Revisiting the Road Not Taken: Integrating Palliative Care Into Oncology Nursing

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Robert Frost’s poem “The Road Not Taken” presents a metaphor for decision making in life (Lathem, 1969). When one comes to a crossroad, the path he or she chooses has major implications for both the traveler and the path itself. I was reminded of Frost’s work several times in the last few years as I walked an oncology career path focused increasingly on pain and symptom management and quality of life. The more familiar one I had followed to that point—one focused on caring for patients undergoing bone marrow transplant and other investigatory anticancer treatments—seemed more distant. Eventually, I realized that in focusing on palliative care, I had made a philosophical shift in my approach to patients. Early on I thought, I’d “keep the first for another day.” But now I realize I could never return to my previous path.

This adventure has been both exciting and humbling in ways I never anticipated. Shifting to a palliative care focus required intense study to understand the evidence supporting my knowledge base of pain and symptom management (Bookbinder, 2001; Ferrell & Coyle, 2001; Wrede-Seaman, 1999). Finding an evidence base for many of the palliative practices applied to or withheld from patients with advanced cancers was a challenge. When consultations were requested and recommendations accepted—when some new nugget of knowledge really benefited a patient and improved his or her quality of life—I was professionally satisfied (Manfredi et al., 2000). The path seemed familiar and easy-going. Sometimes a palliative care focus was met with resistance. Some colleagues only endorsed a curative focus. Healthcare systems were rigid and could only accommodate the care needs of patients with short-term, episodic, fixable problems. Financial barriers included reimbursement systems that provided only for the options of cure or certain death (Lynn & O’Mara, 2001). Patients without a care provider; unwilling to forego beneficial palliative chemotherapy, radiation, or surgery; or with a prognosis that was not absolutely certain to be six months or less, were caught in the middle. This part of the path felt treacherous: we had no trail markers, no compass, and darkness was about to fall.

With help and support, the palliative care team navigated these spots, but not without scrapes and bruises. We suffered from the wounds of unresolved grief, regret, and frustration—wishing we could have made a patient’s or family’s experience of progressing illness, dying, and death closer to their stated preferences of a “good death” (Institute of Medicine, 1997).

I felt heartened by fellow travelers describing an easy-going section ahead. For instance, some cancer centers were making progress in the integration of palliative care (Dauben-
Case Study: The Story of George

George was a 73-year-old, retired tile worker who was living alone at his New Jersey home. His chronically ill wife of 45 years was in a nursing home. George had two children, a son, Ron, who lived two hours away in Pennsylvania with his wife and six-year-old daughter, and a daughter, Denise, who lived in Florida. In September 1993, George’s son received a distressing call from a neighbor, alerting him that his dad was not well. Ron arrived later that day to find his father unconscious in a pool of blood on the bathroom floor. He called 911. At the local hospital, a workup revealed advanced colon cancer with liver metastases. A consulting oncologist ordered 5-fluorouracil (5-FU) continuous infusion, five days a week, for which he would require hospitalization. After his first treatment, George reluctantly agreed to go to his son’s home. He ate his doting daughter-in-law’s meals and thrived on the attention from his son and granddaughter. The staff hardly recognized him when he returned for cycle two. He had gained weight and looked great. After the second treatment, the family asked the oncologist about prognosis. Because of the extensive disease, the oncologist made a prediction of six to eight weeks. Ron called his cousin, an oncology nurse, who concurred. With this new information, they insisted George relocate to Pennsylvania. He reluctantly agreed. Once there, a local oncologist agreed to accept him as a patient and continue his chemotherapy treatment. He received weekly outpatient 5-FU injections until December. At the Christmas play, George didn’t feel well and looked vacant. An ambulance was called, and brain metastases were diagnosed. The oncologist discontinued the treatments and suggested hospice care. However, the local hospice agency required physician certification of terminal illness with a prognosis of six months or less. The oncologist was reluctant to sign the paperwork. An angry exchange between the family and oncologist ensued. Ron wondered why the doctor was willing to care for his father when he was receiving treatments costing $500 a week, but was abandoning him now. The oncologist did sign the paperwork; a family doctor assumed George’s care. With the help of hospice and two paid caregivers, he experienced good times that were love-filled and fulfilling and bad times of fluctuating mental status and symptoms of advancing illness. George died peacefully at his son’s home eight months later.

Challenges of Integrating Oncology Care and Palliative Care: Parallel Paths?

George’s case illustrates some of the challenges that the current “dichotomous” or “transition” model of cancer care presents (World Health Organization [WHO], 1990). The left side of the diagram in Figure 1 shows a care process that focuses on curative or life-prolonging treatment at the time of diagnosis. Then, at some point, a “transition” is made to a focus on palliative care. This transition point is referred to by some as the “awful choice” because it implies a point of failure, death acceptance, and hopelessness. Not surprisingly, physicians, nurses, patients, and families experience conflict and turmoil agreeing on when the “appropriate time” has come to make this dramatic shift. I recall one patient, following such a discussion with her physician, stating emphatically, “I’ll tell you when I’m terminal!”

The right side of Figure 1 proposes a different approach, which focuses to a very small degree on aspects of palliative care from the time of diagnosis. When anticancer or life-prolonging therapy options become less effective, caregivers place an increasing emphasis on palliative treatment. This model focuses on continuous caring and places an increased emphasis on the quality of living, rather than the quantity. Dramatic shifts are not required.

Our current care system follows the first model. Patients undergoing cancer treatments are well managed. When the medical team agrees, those at the very end of life have access to hospice care. The problem is that cancer treatment, even when it cannot cure, can control disease for months to years. Patients with incurable but stable chronic disease are stuck in the middle. No care system has been designed (or reimbursed) to meet their needs.

George’s case reflects a transitional approach. Medical resources primarily directed at anticancer treatment were readily available and reimbursed. Resources to enhance physical function and encourage psychological, social, and spiritual coping, typical of a palliative care approach, were not offered but independently provided by the family. The definition of palliative care appears in Figure 2 (WHO, 1990). With this type of holistic care, the patient thrived. Following the initial crisis, it was George’s family members who prompted a discussion of prognosis. Even though the news was discouraging, they elected to continue treatment, hoping that reducing the tumor would provide symptomatic relief. His family’s awareness of a limited life span also prompted revised priorities, including a choice to spend more time together. Although not described, many activities around life closure took place. Following enrollment in hospice, an approach uncomfortable for George’s oncologist, he lived an additional eight months. For patients on the Medicare Hospice Benefit, this situation is not uncommon. When patients receive appropriate symptom management and care, they often stabilize (Lynn & O’Mara, 2001). This is a cause of great concern for physicians and hospice program administrators, who fear accusations of fraud, abuse, and payment denials (Herbst & Cetti, 2001; Whedon et al., 2001).

“Ivan Illyich suffered most of all from the lie, the lie which, for some reason, everyone accepted: that he was not dying but was simply ill, and that if he stayed calm and underwent treatment he could expect good results.”

From The Death of Ivan Illyich by Leo Tolstoy

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FIGURE 1. MODELS OF CANCER CARE

Palliative care is the active total care of patients whose disease is not responsive to curative treatment.

Control of pain, of other symptoms, and of psychological, social, and spiritual problems is paramount.

The goal of palliative care is achievement of the best quality of life for patients and their families.

**Figure 2. World Health Organization Definition of Palliative Care**

*Note.* Based on information from the World Health Organization, 1990.

In a recent editorial titled “The Terminally Ill: Dying for Palliative Medicine?” oncologist Declan Walsh described cancer research establishments as being in great denial about the need for palliative care (Walsh & Gordon, 2001). He cited as evidence the promotion of studies “that re-examine often ineffective or dangerous treatments” (Walsh & Gordon, p. 203). Oncologists’ deficiencies in symptom management, and a lack of research funding to study effective management of the consequences of advanced disease (Walsh & Gordon).

In 2001, a consensus statement of the Institute of Medicine and the Cancer Advisory Board, chaired by respected Memorial Sloan-Kettering Cancer Center neurologist and cancer pain specialist Kathleen Foley, MD, reached similar discouraging conclusions. In the preface, the panel concluded that “... patients should not have to choose between treatment with curative intent or comfort care. The goal is to maintain the best possible quality of life, allowing cancer patients the freedom to choose whatever treatments they so wish throughout the course of the disease, while also meeting the needs of patients with advanced disease through adequate symptom control” (Foley & Gelband, 2001, p. 9). The statement concluded with an action plan for change.

The panel recommended that cancer centers act as leaders in the oncology community in making this approach a reality in care and education, but especially in pioneering research on palliative care (Foley & Gelband, 2001). Figure 3 includes the key points of the National Cancer Institute (NCI) recommendations (the full text of these recommendations can be found at www.nap.edu). In addition, the consensus statement included a chilling table that cited the amount of research funding in the last few years that could even remotely be connected to advancing the science of palliative care.

The sum total of research funding for those activities represented only 0.9% of the NCI budget (Foley & Gelband).

We all can tell anecdotes of how our cancer centers, office practices, and community centers meet needs of patients with advanced cancer. However, the objective data speak much more loudly about our current reality. Fifty percent of patients are not cured of their diseases. Their needs are not being met by evidence-based approaches, and there is no funding to study these approaches. Why is this the case? Are oncology providers just insensitive to the obvious needs of incurable patients? Patient, provider, and system factors all are responsible for this state of affairs.

**Patient Factors**

Patients go to cancer centers with hopes for miracle cures. Our society traditionally demonstrates a reluctance to accept death from disease as normal (Webb, 1997). Although death is not an optional experience, patients rely on medical authorities to wage war on death as though it were an avoidable enemy.

Faced with our inability to provide false cures, many patients abandon traditional approaches and look to alternative medicine approaches for the cures they seek. Many patients spend precious time and dollars on unproven therapies, especially when they do not get understanding responses from their oncologists (Eisenberg et al., 1998).

Patients who do wish to seek information about the nature, prognosis, and treatment for an advanced cancer will find information about palliative or end-of-life care sorely lacking (Kesselheim, 2001). Most materials focus on treatments or living as a cancer survivor and exclude or minimize information on what can be expected if cancer is incurable.

**Provider Factors**

As described earlier, oncology nurses and doctors practice in a “death-defying” culture that currently accepts a dichotomy of care. Oncology practice environments generally follow a model that focuses either on curative, life-saving treatment or on palliation. Making the shift from curative to palliative care is, at best, difficult and, at worst, too late, to offer patients and families opportunities for life closure (Super, 2000). Enlightened oncology providers who wish to practice differently currently are in the minority.

Even when all agree that cure is unlikely, predicting precisely when to recommend a shift is fraught with imprecision. Many studies describe providers’ inability to accurately predict prognoses (Lamont & Cristakis, 1999). In this dilemma for physicians, both foreseeing (a silent cognitive estimate of a patient’s illness) and foretelling (communication of that prediction to the patient or significant others), contribute to this inaccuracy. Generally, the inaccuracy takes the shape of overly optimistic predictions.

In a series of studies of terminally ill patients, physicians’ predictions misjudged length of survival to be two times longer.
Can we ethically reserve hospice and principles of palliative care only for patients who are “virtually certain to die” within six months? 

physicians are unaware that they are using a coping strategy similar to the patients’ — denial (Lamont & Christakis).

Difficulty with foretelling has its roots in concern over robbing patients of hope and a lack of skill in communicating bad news. Physicians are fearful that when their patients hear the truth, they will become discouraged, and this will somehow negatively affect their survival (Lamont & Christakis, 1999). Literature on hope and terminal illness is scant and does not show an absolute link between the two (Ersek, 2001). Rather, studies suggest a complex relationship, which includes many personal and interpersonal antecedents. Simply being aware of having a life-limiting illness does not cause hopelessness (Breitbart et al., 2000).

Lack of insight into personal biases, insufficient evidence-based information to aid prognostication, and deficiencies in skillful communication are what ultimately deprive patients and their families of hope, opportunities for comfort, and growth when incurable disease is present.

Both patients and providers participate in a conspiracy of silence about the reality of incurable illness. In an 1886 Leo Tolstoy novel, The Death of Ivan Illyich, a high-ranking Russian official is dying from cancer. A quote reminds us of this conspiracy: “Ivan Illyich suffered most of all from the lie, the lie which, for some reason, everyone accepted: that he was not dying but was simply ill, and that if he stayed calm and underwent treatment he could expect good results” (Tolstoy, 1886, 1981, p. 103).

This quote contains two important messages. First, it reminds us that patients are often aware of their situations. However, they are forced to experience it alone, frustrated by the lack of an outlet to share their suffering. We close the door on meaningful dialogue in the name of not destroying hope. Rather than offering some of ourselves, we offer treatments with the best of intentions. We ignore the other side of the picture, which is asking who or what will provide comfort when anticancer treatments are not successful.

Second, when treatments are available, patients’ and providers’ expectations of the goals of treatment may not match. One study on patients’ and physicians’ understanding of the goals of chemotherapy showed that when doctors identified the goal as palliative, 67% of patients thought that the goal of treatment was cure (Varma, Stein, Jacobson, Briggs, & Shapiro, 2001). Sixty percent of patients did not know how much longer they might live with or without chemotherapy.

System Factors

The hospice literature shows evidence of patients’ reluctance to accept a palliative approach. The high quality of end-of-life care provided by hospice results in improved quality of life for many patients and families (Teno, 1999). However, only 29% of people who die in the United States receive hospice care prior to death (National Hospice and Palliative Care Organization, 2001). Even though the majority of patients referred to hospice have cancer, most will have very little opportunity to experience the benefits of hospice care. The median length of stay in hospice declined nationally from 26 days in 1994 to 19 days in 1998, and in some states, this figure is less than two weeks (National Hospice and Palliative Care Organization). As the earlier case study illustrated, even when providers are reluctant to refer, the Medicare Hospice Benefit creates barriers for the vast majority of patients who could benefit (Whedon et al., 2001; Lynn & O’Mara, 2001).

What relationship exists between the systems that provide palliative care and those that conduct research? Figure 4 summarizes the many issues that currently create barriers between research establishments and the patients who could benefit from participation in studies to improve their care (Institute of Medicine, 1997). Patients with advanced disease are ill, vulnerable, and difficult to study. Some believe that patients will not participate in clinical trials that are not focused on cure. Others worry that studies of palliative care approaches will take dollars away from curative research. Despite these difficulties, it is imperative to conduct treatment research while providing patients with the best state-of-the-art care in symptom management. Conducting phase I studies, while providing symptom management support, will likely allow patients to better tolerate treatments. Ultimately, patients who are better able to tolerate experimental treatments may provide us with a better sense of the treatments’ effectiveness. One example of this was evident in a recent study that tested an intervention to improve the quality of care and quality of life of surgical oncology patients with advanced illness (McCorkle, Strumpf, & Nuamah, 2000). In addition to the positive influence that expert

### Development issues
- Limited political constituency and advocacy base
- Weak governmental and commercial funding for research that is not aimed at curing disease
- Lack of links between basic science and palliative care researchers
- Low academic priority of end-of-life care
- Minimal ties to established academic units
- Absence of reorganized medical specialty and multi-institutional research groups

### Ethical concerns
- Patient ability to provide informed consent
- Potential interference with care
- Potential added burden if suffering

### Methodological-logistical problems
- Small population base in clinical and organizational studies
- Changing patient health status and prognostic uncertainties
- Conceptual disagreements (e.g., definition of palliative therapy)
- Absence of internationally recognized systems for classifying, assessing, or measuring most symptoms, outcomes, and quality of life variables relevant to end-of-life care
- Competing demands for time from direct patient care
- Lack of investigator training in appropriate research techniques
- Lack of methodologies adapted to the special problems presented by end-of-life research

**Figure 4. Limiting Factors in Research to Improve Care at the End of Life**

*Note: Based on information from the Institute of Medicine, 1997.*
advanced practice oncology nurses had on the recovery of these patients in the postoperative phase, an unanticipated outcome—improved survival—also was noted. Clearly, the time has come to merge the parallel paths of cancer treatment, hospice, and research so that patients, families, and providers can walk side by side on a journey of improved quality and quantity of life.

Using Past Lessons to Pave a New Reality

Many of the reasons for withholding palliative care at the time of diagnosis are beginning to be challenged. Frequently, research is the first step in challenging our beliefs and paving new frontiers. One example of a now abandoned, fundamental belief from our oncology history illustrates this point. I can recall the practice of administering saline placebo injections, rather than an opioid, usually meperidine, to see if a patient “really” had pain or was just trying to get drugs (McCaffery & Pasero, 1999). If patients responded to placebo, it was determined that they really didn’t have pain. Administering an opioid would only “feed their addiction,” thus ultimately harming them. The problem with this commonplace practice was twofold. First, it was unethical because it required us to lie to patients, and, in doing so, we violated their trust. Second, through research, we learned that even patients in “real” pain responded to placebo because of mechanisms we had not yet understood.

Rather than being ashamed to admit it, I feel relief by “confessing” to this wrongful practice. Because I can’t go back and repair the harm I may have caused those patients, I now do all that I can to make it better for my current and future patients. With these efforts comes some sense of absolution. Making it better has taken on many directions. I acknowledge my naivete to students to teach them to question the status quo, staunchly attack this practice when it still infrequently occurs, encourage development of institutional policies and procedures protecting against it, speak and write about evidence-based approaches, lead quality improvement work, and participate in research (Whedon, 2001; Whedon, Shedd, & Summers, 1992).

We can learn lessons from the above example. First, the placebo example illustrates a major paradigm shift in our thinking about nonmalevolence, pain mechanisms, and pain relief. A paradigm shift of similar magnitude will likely be needed to incorporate palliative care into oncology care. Second, research and openness to new ideas is needed to make progress. We need to question some of our practices. For instance, if we cannot offer patients treatments with curative intent, does offering aggressive symptom control and hospice rob them of hope and chances for cure? What are the effects of maintaining a conspiracy of silence on our patients’ trust and survival? Can we ethically reserve hospice and principles of palliative care only for those patients who are “virtually certain to die” within six months? How does our care system provide for that other population, described as “more likely than not” to die, a population two to three times larger (meaning 100 to 1,000 times more patients) than we currently see as “hospice eligible” (Lynn & O’Mara, 2001)?

I believe we are coming to a crossroad, where withholding discussions of palliative care options at the time of diagnosis will no longer seem right. With our leadership, I predict, that like the placebo example, omitting discussions of palliative care from the care of patients with advanced cancer at the time of diagnosis will be viewed as just as unethical as omitting the opioid from the syringe of a patient in pain. However, we are not there yet, and we may not be met favorably by our less-traveled colleagues.

A Model of Care That Integrates Oncology and Palliative Care

Several ideas from the childbirth movement have been cited as ways to make progress in palliative care (Institute of Medicine, 1997). It was a movement in reaction to “mainstream” medicine that had changed a natural event into a medical one. It involved families. It used education to allay fears of expectant mothers and fathers. It popularized the idea of a midwife who assisted with, rather than controlled, the birth.

Four hospices and cancer centers, funded by the Robert Wood Johnson Foundation, joined forces to bring the best of both worlds together to aide the care of people with incurable cancers (Foley & Gelband, 2001). One such demonstration project, Project ENABLE (Educate, Nurture, Advise Before Life Ends) (Beresford, 2001; Daubenspeck, 1999; Foley & Gelband), combined the clinical expertise of the Norris Cotton Cancer Center with the Hospice Visiting Nurse Alliance of New Hampshire and Vermont to encourage patients with advanced cancer (lung, advanced gastrointestinal, and metastatic breast) and their families to take advantage of clinical palliative services from the time of diagnosis (see Figure 5).

Project ENABLE provided advanced practice nurse, palliative care coordinators at each site to identify eligible patients, assess their needs and preferences, and ensure access to appropriate, early, and continuous palliative care services in conjunction with a newly identified multidisciplinary palliative care team. The project also offered coordinator-led workshops, titled “Charting Your Course,” for patients and family members. The workshops focused on introducing all patients to skills for navigating the healthcare system, learning about community resources, assisting in advanced-care planning and other decision making, managing symptoms and stress, and exploring issues of grief, illness, loss, and psycho-social-spiritual distress (see Figure 6). The model was implemented and evaluated at three sites in New Hampshire selected for geographic, clinical, and cultural diversity (Beresford, 2001; Daubenspeck, 1999; Foley & Gelband, 2001).

The Family Afterdeath Telephone Interview (Teno, 1999), a 67-item, closed interview conducted with the family three to six months after a patient’s death, was one outcome measure used to evaluate the impact of this care coordination demonstration project on end-of-life care. Preliminary analysis of these interviews suggests a greater likelihood of patients spending their final days at their site of choice and a belief that discussions of preferences with healthcare providers early in the course of illness positively influenced the type of care provided at the end of life.

- Minimize impact of symptoms of treatment and disease on quality of life.
- Increase patient/family insight and ability to express their own values and preferences.
- Increase care providers’ integration of patient values and preferences into plan of care.

**Figure 5. Goals of Project ENABLE (Educate, Nurture, Advise Before Life Ends)**
Physical issues
• Train patients and their families in symptom and stress management.
• Open meaningful dialogue between patient and physician.
• Explore the decision making process.
• Integrate complementary therapies.

Psychosocial issues
• Discuss impact on family and friends.
• Assist with financial concerns.
• Connect patients and their families with community resources.

Spiritual issues
• Assist in care planning for the dying patient.
• Discuss what gives life meaning.
• Explore stages of death, dying, loss, and grief.
• Establish advanced directives, durable power of attorney for health care, do not resuscitate, etc.

Figure 6. “CHARTING YOUR COURSE” CURRICULUM

Transforming Care, Transforming Professionals

I began by saying that the path one chooses at a crossroad has major implications for both the path and the traveler. Through the ENABLE project, we clearly had in mind how we might change the path or system of care. But I had no idea of the effect this change would have on me—the traveler. Although it sounds great in theory, what really happens when you empower patients and families to be active participants in decision making? What does it mean to allow patients’ individual preferences to be the ruler by which to measure the quality of medical care? Will we be able to recognize and overcome our own biases about how to provide and measure “good” palliative care?

Case Study: The Story of Fred

Fred was diagnosed in the spring of 2000, at the peak of his career as a 47-year-old anesthesiologist, with unresectable pancreatic cancer. He lived in a lovely lakeside home with his wife, a researcher in the immunology basic science lab, and 12-year-old daughter. Fred was identified at the weekly gastrointestinal disease management group as eligible for the newly initiated palliative care program. Before meeting the palliative care nurse practitioner through the usual means (a scheduled outpatient appointment with his oncologist), an inpatient palliative care consult was called. Fred was admitted for uncontrolled pain for the third time in a week. He had signed himself out against medical advice the day before. From the outset, Fred was plagued by abdominal pain, nausea, fatigue, and weight loss. He declined a recommended celiac plexus block for pain management, nausea strategies, and nutritional advice. Rather than continuous analgesics by oral, subcutaneous, or transdermal routes for chronic pain, he chose intermittent IV injections via peripheral IV catheters inserted (in locations carefully selected so they would not interfere with his golf swing) for his weekly chemotherapy. He used marijuana rather than other antiemetic regimens. He chose a diet of gourmet meals accompanied by an appropriate bottle of wine from his cellar. He altered his treatment schedules to undergo Reiki treatments, through which he found comfort and strength. He accepted hospice home care only to alleviate the financial consequences of the treatment and symptom management. He did his best to maintain the same pre-diagnosis lifestyle. Although his wife was an avid participant in the educational, informational, and psychosocial support components of our program, Fred typically felt too weak or tired to attend. The little exposure he had to our interventions seemed to have little influence on how Fred experienced his disease. Despite his irascible nature, Fred and the team maintained a regular connection. In April 2001, 10 months from diagnosis and one week prior to his death, Fred arrived in the emergency department with severe abdominal pain. This visit was one of his only trips back through the department since diagnosis. The pain was initially thought to be either from constipation or a meal that didn’t agree with him. Within hours, it became known that the abdominal distension was ascites from rapidly growing liver metastases, peritoneal carcinomatosis, and malignant bowel obstruction. As Fred realized he was dying, a long-standing relationship with the palliative care team allowed for frank discussions. Reconciliation, family gathering, communication, and planning for his death marked his final days. In a quote from his wife’s letter after his death, she said, “He respected your knowledge and experience regarding the pain meds he needed. Let me assure you how much of a coup this was for you. And to your credit, you were able to back off when necessary and let him do things his way.” She went on, “You were a great comfort during the last days of Fred’s life. I wish I knew then what I know now, just to be a bit more prepared. You left us in no doubt with each successive day that Fred’s death was imminent. You gave us the opportunity to gather family and friends and provide the love and caring atmosphere that, with Reiki, allowed him to finally free his spirit again.”

Despite this “good death,” I realize how much I struggled personally and professionally while attempting to practice what I preached with a person whose beliefs often flew in the face of some of our best research about pain and symptom management.

The lesson I had to learn again was that the definition of palliative care requires us to make a commitment first to the person who becomes our patient—he or she is the one who defines how we can be of help in achieving the best possible quality of life as illness progresses toward death. Fred wasn’t trying to be contrary or contradict evidence-based approaches—he was trying to teach me that, most of all, he wanted to maintain his dignity—a belief that was linked to being a physician and controlling his care. Little did they know how much of a struggle it was for me to practice what I had preached. As we attempt to move care forward, we must continuously revisit our assumptions and biases if we are to lead systems that care for the people who become our patients.

Conclusion

Oncology care currently is undergoing a transformation from a dichotomous system of care versus cure. Oncology nurses can play a leadership role in the evolution of a system that promises all patients state-of-the-art treatment, cure, and survivorship and, when cure is not possible, a dignified illness experience and dying.

This presentation is dedicated to all of the patients and families who contributed to my learning about how to provide palliative care; to the many colleagues who inspired, mentored, and shaped my thinking for the thoughts in this presentation; and to my family, who is always my first priority and whose support feeds my spirit.

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References


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