

On the Road Less Traveled: Journey of an Oncology Palliative Care Researcher

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In 2001, as the Trish Greene Quality of Life lecturer, I described coming to a career crossroads and cited a metaphor from Robert Frost's poem "The Road Not Taken," realizing that, as I chose to leave the path of bone marrow transplantation clinician and go to that of palliative care nurse, there was no turning back. In this article based on my 2016 Oncology Nursing Society Congress Distinguished Nurse Researcher Award lecture, I would like to continue the Frost metaphor as I describe what has transpired since taking "the one less traveled by"—that of palliative care nurse scientist.

The journey from oncology clinician to palliative care scientist was circuitous and mostly accidental. It was accidental because the quality improvement and small studies that marked my early career were really driven by clinical curiosity and a search for evidence to guide clinical practice. Following graduation with my master's degree and surviving completion of my master's thesis on the sexual counseling needs of women with gynecologic cancers, I was certain I would never do another research study. In 1983, as a new oncology clinical nurse specialist, I focused on the exciting opportunity to create a new autologous bone marrow transplantation (autoBMT) program at Mary Hitchcock Memorial Hospital in Lebanon, New Hampshire. To ensure that the oncology/BMT staff nurses were well educated about investigational drugs and procedures, I became a member of the institutional review board, where all new protocols were reviewed before they were put into practice. I was responsible for understanding the protocol's nursing care implications and ensuring that nursing staff received adequate orientation before the new protocols were introduced.

As a member of the Oncology Nursing Society (ONS) Clinical Practice Committee, I was well aware of the need for competencies in administration and safe handling of chemotherapeutic agents. Our committee developed some of the first ONS practice guidelines for chemobiotherapy (ONS, 1988) and venous access devices (ONS, 1989). In my practice, it became clear that there was a critical need for guidelines to educate nurses caring for patients undergoing bone marrow and stem cell transplantation. Somehow, this desire turned into three edited textbooks on the topic (Bakitas Whedon, 1991; Bakitas Whedon & Wujcik, 1997; Buchsel & Bakitas Whedon, 1995). In writing and editing chapters, it became very clear that so little of what we did in practice was based on evidence.

Betty Ferrell, PhD, MA, RN, my colleague and counterpart as chair of the ONS Research Committee, encouraged a student and me to apply for a small ONS Foundation grant to better understand the long-term effects experienced by autoBMT survivors. Because this was a new treatment, little was known about how autoBMT, compared to allogeneic transplantation, would affect long-term survival. Our small study included a newly validated BMT quality-of-life instrument.

However, Ferrell encouraged me to add a few open-ended questions so that we could get additional thoughts in the patients' own words about the experience. This would be my first foray into the importance of qualitative and mixed methods research. The quantitative study demonstrated the quality-of-life impact of persistent fatigue and family distress (Whedon, Stearns, & Mills, 1995). However, the qualitative data revealed that many autoBMT survivors had persistent cognitive difficulties (Ahles & Whedon, 1999; Stearns & Whedon, 1997); this was a key quality-of-life issue that we would have missed because, at that point, there was no item about cognitive effects on the tool.

In the mid-1990s, pain assessment and management was a prominent clinical issue for oncology nurses. It was at an ONS State-of-the-Science that ideas about understanding pain as the fifth vital sign and having the Joint Commission recognize pain management as a quality indicator took shape (Curtiss, 1999, 2001, 2004; Whedon, Shedd, & Summers, 1992). Ferrell, as my mentor, challenged me to question whether the evidence and ethics of pain management were aligned (Whedon & Ferrell, 1991) and to explore barriers, such as clinician attitudes, that interfered with guideline-consistent pain assessment and management (Furstenberg et al., 1998).

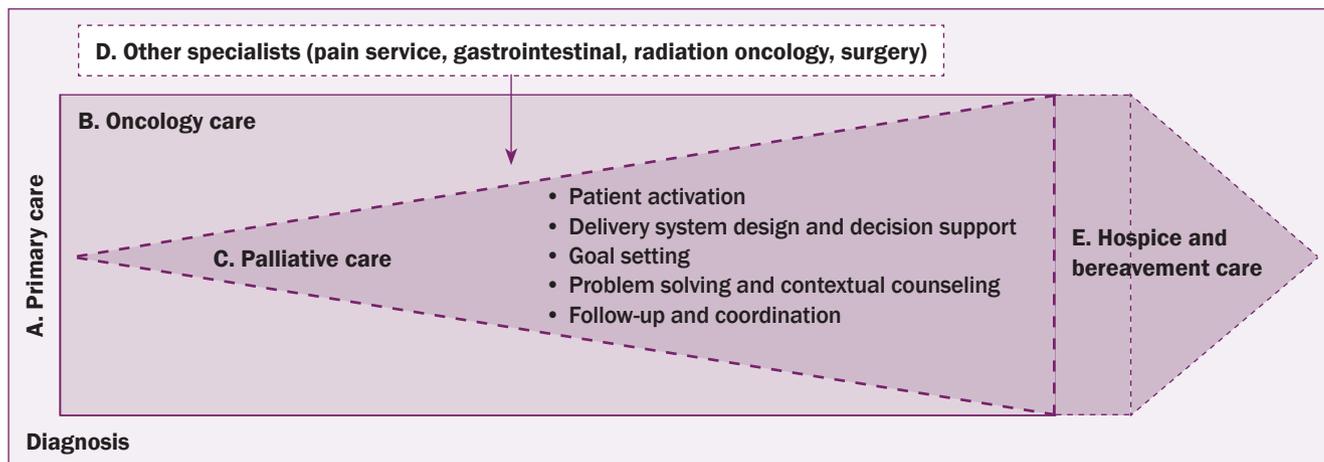
In the late 1990s, I was the clinician member on an ONS Foundation Clinical Scholars grant with researcher Marilyn Bookbinder, PhD, RN, on a project called "QUEST for Pain Relief" that paired oncology nurse clinicians and researchers to understand current research evidence and bring it into practice. Fortunately, Donna Berry, PhD, RN, a mentor of mine, was the reviewer and site visitor for this grant. I had the opportunity to be introduced to the idea of critique

by one of the most kind, but rigorous, researchers as my first grant viewer. With such expert guidance, we were able to shepherd five pain-focused clinical quality projects to completion (Bookbinder et al., 1995; Bookbinder & Whedon, 2000; Lavoie Smith et al., 2009, 2011; Lavoie Smith, Whedon, & Bookbinder, 2002). This work planted a seed that ultimately bloomed years later into my doctoral dissertation on chemotherapy-induced peripheral neuropathy (Bakitas, 2007).

Career at the Crossroads

In the mid-1990s, Lynn et al.'s (1997) landmark study known as SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment) revealed serious deficits in end-of-life care in the United States. While the study was underway, Lynn and SUPPORT coinvestigator Teno challenged us to examine the quality of end-of-life care at our own institution, Dartmouth-Hitchcock Medical Center, which was not one of the SUPPORT study sites. We were confident that we provided top-notch care; however, in our small chart review study, we learned that our outcomes were just as disappointing as what was found in the SUPPORT institutions (Goodlin, Winzelberg, Teno, Whedon, & Lynn, 1998). Patients in our study, half of whom had a cancer diagnosis, had high rates of severe pain, dyspnea, invasive interventions, and little emotional or spiritual support in the 48 hours before death (Elshamy & Whedon, 1997; Goodlin et al., 1998). A follow-up focus group study of family members whose loved ones died on the oncology and medical units provided in-depth information about their experience, which ranged from the good to the bad

FIGURE 1. ENABLE (Educate, Nurture, Advise Before Life Ends) Concurrent Oncology Palliative Care Model



Note. From "Developing Successful Models of Cancer Palliative Care Services," by M. Bakitas, M.F. Bishop, P. Caron, and L. Stephens, 2010, *Seminars in Oncology Nursing*, 26, p. 277. Copyright 2010 by Elsevier Inc. Adapted with permission.

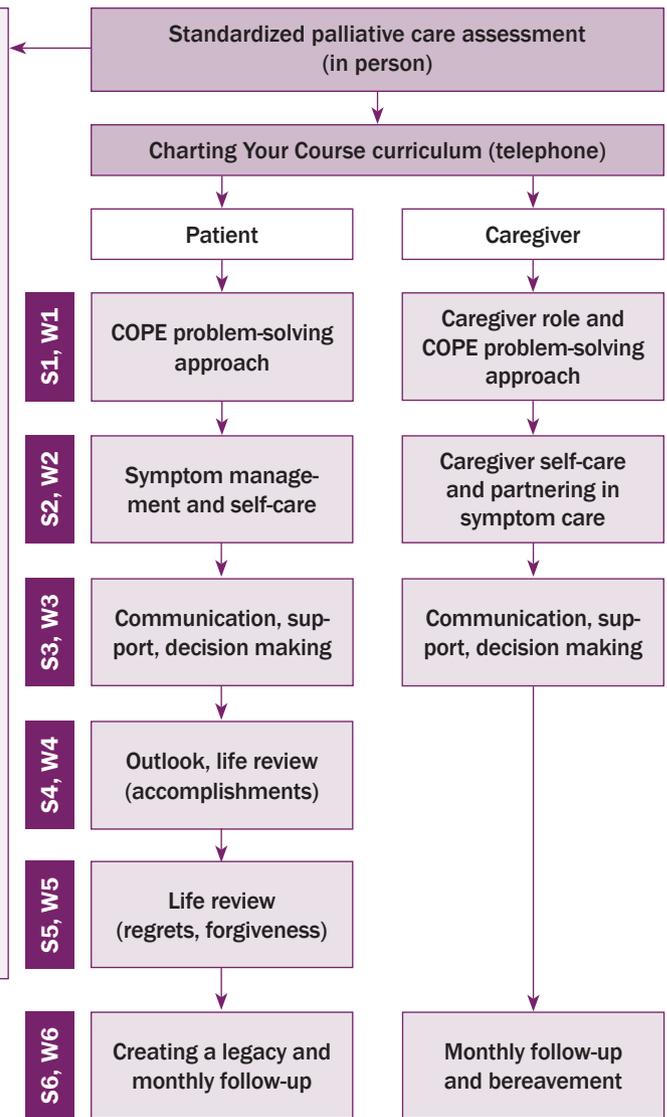
and the ugly (Bakitas & Daretany, 2006). One of our major insights was that, as important as it was to improve care at the end of life, what we really needed to focus on was finding ways to prevent seriously ill patients who did not want invasive treatments to avoid hospitalization at end of life entirely. Looking back, I realize that the results of these small quality improvement projects propelled me down an uncharted path that ultimately influenced the remainder of my career.

By 1999, the palliative care movement was gaining momentum stimulated by the SUPPORT study (Doyle, 1996; Kellar, Martinez, Finis, Bolger, & von Gunten, 1996; MacDonald, 1991; McWhinney, Bass, & Donner, 1994; O'Neill, O'Connor, & Latimer, 1992; Rinck, Kleijnen, van den Bos, Schadé, & Veenhof, 1995; Saunders, 1987; Weggel, 1997). At the

Norris Cotton Cancer Center (NCCC), a philanthropic donation motivated the development of a task force was that was charged with bringing palliative care and hospice principles into the routine care of patients with advanced cancer. Coincidentally, the Robert Wood Johnson Foundation launched a program called Promoting Excellence in End-of-Life Care (Schapiro, Byock, Parker, & Twohig, 2003) to promote demonstration projects that would facilitate radical change in how care was provided to patients with serious illnesses.

The NCCC was fortunate to be selected as one of four cancer centers to promote the integration of hospice principles into a comprehensive cancer center. Our idea, with the acronym Project ENABLE (Educate, Nurture, Advise Before Life Ends), sought to determine if we could put the World Health Organization (WHO) concurrent care model, first proposed in

- Evaluate understanding of illness, treatment, and prognosis.
- Identify preferences, decision-making style, and others who should be included in decision making.
- Explore goals of care.
- Assess physical symptoms.
- Assess social situation, and obtain social history.
- Identify support system, and evaluate family or relational challenges.
- Assess psychological and emotional well-being.
- Obtain spiritual history.
- Review advance care planning, and identify surrogate decision maker.
- Document assessment and pharmacologic and nonpharmacologic recommendations.
- Conduct direct referrals within and outside of the palliative care team.
- Communicate directly with referring clinician and/or primary care clinician.
- Develop follow-up plan.



COPE—Creativity, Optimism, Problem-solving, and Expert information; S—session; W—week

FIGURE 2. ENABLE (Educate, Nurture, Advise Before Life Ends) Concurrent Care Pathway

1990, into practice. The WHO model recommended that, rather than shifting from curative to palliative or hospice care, these principles and care should be introduced at the time of a new diagnosis and gradually increased as disease-modifying and curative therapies were less effective (Bakitas et al., 2004). The ENABLE components were designed based on data from patient, family, and clinician focus groups. Our team queried these groups with a very simple question: “What do you wish you (your patients) had known at the beginning of the diagnosis that would have helped when facing advanced cancer?” (Skalla, Bakitas, Furstenberg, Ahles, & Henderson, 2004). We translated the focus group themes into four weekly in-person patient and family sessions, presented by different disciplines—a model very similar to child-birth classes.

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The Evolution of ENABLE

By 2001, we had demonstrated that the ENABLE early concurrent palliative care approach was feasible and well accepted by patients, families, and oncologists. But we also learned a number of important lessons. Probably the most important was that we needed to overcome the geographic, illness, and other barriers that prevented seriously ill patients with cancer from traveling to NCCC for these sessions (Bakitas et al., 2008). Because we were able to successfully bring this information by telephone to patients who could not attend in-person group sessions, we decided that we would rely heavily on this method for our next study. This important insight paved the way for the current scalable telehealth approach that we continued to refine.

Also in 2001, the Institute of Medicine ([IOM], now the Health and Medicine Division of the National Academies of Sciences, Engineering, and Medicine) published *Improving Palliative Care for Cancer* (Foley & Gelband, 2001), a report that detailed the potential benefits of integrating palliative care into oncology. However, the evidence base to support such an approach was sparse. I think it is fair to say that, even though there was sparse evidence, oncology nurses were light years ahead of other specialties in conceptualizing the possibilities, and that trend continues today. That was the year I reported the results of our completed demonstration project at the Quality of Life Lectureship (Bakitas et al., 2004; Whedon, 2002) and embarked on my doctoral program.

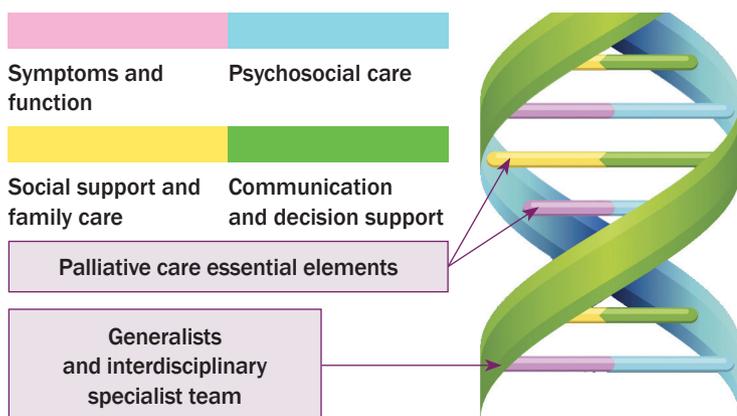
As an aside, many mentors made me realize that, to continue to conduct the work of discovery, I could no longer rely solely on my colleague and mentor Tim Ahles, PhD; I actually needed a PhD of my own. With much gratitude I (blame) thank my nurse mentors, Ruth McCorkle, PhD, RN (Yale University), Tish

Knobf, PhD, RN (Yale University), and Marcia Grant, PhD, RN (City of Hope), as well as my nominators, Ferrell and Berry, for helping me to see the light and getting me through. Importantly, Gilbert Fanciullo, MD, MS, anesthesiology and pain clinic director at Dartmouth-Hitchcock Medical Center, and the other wonderful clinicians I worked with took the plunge and initiated an inpatient palliative care service. Dartmouth's palliative care service was developed to complement the outpatient research program to consult not only on the ENABLE patients with cancer who were admitted to the hospital, but also on all of the other patients with and without cancer and their family and friends who needed expert pain and symptom management, as well as provide excellent communication and assistance with advance care planning and treatment decision making (Bakitas, Bishop, & Caron, 2010; Bakitas, Bishop, Caron, & Stephens, 2010).

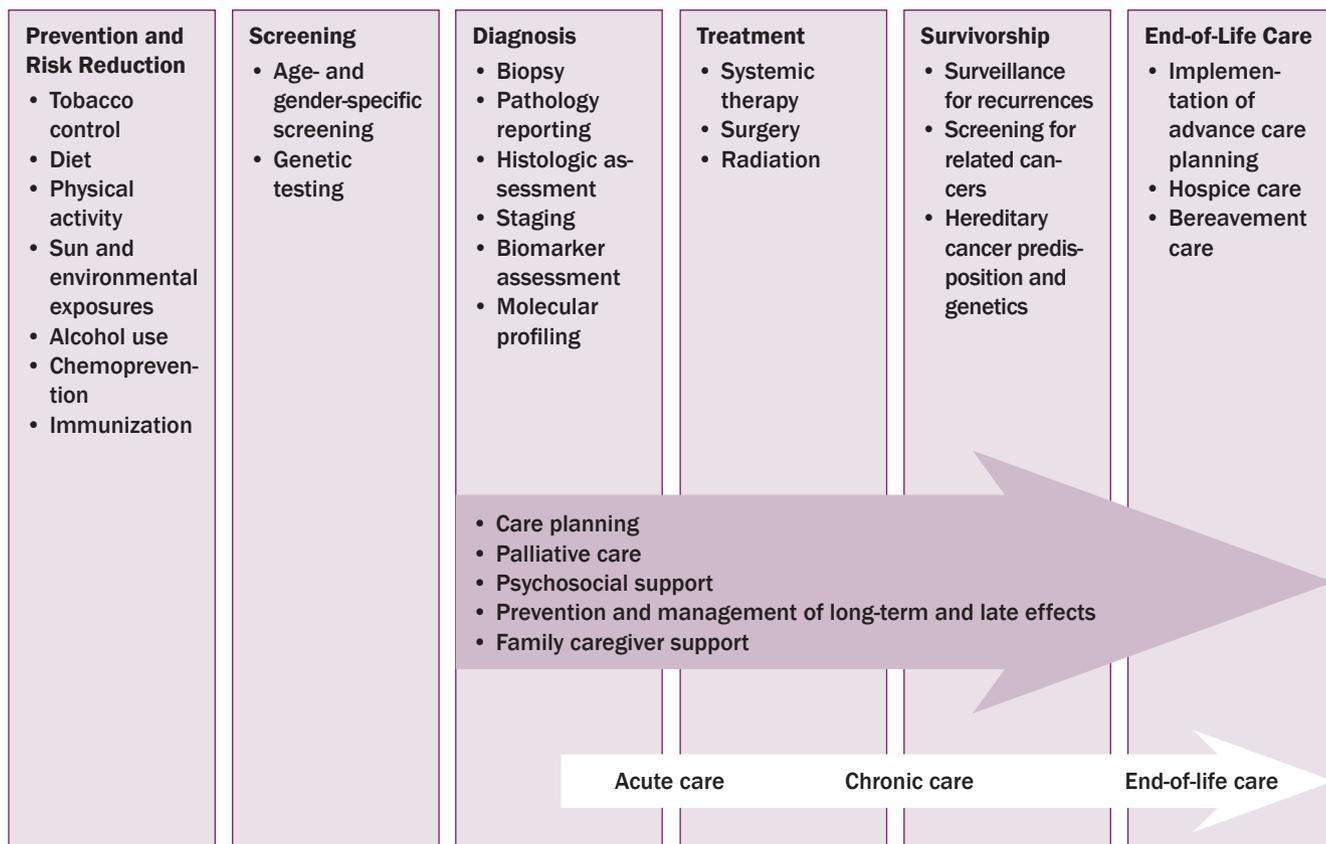
Ahles took the very promising feasibility data generated by ENABLE and crafted the telehealth randomized, controlled trial (RCT) that was funded and conducted at Dartmouth from 2003–2007 (Bakitas, Lyons, Hegel, Balan, Barnett, et al., 2009; Bakitas, Lyons, Hegel, Balan, Brokaw, et al., 2009). This trial was strategically labeled a supportive care trial because the “p” word (palliative) was still very much associated with hospice and end of life. This trial, now called ENABLE II, was focused on initiating a palliative care approach soon after a new diagnosis with one of four common solid tumors (lung, gastrointestinal, genitourinary, and breast). In ENABLE II, we compared this approach to oncology care as usual (Bakitas, Lyons, Hegel, Balan, Barnett, et al., 2009; Bakitas, Lyons, Hegel, Balan, Brokaw, et al., 2009).

The results of the ENABLE II RCT (Bakitas et al., 2004, 2008; Bakitas, Lyons, Hegel, Balan, Barnett, et al., 2009; Bakitas, Lyons, Hegel, Balan, Brokaw, et al., 2009) included improvements in quality of life and depression, and trends toward improved symptom control and survival. These results were included in an American Society of Clinical Oncology (ASCO) consensus statement (Smith et al., 2012) and a Cochrane review (Gomes, Calanzani, Curiale, McCrone, & Higginson, 2013); the methods are available through the National Cancer Institute ([NCI], 2014) Research-Tested Intervention Programs website. Based on the results of seven RCTs, the ASCO provisional opinion statement recommended that “all patients with metastatic disease or high symptom burden” have access to palliative care early in the diagnosis (Smith et al., 2012, p. 880).

FIGURE 3. The DNA of Palliative Care



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Note. From *Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis* (p. 29), by the Institute of Medicine, 2013, Washington, DC: National Academy of Sciences. Copyright 2013 by the National Academies Press. Adapted with permission.

FIGURE 4. Domains of the Cancer Care Continuum, With Examples of Activities in Each Domain

The ENABLE III and Conceptual Foundation

The early success with ENABLE was promising, but, to advance the field, it was important to get a better handle on exactly what we were doing so that others could replicate it if we were able to demonstrate efficacy. Patients with cancer were living longer, and the hospice model of providing palliative care during the last six months of life was no longer a good fit for patients who were living many months to years with symptoms and other quality-of-life concerns. We realized that the framework of Wagner's chronic illness care (CIC) model (Wagner, 1998; Wagner et al., 2001, 2005) contained much of what our patients had told us in the early focus groups while emphasizing the need for patient empowerment and local community support for seriously ill patients in a rural area. Our adaptation of Wagner's model for cancer recognized that patients with newly diagnosed advanced cancer may receive much of their health care from primary care, but that it was important to initiate oncology care and palliative

care concurrently at the time of a new diagnosis in conjunction with primary care providers. In Figure 1, dotted lines indicate porous boundaries between oncology and palliative services. CIC principles, such as patient activation and decision support, are embedded in the model. Hospice and bereavement care are introduced as appropriate.

By now, a fully functional interprofessional consultation team was available, so, for ENABLE III, we modified the intervention in a number of ways: We added an in-person standardized palliative care team (PCT) assessment (see Figure 2) based on National Consensus Project palliative care guidelines. In addition, we enhanced the telehealth component by adding a parallel caregiver intervention that was delivered by a separate advanced practice palliative care nurse (PCN) coach. We also modified the curriculum and patient and caregiver workbooks, which are called *Charting Your Course (CYC): An Intervention for Patients With Advanced Cancer and Their Family Caregivers*.

Patient and caregiver CYC sessions 1–3 incorporated the COPE (Creativity, Optimism, Problem-solving,

Expert information) model (McMillan & Small, 2007). These sessions addressed adjusting to chronic illness, as well as symptom management, communication, and decision making. Patient sessions 4–6 comprised Outlook, a method-of-life review (Bosworth et al., 2004; Steinhauer et al., 2008, 2011). Outlook encourages participants to frame challenges of advanced illness as opportunities for personal growth. In addition, Outlook was found to improve functional status, anxiety, depression, and preparation for end of life (Bosworth et al., 2004; Steinhauer et al., 2008, 2011). In consultation with Steinhauer, we adapted Outlook to be conducted by telephone. The PCT assessment and PCN/CYC components are complementary and reinforcing; the in-person PCT assessment identifies symptom concerns and builds a foundation for future contact, whereas the telephone-based PCN/CYC sessions provide comprehensive information in an unhurried, convenient home setting. Although standardized, ENABLE was able to be tailored to the resources of an individual institution and patient and family needs. Despite modifications, ENABLE III maintains the essential elements or DNA (see Figure 3) of palliative care: addressing symptoms and function, psychosocial care, social support and family care, and communication and decision support. These essential elements are delivered using a combination of generalist and specialist palliative care teams (Quill & Abernethy, 2013).

The ENABLE III study design was called a fast-track model, which allowed us to investigate the effect of early versus delayed introduction of palliative care for patients and family caregivers. ENABLE III demonstrated a statistically significant survival advantage of 15% at one year (63% for early group versus 48% for delayed group, $p = 0.038$), despite overall nonsignificant patient-reported outcomes (quality of life, $p = 0.34$; symptom impact, $p = 0.09$; mood, $p = 0.33$; or before death [quality of life, $p = 0.73$; symptom impact, $p = 0.3$; mood, $p = 0.82$) (Bakitas et al., 2015). Importantly, there were statistically significant treatment effects of early entry from randomization to 12 weeks on caregiver depression ($p = 0.003$) and for subjective burden ($p = 0.02$) and a trend in quality of life ($p = 0.07$) (Dionne-Odom et al., 2015). These findings were featured in ASCO's 11th *Annual Report on Progress Against Cancer* as one of the year's major achievements in clinical cancer (Dizon et al., 2016).

The Journey Continues

It would seem now that professional organizations' (ASCO, 1998; Dizon et al., 2016; Levy et al., 2014) and

Knowledge Translation

- Evidence from early palliative care trials suggests that most patients with advanced cancer should receive this care soon after an advanced cancer diagnosis.
- Mounting evidence shows that family caregivers of patients with advanced cancer also benefit from exposure to early palliative care.
- Palliative care principles are integral to the oncology nurse's role.

the IOM's (2007, 2013, 2014) reports all agree that palliative care and oncology should be integrated from the time of diagnosis (see Figure 4) and that clinical care would follow suit. As a distinguished researcher in this area, I should be able to retire. However, a great deal of work lies ahead. Although patients with cancer are generally more likely to have access to palliative care, disparities are prominent in community-based cancer care, particularly for patients who live in rural areas, patients who are in racial or ethnic minority groups, and family caregivers who provide many hours of care per day. Important gaps include the following:

- What is the best way to provide palliative care, given workforce shortages and lack of a perfect, scalable care model to provide palliative care to diverse populations?
- Do all patients with cancer need palliative care from the time of diagnosis? If not, how can we identify populations who are most likely to benefit?
- What are the essential palliative skills that all oncology clinicians should have, and how can we ensure that accessible opportunities exist for clinicians in training and in practice?
- How do we include family caregivers on the team and ensure that they receive timely palliative care?
- How can we overcome the economic and reimbursement barriers that prevent all patients and family caregivers from receiving timely and comprehensive integrated palliative oncology care?
- Can the beneficial effects of palliative care in oncology be applied to patients with other diseases, such as heart failure and respiratory illness, and their family caregivers?

There are many promising efforts underway in many of these areas, and a new generation of interprofessional scientists is building on some of the work I have described. I will mention just a few of these efforts. The American Cancer Society has funded a study in which we are examining the best way to implement palliative care in community cancer centers (Zubkoff et al., 2015). Lay navigators have been used successfully to assist patients in their home communities to access palliative

and survivorship care through a project funded by the Centers for Medicare and Medicaid Innovation Project (Rocque et al., 2015). Telehealth and health coaching strategies being developed by Dionne-Odom et al. (2015) are tailored to patients and family caregivers representing minority and rural populations. At a basic level, we are beginning to understand some of the mechanisms and essential elements of palliative care (El-Jawahri et al., 2014; Ferrell, Sun, et al., 2015; Greer et al., 2014; Pirl et al., 2012; Prescott et al., 2014; Sun et al., 2015). Two educational endeavors tailored to oncology nurses in practice are assisting them to learn essential palliative care and communication skills. The End-of-Life Nursing Education Consortium is a well-known program in its 25th year that was developed to assist nurses with learning vital palliative care skills (Ferrell, Malloy, & Virani, 2015). More recently, the City of Hope's Division of Nursing Research and Education is presenting "COMFORT™ SM Communication for Oncology Nurses: Improving Patient-Centered Communication and Cancer Care," a professional training program for oncology nurses funded by the NCI (<http://bit.ly/252VNfm>). Finally, oncology nurse scientists are going directly to patients to better understand their needs and to identify automated ways for them to report symptoms so that they are more likely to get attention (Berry et al., 2014; Tariman, Doorenbos, Schepp, Singhal, & Berry, 2014).

Conclusion

Oncology clinical nurses and researchers have long been on the cutting edge of improving the care and quality of life of patients with cancer. They have identified and tested pain and symptom management strategies and approaches for people with cancer, which have later been adapted and applied to patients with other diseases. Following a similar path, oncology nurses are once again poised to lead the way by adopting and applying principles of palliative care early and often for people with metastatic cancers or those with high symptom burden and their family caregivers. For some, this will be as a component of their oncology nursing role, and, for others, it may take them on a divergent road less traveled. Either way, it is through oncology and palliative care science that we are sure to make a difference.

The author gratefully acknowledges the thousands of patients and family caregivers who participated in this research and the many mentees and ENABLE team members from the Norris Cotton Cancer Center; the Dartmouth-Hitchcock Medical Center, Section of Palliative Medicine; and the University of Alabama School of Nursing and Center for Palliative and Supportive Care.

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