Barriers to Effective Symptom Management in Hospice

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Abstract
The barriers to effective symptom management in hospice are not well described. We surveyed nurses of hospices affiliated with the Population-based Palliative Care Research Network (PoPCRN) to identify barriers to the effective management of common symptoms in terminally ill patients. 867/1710 (51%) nurses from 67 hospices in 25 U.S. states returned surveys. Of 32 symptoms, nurses reported agitation (45%), pain (40%), and dyspnea (34%) as the 'most difficult to manage.' The most common perceived barriers to effective symptom management were inability of family care providers to implement or maintain recommended treatments (38%), patients or families not wanting recommended treatments (38%), and competing demands from other distressing symptoms (37%). Patterns of barriers varied by symptom. These nurses endorsed multiple barriers contributing to unrelieved symptom distress in patients receiving hospice care. Interventions to improve symptom management in hospice may need to account for these differing barrier patterns. J Pain Symptom Manage 2005;29:69–79. © 2005 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words
Hospice, palliative care, communication barriers, symptom management, pain

Introduction
Patients, families and professional care providers have identified effective symptom management as an essential component of excellent end-of-life care.1-4 Despite this broadly-acknowledged goal, studies of terminally ill patients consistently demonstrate that pain and other symptoms such as dyspnea, fatigue and depression remain highly prevalent in varied settings.5-7 Even in hospice and palliative care settings—where interdisciplinary teams target the relief of symptom distress as a high priority—studies reveal significant symptom burden.7-11 The extent to which this unrelieved symptom burden reflects ineffective interventions versus the inadequate application of known efficacious treatments is not well described.

Studies examining potential obstacles to effective pain management have demonstrated diverse barriers related to multiple factors.
including patients and their families, health care professionals and the care environment. Patient-related barriers include fear of addiction, beliefs that “good” patients do not complain about pain, and concern about side effects. Family perceptions of pain, caregiver burden, caregiver moods and differences in caregiver experiences of pain significantly influence pain management efforts. Multiple studies have demonstrated that physicians and other professionals—including hospice nurses—possess knowledge deficits and attitudinal barriers that may impede effective pain management. Collectively, these and other factors create substantial impediments to the delivery of consistently effective pain relief.

For symptoms other than pain, the barriers to effective symptom management in terminally ill patients remain less clear. In some cases, a single barrier (e.g., effective medication not on formulary due to cost) may impede optimal treatment, ineffective relief might also relate to barriers at multiple symptom management steps. Further, while some impediments may be widespread across multiple symptoms (e.g., a lack of knowledge regarding general symptom assessment), other barriers may apply to specific symptoms (e.g., fear of hastened death using opioids for dyspnea). Characterizing these variations will help to ensure that future symptom research and interventions target the obstacles that most impede effective care.

The primary goal of this study was to describe barriers to effective symptom management from the perspective of hospice nurses. A secondary goal of this study was to characterize how barriers differ among individual symptoms. Together, these data will serve to inform continued efforts aimed at improving symptom management for terminally ill patients.

Methods

Study Design and Population

This study was a cross-sectional, self-administered survey of hospice nurses. We surveyed nurses affiliated with hospices participating in the Population-based Palliative Care Research Network (PoPCRN), a hospice-based research network modeled after successful primary care research networks. At the time of this study, PoPCRN consisted of 128 hospice organizations in 25 U.S. States and Canada. All PoPCRN organizations providing clinical care during the study period (April–August 2002) were invited to participate. Participating organizations then identified one or more contact persons—usually Clinical Directors or Directors of Nursing—to coordinate survey distribution and collection. All hospice nurses providing clinical care to patients of participating organizations were asked to complete anonymous surveys. Individual participation was voluntary. The University of Colorado Institutional Review Board approved the research protocol.

Survey Tool

Survey questions were developed through an iterative approach involving the study authors and nurses from two Colorado hospices. The authors first constructed a theoretical model of general symptom management based on a literature review of current symptom management approaches in hospice. The model defined five fundamental steps in symptom management: symptom recognition, symptom assessment, care plan design, implementation and reassessment (Fig. 1). The authors utilized this basic model to facilitate discussion with research staff and hospice nurses during survey

\[ \text{Symptom Distress} \]

\[ \text{Recognition/ Acknowledgement of Symptom} \]

\[ \text{Assessment of Symptom} \]

\[ \text{Reassess Intervention} \]

\[ \text{Development of Care Plan} \]

\[ \text{Implementation of Care Plan} \]

Fig. 1. Symptom management model.
development. Authors and the research team drafted an initial list of 23 possible symptom management barriers occurring at each of the five major steps. Next, fourteen nurses at the two pilot hospices refined barrier selections and further clarified survey language. Members of the PoPCRN Clinical Advisory Committee contributed additional modifications to the survey design. The final study instrument consisted of 15 barrier responses that complete the statement “I find it difficult to relieve the distress associated with this symptom because....” Based on patterns observed in the content of the fifteen barrier responses, the authors and nursing staff grouped the barriers (a priori to data collection) into four barrier domains: Knowledge and Experience; Balancing Priorities; Resources; and Implementation (Appendix).

The final 4-page survey consisted of 25 questions in four sections. Section one (5 questions) included demographic information: hospice affiliation, nursing experience, prior hospice training, certification and the setting where they provide most care. In Section 2 (2 questions), nurses identified their key information resources “when unsure of how to best treat a patient’s ongoing symptom distress,” including the availability and use of symptom management guidelines or protocols. In Section 3 (3 questions), participants selected the five symptoms that they consider most difficult to manage from a table of 32 common symptoms. The authors created this symptom table based on the 32 symptoms originally identified in the Memorial Symptom Assessment Scale. For each of their 5 chosen symptoms, participants first provided responses to three questions: How often do you care for patients with this symptom? How often do you ask patients about this symptom? How often are you successful at relieving most or all distress from this symptom? Responses were captured using a five-point Likert scale: never, rarely, sometimes, often or almost always. In Section 4 (15 questions), participants identified barriers to effective symptom management by completing responses to the statement “I find it difficult to relieve the distress associated with this symptom because....” Participants rated 15 specific barriers for each of their 5 chosen symptoms using the same five-point Likert scale. Respondents were also provided space to record “other” barriers for each of the chosen symptoms if applicable. The survey instrument is available from the investigators upon request.

Data Collection

We pilot tested the survey tool and collection methods at the two local hospices. Nursing Directors at each pilot site distributed surveys to all nurses providing care to hospice patients in inpatient, home or other outpatient settings. The pilot test resulted in only minor changes to survey content and structure. All PoPCRN hospices were then contacted to 1) solicit participation, 2) identify key contact personnel and Nursing Directors and 3) determine necessary survey quantities based on estimates of current nursing staff. Surveys were mailed to each participating PoPCRN site with a pre-addressed return envelope. Nursing Directors distributed surveys through intra-office mailings and Interdisciplinary Team (IDT) Meetings and recorded the total number of distributed surveys for response rate denominator data. Completed surveys were returned anonymously by nursing staff to Nursing Directors over a 6-week period. Nursing Directors provided weekly verbal reminders to their nursing staff at IDT meetings. An email reminder of target completion dates was sent to Nursing Directors approximately 3 weeks after each mailing, and data collection was complete at each site after 8 weeks. Nursing Directors collected and mailed completed surveys to the research team.

Data Analysis

Descriptive statistics were calculated for all variables in the survey. With the exception of the symptom list for guideline or protocol use in Survey Section 2, unmarked responses were treated as missing items. In the Section 2 symptom list, unmarked symptoms were treated as “no” in cases where at least one other symptom was marked yes. All analyses were conducted using SPSS statistical software (Version 11.0). The top fifteen symptoms were identified using frequency tables.

Analysis of Barrier Responses. The ratings of barriers to symptom management responses were dichotomized into two groups: never/rarely, and sometimes/often/almost always. As a large number of responses were sometimes, we also
dichotomized and compared the data combining sometimes with never/rarely. We chose the former dichotomy, reasoning that this analysis structure better approximated a yes-no response pattern. Frequency tables were produced from these dichotomized data to determine the top barriers to both combined and individual symptoms.

For barrier-related questions (Section 4), we then analyzed these ordinal-level data as ranks. As each participant provided barrier responses for five symptoms, barrier data were not considered as independent. Dependent, non-parametric data present challenges for analysis and require the use of tests designed to compensate for the shared variance within subjects. The Friedman’s test, a non-parametric equivalent of the analysis of variance, is appropriate for dependent rankings and was applied to the fifteen most frequently selected symptoms.

**Analysis of Barrier Patterns.** Factor analysis was applied to the mean ranks of the top fifteen symptoms to identify potential commonalities in barrier patterns. The initial factor analysis did not yield a readily interpretable factor structure. However, there were clear differences in the variability of barrier rankings among the fifteen most frequent symptoms. Reasoning that barriers with the most variability would provide the best information regarding commonalities among rankings, we eliminated those barriers whose rank mean scores had a standard deviation less than one. The factor analysis was recalculated using the remaining seven barriers demonstrating the most variability: ‘forget to ask;’ ‘have difficulty recognizing the symptom;’ ‘don’t have treatment knowledge;’ ‘the symptom is a tradeoff of treatment;’ ‘the attending MD disagrees;’ ‘the family care providers are unable to implement;’ ‘and the patient/family do not want treatment.’ Principal component analysis was applied using varimax rotation and an extraction criterion of Eigenvalue greater than one. The resulting three-factor model (Results) was highly interpretable and was used to group symptoms based on barrier rankings.

**Results**

Descriptive analysis revealed 867/1710 (51%) nurses from 67 hospices in 25 US States returned surveys. Individual organizations contributed a mean of 11.6 surveys (range 3–55) with response rates ranging from 14% to 100%. Mean nursing and hospice experience were 10.5 years (range 0.5–50 years) and 4.4 years (range 0.1–25 years) respectively. A majority of the nurses were Registered Nurses (64%); other reported degrees or certification included Bachelor of Science in Nursing (26%), Licensed Practical Nurse (9%) and Nurse Practitioner (1%). Most nurses (80%) provided care in the home setting. Of 32 common symptoms, nurses reported agitation (45%), pain (40%), dyspnea (34%), confusion (33%) and pressure ulcers (27%) as “most difficult to manage.” The fifteen most frequently selected “difficult to manage” symptoms are depicted in Table 1.

**Barrier Responses**

Across all symptoms, the most commonly endorsed barriers to effective symptom management were the inability of family care providers to implement or maintain recommended treatments (38%), patients or families not wanting recommended treatments (38%), competing demands from other distressing symptoms (37%), and acceptance of the symptom as a consequence of other treatments (33%). Table 2 highlights the frequency and distribution of all barrier responses relative to the four barrier domains. For all symptoms combined, barriers from the Implementation and Balancing Priorities domains were most common, whereas barriers associated with the Knowledge and Experience and Resources domains were reported less frequently.

Frequencies of nurse-perceived barriers were tabulated for individual symptoms. Results of the Friedman tests showed that barriers were ranked differently across all symptoms ($P < 0.0001$; $X^2 = 7347$; degrees of freedom = 14). The Friedman test, as applied to each of the top fifteen symptoms, also showed statistically significant differences in the rankings of barriers within each symptom. Each of the Friedman tests was statistically significant ($P < 0.0001$), indicating that some barrier ranking within each symptom was different.

**Barrier Patterns**

Recognition that specific symptoms shared similar barrier patterns prompted an exploratory factor analysis (see Methods) to further clarify similarities and differences among individual symptoms. Factor analysis clustered
symptoms into three groups (A, B, C) as depicted in Table 3. The two most prominent barriers for Group A symptoms (e.g., pain, dyspnea, nausea) centered on intervention implementation: the inability of family care providers to implement or maintain recommended treatments (43%), and patients/families not wanting recommended treatments (41%). The two most prominent barriers for Group B symptoms (e.g., fatigue, anorexia, confusion) related to provider priorities: acceptance of the symptom as a consequence of other treatments (52%), and competing demands from other distressing symptoms (50%). Nurses also reported not having the knowledge or experience to effectively treat Group B symptoms (36%). Group C symptoms (depression and irritability/anger) demonstrated a broader spectrum of associated barriers, most prominent of which were patients/families not thinking the symptom was a problem (53%), competing demands from other distressing symptoms (47%), and patients/families not wanting recommended treatments (43%). The wider distribution of barriers for depression and anger/irritability is reflected by the greater number of barriers reported by at least 20% of nurse respondents: 12 barriers (Group C) compared to 6 (Group A) or 7 barriers (Group B).

To identify possible factors contributing to barrier profiles, we compared nurses’ perceived success rates and reported use of symptom management guidelines or protocols among individual symptoms and groups (Table 3). Overall, less than half (43%) of respondents reported feeling ‘often’ or ‘almost always’ successful in relieving distress from their selected symptoms. Nurses reported greatest success in relieving pain (96%), constipation (85%) and nausea (84%), and least success in relieving weakness (7%), fatigue (11%) and anorexia (11%). Nurses were far more likely to report success in relieving distress from Group A symptoms (mean success 73%, range [33–96%]) compared to Group B (mean success 13%, range [7–18%]) or Group C (mean success 20%, range [16–26%]). Most nurses (92%) reported that their organizations provided guidelines or protocols for at least one symptom. Nurses were more likely to report guideline or protocol use for symptoms in Group A (mean use 75%, range [67–85%]) compared to Group B (mean use 32%, range [21–41%]) or Group C (mean use 33%, range [32–34%]).

Table 4 summarizes key findings for the three barrier groups.

**Discussion**

Despite efforts to improve symptom management in terminally ill patients, symptom distress
from pain and other symptoms remains highly prevalent. To design more effective symptom management interventions, clinicians and researchers must first better understand why current efforts have fallen short. While a frequently cited reason for sub-optimal symptom relief includes the inadequate education of professional providers, this study suggests that the barriers to effective symptom management are diverse, extending broadly beyond insufficient provider knowledge.

The fact that nurses endorsed multiple barriers across a broad range of symptoms is important. Whereas simple, unidimensional interventions can impact certain aspects of care delivery, reducing symptom distress may require multifaceted approaches targeting a variety of barriers. For example, consider an education intervention designed to improve hospice nurses’ comfort and confidence with the use of opioids for breathlessness. While enhanced education may improve attitudes, knowledge and skills of the nursing staff—certainly a clinically relevant and achievable goal—this purely provider-focused intervention may fail to address prominent patient- and/or caregiver-related barriers. Subsequent measures of patient distress may change little despite documented improvements in provider knowledge and skills. This concept may explain, in part, why clinical guidelines or protocols alone have failed to consistently improve clinically relevant outcomes in multiple settings.

Data from this study suggest that, at least from the perspective of hospice nurses, symptom management interventions should target more than professional providers. The two most prominent barriers for all symptoms combined center on aspects of the patient-family caregiver-provider relationship. Achieving improved symptom control may necessitate interventions that target collective knowledge and communication among this critical triad. For example, a more effective dyspnea intervention might utilize a 3-stage approach: focused provider training to educate hospice staff on the assessment and treatment of dyspnea; distribution of written resources to patients and family caregivers highlighting strategies and resources to manage

### Table 2
Most Frequently Selected Barriers for All Symptoms Combined

<table>
<thead>
<tr>
<th>Ranking of Barriers (all symptoms combined)</th>
<th>n</th>
<th>% Total responses (n=4335) designating this item as ‘sometimes,’ ‘often’ or ‘almost always’ a barrier</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family care providers unable to implement or maintain</td>
<td>1619</td>
<td>37</td>
</tr>
<tr>
<td>Patient/ family do not want the treatment</td>
<td>1604</td>
<td>37</td>
</tr>
<tr>
<td>More distressing symptoms limit ability to treat this symptom</td>
<td>1549</td>
<td>36</td>
</tr>
<tr>
<td>Symptom is a tradeoff as a consequence of other treatments</td>
<td>1378</td>
<td>32</td>
</tr>
<tr>
<td>The patient/ family caregivers do not see symptom as problem</td>
<td>1361</td>
<td>31</td>
</tr>
<tr>
<td>Lack of knowledge/ experience to treat symptom</td>
<td>1217</td>
<td>28</td>
</tr>
<tr>
<td>Attending MD or Medical Director disagree with treatment</td>
<td>938</td>
<td>22</td>
</tr>
<tr>
<td>Treatment causes more distress than symptom</td>
<td>878</td>
<td>20</td>
</tr>
<tr>
<td>Do not think or forget to ask about symptom</td>
<td>803</td>
<td>19</td>
</tr>
<tr>
<td>No access to medications/ resources</td>
<td>693</td>
<td>16</td>
</tr>
<tr>
<td>No time to effectively manage symptom</td>
<td>558</td>
<td>13</td>
</tr>
<tr>
<td>Difficulty recognizing symptom</td>
<td>461</td>
<td>11</td>
</tr>
<tr>
<td>Lack of knowledge/ experience to assess symptom</td>
<td>426</td>
<td>10</td>
</tr>
<tr>
<td>Too costly to treat</td>
<td>328</td>
<td>8</td>
</tr>
<tr>
<td>Fear that treatment will hasten death</td>
<td>190</td>
<td>4</td>
</tr>
</tbody>
</table>

*8Total nurse responses (n=4335) given each nurse (n=867) provided responses for 5 symptoms
breathlessness; and implementation of a dyspnea care plan that incorporates daily symptom measures and crisis support hotline. Although potentially more effective, such comprehensive interventions might also prove more costly and difficult to implement and deserve further study.

A second important finding from this study is that nurses reported different sets of barriers for different symptoms. While barriers related to treatment implementation and the patient-family-provider triad were most prominent for Group A symptoms (e.g., pain, anxiety and dyspnea), Group B symptoms (e.g., fatigue, weakness and anorexia) demonstrated a pattern centered on goal prioritization. Specifically, the two most prominent barriers for Group B symptoms included the perceptions that “other, more distressing symptoms” take priority and that these symptoms were acceptable consequences or “tradeoffs” of other treatments. Interestingly, several studies in both hospice and non-hospice settings have identified fatigue – not pain – as terminally ill patients’ most severe and distressing symptom. The extent to which patients agree with current provider-centered symptom prioritization or accept “tradeoffs” is not clear and warrants further exploration.

Nurses reported a broader combination of barriers for Group C symptoms: depression and anger/irritability. Effective interventions for these symptoms may need to overcome a wider range of obstacles including inadequate symptom identification, insufficient provider knowledge and problems with treatment implementation. Interestingly, the most prominent Group C barrier was “patients or family care providers do not think the symptom is a problem.” This finding might suggest that providers’ efforts to “fix” these symptoms—depression, for example, in patients who think hopelessness and lost esteem is “normal” or acceptable at the end of life—might be misdirected. Further education efforts to “convince” patients and families of the value of medications for depression treatment may be ineffective and misplaced prior to empathetic dialogue centered on clarification of patients’ understanding of and expectations for depression treatment. Again, interventions that focus on improving communication among the patient-care giver-provider triad would seem warranted.
Interestingly, while 40% of nurses selected pain as one of their five “most difficult to manage” symptoms, nearly all reported success in treating pain. While this finding may, on first review, seem contradictory, these data highlight the fact that some “difficult to manage” symptoms are, nevertheless, effectively treated. The barriers data provide insight into this apparent inconsistency. For a symptom like fatigue, the data suggest that the “difficulty,” at least in part, involves a lack of known efficacious treatments. In this instance, one might reasonably expect nurses to report limited success in treating fatigue. In contrast, for pain, the data suggest that the difficulty is more often related to patient-family-provider communication—arguably, a surmountable barrier, though not without considerable complexity and challenge. Whether or not a provider perceives success in treating pain may depend more on their ability to facilitate implementation of effective treatments. While the required tasks and work associated with managing pain may remain complicated, often time consuming and difficult, several decades of research and education have likely enhanced providers’ abilities to achieve adequate pain relief.

Lastly, these data suggest that the observed barrier patterns may relate to nurses’ perceived success in relieving symptom distress and their reported use of symptom-specific guidelines or protocols—two factors which may help to explain why physiologically disparate symptoms cluster. For example, whereas anxiety, pain and dyspnea differ in many aspects, each of these Group A symptoms have well-described management approaches, effective treatments, and nurses report frequent success in relieving distress. In contrast, while fatigue, confusion and anorexia also are physiologically distinct, each of these Group B symptoms lack known, effective treatments and nurses rarely report treatment success. These groupings may be more than academic. Reducing distress from Group B symptoms (e.g., fatigue), for example, may require innovative strategies aimed at overcoming provider reluctance and/or other factors that could significantly hinder the translation of new treatments into clinical practice.

The strengths of this study include its relatively large sample size and broad hospice representation. Barrier profiles are grounded in a theoretical model created through an iterative approach between study authors and hospice nurses—primary providers of symptom management in terminal illness. The survey was shown to be internally reliable and factor analysis supports the construct validity of the final model.

This study has its limitations. First, the 15 defined barriers from which nurses made their selections might not completely capture the full breadth of important perceived barriers. Somewhat reassuring is the fact that less than 1% of applicants endorsed “other” barriers. Next, nurses who chose to respond to the survey may be different from those who declined participation. While we have little reason to expect a significant response bias, such a finding...
might be important in the context of a 50% response rate. Study results may also be biased as a result of the inherent survey design. Specifically, the extent to which barrier responses of nurses who chose a specific symptom (e.g., fatigue) accurately reflect the broader perceptions of all nurses is not known. Third, the barriers identified for individual symptoms may not accurately reflect barriers for clusters of symptoms. This may be important, as physical and psychological symptoms rarely occur in isolation. Effective symptom management strategies may need to simultaneously account for multiple barriers from different domains.

In summary, hospice nurses report multiple barriers to the effective management of common symptoms in terminally ill patients. As researchers and clinicians seek to improve care at the end of life, targeting these diverse barriers may be critical to significantly reducing symptom burden in hospice and other settings. Further, as barriers differ among different groups of symptoms, symptom-specific interventions may be needed to achieve broader symptom relief. Further research should determine the extent to which multifaceted interventions targeting key barriers can reduce distress and improve the quality of life of dying patients.

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References


Appendix

Survey Barrier Choices Grouped by Barrier Type

“I find it difficult to relieve the distress associated with this symptom because…”

Knowledge and Experience

“I do not think (or I forget) to ask if this symptom is a problem.”
“I have difficulty recognizing this symptom.”
“the patient, family or care providers do not think that this symptom is a problem.”
“I do not have the knowledge or experience to accurately assess this symptom.”
“I do not have the knowledge or experience to effectively treat this symptom.”

Balancing Priorities

“I fear that effective treatment for this symptom may cause more distress than it relieves.”
“I fear that effective treatment for this symptom may hasten my patient’s death.”
“other, more distressing symptoms limit my ability to effectively manage this symptom.”
“this symptom is a tradeoff that we must accept as a consequence of our other treatments.”

Resources

“it is too costly to treat this symptom the way I would like.”
“I do not have the time I need to effectively manage this symptom.”
“I do not have easy access to the medications/resources I want/need to best manage this symptom.”

Implementation

“the attending MD or medical director disagrees with my approach to the treatment of this symptom.”
“the care providers are unable to implement/maintain the treatment I recommend for this symptom.”
“the patient/family do not want the treatment that I recommend for this symptom.”