Oncology nursing: Our past is the prologue... Can we author the future?

By Barbara Love, Esther Green, and Denise Bryant-Lukosius

Abstract

The development of the standards of care, roles in oncology nursing, and role competencies was an opportunity for Canadian nurses to revisit their professional roots, review and validate their present roles, and revise or reaffirm their future roles. The standards of care for individuals with cancer and their families affirmed the centrality of the individual and family in any nursing interaction and gave voice to the stated needs of Canadians at risk for, or living with cancer.

For the first time in Canada, a specialty nursing organization has taken the lead to clearly define contemporary nursing roles and competencies. This new vision has captured the interest of oncology nurses. CANO, the nursing profession, other health care professionals, and health care decision-makers must now also consider how this enlightened view of oncology nursing can be operationalized.

The presenters have had the opportunity to “hear” the stories of Canadian oncology nurses and their experiences in striving for excellence in their practice. These stories highlight the evidence supporting the standards of oncology nursing. In addition, the challenges and facilitators for achieving excellence in oncology nursing practice are identified. Through these stories, the future for the development of oncology practice and operationalization of the new standards of care emerges.

This lectureship commemorates Helene Hudson, an oncology nurse and CANO member whose leadership and vision of oncology nursing are a legacy of our past (the prologue). During her tenure at the Victoria General Hospital, Helene wrote, “The opportunity to reach out and help another human being in a meaningful way should not be taken for granted. It is the very essence of nursing. Working with cancer patients brings joy, satisfaction, and meaning. Patients I have worked with have touched my life in a very special way. Health care professionals are valiant soldiers in the war on cancer, but the real heroes are our patients, whose courage and vitality serve as an inspiration to us all” (personal communication, Marilyn Bruce, 2003).

Through this memorial lectureship, Helene provides all of us with an opportunity to author the future professional role and contribution of oncology nurses within the health care system.

This presentation was founded on the professional stories of oncology nurses. We wish to thank and acknowledge the many nurses who responded to our requests and shared their experiences about how oncology nursing is being enacted across Canada. The purpose of this paper is to:

• reaffirm the hallmarks of excellence in oncology nursing practice;
• identify the challenges to achieving excellence in oncology nursing;
• identify factors that promote achievement of excellence in oncology nursing; and
• identify personal and professional strategies to author excellence in oncology nursing.

The CANO standards of care and role competencies

The twenty-first century presents new challenges and opportunities for oncology nurse clinicians, educators, administrators, and researchers. Opportunities exist to make change, acquire resources, and raise the standards of care to a higher level (Corner, 1996). The CANO (2001) standards of care and role competencies identified for each standard reflect the foundation for excellence in oncology nursing and provide the framework for initiating change to improve cancer care. The standards, roles, and competencies have evolved from our professional past as Canadian oncology nurses. These are based on our current collective values and expectations about the mandate of nursing and are supported by the best evidence documenting the need for and effectiveness of oncology nurses in the delivery of cancer care. More importantly, the standards and role...
The community psychiatric nurse and I were in contact on a regular basis, and I met with Ned three times per week to monitor his progress. I encouraged adequate intake of fluids and appropriate foods. She also introduced myself to Ned, I could see the pain, terror, and confusion in his eyes…and I was overpowered by the smell of feces and the smell of someone who had not washed in several days. From Ned, I learned that, in addition to cancer, he had schizophrenia and his medications made it difficult for him to problem-solve and remember instructions. He had no family and lived in a group home with minimal supervision. He was having trouble managing intermittent diarrhea and constipation and had severe rectal pain from excoriated tissues, but he was too embarrassed to ask for help.

That day, we attended to Ned’s immediate concerns…with a little coaching and encouragement we gave him a sponge bath, clean clothes, wound care, and information about hygiene and nutrition, and increased his pain medication…but I knew that these were just temporary measures. He still had three more weeks of radiation treatment left! I was concerned about infection and the potential for dehydration, bowel obstruction, and uncontrolled pain.

I called his community psychiatric nurse and enlisted her help. She knew Ned well and had a good understanding of his coping style and cognitive capabilities. Together with Ned, we came up with a plan to help him manage his care at home. I developed a notebook and schedule for Ned to follow. The community nurse reinforced our treatment strategies by posting signs in Ned’s room to remind him of simple hygiene practices and when to take his medication, and to encourage adequate intake of fluids and appropriate foods. She also increased her home visits and liaised with the group home manager. I called a team meeting involving the radiation therapist, primary nurse, and oncologist to establish a consistent and continuous plan of care, and I met with Ned three times per week to monitor his progress. The community psychiatric nurse and I were in contact on a regular basis when changes in the treatment plan were required.

Within the first week, I noticed a remarkable improvement in Ned. He had a cheery smile at every clinic visit and proudly reported his success in completing the activities outlined in his schedule. He began trusting the team and was more willing to talk about his concerns. He looked and smelled clean, his wounds were healing, his weight was stable, and his pain was better controlled. Over the next six weeks, Ned completed and recovered from his radiation treatment without any of the serious complications I had feared. More importantly, I knew that he felt involved and in control of his care, and all the members of the health care team were proud of Ned and of their efforts to get him through this difficult treatment.

What attributes of excellence in oncology nursing are apparent in Ned’s story?
The care was holistic and individualized to Ned’s needs. By establishing a partnership with Ned and building on his strengths and capabilities, we empowered him to not only manage his self-care, but to thrive in an environment that ensured his success. The caring he received was professional. It was knowledgeable, responsive, and sensitive…it anticipated his future needs and problems. There was coordination of care: promotion of continuous care through collaboration and communication with various health care providers both within and outside the cancer centre. Professional leadership and navigating the system were also evident in encouraging a team approach, maximizing the individual contribution of various health care providers, and using the available services and supports.

Lisa’s Story
Lisa was a 37-year-old wife and mother diagnosed with sarcoma. Standard therapy offered a short period of remission. Recurrence came with few treatment options, and none offered a cure. Lisa, her husband, and their family had to quickly confront end-of-life issues. The diagnosis of recurrence was devastating. Disbelief became shock. Shock became fear and dread. Lisa needed radiation immediately to prevent paralysis. She also needed steroid therapy. Weight gain secondary to steroids brought a great deal of distress to Lisa. She struggled with her impending death. She struggled with her hopes that would never be realized. Most paramount, Lisa struggled with her appearance change. It was a constant reminder of her illness and impending death. Lisa did not want to die looking like this!

The social worker asked me to explore with Lisa her understanding of steroid treatment and its side effects in the context of end stage sarcoma, and her perception of its value in light of her impending death. My visit with Lisa began with an understanding of why I was asked to see her. We then proceeded to discuss her concerns. Throughout the conversation, I was conducting a comprehensive, holistic assessment with in-depth focus on her understanding of palliative care. Bodies of knowledge pertaining to self-esteem, sarcoma, and death and dying guided my assessment of her self-esteem. It became clear that Lisa’s perception of herself was changing because of her appearance. She didn’t want her children growing up remembering her as she looked because of the steroid. We discussed the value of the drug and the implications of not taking it. More importantly, we discussed what mattered most to Lisa – how her children and others would remember her. I used a number of strategies to guide further discussion, such as role-playing, re-framing, etc. Together, we identified ways to help Lisa’s children remember her the way she wanted to be remembered.

I sensed that something else was bothering Lisa; I acknowledged the same with her. This exchange triggered a discussion about getting one’s affairs in order. Her main concern was that her husband could not access her bank account. He had refused to go to the bank with her to sign the required papers allowing his access. Upon exploration, it was clear that Lisa appreciated the reason for his refusal. She

Standards and excellence in oncology nursing: How they look in practice
Ned’s Story
Staff in the radiation department called me to see Ned, a young man who was receiving radiation therapy to the rectum. As I introduced myself to Ned, I could see the pain, terror, and confusion in his eyes…and I was overpowered by the smell of feces and the smell of someone who had not washed in several days. From Ned, I learned that, in addition to cancer, he had schizophrenia and his medications made it difficult for him to problem-solve and remember instructions. He had no family and lived in a group home with minimal supervision. He was having trouble managing intermittent diarrhea and constipation and had severe rectal pain from excoriated tissues, but he was too embarrassed to ask for help.

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recognized that she was much further ahead in accepting her impending death. We discussed the pros and cons of not getting the papers signed. We talked about varied ways to get the papers signed. Suggestions were offered that Lisa could follow through with as needed. Of importance was that she was able to talk about her concern. It helped her see the situation more clearly. It gave her strategies to try. A plan was then made for the social worker to continue supporting Lisa with her end-of-life issues. I would be available as needed for continued support and education. My focus switched from working with Lisa to providing consultation for the social worker so that she could support Lisa and her family.

What attributes of excellence in oncology nursing are evident in Lisa’s story?

Exploring issues of self-image and fear of death provided individualized and holistic care. In recognizing how each member of the family was coping with Lisa’s impending death, the nurse provided family-centred care. Further, she established a therapeutic relationship and helped Lisa to identify her concerns and to explore options. The nurse showed professionalism in applying scientific and theoretical knowledge about end-of-life issues, body image, and coping. As a leader, she mentored and facilitated the effective role of other health care providers in managing patient-centred and collaborative care.

The CANO (2001) standards of care are based on the international literature regarding the needs of individuals with cancer and their families. This “list of needs” was consolidated in the form of the standards and was shared with Canadians with cancer, advocacy groups, family members, and professional caregivers. The standards of care were revised, resubmitted, and finally approved by Canadians with cancer. The standards are the nine “touchstones” or the essential elements of care required at each contact with the health care system. Further, role competencies were defined as to how these standards would be actualized.

The two stories we have told you illustrate the outcomes of exemplary nursing care. Through experience and intuition we know that exemplary care makes a difference. We all have anecdotes. Each one of you has a story about a time when you cared for someone in an exemplary fashion. But the seventh standard (CANO, 2001) recognizes the importance of using the best available evidence to guide our practice, so let’s further solidify the argument and do so using research.

Research supports the standards of care

Specialized oncology nurses improve the health outcomes of patients related to pain and symptom management, psychosocial well-being, quality of life, treatment outcomes, use of health promotion strategies, self-care and treatment compliance, and patient knowledge regarding their disease and treatment. Excellence in oncology nursing practice is also associated with improved quality of care, reduction in health care costs, patient satisfaction with care, and nurse and health care provider job satisfaction.

More specifically, in a qualitative study involving patients with cancer, Radwin (2000) found that patients who received individualized nursing care felt an improved sense of physical and psychological well-being. Patients felt they could share their true feelings and concerns, that the nurse understood these concerns, and that they received care that was specific to their preferred coping style. Rapport, mutual sharing, attentiveness, and caring characterized how nurses established a supportive therapeutic relationship with patients. This type of relationship helped to reduce patient anxiety and psychological distress, promoted a sense of being cared for and of being valued, increased the patient’s sense of personal strength or fortitude in continuing with their cancer care, and promoted feelings of optimism and trust.

Radwin (2000) also found that professional care involving the application of experiential knowledge, scientific knowledge, and technical skill promoted patient satisfaction with care. The nurse’s ability to demonstrate knowledge and technical competency promoted patient trust in their care and a sense of safety. Knowledgeable nurses also promoted patient optimism and feelings that the patient would be successful in managing treatment side effects. Continuity and coordination of care reduced the burden for patients of having to repeat their story over and over, and they were more likely to receive successful supportive care interventions. Through effective patient education, exemplary nurses empowered patients to become partners in their own care and to be actively involved in decisions about their health.

In the United Kingdom, specialized oncology nurses have been found to improve the emotional and cognitive well-being of patients with advanced cancer by establishing a supportive and therapeutic relationship with the patient and family, providing information, coordinating complex care issues, and collaborating with other health care providers, particularly with respect to advocating for and directing strategies to improve symptom management (Corner et al., 2003).

In an early randomized controlled trial of home nursing care compared to standard medical care, patients with advanced lung cancer who received ongoing, continuous care from nurses with specialized oncology education and experience were more likely to have better quality of life and more prolonged periods of improved quality of life compared to patients receiving standard care (McCorkle et al., 1989). Patients cared for by specialized oncology nurses were also more likely to have improved symptom management and higher levels of functional independence, and were less likely to require admission to hospital.

More recent randomized controlled trials of specialized oncology nurse-led care have demonstrated similar results for patients with advanced lung cancer, breast cancer, and prostate cancer (Bredin et al., 1999; Corner, Plant, A’Hern, & Baile, 1996; Faithfull, Corner, Meyer, Huddart, & Dearnaley, 2001; Hegelson et al., 2000; Loftus & Weston, 2001; Ritz et al., 2000). Patients randomized to specialized oncology nurse-led care, demonstrated improved satisfaction with care, better quality of life, decreased symptoms of anxiety and depression, improvements in performance status even in the context of progressive disease, decreased symptom distress, and up to a 37% reduction in health care costs compared to patients receiving standard care alone. These positive outcomes are attributed to individualized and holistic nursing interventions, continuity and coordination of care, improved patient education, and application of specialized knowledge and skills related to pain and symptom management and psychosocial support.

Challenges to excellence in oncology nursing

Despite the evidence documenting the benefits of specialized oncology nurses, our experiences suggest that achieving excellence in oncology nursing is often a challenge. Here are some stories from our colleagues that illustrate some of these challenges:

A story of valuing

I am in shock! I arrived at work today to find out that I have been reassigned to another team. I won’t even get a chance to say goodbye to patients I have followed and cared for for many years. It is a job that I love and am good at! I have an excellent collaborative relationship with the team and have acquired
considerable expertise in caring for our patients. Over the past few years, I have been able to further develop and expand my role to improve the coordination and continuity of patient care. I had planned to further my education and career in working with this patient population.

I could cry. What will happen to my patients? Who is going to manage their care during this transition period? I don’t understand why this is happening or why I wasn’t included in the decision-making about this change in my practice. It does not seem to matter that I am always giving to this job: missing lunch, working late. I participate in several nursing committees at work, fund-raising, taking extra courses, and doing my best to work in a positive and constructive manner. It seems to be an arbitrary decision with no regard to patient safety or quality of care, or the quality of my work life or job satisfaction. I feel sad…so sad for my patients…and myself … and the nursing profession. Obviously my knowledge and skills in providing care to this patient population are not highly valued. I feel so expendable!

A story about patient-focused care

In April of this year, my grandmother was having some tests because she had “low blood.” This testing seemed to go on for a long time and my grandmother had difficulty getting any information about her condition. In August, she was admitted to hospital because of problems with her diabetes and high blood pressure. Because I am an oncology nurse and was concerned about this persistent anemia, I talked to the internist about doing a bone marrow. My fears were confirmed with the bone marrow results…..my grandmother had multiple myeloma!

I just happened to bump into her family doctor in the hallway outside her room.

Before I could even say hello…he started to berate me with this angry condescending tone. He told me that if I ever questioned his practice again, he would fire my grandmother from his service. Now we are afraid….There are no family doctors taking new patients in our community…my grandmother had multiple myeloma!

There is a growing body of research identifying factors that are facilitators or barriers to nursing excellence, and that ultimately impact on a variety of patient and family, nursing, health care provider, and health care systems outcomes (see Figure One).

Shaman and Chalmers (1996) identified over 14 social, professional, organizational, political, and systems barriers to optimal utilization and effectiveness of nursing roles. Social factors frequently identified as a barrier to nursing excellence relate to the profile or undervaluing of nursing by other health care providers, the public, and among nurses themselves. Physicians are not only gatekeepers related to medical care, but continue to have significant influence over the nature and scope of nursing practice roles, the extent to which patients and families can access oncology nursing expertise, and the degree to which nursing recommendations are considered in clinical decision-making. As one senior oncology nurse with a wealth of critical care and oncology expertise described with frustration, “The physician I work with has such a need for control that I don’t even get the opportunity to provide education so that patients and families are better able to manage their care at home…. He just has to do it all!” Multiple studies have shown that physician acceptance and support is associated with optimal utilization of nursing roles, quality of care, and nursing job satisfaction (Cameron & Masterson, 2000; Centre for Nursing Studies, 2001; Irvine et al., 2000).

Other health care providers also have inaccurate perceptions of the oncology nursing role. In recent standards published by the Canadian Association of Psychosocial Oncology (1999), the important role of nursing as a main provider of psychosocial care is not recognized. Such views can lead to compartmentalization of nursing care focused on disease and treatment, and inhibit opportunities to address the needs and concerns of patients and families in a holistic manner. Patients and families may not have a comprehensive understanding of the nursing role and how nurses can help them to cope with their cancer. For example, Margaret Fitch and her colleagues (Fitch, Johnson, Gray, & Franssen, 1999) found in a national survey of men with prostate cancer that many patients did not identify nurses as a main source of information or support.

Nursing is a female-dominated profession in a society in which women now have more options and opportunities to establish careers in other professions associated with greater prestige, better working conditions, and opportunities for advancement. Recruiting high quality students into the nursing profession is a challenge, and recruiting nurses to the field of oncology is further challenged by the negative perceptions of cancer and cancer treatment found in society at large.

Individuals with cancer recognize and value the nursing presence across the continuum, but its significance increases as patients encounter the limits of treatment, face the realities of end of life, and seek meaning in their lived experiences (Stanley, 2002). Presence is invisible; it is a demanding aspect of caring, and it has been described as having the power to “create order out of chaos” (McKivergin & Day, 1998, p. 96).

The need for increased access to education cannot be overstated. Nurses who have attended specialty and post-basic education programs are more likely to participate in professional nursing associations, seek further continuing education, read professional journals, and participate in other scholarly and professional activities such as presentations and publications. A recent study by Aiken, Clarke, Cheung, Sloan, and Silber (2003) found that hospitals with a higher proportion of baccalaureate-prepared nurses have lower patient mortality rates. In addition, graduate-prepared nurses with research skills are needed to conduct the studies necessary for generating new knowledge to support nursing practice.

The notion of labelling nurses in relation to treatment modalities creates walls around the value of our practice and our influence on outcomes in patient care. Oncology nursing is not about treatment; it is about patients and their families, and achieving their goals for optimal

Figure One: Factors Affecting Nursing Excellence

![Diagram of Factors Affecting Nursing Excellence]
health and well-being. Be proud to call yourself a specialized oncology nurse, and refrain from using terms such as “chemo nurse.” Such views can lead to the medicalization of nursing care and inhibit opportunities to address the health needs and concerns of patients and families in a comprehensive and holistic manner. Remember, we don’t nurse the treatment, we nurse the individual and their family.

The delivery of cancer care services across this country is under reconstruction, and this has led to the introduction of many new types of nursing roles in clinical practice, education, research, and administration. We received a number of stories from nurses in these varied roles describing the high degrees of resistance, animosity, lack of support, and lack of respect they experienced from nursing colleagues as they endeavoured to develop and implement new roles. Regardless of the type of role or setting, there was a common theme amongst these stories about the lack of valuing that nurses had for each other and their individual contributions to patient care. We cannot afford to bicker amongst ourselves. We need to learn about each other’s roles, appreciate each other’s knowledge and experience, and establish collegial relationships that maximize nursing expertise in meeting patient needs across the cancer continuum. Furthermore, we need to encourage the individual efforts of nurses who are striving to achieve personal growth and professional excellence by acting as role models (Johnson & Gravelle, 2002), offering formal and informal mentorship, and by providing practical resources and moral support.

At the organizational level, administrative support is perhaps the single most important factor necessary for creating work environments that promote nursing excellence and optimal nurse and patient outcomes. Two international studies have demonstrated that administrative support is associated with nurse job satisfaction, nurse burn-out, quality of care, and patient satisfaction with care (Aiken, Clarke, & Sloane, 2002; Aiken, Clarke, Sloane, Sochalski, & Silber, 2002). Positive administrative support is characterized by: priorities and actions for improving quality of care and clinician support, management that gives nurses authority for designing work and staffing patterns, management that listens and responds to nurses’ workplace concerns, investment in continuing education, and creating a culture of retention.

Specific nursing leadership styles also have important implications for nursing excellence, particularly in health care systems undergoing organizational change. In hospitals undergoing restructuring, those with resonant leaders who led by example with vision, coaching, collaborative and democratic approaches had better nurse and patient outcomes compared to those with dissonant leaders who used pacesetting and commanding approaches. Resonant leadership was associated with greater met patient health needs, better emotional and physical well-being of nurses, better team collaboration, and higher retention of nurses (Cummings & Hayduk, 2003).

Research on the positive outcomes of specialized oncology nurse-led care illustrates the importance of creating patient-focused models of care delivery where patients have the opportunity to access nursing expertise, and where nurses have the opportunity to address patient and family health needs in a holistic, systematic, continuous, and coordinated manner (Bredin et al., 1999; Corner et al., 1996; Faithfull et al., 2001; Hegelson et al., 2000; Loftus & Weston, 2001; Ritz et al., 2000).

In Canada, the Centre for Nursing Studies (2001) has identified that existing health care legislation and health care policies restrict nursing scope of practice and patient access to nursing expertise. The development of nursing roles and nursing knowledge is further influenced by political and administrative decisions about the allocation of funds for specialized oncology nursing education, research to develop and evaluate therapeutic nursing interventions, and expansion of nursing roles within new models of cancer care.

The recent consultative process involved in the development of the Romanow Report for Health Care Renewal and the recent SARS experience in Ontario and British Columbia illustrate the importance of nursing input within a variety of decision-maker environments. We all have the responsibility for bridging the knowledge gap within political, administrative, research, and health care decision-making environments regarding patient health needs and the value-added contribution of nursing as part of the solution for change.

It is only through positive connections and partnerships with decision-makers that innovative change with respect to oncology nursing roles will occur. For many of us, establishing connections and partnerships with key decision-makers both within and beyond our nursing role environments will require renewed confidence and new skill sets related to evidence-based practice, effective listening and communication, and leadership.

The mandate of nursing is to provide patient-centred, health-focused, and holistic care (Chinn & Kramer, 1999; Corner, 1996; McMahon, 1992; Watson, 1995). These goals are often in conflict with a health care system limited by finite financial and human resources. Nurses are often confronted with dilemmas regarding timely access to care or financial restrictions on potentially therapeutic, but expensive, interventions. In these situations, the needs of the majority often take precedence over those of the individual. For example, who should get the last available hospital bed – the elderly woman in the final days of her life, or the young university student with testicular cancer needing curative chemotherapy? More and more, nurses will be called on to assist patients and health care providers in making ethical, evidence-based decisions about the optimal utilization of health care resources.

We have been reminded of our past – the prologue. We have illustrated the standards of care for individuals with cancer through stories, and demonstrated how the standards have or have not been actualized. We have used the evidence to remind ourselves that oncology nurses do make a difference in patient and health care system outcomes. We also referred to the evidence that identifies areas requiring improvement and change. Now let’s focus on where we go and how we get there. Let’s talk about how we can author the future!

Authoring the future...

CANO has endorsed the standards of care for individuals with cancer and their families. CANO believes that the standards are the entitlement touchstones for every individual with cancer in this country. Further, CANO has defined roles and competencies for the oncology nurses involved in the care of these individuals. But... do you believe that these are the entitlements of individuals with cancer? Do you affirm the standards? Do you practise with client centrality? And will you continue to critically examine and revise the standards so that they remain relevant to the future health needs of Canadians and contemporary oncology nursing roles?

One group of nurses chose to post the standards at the entry to their unit. They displayed their pictures around the standard statements as an affirmation of their commitment... and, as a further endorsement, each nurse signed her name on the surrounding poster mat. Now patients and families and other health care providers are also aware of the central mandate of the nursing role in providing professional, patient-centred, and holistic care.

Each provincial regulatory College of Nursing across the country has endorsed the integration of self-reflection in practice. It is imperative that we build in thinking time, that we strive for deep critical reflection of our practice and, consequently, ourselves in practice. Only as we review ourselves, our values and their impact on our practice, can we reaffirm, reframe, and/or refute our beliefs and approaches.

As specialized oncology nurses, we have a depth and breadth of knowledge about cancer and its impact on the individual, his/her family, and community. This knowledge is rooted in theory and gained through 24-hour exposure at the bedside, in the clinic, and in the home. No one else has this knowledge! We have the capacity, the
right, and the responsibility to “broker” this knowledge to the requisite professionals.

Nursing theorists gave us a language to describe what it is that we do. Perhaps our language and voice have been indistinct, or indecipherable, or unspoken. It may be that we need new metaphors and new images to communicate our essence (Kitson, 1997). It may be that we need to find and use our voice.

How often do we hear the phrase, “I am just a nurse?” It is a phrase of deference, of apology, of inadequacy. Our history is one of pride. We have the capacity to make a difference…and do so on a daily basis. We have chosen a caring paradigm rather than a curative one. This gives us the power to celebrate cures and the strength to support passages.

We may have chosen this profession because our choices were curtailed by social circumstance. We may remain in it because of economic circumstance…but the vast majority of us are here because we love our work…not the organization and not the politics, but the day-to-day ‘being with.’ We are told regularly, “I could not do, what you do”…and sometimes it is hard for us. But we are good at what we do. It is not what pharmacists do, or physicians, or social workers…it is some of that, but so much more. Until we commit to our profession with pride, we will always be vulnerable. We have the capacity to move our profession forward with a positive, strong voice. But only if we commit to the profession.

Because of the ways in which treatment is organized, we often have a skewed view of the cancer care continuum. We see the individual and family at the point of acute illness…or at the point of genetic testing. Often times we are unaware of outcomes. It’s as if we see the patient in a silo. By knowing our “community of care” and networking across organizational boundaries, our perspective becomes broader without losing depth…like seeing the forest and the trees.

We need to know the communities with whom our clients link…and we need to maximize these linkages. An oncology nurse in a rural hospital brought together patients and health care providers involved with cancer care in her community. Together, they looked at the community strengths and gaps in cancer care and redesigned the model to promote increased access to services and greater continuity of care. By bringing all of the stakeholders to the table, the nurse “brokered her knowledge” to make change and contributed to a more efficient flow of information and services across the cancer continuum.

Although nurses work autonomously, they also interact with multiple others…sometimes fellow nurses…sometimes other professionals. These relationships require nurturance to become fruitful partnerships. They also require clear delineation of role responsibility and accountability.

One nurse reminded us that the standards that apply to individuals with cancer apply equally well to the caregivers at all levels. Each one of us needs to be acknowledged as an individual. We need to be treated as individuals, to feel that we have a role in decision-making and that our leaders are informed and informing. We need to know that the best evidence is driving government policies in health and education. We need to know that our leaders are principled and ethical and trustworthy.

We are accountable to our clients, our profession, and our organization. We, in turn, need to know that there is reciprocal accountability. To whom does your executive director report? Do you know who is on your organization’s board of directors? Even the smallest cog has the capacity to change the responsiveness of the organization.

It’s important for nurses to speak out against deteriorating patient care rather than trying to adjust to the changes in the health care system. Gordon (1998) wrote, “At some point, adaptation perpetuates noxious circumstances.” Davis et al. (2003) have written about the temporal lag between the publication of best-practice evidence and its incorporation into practice. As our search skills are refined and language and vision become clearer, we have the data to challenge the status quo. Nurses need to access this literature, bring it to the table, and use it strategically. This means knowing how…Being at the right table…Advocating for the leaders who have demonstrated an understanding of the vision. We have a history of advocating for our clients. We need to do this beyond the bedside and advocate in the board room, at the voting poll, and in the newspaper.

Miaskowski (1990) has written, “To predict the future is extremely risky. Some say it is the province of both the sage and the fool and only time distinguishes one from the other” (p. 461). We concede ignorance, and have no desire to play the fool. We know NOT how the plot will unfold…what the last page will contain. There is an increasing body of literature providing evidence about the difference that excellence makes and the devastation that mediocrity can provoke. It is clear that certain qualities and capacities will help us to author a patient-centred future. Nightingale (1861) noted that “unless we as nurses are making progress every year, every month, every week, nursing will go backwards. No system shall endure which does not march”.

The history of oncology nursing integrates innovation, caring, and comfort with ambiguity. We have written our prologue…. In what direction do we march? To whose drum? Will we author our own future…. Will the future contain excellence? Let us offer you one last story.

Lynda’s Story

It was diagnosis day, late afternoon, and the oncologist emerged from the clinic room where he had told Mr. Lancaster that he had cancer. Dr. Smith had given his diriatrie about treatment options, but the patient interrupted and politely said, “No thanks.” “No treatment? Your kind of cancer is very responsive to treatment,” said Dr. Smith. “No thanks!!” said an emphatic Mr. Lancaster. Dr. Smith left the room saying, “…the nurse would be in shortly.” To the nurse, Dr. Smith said, “He doesn’t want any treatment. Who is the next patient?” “Why no treatment?” said the nurse.

She went to the room, introduced herself, and gave a strong handshake (you know the one, hearty, web to web, really making contact, the one that says I’m here for you right now. I’m willing to touch you. Your cancer doesn’t frighten me away!). Then she asked, “Tell me what’s going on” and he told her that he was a stonemason, new to the community…in fact, he and his wife had recently retired there and were still unpacking when a bout of illness sent them back to their former physician in Toronto. His wife’s flu was in fact metastatic disease which responded poorly to conventional treatment. She had died six weeks earlier. Routine testing by the family physician had led to his current cancer diagnosis. He had no children and the activities that he enjoyed had been ones that he and his wife had shared…fishing and dancing.

The nurse said, “I had learned to formulate hypotheses and validate or refute them. So my hypotheses included: cancer kills, chemotherapy makes you sick, cancer can’t be cured, and there’s nothing to live for anyway.” I shared these and together we determined that Mr. Lancaster had no community of caring. And so, I proposed an intervention. “Let us be your community.” But I knew that an assertive statement often needs a positive reinforcement, so I urged the ante: “Try us for three months and I’ll dance with you. We will set our objectives and we will choose the outcomes together.”

He came for his chemotherapy and met other locals ‘on the journey.’ He was sick, but his peer group, and the symptom control group worked to titrate treatments. He and one of the other cancer ‘travellers’ went fishing together and, at the end of three months, he arrived at the clinic. As he walked towards the chemo suite, there was
the sound of a string trio and he was touched on the shoulder...and there was his nurse...dressed in a ball gown. She invited him to dance...and they did. The music ended and he went to Mrs. Khan, helped her to her feet and together they waltzed with her IV pole with chemotherapy infusing.

The nurse said, “My mentors taught me to think outside the box. To set objectives and strive for them, and evaluate the process. My best mentors have been those with cancer.”

Lynda is not “JUST A NURSE”! She is a creative, caring, committed, specialized oncology nurse!!!

And if your stories are you and you are your stories...you also are creative, caring, and committed specialized oncology nurses. You are making a difference. You will author a strong caring future.

You are specialized oncology nurses!

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References


