook that could then be used by all staff to monitor patient symptoms.

Extent of Symptom Distress

A total of 392 symptom episodes were recorded in 46 patients (Table 2). The median (minimum, maximum) frequency of episodes per patient was 5 (1, 52), while the median (minimum, maximum) frequency of symptoms per patient was 3 (1, 11).

Pain, tiredness, decreased sense of well-being, and appetite were the four most frequently experienced symptoms. Twenty-nine patients had a median of two episodes of moderate-to-severe pain. This was followed-up by 25 patients who experienced at least one episode of tiredness, 23 patients with episodes of decreased sense of well-being, and 21 patients with episodes of lack of appetite. Other prominent symptoms were depression, experienced by 15 patients, insomnia and anxiety, experienced by 12 patients each, and drowsiness by 10 patients.

Symptom Changes at 48 Hours

Table 2 also shows the median ESAS score at 48 hours for each of the 15 symptoms, along with P-values for the 8 symptoms with sample sizes greater than or equal to 10. Comparing median values at onset with median values after 48 hours showed very little change in central tendency of the patients. However, looking at the minimum and maximum values at onset and at 48 hours indicates considerable improvement in at least some patients. For example, the 29 patients who presented with pain had onset ESAS scores that ranged between 5 and 10, with 50% of those scores between 5 and the median value of 7. After 48 hours, their pain scores ranged between 0 and 10 with 50% of scores falling between 0 and 6.

These changes are supported by the statistical comparison of ESAS scores at onset and after 48 hours using generalized linear modeling. Symptom burden improved significantly in the case of pain (P = 0.001), tiredness (P = 0.004), well-being (P = 0.003), depression

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Result</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>29 (63%)a</td>
</tr>
<tr>
<td>Age</td>
<td>47.1 (30, 85)b</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
</tr>
<tr>
<td>African-American</td>
<td>23 (50%)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>14 (30%)</td>
</tr>
<tr>
<td>Caucasian</td>
<td>9 (20%)</td>
</tr>
<tr>
<td>Primary diagnosis</td>
<td></td>
</tr>
<tr>
<td>AIDS</td>
<td>31 (67%)</td>
</tr>
<tr>
<td>Cancer</td>
<td>12 (26%)</td>
</tr>
<tr>
<td>Geriatric</td>
<td>3 (7%)</td>
</tr>
</tbody>
</table>

a All results presented as number (%) except where noted.
b Median (minimum, maximum).
Appetite had a \(P\)-value less than the standard level of 0.05 but above the Bonferroni-Holm adjusted significance level of 0.0167, while anxiety and drowsiness had \(P\)-values above 0.05. The significant differences found for pain, tiredness, sense of well-being, depression, and insomnia did not change when order of the episode was entered as a covariate. In addition, order of the episode itself was related to magnitude of the ESAS scores. For three of the symptoms, there was a small but significant negative trend indicating less severe symptom burden with successive episodes in a patient: pain (\(P = 0.02\)), sense of well-being (\(P = 0.02\)), and insomnia (\(P = 0.01\)). In contrast, for depression, there was a significant positive trend indicating that symptom burden tended to increase with successive episodes in the same patient (\(P < 0.001\)). There was no significant episode effect for tiredness (\(P = 0.41\)).

**Discussion**

Key elements in developing a palliative program in a long-term setting include identification of patients with advanced illness, monitoring of patients’ symptom burden, and measurement of outcome. This pilot study sought to determine 1) the feasibility of a routine nursing assessment/reassessment protocol to activate prompt treatment of symptoms using a standardized tool (ESAS); 2) the extent of moderate-to-severe symptom distress experienced in patients with advanced illness in this setting; and 3) whether improvement of symptom distress could be achieved within 48 hours after onset.

Our pilot findings show that use of the ESAS by nurses as a daily symptom assessment tool in patients with advanced illness is a practical and acceptable approach in this LTCF, but that further refinement is desirable. The feasibility of completing the ESAS was an evolving process requiring ongoing dialogue and feedback between investigators and nursing management. While nearly all assessments were completed, moving the activity from a shift to daily assessment proved less burdensome and time-consuming for nurses and patients. Time to learn and complete the ESAS was short. Two years after the pilot, the daily symptom assessment protocol continues for patients with advanced illness.

This pilot identified 108 patients with advanced illness during the 7-month study period. It represents a prevalence of 20–30 patients per day with advanced illness, or 3%–4% at the 729-bed Center. Forty-six patients had one or more episodes of moderate-to-severe pain, with pain, tiredness, lack of well-being, and lack of appetite showing up as the most frequent symptoms. Statistically

### Table 2
Prevalence of Symptom Episodes and ESAS Scores at Onset of Episode and at 48 Hours

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Patient, (n)</th>
<th>Total No. of Episodes</th>
<th>No. of Episodes per Patient:</th>
<th>Onset ESAS:</th>
<th>48-Hour ESAS:</th>
<th>Percent ESAS &lt;5 at 48 Hours</th>
<th>(P)-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>29</td>
<td>95</td>
<td>2 (1, 17)</td>
<td>7 (5, 10)</td>
<td>6 (0, 10)</td>
<td>23</td>
<td>0.001*</td>
</tr>
<tr>
<td>Tired</td>
<td>25</td>
<td>55</td>
<td>1 (1, 5)</td>
<td>6 (5, 10)</td>
<td>5 (0, 10)</td>
<td>42</td>
<td>0.004*</td>
</tr>
<tr>
<td>Well-being</td>
<td>23</td>
<td>39</td>
<td>1 (1, 6)</td>
<td>6 (5, 9)</td>
<td>5 (0, 8)</td>
<td>26</td>
<td>0.005*</td>
</tr>
<tr>
<td>Appetite</td>
<td>22</td>
<td>49</td>
<td>2 (1, 9)</td>
<td>6 (5, 10)</td>
<td>6 (0, 10)</td>
<td>27</td>
<td>0.02</td>
</tr>
<tr>
<td>Depressed</td>
<td>15</td>
<td>27</td>
<td>1 (1, 5)</td>
<td>5 (5, 10)</td>
<td>5 (1, 10)</td>
<td>22</td>
<td>0.009*</td>
</tr>
<tr>
<td>Insomnia(^a)</td>
<td>12</td>
<td>30</td>
<td>1.5 (1, 9)</td>
<td>7 (5, 10)</td>
<td>6 (0, 8)</td>
<td>30</td>
<td>0.001*</td>
</tr>
<tr>
<td>Anxious</td>
<td>12</td>
<td>14</td>
<td>1 (1, 2)</td>
<td>5 (5, 10)</td>
<td>4 (0, 10)</td>
<td>50</td>
<td>0.06</td>
</tr>
<tr>
<td>Drowsy</td>
<td>10</td>
<td>21</td>
<td>1 (1, 5)</td>
<td>6 (5, 10)</td>
<td>5 (0, 10)</td>
<td>38</td>
<td>0.08</td>
</tr>
<tr>
<td>Pruritus(^a)</td>
<td>9</td>
<td>13</td>
<td>1 (1, 5)</td>
<td>6 (5, 8)</td>
<td>6 (0, 8)</td>
<td>21</td>
<td>—</td>
</tr>
<tr>
<td>Nausea/Vomiting(^b)</td>
<td>9</td>
<td>17</td>
<td>1 (1, 7)</td>
<td>6 (5, 8)</td>
<td>4 (0, 10)</td>
<td>39</td>
<td>—</td>
</tr>
<tr>
<td>SOB</td>
<td>8</td>
<td>10</td>
<td>1 (1, 4)</td>
<td>9 (5, 10)</td>
<td>5 (3, 9)</td>
<td>20</td>
<td>—</td>
</tr>
<tr>
<td>Diarrhea(^b)</td>
<td>7</td>
<td>9</td>
<td>1 (1, 2)</td>
<td>7 (5, 9)</td>
<td>3 (0, 9)</td>
<td>56</td>
<td>—</td>
</tr>
<tr>
<td>Constipation(^b)</td>
<td>4</td>
<td>5</td>
<td>1 (1, 2)</td>
<td>6 (5, 6)</td>
<td>3 (0, 6)</td>
<td>60</td>
<td>—</td>
</tr>
<tr>
<td>Stomatitis(^b)</td>
<td>2</td>
<td>3</td>
<td>1.5 (1, 2)</td>
<td>6 (5, 6)</td>
<td>6 (5, 6)</td>
<td>0</td>
<td>—</td>
</tr>
<tr>
<td>Hiccups(^b)</td>
<td>2</td>
<td>3</td>
<td>1.5 (1, 2)</td>
<td>5 (3, 6)</td>
<td>5 (2, 5)</td>
<td>67</td>
<td>—</td>
</tr>
</tbody>
</table>

\(SOB = \text{shortness of breath.}\)

\(^a\)\(P\)-value < Bonferroni-Holm corrected alpha.

\(^b\)Symptoms added to ESAS ‘‘Other’’ category for this study.
significant resolution of symptom burden was achieved in the case of three of the most frequent symptoms: pain, tiredness, and lack of well-being.

It is important to note that 32 of the patients with advanced illness were nonverbal, due usually to degenerative diseases of the central nervous system leading to dementia. The palliative needs for this special population have been described.13,14 That 30% of the patients with advanced illness were nonverbal points out the need for a behavioral assessment tool to measure symptoms in this population. The use of behavioral pain and sedation scales are being evaluated for the symptom assessment protocol. Of the 76 verbal participating patients, 30 (39%) never developed moderate-to-severe symptom(s) during the study period, despite being monitored on a daily basis. This is presumably due either to the lack of intense symptoms in these patients or to the presence of adequate symptom control.

The ESAS proved to be a useful tool in monitoring patients’ symptoms on a daily basis. The original ESAS has been determined to be validated and reliable in previous studies, and the results of this study indicate that it may be unnecessary to modify the original ESAS since so few episodes occurred in most of the added symptoms on the list. The ESAS easily captured symptom presence and intensity, and was readily accepted by staff once a daily routine was established. The ESAS also proved to be useful for measuring changes over time, at least up to the 48-hour interval used in this study. As a routine practice at the Center, ESAS administration now helps staff to accurately articulate the unmet needs of the Center’s patients with advanced illness.

This pilot supports the use of the ESAS to identify patients with advanced illness and monitor their symptom burden in a long-term health care setting. It is an appropriate and adequate measurement tool for monitoring symptom control over the course of 48 hours. Continuous use of such measurements may lead eventually to improvement of symptom control over longer intervals of time and, in turn, to better quality palliative care and the ability to monitor a program’s overall quality improvement outcomes.

Several limitations are recognized in these pilot data. Some patients may have been excluded from the pilot because of physicians’ inaccurate estimations in predicting the time of death. Although life expectancy can be projected with some accuracy for cancer, the trajectory is less certain for many of the chronic, slowly progressing conditions that afflict most nursing home residents. We did not monitor the timeliness of reporting distressing symptoms. The opportunity to measure change in the 48-hour window may have been missed if there was a delay in reporting or treating a symptom. Patient acuity was not measured and may have affected symptom assessment or treatment. Treating nurses obtained the measurements and this may have biased the reporting.

These limitations notwithstanding, this pilot suggests that using the ESAS to monitor symptom distress in patients with advanced illness in a long-term health care setting is feasible and worthwhile. The ESAS was an appropriate and adequate measurement tool for monitoring symptom. Continuous use of such measures may improve the quality of palliative care in this setting. Recent studies suggest that decreased symptom distress relates to increased function and quality of life in the face of declining progressive illness.15 At this Center, the pilot results served to support the start of a palliative care program to improve patient outcomes in patients with advanced illness. Future studies should consider measuring the rates of improvement for longer intervals, and examining the relationship between treatment protocols for specific symptoms and improvement rates, the timing and frequency of monitoring, the role of treatment guidelines (drug and nondrug), staff and family response to using the ESAS, and factors that facilitate or hinder patient’s responses to selected symptoms.

References


