# Nurse's Role in Increasing Patient Access to Hospice Care

hree contributing factors account for the increase in hospice use: patients' preferences for dying at home, bereaved family members' high satisfaction with hospice care, and Medicare payment system associated with the Balanced Budget Act of 1997 (Park-Lee & Decker, 2010). Medicare is the single largest payer for hospice care. Although a significant increase in hospice use has occurred in the last 10 years, one-half of the patients enroll in the last 3 weeks of life (National Hospice and Palliative Care Organization [NHPCO], 2009). Additionally, research reveals that about onethird enroll in the last week of life, and 10% enroll on the last day. The mean length of stay is 49 days, with less than 17% of patients receiving 6 months of care (Medicare Payment Advisory Commission, 2009). Also 60% of Medicare decedents were not enrolled in hospice at the time of their death.

These dismal statistics reinforce the importance of the role of nurses in helping patients weigh the benefits and burdens of continued treatment, understand their prognosis, and deliberate on the option of palliative treatment, including the hospice care option. *The Code of Ethics for Nurses*, provision 1.4, directly addresses to this patient right of self-determination and the nurse's role.

Patients have a moral and legal right to determine what will be done with their own person; to be given accurate, complete, and understandable information in a manner that facilitates an informed judgment; to be assisted with weighing benefits, burdens, and available options in their treatment, including the choice of no treatment. To accept, refuse, or terminate treatment without deceit, undue influence, duress, coercion, or penalty; and to be given necessary support throughout the decision-making and treatment process. Such support would include the opportunity to make decisions with family and significant others and the provision of advice and support from knowledgeable nurses and other healthcare professionals. (American Nurses Association [ANA], 2001, p. 8)

Therefore, the necessary involvement of nurses in assisting patients and families in making important end-of-life decisions, specifically facilitating the discussion of the hospice care option, will be addressed. This discussion

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will include an overview of the three barriers to hospice care, the positive effect of the increasing number of palliative care consultation services, and the key variable of physician communication in advance care planning.

## **Barriers to Hospice Enrollment**

First is the requirement patients have a prognosis of less than or equal to 6 months to live. Inaccurate prognostication and optimistic prognostic judgments make it difficult to determine which patients are eligible. Research suggests nurses view disagreements among and with physicians regarding prognosis as one of the biggest obstacles to delivering quality terminal care (Espinosa, Young, Symes, Haile, & Walsh, 2010). A welcome change would be hospice eligibility based on medical indications outlined by The National Hospice and Palliative Care Organization, not prognosis.

The second barrier is the requirement patients must choose between life-sustaining treatment and hospice services. Except for larger hospices, most are unable to bear the cost burden of palliative radiation or palliative surgery. Palliative home care programs can provide selected hospice services while the patient receives life-sustaining treatment. As valuable as these services are, they are not a substitute for the coordinated, interdisciplinary care hospice offers (Corcoran & Casarett, 2010).

The third barrier is the lack of conversations between physicians and patients about advanced care planning, do-not-resuscitate orders, or discussion of hospice option (Fine, Reid, Shengelia, & Adelman, 2010; Hirschman, Corcoran, Straton, & Kapo, 2010; Keating et al., 2010). Patients prefer their physician initiate advance directive discussions early in their disease course. Nurses struggle with physician communication with patients and family members that does not address the needed information for an autonomous decision. Nurses also can initiate such discussions with patients, and the SPIKES framework can provide nurses with the steps in breaking bad news (Kaplan, 2010).

# Supporting Physician Communication with Patient and Family

In 2006, two-thirds of the deaths among hospice patients were related to noncancer diagnoses (Centers for Disease Control and Prevention, 2007; Medicare Payment Advisory Commission, 2009). Therefore, physicians need

to be familiar with the Palliative Performance Scale, Functional Assessment Staging for Dementia, and criteria of end-stage cardiopulmonary disease (NHPCO, 1996). Nurses also need to be familiar with these scales to know when to recommend to physicians to discuss hospice options with patients (Kaprow, 2010).

End-of-life conversations have been well researched and authors have condensed this research into advice for physicians (Moore & van Gunten, 2010; Tulsky, 2005). A great deal of the research points to the need for education on palliative care and effective communication in difficult conversations. Better-informed physicians are more likely to recommend hospice care, as well as facilitate the transition of patients into the hospice program.

National guidelines recommend advance care planning for patients with a terminal illness and a life expectancy of 1 year or less (National Comprehensive Cancer Network [NCCN], 2005). Using these cancer guidelines and the "Medical Guidelines for Determining Prognosis in Selected Non-Cancer Diseases" (NHPCO, 1996), physicians and nurses can know when these conversations are needed. Important components of this advance care planning include clear and consistent discussions about prognosis, information regarding advance directives, exploration of the "do-not-resuscitate" (DNR) option, information about palliative care options including hospice, and elicitation of patients' preference for site of death (NCCN, 2005).

Keating and colleagues (2010) conducted a large, multi-regional study of 4,074 physicians focused on assessing the timing of end-of-life discussions. The physicians were given a scenario of a newly diagnosed patient with metastatic cancer with an estimated 4-6 months to live, but currently feeling well. They were asked when they would discuss various components of advance care planning. The choices ranged from "now" to "only if the patient and family bring it up." Of these respondents, 65% would discuss prognosis now, 44% would discuss DNR now, 26% would discuss hospice now, and 21% would discuss the preferred site of death now. Only twothirds of physicians reported they would discuss prognosis; this suggests prognosis discussions are not seen as part of advance care planning. Patients' beliefs about prognosis influence their treatment preferences, and inaccurate estimates or no estimates may influence patients to not initiate discussions about goals of care. Younger physicians were more likely to discuss all these components now. This may be a positive reflection of their awareness of guidelines or more emphasis on palliative care in their medical training. Surgeons and oncologists, more than non-cancer specialists, were more likely to discuss prognosis now. However, non-cancer physicians were more likely to discuss a DNR order, hospice, and site of death now. Physicians delayed their discussion with patients, perhaps because they disagreed with guidelines or were unaware of them, or they may have been aware of them and delayed the discussions because they were difficult. Physicians who strongly agreed they were knowledgeable to discuss end-of-life options did discuss DNR status, hospice, and preferred site of death.

Zhou, Stoltzfus, Houldin, Parks, and Swan (2010) studied 300 oncology advanced practice nurses and found fairly positive attitudes toward advance care planning. The modestly high correlations in this study indicated the comfort level with advanced care planning was associated positively with hospice referrals and advance directive discussions. The nurses saw advance care planning as a professional responsibility. These results were similar to the results found among general NPs and RNs (Badzek et al., 2006).

Although nurses appear to be the individuals most aware and ready to discuss advance care planning, most patients also want to have these important conversations with their physicians. Anderson and Goldstein (2010) critiqued journal articles from January-December 2008 to assess what changes would have the highest impact on the clinical practice of hospice and palliative care. Two conclusions were relevant to physician-patient communication:

- End-of-life discussions are associated with less-aggressive medical care and better quality of life for patients and caregivers.
- 2. Clearly communicating pessimistic information may improve patients' understanding of the prognosis.

In a study by Broom and Adams (2010), nurses wanted physicians to deliver a realistic prognosis, but the nurses also believed they often were left to "pick up the pieces," mostly because of how the information was conveyed. Interviews with 12 nurses consistently indicated they reported a key role in the aftermath of the talk, supporting distraught patients who were attempting to make sense of their prognoses and statistical probabilities around survival. Rather than dispute the physician's advice, the nurses used anecdotes of other patients who had done well. Nurses recognized a need to maintain the delicate balance between the prognostic truth and the patient/family need for hope.

Fine and colleagues (2010) conducted a systematic review of palliative and end-of-life discussions, which led to the following specific recommendations for improvement in the content and process of physician communication:

- 1. Initiate and explore emotional issues in life-threatening illness.
- 2. Reprioritize emotional and quality-of-life issues to take precedence.
- 3. Take advantage of educational opportunities to expand the role as communicator.
- 4. Enlist the help of other health professionals.
- 5. Speak less, listen more.
- Offer support and emotional validation (e.g., "Whatever you choose, we will not stop taking care of you").

Physicians who are uncomfortable in establishing palliative care goals and initiating possible hospice referrals should consult with a specialist in palliative care.

## Palliative Care Service

Palliative care is focused on maximizing quality of life for seriously ill patients and their families. In 2005, 30% of hospitals in the United States and 70% of hospitals with over 250 beds reported the presence of palliative care programs — a 96% increase since 2000 (American Hospital Association, 2007). Currently, over 1,500 U.S. hospitals have a palliative care team (Joint Commission, 2011). On September 1, 2011, the Joint Commission (2011) will demonstrate the importance of palliative care to overall quality of care by recognizing exceptional palliative care programs. This represents a giant step forward for the field of palliative care consultation services. The Joint Commission (2011) will recognize hospitals with exceptional palliative care programs, with an emphasis on the following:

- A formal, organized palliative care program led by an interdisciplinary team whose members possess the requisite expertise in palliative care
- Leadership endorsement and support of the program's goals for providing care, treatment, and services
- A special focus on patient and family engagement
- Processes which support the coordination of care and communication among all care settings and providers
- The use of evidence-based national guidelines or expert consensus to guide patient care

Palliative care not only lowers cost by reducing unnecessary tests and treatments, but the multidisciplinary focus of palliative care provides a focus on improving quality of life and patient dignity (Morrison et al., 2008; Penrod et al., 2006). Patients who accepted palliative care while in the hospital were more likely to be transferred to hospice on discharge or expired in the hospital (Celso & Meenrajan, 2010). This affirms the importance of implementing a palliative care consultation service in all hospitals.

### Conclusion

The good news is the number of individuals seeking hospice continues to increase. The bad news is the three primary barriers continue — prognosis requirement of 6 months or less to live, forced choice between life-sustaining therapy and hospice, and the lack of communication between physician and patient/family in advanced care planning of prognosis, DNR, hospice, and preferred site of death. Nurses can play a key role in supporting these conversations with patients using the SPIKES framework and ensuring physicians do their best in managing these difficult conversations. Per the Code of Ethics for Nurses (ANA, 2001), nurses have an obligation to be knowledgeable of the clinical issues their patients face in their projected last year of life, and help them weigh the benefits and burdens of continued treatment. In addition, nurses need to facilitate honest conversations between their patients' attending physicians and patients and/or their families. This includes the discussion of changing the goals of care from cure to the care goals of hospice.

As baby boomers enter the last stages of their lives, clinicians need the mastery of clinical and interpersonal skills for advanced care planning conversations so the wishes and needs of the patients and families can be met. Nurses have the ethical obligation to support patients in the "planning of their own health care to the extent they are able and choose to participate" (ANA, 2001, p. 8). Throughout the terminal illness journey, nurses should enable patients to remain informed of their options, including hospice.

#### REFERENCES

- American Hospital Association. (2007). AHA hospital statistics. Chicago: Author.
- American Nurses Association (ANA). (2001). Code of ethics for nurses. Silver Spring, MD: Author.
- Anderson, W.G., & Goldstein, N.E. (2010). Update in hospice and palliative care. *Journal of Palliative Medicine*, 13(2), 197-202.
- Badzek, L.A., Leslie, N., Schwertfeger, R.U., Deiriggi, P., Glover, J., & Friend, L. (2006). Advanced care planning: A study on home health nurses. *Journal of Nursing Research*, 19, 56-62.
- Broom, A., & Adams, J. (2010). The reconfiguration of expertise in oncology: The practice of prediction and articulation of indeterminacy in medical consultations. *Qualitative Health Research*, 20, 1433-1439.
- Celso, B.G., & Meenrajan, S. (2010). The triad that matters: Palliative medicine, code status, and health care costs. American Journal of Hospice and Palliative Medicine, 27, 398-401.
- Centers for Disease Control and Prevention. (2007). National vital statistics system. Leading causes of death. Retrieved from http://www.cdc.gov/nchs/fastats/icod.htm
- Corcoran, A.M. & Casarett, D.J. (2010). Improving communication and rethinking hospice care. Chest, 137(6), 1262-1263.
- Espinosa, L., Young, A., Symes, L., Haile, B., & Walsh, T. (2010). ICU nurses' experiences in providing terminal care. *Critical Care Nursing Quarterly*, 33(3), 273-281.
- Fine, E., Reid, M.C., Shengelia, R., & Adelman, R.D. (2010). Directly observed patient-physician discussions in palliative and end-of-life care: A systematic review of the literature. *Journal of Palliative Medicine*, 13(5), 595, 603.
- Hirschman, K.B., Corcoran, A.M., Straton, J.B., & Kapo, J.M. (2010). Advance care planning and hospice enrollment: Who really makes the decision to enroll? *Journal of Palliative Medicine*, 13(5), 519-523.
- Joint Commission. (2011). Advanced certification for palliative care programs. Retrieved from http://www.jointcommission.org/certification/palliative\_care.aspx
- Kaplan, M. (2010). SPIKES: A framework for breaking bad news to patients with cancer. Clinical Journal of Oncology Nursing, 14(4), 514-516.
- Kaprow, M.G. (2010). Use of hospice care for patients without cancer. American Family Physician, 82(10), 1196.
- Keating, N.L., Landrum, M.B., Rogers, S.O., Baum, S.K., Viring, B.A., Huskamp H.A., ... Kahn, K.L. (2010). Physician factors associated with discussions about end-of-life care. *Cancer*, 116, 998-1006.
- Medicare Payment Advisory Commission. (2009). Report to Congress. Medicare payment policy. Retrieved from http://www.med pac.gov/documents/Mar09\_entirereport.pdf
- Moore, S., & van Gunten, C.F. (2010). Pulmonary/critical care physicians and hospice patients: Billing specialty care for patients enrolled in hospice program. Chest, 137(6), 1427-1431.
- Morrison, R.S., Penrod, J.D., Cassel, J.B., Caust-Ellenbogen, M., Litke, A., Spragens, L., ... Meier, D.E. (2008). Cost savings associated with US hospital palliative care consultation programs. Archives of Internal Medicine, 168(16), 1783-1790.
- National Comprehensive Cancer Network (NCCN). (2005). Practice guidelines in oncology. Palliative care. Retrieved from http://www.nccn.org/professionals/physician\_gls/PDF/palliative.pdf
- National Hospice and Palliative Care Organization (NHPCO). (1996). Medical guidelines for determining prognosis in selected non-cancer diseases (2nd ed.). Arlington, VA: Author.

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## In this Together

#### To the Editor:

The article "Why Are Nurses Leaving? Findings from an Initial Qualitative Study on Nursing Attrition" (Vol. 19, No. 6, pp. 335-340) brought back memories of when I used to precept new nurses on a 30-bed medical-surgical floor. The faces of those nurses who left before their 6-month orientation was over will be instilled in my mind forever, as well as those nurses who had worked with me for so many years who knew the time had come. The looks were of defeat and disappointment and the overwhelming feeling of failure that came with leaving something for which they had worked so hard and had so much compassion. The reasons cited in the article reminded me of why those nurses left the bedside.

It is not an uncommon occurrence for a nurse to feel completely alone while taking care of patients. Due to the fact others are so involved with their own patients, it may go unnoticed that a colleague can be in trouble balancing the demands of her or his assignments. Often, when they seek help from their peers, many are involved with their own issues and are unable to free themselves to assist others. This can be frustrating to those who are in need of help and leave them with a feeling of inadequacy.

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Then there is that emotional distress related to patient care or the lack thereof. With all the wonderful technology that has come along to assist in improving patient care, the time spent at the bedside is becoming less frequent. I have had many nurses tell me that when they go home at the end of their shifts, the feeling of disappointment is overwhelming with the lack of time they spent with their patient.

Fatigue and exhaustion go hand in hand with nursing at the bedside today. Patient acuity is higher, the assignments consist of more than four patients to care for at one time, and the demand for early discharge adds more stress to the daily routine.

The same comment has been stated to me by new grads and nurses in the profession for years, "This is not what I thought nursing was going to be like." To have a work environment that allows us to provide quality patient care and be satisfied with the care we have given, we need to be supportive of one another. We need to provide proper preceptorship for new graduates, create an environment that is supportive with resources that will allow the new grads to grow and develop self-esteem. At the same time, we need to support each other with strong leaders who have the ability to provide assistance to those who are struggling with the daily demand of bedside nursing. We are all in this together.

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National Hospice and Palliative Care Organization (NHPCO). (2009). NHPCO facts and figures: Hospice care in America. Retrieved from http://www.nhpco.org/files/public/statistics\_Research/NHPCO\_facts\_and\_figures.pdf

Park-Lee, E.Y., & Decker, F.H. (2010). Comparison of home health and hospice care agencies by organizational characteristics and service provided: United States, 2007. National Health Statistics Reports, 30, 1-23.

Penrod, J.D., Deb, P., Luhrs, C., Dellenbaugh, C., Zhu, C.W., Hochman, T., ... Morrison, R.S. (2006). Cost and utilization outcomes of patients receiving hospital-based palliative care consultation. *Journal of Palliative Medicine*, 9(4), 855-860.

Tulsky, J.A. (2005). Beyond advance directives: Importance of communication skills

at end of life. *JAMA*, *293*(11), 1374-1381.

Zhou, G., Stoltzfus, J.C., Houldin, A.D., Parks, S.M., & Swan B.A. (2010) Knowledge, attitudes, and practice behaviors of oncology advanced practice nurses regarding advance care planning for patients with cancer. *Oncology Nursing Forum*, *37*(6), E400-E410.

### **LVAD Deactivation**

#### To the Editor:

The article by Vicki D. Lachman, PhD, MBE, APRN, "Left Ventricular Assist Device Deactivation: Ethical Issues" (Vol. 20, No. 2, pp. 98-100), is quite thought provoking and especially relevant at UNC Healthcare. I worked on the cardiothoracic step-down unit in the mid-'90s when persons with LVADs remained hospitalized as the device was "a bridge to transplant." With increased and longer-term use of these devices has come more complex ethical considerations – as Dr. Lachman addresses so well.

I have shared this article (via the UNC-CH Health Sciences Library) with our heart and vascular and rehab nurse educators as I think staff in both those areas will benefit from reading it.

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