Oncology Nurses’ Perceptions of Obstacles and Supportive Behaviors at the End of Life

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Every year an estimated 1.4 million people are diagnosed with cancer and more than 560,000 die of the disease (Horner et al., 2009), making 1 out of every 4 deaths in the United States a cancer-related death (American Cancer Society [ACS], 2008). Cancer is the second most common cause of death in the United States, surpassed only by deaths from heart disease (ACS). With so many cancer-related deaths, oncology nurses are providing end-of-life (EOL) care for patients with cancer on a daily basis.

In 1995, the study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT) brought attention to shortcomings in EOL care of seriously ill hospitalized adults. Patients were reported to die in pain, with minimal communication with care providers and without having their identified wishes met (SUPPORT Investigators, 1995). In response, the World Health Organization (2002) issued a statement that patients with terminal illnesses and their caregivers deserve supportive and reliable care, which could improve patients’ quality of life and help them to be as active as possible until the time of their death.

Two other national associations have spoken out regarding their visions for EOL care for patients with cancer. The Oncology Nursing Society (ONS) and the Association of Oncology Social Work (2003) position statement concluded that EOL care should reflect the needs of patients and families in a coordinated and interdisciplinary manner that is strengthened and supported by evidence-based research. The two national associations also stated that optimal EOL care should reduce the physical suffering patients with cancer experience through excellent assessment, reassessment, and management of physical symptoms and that psychosocial and spiritual care should be integrated to support coping.

Since the SUPPORT investigation, several studies have addressed various aspects of EOL care, such as patient and family perceptions of EOL care (Heyland et al., 2006; Lynn et al., 1997; Steinhauser et al., 2000), help for patients in discussing EOL issues with physicians (Clayton et al., 2007), and quality of medical care at EOL (Yabroff, Mandelblatt, & Ingham, 2004). Studies involving oncology nurses in the United States have been limited to nurses’ perceptions of education related
to EOL care (Coyne et al., 2007; White, Coyne, & Patel, 2001). No study was found that identified barriers or supportive behaviors oncology nurses encounter in delivering EOL care.

**Research Questions**

Two research questions were addressed in the study: (a) What is the magnitude of selected obstacles to providing EOL care to patients with cancer as perceived by oncology nurses? (b) What are the supportive behaviors in providing EOL care to patients with cancer as perceived by oncology nurses?

By studying obstacles that stand in the way of providing optimal EOL care as well as supportive behaviors that increase the quality of EOL care, nursing educators and managers will be better able to educate and support bedside oncology nurses in delivering EOL care. In addition, nurses, nurse managers, and advanced practice nurses can use the information to work together with the interdisciplinary team to change and improve EOL care for patients with cancer and their families.

**Methods**

**Respondents**

Following institutional review board approval, a geographically dispersed random sample of 1,000 oncology nurses was obtained from ONS membership, which totals more than 36,000 RNs and other healthcare providers. ONS members who cared for inpatient patients with cancer, could understand English, and had experience in EOL care were considered eligible. Consent to participate was assumed upon return of the questionnaire.

**Instrument**

The Survey of Oncology Nurses’ Perceptions of End-of-Life Care was adapted from two similar surveys with critical care nurses (Beckstrand & Kirchhoff, 2005) and emergency nurses (Beckstrand, Smith, Heaston, & Bond, 2008). The questionnaire was revised, where needed, to more closely apply to oncology EOL care. To strengthen content validity, information from literature and expert opinions were used to further revise initial obstacle and supportive behavior items. The questionnaire was piloted with 28 experienced oncology nurses from three different hospitals in one western state. Mean completion time for the questionnaire was 28 minutes for those who recorded time (61%).

Recommendations from those 28 nurses were reviewed by an experienced oncology nurse. Three obstacles and four supportive behaviors were removed from the existing instrument because they did not directly relate to EOL care of patients with cancer. In addition, the words “life support” and “life saving” in two existing items were changed to “aggressive care” and “aggressive treatments” to better reflect the oncology setting. Possible consequences of choosing aggressive treatments that were listed as examples were nausea, diarrhea, and fever. The two new obstacle items added were physicians who insist on aggressive care until patients are actively dying and families being overly optimistic despite patients’ poor prognosis.

The three supportive behaviors added based on pilot test results were (a) having social work or palliative care as part of the patient care team, (b) having social work or palliative care staff establish rapport with patients and families before patients are actively dying, and (c) having an experienced nurse model EOL care for a new nurse. Another supportive behavior, having educational inservice presentations (e.g., End-of-Life Nursing Education Consortium) on how to talk to and take care of dying patients, was added after reviewing the literature (Coyne et al., 2007; White et al., 2001). The final questionnaire contained 68 items, including 50 Likert-type items, four open-ended questions, and 14 demographic questions.

**Procedure**

Participant mailing information was purchased from ONS. Prior to mailing questionnaires, each participant was assigned a numerical code for ease of data management. The list matching names and code numbers was kept in a locked office. Questionnaires were mailed in October 2007 with a cover letter explaining the purposes of the study and a self-addressed stamped envelope. As an incentive for quick return, a one-dollar bill was included with each questionnaire in the first mailing. Two additional mailings, one in January 2008 (N = 754) and another in March 2008 (N = 610) to nonresponders were completed after the initial mailing of the questionnaire. Both mailings included a new cover letter, a copy of the questionnaire, and a self-addressed stamped envelope.

Oncology nurses were asked to rate the magnitude of listed obstacles and the supportive behaviors in giving EOL care to dying patients with cancer. Nurses also were asked to list any additional obstacles and supportive behaviors they had encountered while caring for dying patients that had not been included as items on the questionnaire.

When questionnaires were returned, responses were entered into SPSS® version 10.0. Frequencies and measures of central tendency and dispersion were calculated. Items were ranked from highest to lowest on the basis of mean scores to determine which items were the largest obstacles and the most supportive behaviors. Cronbach alpha scores were calculated to determine internal consistency estimates of reliability. Responses
from open-ended questions were analyzed with content analysis and categorized with like items placed in the same category and frequency counts made.

Results

Of 1,000 potential respondents, 93 were eliminated from the study because the questionnaire could not be delivered (n = 4), the nurse was retired (n = 4), or recipients reported they were ineligible (n = 85). Usable responses were received from 375 nurses for a response rate of 41%.

Of the respondents who reported their gender (n = 369), 351 were women (94%) (see Table 1). Respondents ranged in age from 23–72 years (X = 48 years). They were employed as staff or charge nurses (71%), clinical nurse specialists (7%), or other (23%), primarily as managers and educators. Reported practice settings included nonprofit community hospitals (58%), for-profit community hospitals (11%), university medical centers (20%), county hospitals (4%), federal hospitals (2%), state hospitals (1%), county hospitals (4%), military hospitals (1%), and other (3%).

Respondents worked a mean of 36.1 hours per week, had been RNs for a mean of 18 years, and had worked in oncology for a mean of 12.5 years. Certification as an oncology certified nurse (OCN®) or advanced oncology certified nurse (AOCN®), certified ostomy care nurse, or advanced drawing charge nurse had been achieved by 242 (67%) of the respondents, of which 207 (54%) were currently certified. The mean number of years as an OCN® was 7.4. The mean number of years as an advanced certified nurse was 7.7. Most nurses (69%) reported caring for more than 30 dying patients (highest listed option on the instrument) throughout their careers.

The highest level of education in the sample of oncology nurses was diploma (8%), associate degree (22%), bachelor’s degree (49%), master’s degree (20%), doctoral degree (1%), and other (less than 1%).

Obstacles

On a scale of 0 (not an obstacle) to 5 (extremely large obstacle), mean obstacle scores ranged from a 1.02–3.56 for the 25 items (see Table 2). Cronbach alpha for the 26 obstacle size items was high at 0.92.

Eight of the top 10 obstacles related directly to family attitudes and behaviors. The highest-rated obstacle to providing EOL care was nurses having to deal with angry family members (X = 3.56), followed closely by families not accepting the patient’s poor prognosis (X = 3.55). Two similar top 10 obstacles were the fourth-ranked item, dealing with anxious family members (X = 3.51), and the sixth-ranked item, the family being overly optimistic about patients’ poor prognosis (X = 3.44). In addition, families not wanting patients to be overly sedated by too many doses of pain medication (X = 3.36) ranked seventh, frequent phone calls from various family members for updates on patient condition (X = 3.35) ranked eighth,
and intrafamilial fighting about whether to continue or stop aggressive treatment ($\bar{X} = 3.31$) ranked ninth. Oncology nurses identified the third-ranked obstacle as being called away from dying patients and families to help with a new admit or to help other nurses care for their patients ($\bar{X} = 3.53$). This highly-ranked obstacle also was supported by free text data where 10 of 78 nurses reported staffing ratios, high nurse and patient load, or lack of time to care for dying patients as large obstacles in delivering EOL care.

The fifth-ranked obstacle involved physicians who insisted on aggressive care until patients are actively dying ($\bar{X} = 3.47$). Patients having pain that is difficult to control or alleviate ranked ninth. The two obstacles also were mentioned in the free text data. Nurses commented that physicians were reluctant to refer patients to hospice or palliative care ($n = 10$) and were either uncomfortable or inexperienced in ordering adequate pain medication ($n = 9$).
Three items perceived by oncology nurses to be the smallest obstacles included restrictive visiting hours ($\bar{X} = 1.02$); no available support person for the family, such as a social worker or religious leader ($\bar{X} = 2.03$); and pressure to limit family grieving after patients’ deaths to accommodate a new admit to that room ($\bar{X} = 2.14$).

Supportive Behavior Items

On a scale of 0 (not a help) to 5 (extremely large help), mean scores for the 24 supportive behavior items ranged from a high of 4.58 to a low of 3.72 (see Table 3). Cronbach alpha for the 24 supportive behaviors was high at 0.9. Two of the top 10 supportive behaviors identified by oncology nurses were things nurses could control such as allowing family members adequate time alone with patients after death ($\bar{X} = 4.58$) and providing a peaceful bedside scene after patients die ($\bar{X} = 4.5$).

The second most helpful factor was having a social work or palliative care staff as part of the team ($\bar{X} = 4.55$). In addition, other helpful interdisciplinary factors were having the physicians involved agree about the direction of patients’ care ($\bar{X} = 4.51$) and having social work or palliative care staff develop a rapport with patients and families before patients are actively dying ($\bar{X} = 4.38$).

Within nursing, having experienced nurses model EOL care for new nurses ($\bar{X} = 4.39$) had the sixth-highest mean score, and verbal support from a fellow nurse after patients die ($\bar{X} = 4.38$) scored as the seventh-highest.

Oncology nurses identified having family members accept that patients are dying ($\bar{X} = 4.53$) as the third-most supportive behavior. The last 2 top 10 helpful behaviors involved families, including teaching family members how to act around dying patients ($\bar{X} = 4.33$), and having one family member as a designated contact for other family members regarding patient information ($\bar{X} = 4.33$).

Lowest scoring supportive behaviors were having families physically help care for dying patients ($\bar{X} = 3.72$), nurses drawing on their own previous experiences with EOL care of patients or family members ($\bar{X} = 3.78$), and having fellow nurses cover other patients to allow nurses to get away from the unit for a few minutes after patients die ($\bar{X} = 3.78$).

Discussion

Participants were highly experienced and knowledgeable, with more than half of the nurses reporting having been certified as an OCN® at some time. Nurses in this sample were members of their professional nursing organization and may possibly be more experienced, on average, than oncology nurses who are not members of ONS. Nurses in the study may realize the importance and power nursing organizations can have on nursing practice, so their responses to obstacle and supportive behavior questionnaire items may be different than responses from a sample of nurses who do not belong to ONS. Because the sample was randomly selected, geographically dispersed, and of adequate size, results are generalizable to the population of ONS members who work in an inpatient oncology setting.

Obstacle Size

The high mean score of reported obstacles by oncology nurses is notably lower than the critical care nurses highest mean obstacle score ($\bar{X} = 4.03$) (Beckstrand & Kirchhoff, 2005) and the emergency nurses highest mean obstacle score ($\bar{X} = 3.8$) (Heaston, Beckstrand, Bond, & Palmer, 2006). The lower mean obstacle score may reflect the fundamental nature of oncology nursing as it relates to EOL issues. Cancer is second only to heart disease in cause of adult deaths in the United States (ACS, 2008). Oncology nurses frequently are exposed to EOL situations and, through experience, become experts in working with families during EOL. Deffner and Bell (2005) noted that older, more experienced nurses felt more comfortable discussing death and EOL issues with patients and families.

Families are an integral part of EOL care in oncology and provide a unique set of challenges. Eight of the top 10 obstacles to EOL care identified in the study directly related to families. Oncology nurses identified dealing with angry, anxious, and overly optimistic families as well as families who do not understand or accept patients’ prognosis as significant obstacles to EOL care of patients with cancer. Dealing with upset family members is further complicated by individual family members’ reaction to information. Some family members desire open communication about disease staging, treatment options, and prognosis, whereas others would rather not know (Royak-Shaler et al., 2006). Waldrop (2007) noted that the most common psychological and emotional responses to grief were predominantly intense sadness and anger. Oncology nurses must not only work with individual families to understand dying patients’ situations, they must do so as families are in a heightened state of anxiety, depression, nervousness, restlessness, and fear, leading to difficulty remembering, concentrating, and completing tasks (Waldrop).

The three smallest obstacles (a) visiting hours that are too restrictive, (b) no available support person for the family such as a social worker or religious leader, and (c) pressure to limit family grieving to accommodate a new admit to that room reflect the importance of clear, family-oriented hospital policies and administrative support in EOL care. Open visiting hours, adequate numbers of social workers on staff, and willingness to allow ample family grieving time reflect a few areas of overall hospital support in EOL care.
Table 3. Mean Supportive Behavior Size Reported by Oncology Nurses With Regard to End-of-Life Care

<table>
<thead>
<tr>
<th>Rank</th>
<th>Supportive Behavior</th>
<th>( \bar{X} )</th>
<th>SD</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Allowing family members adequate time to be alone with patients after death</td>
<td>4.58</td>
<td>0.61</td>
<td>366</td>
</tr>
<tr>
<td>2.</td>
<td>Having social work or palliative care staff as part of the patient care team</td>
<td>4.55</td>
<td>0.68</td>
<td>365</td>
</tr>
<tr>
<td>3.</td>
<td>Having family members accept that patients are dying</td>
<td>4.53</td>
<td>0.65</td>
<td>369</td>
</tr>
<tr>
<td>4.</td>
<td>Having the physicians involved agree about the direction of patients’ care</td>
<td>4.51</td>
<td>0.69</td>
<td>368</td>
</tr>
<tr>
<td>5.</td>
<td>Providing a peaceful bedside scene after patients die</td>
<td>4.5</td>
<td>0.71</td>
<td>367</td>
</tr>
<tr>
<td>6.</td>
<td>Having experienced nurses model end-of-life care for new nurses</td>
<td>4.39</td>
<td>0.79</td>
<td>368</td>
</tr>
<tr>
<td>7.</td>
<td>Having social work or palliative care staff establish rapport with patients and families before patients are actively dying</td>
<td>4.38</td>
<td>0.75</td>
<td>367</td>
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<tr>
<td>8.</td>
<td>Having fellow nurses tell you, “You gave great care to that patient,” or some other words of support after patients die</td>
<td>4.38</td>
<td>0.79</td>
<td>367</td>
</tr>
<tr>
<td>9.</td>
<td>Teaching families how to act around dying patients such as saying to them, “She can still hear, it is okay to talk to her.”</td>
<td>4.33</td>
<td>0.76</td>
<td>366</td>
</tr>
<tr>
<td>10.</td>
<td>Having one family member be the designated contact person for all other family members regarding patient information</td>
<td>4.33</td>
<td>0.8</td>
<td>369</td>
</tr>
<tr>
<td>11.</td>
<td>Having enough time to educate families about their loved ones’ expected process of dying</td>
<td>4.26</td>
<td>0.77</td>
<td>370</td>
</tr>
<tr>
<td>12.</td>
<td>A unit designed so that families have a place to go to grieve in private away from patients’ rooms</td>
<td>4.26</td>
<td>0.85</td>
<td>370</td>
</tr>
<tr>
<td>13.</td>
<td>Having a unit schedule that allows for continuity of care for dying patients by the same nurses</td>
<td>4.25</td>
<td>0.84</td>
<td>369</td>
</tr>
<tr>
<td>14.</td>
<td>Having family members thank you or in some other way show appreciation for your care of patients who die</td>
<td>4.21</td>
<td>0.9</td>
<td>367</td>
</tr>
<tr>
<td>15.</td>
<td>Allowing families unlimited access to dying patients even if it at times conflicts with nursing care</td>
<td>4.21</td>
<td>1.06</td>
<td>364</td>
</tr>
<tr>
<td>16.</td>
<td>Talking with patients about their feelings and thoughts about dying</td>
<td>4.19</td>
<td>0.82</td>
<td>366</td>
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<tr>
<td>17.</td>
<td>Having educational inservice classes on how to talk to and take care of dying patients</td>
<td>4.09</td>
<td>0.94</td>
<td>366</td>
</tr>
<tr>
<td>18.</td>
<td>Having fellow nurses put their arms around you, hug you, pat you on the back, or give some other kind of brief physical support after patients die</td>
<td>4.01</td>
<td>1.1</td>
<td>367</td>
</tr>
<tr>
<td>19.</td>
<td>After patients die, having support staff members compile all the necessary paperwork for you that must be signed by families before they leave the unit</td>
<td>3.94</td>
<td>1.13</td>
<td>360</td>
</tr>
<tr>
<td>20.</td>
<td>Having the physician meet in person with the families after patients die to offer support</td>
<td>3.85</td>
<td>1.13</td>
<td>366</td>
</tr>
<tr>
<td>21.</td>
<td>Having a support person outside of the work setting who will listen to you after patients die</td>
<td>3.83</td>
<td>1.22</td>
<td>366</td>
</tr>
<tr>
<td>22.</td>
<td>Nurses drawing on their own previous experience in end-of-life care with either patients or family members</td>
<td>3.78</td>
<td>1.04</td>
<td>366</td>
</tr>
<tr>
<td>22.</td>
<td>Having fellow nurses take care of other patients while you get away from the unit for a few moments after patients die</td>
<td>3.78</td>
<td>1.07</td>
<td>365</td>
</tr>
<tr>
<td>24.</td>
<td>Having families physically care for dying patients</td>
<td>3.72</td>
<td>1.04</td>
<td>367</td>
</tr>
</tbody>
</table>

Supportive Behavior Size

Mean scores for supportive behaviors were much higher than for obstacles because the highest scoring behaviors usually were behaviors that were under nurses’ control and, therefore, were perceived as very helpful. Two of the top 10 supportive behaviors, allowing family members time after patients’ deaths and providing a peaceful bedside scene after death, were not only not under control of nurses but occurred after patients had died. Because oncology EOL care intensely involves families, nurses’ roles in EOL care do not end with patients’ last breath. Albinsson and Strang (2003) identified supporting the family after patients die as a significant
part of oncology EOL care. Oncology nurses face EOL care and issues on a regular basis, so they focus on and maximize family support through things over which they have control. In addition, the nurses identified the helpfulness of interdisciplinary support from social workers and palliative care staff. Because nurses often are called away from dying patients (third-largest obstacle size), the expertise of social work and palliative care staff provide essential support for nurses, patients, and families. Often, physicians do not discuss with patients and families the incurableness of the illness or short life expectancy until the last month or even week of patients’ lives (Cherlin et al., 2005). Even when patients and families are aware of the gravity of the situation, family members may require additional time to understand and accept the information (Cherlin et al.). Social work and palliative care team members provide essential support to nurses, patients, and families throughout patients’ illnesses.

The least supportive behavior was having family help to physically care for patients. This may have been rated as the lowest supportive behavior because of the efficiency of this highly experienced sample of nurses or because of families’ hesitancy in participating in the physical care of dying loved ones.

Although the importance of educational in-service classes to help student and new nurses competently and compassionately care for dying patients has been repeatedly emphasized (Caton & Klemm, 2006; Mallory, 2003), nurses in the study gave the helpfulness of educational in-service classes a surprisingly low ranking (17th). At the same time, those nurses ranked having experienced nurses mentor new nurses as the sixth-highest supportive behavior. The focus on personal mentoring rather than impersonal group instruction from educational in-service classes most likely reflects the wishes of experienced nurses who participated in the study.

The common top 10 obstacle items among oncology, critical care, and emergency nurses related to issues surrounding dying patients’ families (Beckstrand & Kirchoff, 2005; Beckstrand et al., 2008; Heaston et al., 2006). These common highly-rated obstacles included nurses having to deal with angry family members and family members who will not accept patients’ poor prognosis, do not understand the consequences of aggressive treatment, and continually call the nurse for information on patients’ conditions. Interestingly, the four obstacles were consistently high across multiple settings and identify universal issues in EOL care.

Five of the top 10 supportive behaviors reported by oncology nurses also were reported by emergency and critical care nurses. They were (a) allowing family members time after patients die, (b) providing a peaceful bedside scene after death, (c) having family members accept that patients are dying, (d) having physicians agree about the direction of patient care, and (e) having one family member as the designated contact for information. These five supportive behaviors were common across all three areas of nursing.

Limitations

As discussed previously, nurses in the study were highly experienced in nursing and in oncology. Although their experience makes them experts in their field and valuable respondents, their perceptions of EOL care may differ from their potentially less-experienced colleagues. In addition, the frequency of occurrence of the obstacles and supportive behaviors was not analyzed to determine the overall magnitude of each obstacle and supportive behavior. Highly rated obstacles and supportive behaviors should not be interpreted as those that also occur most frequently in oncology EOL care.

Conclusions

The purpose of the study was to determine the biggest obstacles and most supportive behaviors surrounding EOL care as perceived by oncology nurses. Although respondents reflect only a small percentage of ONS members, important information was obtained from this random sample of experienced nurses.

Oncology nurses are dedicated, experienced, and comfortable handling most issues in EOL care. This is especially true of obstacles and supportive behaviors that are in nurses’ control. Recommendations to support nurses who deliver EOL care to patients with cancer include strategies to effectively interact with angry, anxious, or overly optimistic family members, and to work with family members to understand and accept the prognosis and dying process of their loved ones. Further recommendations include involving social work and palliative care staff on the oncology interdisciplinary team to support physicians, nurses, patients, and families in EOL care. Lastly, nurses, nurse managers, and advanced practice nurses can use this information regarding identified obstacles and supportive behaviors to facilitate discussion and change within their interdisciplinary teams, and ultimately to improve EOL care for patients with cancer and their families.

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