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Oncology Nurses' Suggestions for Improving
Obstacles in End-of-Life Care

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A thesis submitted to the faculty of
Brigham Young University
in partial fulfillment of the requirements for the degree of

Master of Science

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ABSTRACT

Oncology Nurses' Suggestions for Improving Obstacles in End-of-Life Care

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The purpose of this paper was to determine the most important changes needed to improve the quality of end-of-life (EOL) care to terminal cancer patients as perceived by experienced oncology nurses. The study was designed as a cross-sectional survey, sampling 1,000 Oncology Nursing Society members from the United States with experience caring for inpatient cancer patients, who could read English, and had experience in EOL care.

Eligible nurses responded to an open-ended item sent to them as part of a mailed questionnaire. Nurses were asked to respond to the following question: "If you had the ability to change just one aspect of the end-of-life care given to dying oncology patients, what would it be?" Open-ended text answers were categorized and coded by a team of four nurse researchers.

Respondents identified five major and six minor themes they determined as requiring interventions to improve the dying experience for their patients. Major areas identified included better staffing, improvement to the environment, increased education, improvement in issues surrounding physician behaviors, and earlier EOL interventions. Minor areas reflected needs to facilitate a more peaceful death, initiate earlier palliative and hospice interventions, end care deemed futile, and provide for spiritual needs.

The suggested improvements shared by shared by oncology nurses provide opportunities to identify and alleviate obstacles in EOL care which may prevent optimal patient quality of life when dying. Improving care in the identified areas may address the many needs of dying oncology patients as nurses become better able to facilitate a quality experience at the end of life.

Keywords: Obstacles, Oncology, Nurses, End-of-Life Care

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Oncology Nurses' Suggestions for Improving Obstacles in End-of-Life Care

Despite significant advances in the prevention and treatment of cancer, with 5-year survival rates projected to reach either 57% (American Cancer Society, 2013) or 64% (de Moor et al., 2013), the diagnosis of cancer remains fraught with uncertainty for many patients (Miller, 2012). Cancer is the second leading cause of death in the U.S. and is ranked first for those between the ages of 45 and 64 years (Kochanek, Jiaquan, Murphy, Minino, & Hsiang-Ching, 2011). In the U.S., 1,660,000 cases of cancer were diagnosed in 2013 with approximately 580,350 fatalities (American Cancer Society, 2013). Older Americans are anticipated to make up a larger percentage of the future population so increasing numbers of cancer deaths will likely occur (Caffrey, Manisha, Moss, Harris-Kojetin, & Valverde, 2011; de Morr et al., 2013).

Background

Healthcare providers, researchers, and policy makers have collaborated to improve end-of-life (EOL) care delivery and establish nursing proficiency (Kehl, 2006) in the care of dying oncology patients. The SUPPORT study (Connors et al., 1995) along with other research (Mack et al., 2012; Magarotto et al., 2011; Smith et al., 2012) identified EOL care obstacles leading to a decreased quality of life for terminally ill patients. These obstacles included faulty communication, aggressive treatment at the EOL, and difficulties associated with the location of death.

Beckstrand, Moore, Callister, and Bond (2009) surveyed a national sample of 1000 oncology nurses to determine the largest barriers and most supportive behaviors in providing EOL care to patients with cancer. Seven of the top 10 identified obstacles related to issues with family members. Supportive behaviors included allowing adequate time for families to be with the patient after death, providing a peaceful environment, and having family members accept that

the patient was dying (Beckstrand et al., 2009). A second report (Beckstrand, Collett, Callister, & Luthy, 2012) included frequency of occurrence data to illicit impact scores for both obstacles and supportive behaviors. The researchers concluded that dealing with the family is vital in providing optimal EOL care to patients dying from cancer.

The purpose of this paper is to augment current research by reporting suggested improvements to obstacles in EOL care as identified by experienced oncology nurses. The research focused on the following question: Which one aspect of EOL care would oncology nurses most like to see changed? Evaluating the qualitative answers to this question may enable health care providers to determine the changes which would be most beneficial to implement in terminal oncology patient care.

Methods

Design

Institutional Review Board approval was obtained for a national, random, geographically disperse sample of 1,000 oncology nurses obtained from the Oncology Nursing Society. Inclusion criteria for subjects completing the questionnaire allowed for only those individuals who were able to read and understand English, and who had cared for at least one dying cancer patient at EOL. Consent to participate was implied by the return of the questionnaire (Beckstrand et al., 2009).

Instrument

The *National Survey of Oncology Nurses' Perceptions of End-of-Life Care* questionnaire was adapted from two similar research studies involving critical care nurses (Beckstrand & Kirchhoff, 2005) and emergency room nurses (Beckstrand, Smith, Heaston, & Bond, 2008). Revisions were made after a review of the literature and consultation with experts in order to adapt it more appropriately for oncology EOL care. The final instrument consisted of 68 items,

including 50 Likert-type items, 4 open-ended questions, and 14 demographic questions. Upon return, open-ended responses to the research question for this study were entered into Microsoft Word® (Microsoft Corporation, 2009).

To improve return rate, the questionnaire was mailed two more times to non-responders. Of the 1,000 questionnaires mailed, 93 were eliminated from the study because these questionnaires were either undeliverable (n = 4), respondents reported ineligibility (n = 85), or the subject responded as retired (n = 4). The return, after three mailings, generated 380 usable questionnaires from 907 eligible respondents for a return rate of 41.9%.

Data Analysis

Open-ended statements were transcribed and then reviewed for accuracy by four nurse researchers. The researchers independently coded the transcript data. Inter-coder reliability was determined by discussion among the four researchers conducted on 10% of the data and found to be .88 on all categories. Finally, two researchers reviewed the coding for all responses using strict coding criteria, reached an agreement of .97%, and further delineated research data into categories comprising five major themes (those with 22 or more responses) and 6 minor themes (≤ 18 responses).

Results

Of the 380 usable questionnaires returned, 187 (49.2%) nurses wrote responses to the specified item. Although only one submission was requested, 22 nurses (11.8%) wrote more than one suggestion, resulting in a total of 225 ideas for improvement in the EOL care for oncology patients.

Demographics

The 187 oncology nurses who provided suggestions for changing EOL ranged in age

from 26 to 71 years for a mean of 50 years ($SD = 10.3$). A total of 96.3% were women. Of those reporting hospital position held, respondents were staff nurses (31.9%), staff/charge nurses (34.1%), clinical nurse specialists (9.2%), and in other roles (24.9%). Respondents had been registered nurses for a mean of 18.7 years ($SD = 11.1$) and had worked in oncology for a mean of 13.1 years ($SD = 8.7$). Among the respondents, 73.8% had cared for at least 30 dying patients during their career (see Table 1).

Major Themes

Five major themes demonstrating EOL care obstacles affecting dying oncology patients were identified (see Table 2):

1. Reducing nurse workload and/or having better staffing when patients are actively dying.
2. Providing a better environment or place of death.
3. Focusing EOL education for healthcare providers and families.
4. Obstacles surrounding physician behavior, including more honest communication and the nurse being seen, by the physician, as part of the EOL care team.
5. Earlier EOL intervention for patients and their families.

Reduction in nurse workload/better staffing. A majority of nurse suggestions ($n = 38$ or 16.8%) expressed a desire for a more appropriate workload when caring for dying oncology patients. Heavy workloads with multiple assignments or assignments complicated by the need to care for clients requiring intense nursing interventions, in addition to caring for those actively dying, were deemed barriers to optimal care. Addressing the need for more time, one nurse suggested that, "[having] the staff being able to spend more time with patients and family without being rushed and hurried" would be optimal. In reference to an inappropriately weighted workload, another nurse wrote, "More support and time to spend with the grieving

patient. Sometimes I feel like my work load is seen as 'NOT AS HEAVY' (respondent's emphasis) because I have a comfort care patient.”

Another expressed difficulty dividing time between actively dying patients and those requiring intense nursing interventions saying,

The hardest thing is to be split between acute care and end-of-life care and to not have time for the dying patient’s family. It's best not to have to be giving chemotherapy or to have busy acute care patients at same time as end of life care patients’ families.

One nurse noted that dying patients were not seen as priority patients to those in charge of making work assignments,

I would like the care of dying patients to be as important as the care of other oncology patients. Sometimes the tasks involved with caring for 'full code' patients - chemotherapy, blood, etc. require immediate attention, and the dying patients (and their families) don't get the attention they deserve.

And finally, another nurse said that inadequate time was the greatest barrier to quality care in this statement: “[The nurse] having more time. We often care for acutely ill patients at the same time as dying hospice patients. Time is the ‘biggest’ barrier to excellent care.”

Providing a better environment or place of death. Environmental factors as obstacles were reported in 32 (14.2%) nurses’ suggestions. Nurses believed effective care included peaceful physical surroundings comprised of beautiful, comfortable, and quiet rooms with space and privacy for all family members who wished to be present.

The desire for larger, more beautiful surroundings was a common theme, including statements such as, "Private rooms for everyone,” and, "more beautiful and spacious surroundings.” Other nurses expressed a need to improve the comfort of family members with such suggestions as having, "[A] private family room attached to [the] hospital room away from

[the] nurse[s] desk,” or, “... a longer-than-average patient room with a pullout bed and comfortable chaise.”

A peaceful environment was also deemed important. One nurse stated, “A more quiet and peaceful environment - away from the hustle and bustle of a busy oncology floor.” Another indicated a desire to allow the patient a respite from the hospital room itself with this comment, “The ability to step or wheelchair outdoors for [a] fresh breath once in a while [would be desirable].”

EOL education for healthcare providers and families. Many nurses, 31 (13.8%), expressed a desire for family, physicians, ancillary personnel, and the nurses involved with dying patients to be educated about the various aspects of quality EOL care and properly informed regarding the processes and treatment possibilities. Primarily, nurses wanted other nurses, physicians, as well as families informed about pain control. One nurse wrote, “Increase knowledge of EOL care with interns and residents as well as new RN’s so they are not so hesitant to prescribe medications/treatments that aid in a comfortable and peaceful death.” Another stated, “Educate physicians about adequate pain control and comfort measures.” A third nurse stated, “Being able to have family willing to let the patient be medicated even if they [the patient] ‘are too sleepy’,” were statements indicating the importance of education on pain and symptom management.

Education of families regarding changes in focus toward terminal care was also seen as vital. “Making the family understand that ‘comfort care’ doesn’t mean we are giving up on nursing care of the dying patient,” and, “family members should be told what DNR means – no more antibiotics, pressors, or other medications previously given,” were both stated by respondents.

Education regarding attitudes about death itself was mentioned. “Helping nurses to understand death is not failure,” and, “I wish I had the ability to change everyone’s attitude towards this [dying] process; to be more involved in it as well as increase the respect of dying,” were two such suggestions.

Finally, one respondent expressed the need to educate professionals about how attitudes can help or hinder families working through grief. “I would teach healthcare professionals to respect the grieving process. We meet families and patients outside of their usual contexts...[and] have to be willing to meet everyone where they are without being judgmental about their decisions.”

Obstacles surrounding physician behavior. Obstacles involving physicians were noted by 24 (10.7%) nurses with issues regarding communication, physician behaviors, and having the physician ‘be on the same page’ suggested as barriers to quality care. Poor communication with patients, including honesty about prognosis and treatment options, was noted by several respondents. A few representative comments were, “More MD involvement on [the] front end being honest with patients about prognosis!” or, “Many doctors will not discuss death and dying with patients and families. If they do, it is done 24-48 hours prior to death.” Another nurse stated, “Physicians need to discuss end of active treatment long before they [currently] do.”

Physician behavior included issues around denial. One nurse wrote, “The absolute worst thing is we have one oncologist who finds herself to be unrealistic and too hopeful at times and it feels like such a disservice to the patient and family [for them] to not be better informed.” Being on the “same page” as others on the team was also seen as an important goal for continuity of care. “Have care conferences with MDs, RNs and interdisciplinary team[s] for every oncology patient actively dying in hospital rather than the fragmented care that occurs,” and, “[the need

for] frequent family meetings to update patient; family; and get MDs, patient, and family all on the same page about current status, prognosis, [and] direction of care,” were both suggested.

Earlier EOL intervention for patients and their families. A number of respondents (n = 22, 9.78%) reported the desire to have patients and families knowledgeable and prepared for the experience they were facing. Several nurses expressed difficulties in providing quality care when patients and families were not allowed to make appropriate choices regarding EOL wishes due to lack of knowledge or lack of time. Statements from these nurses included the following: “Comfort care happens too late; we need to look more at quality of life;” “introduce palliative care concept earlier in disease process, so patient and family can have an idea of care options before patient is actively dying;” and, “I wish they all had the ability to choose hospice in a timely manner & benefit from its advantages.”

Another nurse recommended early EOL planning to facilitate more appropriate interventions by suggesting, “Earlier understanding of changing care focus from medical treatment to support. Stopping painful treatments sooner.” Another nurse succinctly suggested for improved EOL care, “Start sooner.”

Minor Themes

Six minor themes were identified from this data reflecting the need for more peaceful and comfortable deaths, earlier palliative and hospice intervention, ending futile care, and providing spiritual care (see Table 2). There were also 14 miscellaneous suggestions that could not be categorized including discussion of issues arising after death, alternative medicines, and compassion fatigue.

More peaceful and comfortable death. Statements on more peaceful deaths from 18 (8%) nurses are typified by these following suggestions. “I would want the patient to be comfortable. Make the dying experience as peaceful as possible for patient and family,” and, “[I

would like] the true freedom to give the patient comfort and peace." Peace at the EOL was viewed as highly desirable by nurses.

Minimize patient suffering by managing pain. Managing pain was determined to be essential to some respondents. Sixteen (7.1%) nurses desired better management of pain and suffering. Statements included, "Proper and timely pain management. Far too many dying patients are under-medicated," and, "... provide better pain control sooner." One nurse wanted patients to be, "pain free, no matter the dose [necessary]."

Earlier initiation of palliative and hospice care. Fifteen respondents (6.67%) stated that they desired earlier initiation of specialized EOL care. Some wrote, "Get hospice involved earlier" and, "Get palliative care involved much earlier in the care of patients. They do a wonderful job, but physicians are reluctant to suggest this to patient/family as it is perceived as *giving up* (respondent's emphasis)."

End futile care. Nurses expressed frustration with treatments they deemed unnecessary or futile. "[Physicians] keep offering the patient/family one more magic trick from their bag of tricks --- giving patient and family false hope," and, "I think we sometimes do too many tests/treatments/procedures that will not change the patient's outcome."

Providing spiritual care. Attending to spiritual needs at EOL was important to 7 (3.1%) respondents. One nurse suggested, "[the] availability of pastoral care personnel" for terminal patients. Another said, "Include a spiritual component from the start, before the dying process."

Discussion

Nurses in this sample were highly educated with over 72% having been either an Oncology Certified Nurse (OCN) or Advanced Oncology Certified Nurse (AOCN) at some time in their practice. The sample was randomly selected, geographically dispersed, and of a

significant size, so results can be generalized to ONS members who work in a hospital-based setting.

Nurses were emphatic regarding aspects of care they deemed most important and their statements reflected observations gleaned from years of interaction with terminal patients. These nurses' suggestions reflected an understanding of the characteristics of a "good death" such as having the time to providing comfort and relieve pain, to provide care for families, and the need for improving EOL care education (Kehl, 2006; Beckstrand, Callister, & Kirchhoff, 2006). The large number of responses revealed a perceived need for improvement in the care of dying oncology patients and demonstrated that quality EOL care may be complicated by several factors.

Decreased Workload and Improved Staffing

Many nurses specified the need for increasing patient physical and psychosocial care at EOL, but experienced difficulty fulfilling needs due to lack of time or heavy workloads. Lack of time for care mirrors the expressed coping difficulties, frustration, emotional stress, and feelings of helplessness noted in other studies by nurses experiencing similar time constraints and workloads (Erickson, 2013; Dougherty et al., 2009; Valiee, Negarandeh, & Nayeri, 2012).

Improved Environment or Place of Death

For a patient dying of cancer, the focus of care switches from curative treatments to promoting quality of life (QOL) (Zhang, Nilsson, & Prigerson, 2012). The care environment for terminal patients affects their QOL. In a study of 396 advanced cancer patients and their caregivers, experiencing the final week of life in an intensive care unit (ICU) or dying in a hospital were the two most important determinants of poor QOL (Zhang et al., 2012). Dying at home with hospice available was associated with the highest QOL at EOL (Wright et al., 2010).

However, the level of care needed during prolonged illness or family preference superseding patient desires to leave the hospital does result in patients dying in a hospital setting (Ishikawa et al., 2013; Jack & O'Brien, 2010). In these instances, a peaceful, homelike setting with space for family to gather was felt to be important by our sample of nurses.

Focused EOL Education

Although excellent in their management of symptoms related to chemotherapy and other treatment modalities, nurses may struggle incorporating advanced palliative care into practice (Ferrell, Virani, Malloy, & Kelly, 2010; Mahon & McAuley, 2010). EOL education was also deemed lacking in physicians dealing with terminal cancer patients. Buss et al. (2011) reported that 95% of oncology fellows believed learning to care for dying patients was important, but rated their training in such areas as pain management, psychosocial needs, and communication skills as inadequate or inferior to their overall oncology training. These studies support our nurses' suggestions regarding the need for EOL education for all individuals involved with terminally ill patients.

Physician Behavior

Noted obstacles involving physicians included poor communication, denial or acts of evasion regarding patient prognosis, and a lack of congruency with others on the oncology team. Nurses' suggestions regarding physician behavior may be validated by a previous report that oncologist discuss EOL issues with only 27% of their patients with most conversations occurring just 1 month prior to death (Mack et al., 2012). Von Gunten, Lutz, and Ferris (2011) found that some oncologists consider prolonged chemotherapy a type of "placebo" to ease a patient's psychological pain and a means of replacing the physicians in engaging in difficult EOL dialogue. Keating et al. (2010) reported most physicians delayed discussing EOL options with

terminal patients who were feeling well; waiting, instead, until symptoms occurred or treatment options ended. Helft, Chamness, Terry, and Uhrich, (2011); and McLennon, Uhrich, Lasiter, Chamness, and Helft (2012) reported that many nurses felt uncertain, had incomplete information, or deemed physicians evasive about patient prognosis; consequently, discussion and decisions between physicians, nurses, patients, and family members regarding the best course of action were inhibited. Physician-nurse teams were considered optimal for the delivery of prognosis-related information (McLennon et al., 2012).

Earlier Palliative and Hospice Care

For terminal patients, timely access to advanced EOL care can maximize a quality experience at the end of life (Volgelzang et al., 2012; Wittenberg-Lyles, Goldsmith, & Ragan, 2010). For most patients and their families, the diagnosis of cancer generates a myriad of significant financial, physiological, and psychological ramifications, presenting them with complex decisions that they may feel unprepared to make (Mahon, & McAuley, 2010), as overwhelming emotions, associated discomfort in broaching the discussion, difficulty acknowledging treatment failures (Weeks, et al., 2012), and/or unexpected events may preclude appropriate planning for EOL care options (Woo, Maytal, & Stern, 2006).

Conclusion

The process of dying has changed considerably since the advent of modern medical practice. The terminally ill used to die in familiar surroundings. Now many die in hospital settings with varied environs, and a plethora of unfamiliar people providing terminal care (National Institute on Aging, 2012). According to the Quality of Life Model by Betty Ferrell, based on Dame Cicely's philosophy of holistic care, the entire person's physical, psychological, spiritual, and emotional well-being are viewed as equally important (Ferrell, Virani, Malloy, &

Kelly, 2010). Providing this care must be assumed with compassion and sensitivity (Valiee, Negarandeh, & Nayeri, 2012).

Many factors can influence the ability of nurses to provide quality care, including the complex associated emotional and treatment factors inherent with EOL oncology care. The results of this study demonstrated the factors that oncology nurses deem most important to improve the quality of care provided patients at the EOL including time, environment, education, physician issues, and earlier interventions. When planning for the care of terminal patients, these factors should be considered and interventions made to ensure that quality care becomes the standard.

Limitations

These results are generalizable to nurses who are members of the Oncology Nurses Society. More suggestions for improvement in EOL care may have been received if we had not asked the nurses to limit their response to only one suggestion.

Future Research

The American Nurses Association noted that empirical research for determination of factors positively influencing quality EOL care and outcomes is currently limited, but growing (American Nurses Position Statements, 2010). This study focused on changes perceived as necessary to improve care. Many research studies provide concrete recommendations, addressing the EOL obstacles identified by this cohort of nurses such as pain management, communication, physician challenges, collaboration, and EOL education (Gaertner, Weingartner, Wolf, & Volz, 2013; Landry, 2012; Orgel, McCarter, & Jacobs, 2010; Quill, 2000; Taylor, Gustin, & Wells-DiGregorio, 2009; Thompson, 2011). Implementing these recommendations and continuing further research may prove useful in turning measured variables into appropriate

practice standards, thus enabling oncology nurses to implement the highest quality of support at the end of life for patients and their families (American Nurses Position Statements, 2010).

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Tables

Table 1 Demographics of Nurses. N = 1000, 473 returned, 380 usable, 93 not eligible, 187 responding to item = 49.2% response rate.			
Characteristics			
Sex	<u>n</u> <u>%</u>		
Female	180 (96.3)		
Male	6 (3.2)		
Did not report	1 (0.5)		
	<u>M</u>	<u>SD</u>	Range
Age	50.0	10.3	26 - 71
Years as RN	18.7	11.1	1.5 - 45
Years in oncology	13.1	8.7	1 - 40
Hours worked/week	36.4	11.4	0 - 80
Number of beds in oncology unit	28.5	10.1	0 - 59
Dying patients cared for:	<u>%</u>		
>30	73.8		
21 - 30	6.4		
11 - 20	12.3		
5 - 10	5.3		
<5	0.5		
Highest degree:	<u>%</u>		
Diploma	9.7		
Associate	23.0		
Bachelor	44.7		
Master	22.1		
Doctoral	0.5		
Ever certified as OCN or AOCN	<u>n</u> <u>%</u>		
Yes	130 (72.6)		
No	49 (27.4)		
Currently OCN or AOCN	<u>n</u> <u>%</u>		
Yes	118 (63.1)		
No	03 (1.6)		
Did not respond	66 (35.3)		
Years as OCN	7.3	5.3	1 - 20
Years as AOCN	7.7	0.4	2 - 12
Ever participated in ELNEC program	<u>n</u> <u>%</u>		
Yes	40 (21.4)		

No	133 (71.1)	
Did not respond	14 (7.5)	
Practice area:		<u>%</u>
Bedside/Direct Care Nurse		31.9
Staff/Charge Nurse		34.1
Clinical Nurse Specialist		9.2
Other (Manager, Educator, etc.)		24.9
Hospital type:		<u>%</u>
Community, non-profit		61.5
Community, profit		9.6
University medical center		18.7
Federal hospital		1.6
County hospital		3.7
Other		1.1

Table 2. Major and Minor Themes Derived Oncology Nurses Suggestions*

<u>Major Themes</u>	<u>Minor Themes</u>
1. Reduction in nurse workload/better staffing when patients are actively dying ($n = 38$)	1. More peaceful and comfortable death for the patient ($n = 18$)
2. Providing a better environment or place of death ($n = 32$)	2. Minimize patient suffering by managing pain ($n = 16$)
3. Focused EOL education for healthcare providers and families ($n = 31$)	3. Earlier initiation of palliative and hospice care ($n = 15$)
4. Obstacles surrounding physician behavior, including honest communication and being seen as part of the EOL care team ($n = 24$)	4. Stop providing or end futile care earlier ($n = 8$)
5. Earlier EOL intervention for patients and their families ($n = 22$)	5. Provide spiritual care ($n = 7$)

*Major themes were themes that had 22 or more responses. Minor themes had ≤ 18 responses. There were miscellaneous comments ($n = 14$) that could not be categorized.