

Nurses' Perceptions of Educational Gaps in Delivering End-of-Life Care

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The approach toward life-limiting diseases or conditions in the United States generally involves highly technical interventions meant to prolong life and sustain hopefulness for a cure in hospitals. Although most Americans die in hospitals or nursing homes, most healthcare organizations are ill-prepared to offer their patients a peaceful death (Martensen, 2008) through adequate symptom assessment and amelioration, communication, and emotional support (Meier, 2010). Nurses, more than any other health professionals, are the frontline caregivers for patients with life-limiting diseases or conditions (Cummings, 2008). However, gaps are evident in undergraduate (Wallace et al., 2009), graduate (Paice et al., 2006), and continuing education (Murray, Wilson, Kryworuchko, Stacey, & O'Connor, 2009) programs.

When a person has a life-limiting condition or disease, they may choose to forego highly technical and expensive interventions in exchange for palliative care to improve the quality of life. Palliative care services may be continuous or episodic depending on the stage of advanced illness. A person's life expectancy could be years, months, or days, and palliative care services can be initiated at any point in the disease process. As palliative care becomes more normative and is contained in the curricula of nursing and medical schools, included in textbooks and licensure examinations, and integrated into clinical practice guidelines, improvements will be made in nurses' competencies regarding end-of-life (EOL) care. Despite a greater awareness of EOL and palliative care services, nurses may be uncomfortable discussing death and dying with patients and their families (Schulman-Green, McCorkle, Cherlin, Johnson-Hurzeler, & Bradley, 2005; White, Coyne, & Patel, 2001) and often misunderstand palliative care (Mahon & McAuley, 2010).

Palliative care in the late 20th century was focused mainly on managing pain. In the early 21st century, researchers continue to investigate knowledge gaps in pain assessment and relief (Morrison et al., 2006), although the concept of palliative care now is extended beyond pain management to include assessment and management of other physical, psychosocial, emotional, and spiritual dimensions (Coyle, 2010); facilitation of

Purpose/Objectives: To assess end-of-life (EOL) care core competencies deemed most important with corresponding educational needs from oncology nurses and to describe the characteristics of the respondents that are associated with selection of the top-ranked core competencies.

Design: Descriptive, cross-sectional study.

Setting: Mailed and online surveys.

Sample: 714 members of the Oncology Nursing Society from Georgia, Virginia, Washington, and Wisconsin.

Methods: Responses to a mailed or e-mailed researcher-developed questionnaire during a six-month period were collated and analyzed.

Main Research Variables: Ranking of EOL care core competencies and perceived gaps in EOL continuing education.

Findings: Almost all of the respondents indicated that EOL care was a part of their practice and that continuing education was important, but more than half of the respondents had fewer than two hours of continuing education regarding EOL care in the past two years. Twenty-five percent of the respondents do not believe they are adequately prepared to effectively care for a dying patient. Symptom management was the top-rated core competency, consistent across age, education level, practice role, and practice setting. How to talk to patients and families about dying and what comprises palliative care also was selected frequently.

Conclusions: Symptom management is the number one core competency, and the quantity and quality of EOL continuing education is inadequate. Educational gaps exist in EOL nursing care.

Implications for Nursing: Assessing what nurses believe to be leading EOL core competencies is useful in improving educational curricula along with considering characteristics of nurses when planning EOL educational programs.

communication with patients and families (Ferrell & Winn, 2006; Matzo, Sherman, Sheehan, Ferrell, & Penn, 2003); preparation of the family and staff for death (Coyle, 2010); alternative sites of care (Ferrell et al., 2007; Quest, Marco, & Derse, 2009); and care of pediatric (Malloy, Sumner, Virani, & Ferrell, 2007) and geriatric (Ersek & Ferrell, 2005) populations. Cost savings have been identified for inpatient palliative care units (White & Cassel, 2009), transfers from higher acuity units (White,

Stover, Cassel, & Smith, 2006), and the use of palliative care consultation teams (Morrison et al., 2008).

In a study conducted by White et al. (2001), 760 RN members of the Oncology Nursing Society (ONS) in four states responded to a questionnaire intended to assess quantity and quality of EOL education, along with a ranking of competencies needed to care for dying patients. The perceptions of the respondents indicated that significant barriers existed to providing high-quality palliative care. Respondents most often ranked the number one core competency in which they lacked expertise to be discussion of the dying process with patients and their families. The second most often cited core competency in which the respondents lacked expertise was pain control techniques.

Models of palliative care programs have proliferated in U.S. hospitals (Goldsmith, Dietrich, Du, & Morrison, 2008) since hospital palliative care programs first were examined in 2001 (Pan et al., 2001). Concomitantly, palliative care educational programs have grown to stay abreast of the demand. Post-baccalaureate certificate programs, in-house continuing education classes, and centers of excellence have been developed, as well as national and international train-the-trainer programs sponsored by the End-of-Life Nursing Education Consortium (ELNEC) (Malloy, Paice, Virani, Ferrell, & Bednash, 2008) and the Center to Advance Palliative Care. Although the early palliative care programs were largely delivered by teams of caregivers for patients with cancer diagnoses, models of palliative care have been extended to other hospital settings (e.g., intensive care units, emergency departments) (Ferrell et al., 2007; Quest et al., 2009).

Given the growth in the palliative care movement, with the concomitant increase in palliative care awareness and educational programs for nurses, the authors conducted a repeat study of nurses' perceptions of their preparation for caring for patients at or near EOL. The following questions were asked.

- How prepared in caring for patients and families with life-limiting illnesses or conditions do nurse respondents believe they are?
- How much continuing education about EOL care have the respondents had from 2007–2009?
- Which EOL care core competencies do nurses believe are most important for educational purposes?
- Are certain characteristics of the respondents associated with rank ordering of core competencies needed in delivering care at or near the EOL period?

Methods

Sample Selection

For comparison with the authors' previous work (White et al., 2001), RN members of ONS living in Georgia, Virginia, Washington, and Wisconsin were again selected. Those states were similar in size, geographic

diversity, and number of ONS members, and all four do not have continuing education requirements for licensure renewal. The authors were interested in surveying a large sample of nurses who provide care at or near the time of death in an organizational setting to solicit their opinions on EOL care competencies important to their nursing practice.

Survey Design and Administration

The design of the survey instrument was based on the one that was used in 1999 (White et al., 2001). The original survey instrument was developed in two phases. The first phase consisted of a convenience sample of 56 RNs employed at a large, tertiary medical center in a southeastern U.S. city who responded to a survey with open-ended questions. In addition to a request for demographic information, the RNs were asked to list gaps in educational preparation for caring for patients at or near EOL. The responses then were collated, like items were combined, and themes were identified.

The second phase of the original survey was a mailed survey using the literature and the identified themes in the first phase. The survey instrument included items about nurses, the organization of practice, experience with EOL education, and rank-ordering of EOL core competencies with perceived educational gaps. Three consultants reviewed the survey, which then was revised extensively. The consultants had expertise in palliative nursing care, nursing education, and survey research design.

For the current study, the authors modified the second phase of the original survey by including additional questions about the organization of practice and the organization's involvement in formalized palliative care services. The *Clinical Practice Guidelines for Quality Palliative Care* (National Consensus Project for Quality Palliative Care, 2009) was consulted to ensure that the original 12 core competencies were representative of the National Consensus Project domains and corresponding National Quality Forum preferred practices. As shown in Table 1, the original core competencies were retained, although comfort care measures was relabeled as symptom management to be consistent with changes in practice language. Respondents were asked to rank order the 12 EOL core competencies from 1 to 12 in order of importance for nursing practice.

After institutional review board approval by Virginia Commonwealth University, the survey was mailed in October 2009 to 2,530 nurses (Georgia, 672; Virginia, 667; Washington, 639; Wisconsin, 552) along with a letter containing information about the study and a postage-paid return envelope. The nurses in the sample were assured anonymity. Via e-mail (addresses supplied by ONS), the authors transmitted a second mailing of the survey to 1,996 ONS members in the four states in February 2010. The e-mail message contained a link to an online survey, which was identical

to the mailed survey. For the second mailing, an online survey was used for its ease of dissemination, reduced costs, the protection of anonymity, and to add another choice of response mechanism. The number of nurses in that sample was fewer than the mailed sample because of changes in membership status and members not having e-mail addresses. A third transmission of the survey link was sent via e-mail in April 2010 and targeted 382 ONS members in the four states (Georgia, 95; Virginia, 122; Washington, 95; Wisconsin, 69)

who had not received at least one other survey. Of the potential 2,530 respondents, six completed the survey twice, three were returned as undeliverable, and 11 were ineligible because they had retired, moved out of the state, or declined to participate; reducing the potential respondents to 2,510. A total of 765 responses (30% return) were received from mailed and electronically transmitted surveys by the designated date. Fifty-one surveys were incomplete or unusable, reducing the final sample for analysis to 714.

To compare the respondents with the total population of ONS members, demographic characteristics were examined. The respondents in all four states represented the age, race, gender, practice role (staff nurse), educational preparation, years in practice, and specialty certification of the total ONS membership (ONS, 2010).

Measures and Variables

Interest and involvement in end-of-life care: Respondents were asked if EOL education is important to them, and if EOL care is a part of their nursing practice.

Ongoing educational preparation: Respondents were asked if they had received education related to EOL care from 2007–2009, and, if so, to estimate the number of hours of EOL education, whether the education was useful and current, and if the education had been applied in their nursing practice. They were asked to rate the quality of that education and to respond to the level of preparation for effectively caring for a patient and their family with a life-limiting illness or condition.

Organizational commitment to palliative care: Respondents were asked if their organization provided formalized palliative care services, and, if so, if that service is provided in a specialized palliative care unit or as a consultation service. In addition, they were asked to subjectively estimate the effectiveness of palliative care services in their organization.

Palliative care core competencies: Respondents were asked to rank order 12 competencies in providing EOL care, from 1 (most important) to 12 (least important) in dealing with EOL issues in their nursing practice.

Table 1. National Consensus Project Domains, National Quality Forum Preferred Practices, and Relationship to Survey Instrument Questions

National Consensus Project Domains	National Quality Forum Preferred Practices	Survey Instrument Question
Care of the imminently dying patient	Recognize transition to active dying phase. Provide adequate analgesics.	Ranking: recognizing impending death (physiologic changes) Ranking: pain control techniques
Cultural aspects of care	Include cultural assessment.	Ranking: religious and cultural perspectives
Ethical and legal aspects of care	Make advance directives and surrogacy designations available.	Ranking: advance directives; ethical issues (i.e., determining nurses' roles in therapies)
Physical aspects of care	Assess and manage symptoms.	Ranking: symptom management
Processes and structure of care	Provide access to palliative and hospice care 24/7.	Does your organization provide formalized palliative care?
	Provide continuing education to all healthcare professionals on the domains of palliative and hospice care.	Ranking: What comprises palliative care? What comprises hospice care?
	Provide adequate training and clinical support to ensure that professional staff is confident in their ability to provide palliative care for patients. Hospice care and palliative care professionals should be appropriately trained, credentialed, or certified in their area of expertise.	How effective do you believe the palliative care service is in your organization? What is your certification type?
Psychological and psychiatric aspects of care	Assess and manage the psychological reactions of patients and families.	Ranking: dealing with angry dying patients and their families
Social aspects of care	Communication with family and other caregivers	Ranking: how to talk with patients and their families about dying
Spiritual, religious, and existential aspects of care	Include spiritual care services.	Ranking: religious and cultural perspectives

Note. Based on information from National Consensus Project for Quality Palliative Care, 2009.

Demographic variables: Several measures were used as demographic or control variables, including gender, highest level of formal nursing educational preparation, age, race, number of years as an RN, certifications (basic or advanced), practice setting, type of practice population, and nursing role. Organizational control variables of interest included ownership (nonprofit or for-profit).

Data Analysis

Statistical tests included measures of central tendency and analysis of variance (ANOVA). To determine factors associated with the stability of selection of the core competency for caring for patients at or near EOL as the first choice, ANOVA was conducted to determine variance within and between descriptive categories. Once significant variance was determined, additional analysis was conducted to determine the source of the variance. The respondent profile information of interest included geographic location (Georgia, Virginia, Washington, or Wisconsin), age (stratified by those born before 1956, those born 1956–1974, or those born after 1974), specialty certification, education level (master's and higher, baccalaureate, or associate or high school diploma), practice role (staff nurse, advanced practice nurse, management, education, or other), practice setting (inpatient, outpatient, home, long-term care, education, or other), organizational ownership (nonprofit or for-profit), and organizational setting (inpatient, outpatient, or other).

Results

Characteristics of Respondents

The mean time since becoming licensed as a nurse was 21.3 years, and the mean age was 48.5 years (range = 24–79 years). Most (97%) of the respondents were women and, of the 97% currently working, most worked full time (79%) with adults as the focus of their practice (78%). Respondents practiced in Virginia (30%), Washington (25%), Wisconsin (24%), and Georgia (19%) (2% did not indicate their location). The predominant location of practice was an outpatient hospital (48%), followed by inpatient hospital (41%), and long-term care, home care, management, or education (11%). Sixty-three percent of the respondents practiced as a staff nurse, 18% were APNs providing direct patient care, and the remaining 19% of respondents represented education, management, or other roles. Most of the organizations of practice had nonprofit ownership (72%) and, of those nonprofits, 18% were religious-affiliated. Thirty-one percent of the respondents had obtained a high school diploma or associate degree in nursing education, 39% reported the baccalaureate degree as the highest level of education, and 30% had master's or doctoral degrees. Eighty percent of respondents held basic or advanced certification in a nursing specialty, such as oncology, palliative care, or other.

End-of-Life Care Continuing Education

Of the 714 RN members of ONS who responded to the survey, 99% stated that EOL care education was important and that EOL care was part of their professional practice (85%). Sixty-three percent of the respondents had received EOL care education from 2007–2009, with 46% having attended educational sessions for more than four hours. Twenty-six percent had received three to four hours during that period; 27% received one to two hours. Sixty-eight percent believed the education was very useful, with 32% stating their education was fairly or not at all useful. Most (72%) of those who received any education believed it to be very current, with 69% of the respondents indicating they were able to use the information in their nursing practice. The respondents rated their continuing education as good or excellent (83%), and 75% of the respondents believed they had good or excellent preparation in effectively caring for dying patients. However, 25% did not believe they were adequately prepared to care for dying patients.

End-of-Life Care Competencies

Respondents were asked to rank order 12 competencies that comprise EOL care for nurses, with 1 being the most important competency and 12 being the least important competency. Table 2 shows the aggregated rank-ordered responses indicating the number one EOL competency from the nurse respondents. Almost two-thirds of the respondents ranked one of three competencies highest: symptom management ($n = 163$, 26%), how to talk to patients and families about dying ($n = 130$, 21%), and the meaning of palliative care ($n = 120$, 19%). The nine remaining aspects of palliative care competencies received 0.3%–12% in the bottom third of the rankings. Rankings differed slightly by state. Nurses practicing in Washington and Wisconsin followed the pattern of the aggregated group in ranking the top three EOL competencies. Nurses practicing in Georgia and Virginia ordered the competencies differently, but designated the same top three competencies.

Demographic characteristics differed slightly among respondents who rank ordered the top three educational gaps. All nurse respondents, regardless of educational preparation, ranked symptom management as the number one EOL competency. However, master's- and doctoral-prepared nurses ranked the knowledge domain of palliative care as their third most important competency after communication with patients and their families about death and dying, whereas associate, diploma, and baccalaureate nurses indicated they needed more knowledge about palliative care, ranking it second. Nurses practicing in inpatient and outpatient settings ranked symptom management as the number one competency. The top competency for staff nurses and APNs was symptom management and, for nurses in management and education, the top competency was

Table 2. End-of-Life Core Competencies Ranking

Core Competency	N ^a	Ranked as 1 ^b	\bar{X}	SD
Symptom management	624	163	3.59	2.66
Communication about death and dying	622	130	3.79	2.48
What comprises palliative care	620	120	5.43	3.65
Pain control techniques	625	72	4.14	2.75
Dealing with your own feelings	622	49	7.85	3.73
What comprises hospice	620	26	6.98	3.47
Recognizing impending death	622	23	7.12	3.22
Advanced directives	622	23	7.27	3.17
Ethical issues	621	9	7.75	2.89
Dealing with angry patients and families	620	5	6.94	3
Legal issues	622	5	8.67	3.06
Religious and cultural perspectives	621	2	8.2	2.78

N = 688

^a 614 participants responded fully to this question, 11 partially, and 63 not at all.

^b On this scale, 1 is most important and 12 is least important.

Note. Twenty-six of the 714 participants responded incorrectly and were removed from this analysis.

identifying what constitutes palliative care services. Thirty-seven percent of APNs and 27% of staff nurses ranked symptom management as the number one EOL competency. Nurses born before 1956 (i.e., baby boomers) were more likely than younger nurses (born after 1956) to select the meaning of palliative care as a higher-ranked EOL issue than symptom management. Baby boomer nurses chose their order of core competencies to be (1) palliative care knowledge, (2) symptom management, and (3) pain control techniques.

Nurse respondent practice settings and the organizational ownership of the practice site revealed consistency in following the aggregated group on the top three EOL competencies. Both inpatient and outpatient and for-profit and nonprofit organizations followed the aggregated group, with the top competency being symptom management followed by how to talk to patients about dying and the meaning of palliative care.

Organizational Commitment to Palliative Care

Of the respondents, 73% worked in organizations with formalized palliative care services, either as a specialized palliative care unit (23%) or consultation service (77%). Two-thirds of the respondents rated their palliative care service as effective, whereas almost 22% rated their palliative care service as average and 13% believed it was marginal or ineffective.

Discussion

Given that a decade has passed since the previous study (White et al., 2001), which included a question about the amount of EOL continuing education in the previous two years (1997–1999), it is surprising that the percentage of respondents who had received any EOL continuing edu-

cation in this study (2007–2009) had decreased from 74% in 1999 to 63% in 2009. That indicates that ONS nurse respondents perceive an ever-widening gap in quantity and quality of continuing education. A need exists to provide more and better EOL and palliative care education in the workplace to keep pace with changing nursing practices and societal expectations.

One possibility is that hospitals may have decreased budget and program commitments for EOL care continuing education for this group of specialized nurses. One limitation of this question is that the authors do not know if the continuing education was provided in-house or if it was in the form of educational conferences outside the organization. Because of economic constraints, hospitals may have decreased the amount of educational travel and, as suggested by Mahon and McAuley (2010), many organizations may lack personnel with direct education and practice experience in EOL or palliative care to provide in-house continuing education. By identifying the most important competencies in their practices, oncology nurses in this study have indicated their top educational needs to be symptom management, how to talk with patients and their families about death and dying, and basic knowledge of palliative care.

Results indicate that respondent nurses who are specialists in oncology nursing most often selected symptom management as the number one core competency. Although discussion of the dying process with patients and their families is a close second, nurses need to know how to care for patients to ease their suffering, a core value of nursing (Ferrell & Coyle, 2008). Although improvements have been made in pain management and the palliative care movement has grown rapidly, the continuing education of nurses in managing symptoms to ease their patients' suffering is lagging. Continued efforts should be made to define and improve symptom management nursing interventions in professional and continuing education programs. For nurses not involved in direct patient care, symptom management is less important than knowledge about what comprises palliative care.

One aspect of symptom management is pain control. However, given the focus of pain management by The Joint Commission and other regulatory and consumer groups—requiring a closer monitoring and relief of pain and organizational reporting of pain management indicators—pain control was a separate item in the 12-item competency ranking survey. An important finding is that, since the 1999 study, pain control techniques fell from second to the fourth overall rank. A decade has apparently made a difference with pain management education. One exception is that nurses born before 1956 (i.e., baby boomers) rank pain control techniques as third in their list of competencies.

Although the respondents were mostly practicing oncology nurses in hospital inpatient and outpatient settings—who might have more exposure to patients with life-limiting illnesses than nurses in other specialties—these findings have important implications. First, a significant decrease is noted in quantity of EOL or palliative care continuing education compared to what was reported a decade earlier. The number of respondents rating the education as fair to poor decreased from 25% in 1999 to 17% in 2009. The decline in extent of EOL and palliative care education of nurses who care for people with life-limiting illnesses raises questions about the EOL and palliative care competency levels for nurses in all practice settings and specialties.

Second, the age of nurses is important when considering educational needs and the top-rated competencies of EOL or palliative care. The mean age of the respondents is 48.5 years, nearly three years older than the respondents in the 1999 survey. Although younger age cohorts of Generation X (born 1956–1974) and Millennial (born after 1974) nurses responded with the same top three competencies of import, the overall order differed from baby boomer nurses. For example, baby boomers were more likely to list basic knowledge of palliative care as the number one competency in which they would like more education, followed by symptom management and pain control techniques. Generation X and Millennial nurses were more likely to list symptom management, followed by how to talk to patients and families about death and dying and basic knowledge of palliative care. This difference by age group might be related to the times the nurses were educated, longer spans of patient survivorship, and increasing attention being focused on palliative care. The increasing mean age may lend to more experience and, therefore, greater ease in talking to patients and their families about death and dying. With the paltry amount of EOL and palliative care continuing education, older nurses would naturally sense an educational gap in basic palliative care knowledge.

Third, although an overwhelming majority of the respondents indicated that EOL care is an important aspect of their nursing practice, 25% indicated that their preparation level for effectively caring for dying patients and their families is fair to poor. That may be related to the finding that 17% of those who received any EOL or palliative care education during 2007–2009 rated the quality of the education as fair to poor. That finding is useful in assessing the comfort level of nurses and designing continuing education programs around the gaps in perceived preparation. It also is useful to improve the quality of nurse educators who participate in EOL and palliative care continuing education.

Fourth, the EOL care competencies—symptom management, how to talk to patients and families about death and dying, and basic palliative care knowledge—were consistently ranked as the top three by respondents

across states, education levels, certification levels, practice settings, practice roles, organizational affiliation, and age with the one exception of baby boomer nurses ranking pain control techniques ahead of communication with patients and families about death and dying. The order differed in some instances; however, this shows what practicing oncology nurses believe to be key aspects of their practice and the determination of EOL care educational needs across a spectrum of demographic variables related to nursing practice.

Fifth, no variation is noted in ranking of EOL nursing competencies by organizational ownership, although the majority of the respondents were affiliated with nonprofit healthcare organizations. However, nurse respondents who work in inpatient settings received more EOL continuing education than their counterparts who work in outpatient or other settings. That finding is similar to results from 1999 for nurses across all demographic variables and organizational affiliations.

Finally, the study sheds light on the perceptions of oncology nurses about the EOL competencies they believe are most important, along with their assessment of the amount and quality of education they have received on EOL and palliative care during 2007–2009. It appears that progress has been made in educational programs and nursing practice developments related to pain management and how to communicate with patients and families about death and dying. However, the amount and quality of EOL and palliative care education is inadequate. Educational resources should be stepped up for nurses in all specialties to keep pace with longer life spans and survivorship, increasing consumer demand for palliative care, and the rapidly changing practice in symptom management of those persons with life-limiting illnesses or conditions.

Limitations

The current study has several limitations. First, the sample is a homogeneous group of nurses who had more education than the general population of nurses and a higher percentage was certified by a specialty organization. That might present a bias in nurses' views of EOL care competencies and it also might indicate that more education equals more motivation to learn about EOL and palliative care on one's own or in preparing for a certification examination. Also, these respondents were slightly older than the national average (Health Resources and Services Administration, 2010) and could have had more experience.

Conclusion

Significant barriers continue to exist in providing educational resources to nurses who are actively engaged in delivering or supporting EOL or palliative care. More and better continuing education based on

the top-ranked core competencies, along with improved team-oriented approaches, are needed to assess and manage symptoms at or near EOL.

Implications for Nursing Practice

Despite stepped-up efforts to educate nurses on EOL and palliative care, oncology nurses are unfortunately receiving less education about palliative care than they did a decade ago. However, the perceptions are that the education they do receive is of slightly higher quality. Oncology nurses need more and better education on symptom management, communication skills, and fundamental knowledge of palliative care. A need for quality palliative care education continues, and some variations in educational requirements exist as demonstrated by the authors' study based on the age, role, or practice setting of the nurse. Practice implications include designing continuing education sessions

with the educational gaps identified in this research as topics, as well as including more and better sessions. With rapid changes in interprofessional palliative care delivery modalities, palliative care continuing education should be viewed as a basis for continued competency in evidence-based nursing practice.

The authors gratefully acknowledge Betty R. Ferrell, RN, PhD, MA, FAAN, for review and editorial support, and Ju Yeon Lee, MHA, for data entry and research assistance.

Kenneth R. White, PhD, MSN, RN, is a professor in the Department of Health Administration and Nursing and Patrick J. Coyne, MSN, APRN, ACHPN, ACNS-BC, FAAN, FPCN, is the clinical director of the Thomas Palliative Care Program, Massey Cancer Center, both at Virginia Commonwealth University Medical Center in Richmond. Inova Health System provided funding for the administrative costs of preparing, mailing, and collating the survey responses. White can be reached at krwhite@vcu.edu, with copy to editor at ONFEditor@ons.org. (Submitted July 2010. Accepted for publication December 3, 2010.)

Digital Object Identifier: 10.1188/11.ONF.711-717

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