Cancer nursing: Weaving the tapestry for our second century

By Connie Henke Yarbro

Editor's note

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It is an honour and a privilege to have been invited to give the closing address for your twelfth annual national conference on "Weaving the new tapestry for oncology nurses: Our future is now."

I am sure each of us has a mental picture of a tapestry. I think of the many beautiful tapestries, truly works of art, in museums around the world, tapestries of heavy cloth woven with rich, varicolored designs, scenes from history, stories from our past. Some hang in tatters, scarred by the passing of time, but even so they maintain their beauty, symbols of glorious days gone by. The dictionary speaks of tapestry as "heavy," and "handwoven," and "complex." The making of a tapestry has been called a "collective art" because it combines the talents of the designer, the painter, and the weaver. When one logs on to the Internet, tapestry relates to land, time, music, food. What we have been relating to in the past few days is the "tapestry of cancer nursing." Nursing, like a tapestry, is a collective work of art that requires the input of many. The warps of cancer nursing stretch throughout our history like the threads of the fabric web that support a tapestry - caring, commitment, cooperation, a dedication to learning, to discovering what is new. On this foundation, each of us weaves our own individual weft, our own individual contribution which, collectively, paint the full picture of our time. Alone, we are a tiny thread. No weft thread carries the full widths of the tapestry. Collectively, however, **we** are the tapestry. Here today, we are creating new masterpieces for the future. Consider the cancer nurses' tapestry of the past century. Were those nurses not weaving the threads for our own future?

Over 100 years ago, Florence Nightingale said, "Unless we nurses are making progress every year, every month, every week, nursing will go backwards. No system shall endure which does not march" (Nightingale, 1969). The tapestry begins. The "nurse in white" emerged in the early 1900s when nurses were trying to dissociate themselves from the profession's previous drunken and unkempt image. Until then, nurses had worn dark colours characteristic of military and religious roots. Nurses began establishing their professional organizations.

At the turn of the century, cancer was an incurable disease. The death rate was 90% and many people thought it was contagious. Sources of information about nurses in cancer care were minimal in those early years. The Nursing Studies Index lists only 16

articles related to cancer between 1900 and 1930 (Henderson, 1972). Nurses wrote three of these articles. These nurses added their stitches to the tapestry of nursing. Rice (1902) stated, "While cancer has not yet been classed with the transmissible diseases, there are authentic cases where a wife has been infected with cancer by her husband and vice versa" (p.89). This belief was so common that some nurses refused to care for patients with the disease.

In 1906, Charles Plumley Childe, a British physician, wrote the first book to inform the public about cancer: **The control of a scourge** (Ross, 1987). It is of interest that the word cancer was not used even at a time when hospitals for cancer patients existed and the organizational fight against cancer was beginning.

Cancer nursing in the early 1900s was primarily concerned with bedside care and comfort measures for surgical patients (Yarbro, 1996, 1998). The majority of cancer patients presented with advanced cancer and nurses had to develop creative ways to handle the numerous difficulties encountered. In 1915, Tucker discussed caring for a patient with bladder and rectal fistulas as a result of pelvic cancer (Tucker, 1915). Pads were not thick enough to prevent the bed sheets from getting wet. She improvised by using an air cushion with newspapers underneath and muslin wrapped around the cushion and newspapers. When soiled, only the muslin needed cleaning, which meant a great saving on laundry expenses. As a home nurse, she was provided a budget to carry out her work but was expected to save as much as possible. In those early days, there were considerable delays in detection and treatment of cancer. Examples of medical misinformation sound shocking today: a woman with breast cancer was told by her physician to "wait until it begins to bleed and then come back, and I will tell you what to do." Bleeding of a cancerous uterus was ascribed to "a return of menstruation," "rheumatism," or "a cold in the pelvis." Other common sayings were, "It is your menopause," "Don't bother it till it bothers you," and "Go home and forget about it" (American Cancer Society, 1924-1925).

During the 1930s and 1940s, documentation of cancer nursing practice and care was still minimal. Cowan (1934) noted that cancer nurses need to pay attention to pain control and the mental needs of patients. Colonic irrigations of a salt solution were used to treat patients with colon cancer. The role of the radiation therapy nurse was described by Hopp (1941) who noted that no special routine was followed in caring for patients with cancer and efforts to alleviate side effects of nausea and vomiting had not been successful. Lemon juice, sour wine sipped slowly, and ginger ale were used for nausea, vomiting, and anorexia.

The first half of the 20th century is noted for the use of ionizing radiation in the diagnosis and treatment of cancer and the extension of surgical procedures. Progress was made by surgeons and radiotherapists, but it was the nurse who provided the care and comfort (Yarbro, 1998). Think about the conditions under which those nurses worked. Think about the advantages **we** have today.

The second half of the century is noted for significant progress in systemic chemotherapy, further progress in radiation therapy, multimodality therapy, and an increased understanding of cell biology. Cancer nurses at major institutions of cancer care developed innovative programs to provide care to cancer patients. Exercise classes to piano music were held for patients with breast cancer who had radical mastectomies, the procedure of colostomy irrigation was developed, and tube feeding was considered technology at its best! (Yarbro, 1996).

By the late 1950s, the nursing profession began to be concerned with educational preparation and about who we were and what we

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should be doing. Changes in nursing practice and scientific advances expanded and extended nurses' roles. There was a critical need to provide expert, technically complex nursing care at a time that technology in health care was exploding and also at a time when a general nursing shortage existed, thus the role of the clinical nurse specialist was developed (Yarbro, 1996, 1998).

By the late 1970s and '80s, oncology nursing as a specialty was internationally recognized and nurses were expanding their roles to all aspects of cancer care (Yarbro, 1998). Oncology nursing societies were established: the Oncology Nursing Society in the United States in 1975, the Royal College of Cancer Nursing Society in 1978, and the Canadian Association of Nurses in Oncology in 1985. The first International Conference on Cancer Nursing was held in 1978 in London. The establishment of the International Society of Nurses in Cancer Care (ISNCC) in 1984, the emergence and progress of cancer nursing research, the proliferation of educational programs, cancer nursing literature, and the development of standards and guidelines for cancer nursing services and cancer nursing education are just a few milestones on the road of progress in cancer nursing. The decade of the 1990s paved the way for our entry into the 21st century. The last five years of the 20th century witnessed more dramatic progress in cancer treatment than the first 95 years.

Throughout the history of cancer nursing, nursing leaders encountered problems and challenges but moved forward by taking advantage of the opportunities at hand. I believe that we will do no less! However, we confront an even greater challenge because the problems and issues facing us today go beyond bedside care. These challenges concern health care systems, complex questions of ethics and problematic economics, and new nursing roles. I believe the changes happening today are

providing exciting new opportunities for nurses. In his keynote address yesterday, Ken Stratford reminded us to embrace change, be flexible and that we are the "*change agents*." Thus, we do have the opportunity to be a strong force in the 21st century.

The physician-dominated, illness-focused, hospital-based, health care model will be replaced by preventive, community-defined, collaborative health care. Nurses will have expanded opportunities for new independent and interdependent roles (Orchard, Smillie, & Meagher-Stewart, 2000). But as health care changes, we will have to change with it. And, the question is - how do we do this? What challenges will we face? How should nursing evolve in the changing health care environment? What must we do to create a preferred future for nursing? A preferred future is what we want to happen. What threads must we place into the tapestry of our profession to draw the picture of what we want nursing to be, to make nursing what it should be? What threads will **you** add to our tapestry? Let us look at some areas where you can make significant contributions to our tapestry.

We are learning how to prevent most cancers. Nurses must lead the way in cancer prevention effort. Even though we have made incredible progress in cancer care, cancer is forecasted to be the number one cause of death in my country [USA] within 10 years. Worldwide, cancer cases are expected to reach 20 million new cases by 2020. Seventy per cent of these cases will be in developing countries (WHO, 1999). We are fortunate to have the resources we have. Nurses in developing countries who creatively work to provide prevention and care with minimal resources constantly amaze me. They are adding their contributions to our tapestry as well. Life expectancy will double over the next 20 years in many developing countries. Indeed, cancer is a world

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health concern. Therefore, cancer prevention must be a part of our tapestry. We cannot speak of prevention without thinking about tobacco.

The 20th century has been the cigarette century with a tremendous surge in smoking, especially during the 1930s through the 1980s, and as you know the increase in lung cancer deaths corresponds with this surge in smoking. Tobacco is the cause of one out of every seven cases of cancer and four million deaths annually worldwide (WHO, 1999). By 2020, tobacco use will be killing more people than any single disease. Trends in per capita consumption indicate that smoking is high in high income countries, but as midlevel income countries become more westernized, smoking increases. It is a worldwide concern as evidenced by antismoking posters and other advertising developed by many different countries.

Nothing kills like tobacco. Cigarettes kill more Americans than AIDS, alcohol, car accidents, fires, cocaine, heroin, murders, and suicides combined (U.S. Department of Health, 1990). Cancer control objectives are aimed at reducing the number of smokers, particularly among youths and young adults. Restrictions on advertising, smoking cessation programs, prevention programs targeted to grade school children, and increasing tobacco taxes are some of the current efforts underway. Labeling requirements for cigarettes vary from country to country. The United States' regulations fall short of some other nations. Poland has laws requiring labeling equivalent to the current 30% front panel coverage required by Canada (Miller, 2000). New proposed labeling regulations in Canada require that deterrent messages cover 60% of the front panel of cigarette packages. These messages have never been tried before. Hopefully, this education will help reduce smoking rates.

The taxes on cigarettes in major industrialized nations are quite variable. The highest cost in Canada is in Newfoundland and the lowest cost is in Ontario (Mitka, 2000). Canada reported that teen smoking declined by more than 60% between 1981 and 1991 in association with raising tobacco taxes, but smoking among Canadians age 15-19 rose from 21% to 28% during the 1990s (Miller, 2000). Laws alone will not accomplish our goal. Only social pressure, peer pressure, will work.

We have, in America, been far more successful at decreasing smoking by physicians than we have for nurses. Why is that? When nurses smoke, can we expect our patients to abstain? Nurses should lead the way in setting the social standard of a smoke-free society. The ISNCC has addressed this through its position statement on tobacco and health, and is in the process of establishing an International Coalition of Nurses Against Tobacco. Who better than cancer nurses to move forward in this area? A collaborative effort by many organizations, including yours [CANO], will help us move towards a smoke-free society in the 21st century.

Advances in science and technology are a major part of our tapestry today and in the future. The advances in cancer treatment that develop at a rapid pace in the 21st century will be selectively targeted to genes and individuals. For the first time in the history of cancer care, we stand on the threshold of specific treatments based on known alterations in the genetics of the cancer cell and on individual genetic differences (Yarbro, 1998). We are entering an era when disease will be predicted before it occurs, and treated specifically when it does occur. Nurses will need to acquire knowledge in biology, immunology, and genetics that serves as a foundation for this new understanding. The old pattern of chronic disease is shifting to a new pattern that focuses on prediction and specific management of illness. Health promotion and prevention will finally become an increasingly more important aspect of our care, a continuing thread in the tapestry of cancer nursing.

The Human Genome Project has been completed four years earlier than predicted. This worldwide collaborative project has

mapped and sequenced the estimated 50,000 genes that make up the human genome, including the genes responsible for cancer. Some of these have already been identified. As a result of the advances in genetics and molecular biology, we will soon understand the steps needed to alter the biology of cancer. We will identify high-risk groups and better target our cancer prevention and treatment. Now imagine yourself just a few years from now. A new line of drugs will be available. You will need to explain treatments to your patients using an entirely new vocabulary. You will be asked to deal with quite different toxicity spectra. The same DNA technology that showed where O.J. Simpson was will be applied to stool, and blood, and sputum to tell us where cancer is.

Nurses are already encountering a human dimension of cancer genetics. The popular test for the breast cancer gene BRCA1 provides information that gives women many options. While the gene apparently confers an 85% risk of developing breast cancer and a 40% to 60% risk of ovarian cancer, women who test positive may reduce that risk. Some women adopt a program that includes low fat diet, exercise, and avoidance of estrogen after menopause, and some even opt to have prophylactic mastectomies and have their ovaries removed. How do you respond when a patient asks about her risk? What about the 30-year-old woman whose biopsy has just revealed breast cancer and she asks you, "What does this mean for my daughter?" Cancer nurses are going to need to understand cancer genetics. Especially when one considers that 20 years from now, most cancers may have gene therapy as part of their treatment. Cancer nurses must master the language of genetics and respond appropriately to questions patients will ask.

Ethical issues will increase as a result of these advances and will be a major part of nursing responsibilities. As you know, cloning, genetic testing, and assisted suicide are the issues we are facing today and this will continue in the world of biological politics. Genetic testing is already raising a number of ethical and legal questions. For example, can the results of these tests be used by insurance companies and employers to identify people who might be occupational risks? How do we keep this information private? Should anyone be tested before the age of consent? The ethical dilemmas of life and death will increase. Do individuals have the right to die? Or do they have a duty to die if their prognosis is poor and they are elderly? Tranmer's presentation stressed that nurses must assume a professional role in the end-of-life care.

What about health care rationing? The demand for health care is limitless and there has always been and will continue to be some system of rationing. As technologies proliferate and costs escalate, the issue of rational and equitable distribution of health care goods to our population will continue. The question is, "Who will control the system of rationing?" Further, who should have access to which resources and technology? If you smoke, who should pay for the damage to your health? The way we answer these questions, the way we take a leadership role in speaking out on these issues, the way we ensure the rights of our patients, the way we work collaboratively with other health care professionals, all of these will paint a picture on the tapestry of 21st century cancer nursing.

The changing consumer is another of the challenges we have in weaving the tapestry of cancer nursing. The future consumer of health care will be dramatically different than the consumer of today. The public is more assertive, better informed, and concerned about health care choices.

As a result of remarkable gains in life expectancy across the world, the elderly population will reach 423 million this year, with 250 million living in developing countries (WHO Study Group, 1994). With the majority of cancers occurring in patients over 65 years of age, this century will encounter an increase in demand for treatment of cancer. This demand is of great concern to us in the United States, where 76 million baby boomers will start to retire in 2011. The

demand already exists today. For example, we know that one-third of health care consumption is by the elderly; the majority of hospital admissions involve the elderly; most elderly care is given by the family; the majority of the elderly fail to take medications properly, and there is an increasing number of individuals leaving jobs to assume caregiving responsibilities. During our second century of cancer nursing, geriatrics will be a major focus in oncology and a required part of medical and nursing education. Additionally, more informal caregivers will be needed. Nurses must interact more closely with the family members and these informal caregivers by developing creative programs that will allow the multidisciplinary health care team to collaborate closely with these caregivers (Yarbro, 1998).

The cancer survivor is increasingly at the forefront of public awareness. Patient advocacy groups that once were fairly general are now arising as specialty support groups with a powerful voice and are making an impact on legislation and sources of funding. One out of five people will still get cancer, two out of three cancer patients will be cured in the 21st century, and one out of 1,000 individuals reaching the age of 20 will be a survivor of childhood cancer. We have a population of children and adolescents that will continue to need follow-up care as they age. Living with long-term effects from cancer therapy and screening for second or third malignancies will require astute assessment, psychological support, and numerous rehabilitative efforts.

Consumers of health care are demanding affordable, safe, and comprehensive care. They are discharged earlier from the hospital, earlier and sicker, and waiting for treatment. Many are told to take on new responsibilities for self-care and they are not ready. Florence Nightingale would be delighted with this movement to self-care and autonomy. Over a century ago she said, "Whatever a patient *can* do himself, it is better" (Nightingale, 1969). The nurse must be at the forefront of teaching patients how to cope with the burdens of self-care.

Individuals, families, and communities will play a larger role in determining and meeting their own health needs. The electronic Internet has helped patients make contact with fellow cancer patients and learn about their disease and treatments. Web research has transformed the visit to the doctor. With an estimated 100,000 medical websites, patients can look up any disease, drug, or medical condition in seconds. It is quite common for a patient to arrive for treatment with a copy in hand of a new therapy being tried at another institution or suggestions on how to handle a specific toxicity. The Internet has numerous listings for cancer support groups, some of which relate to specific cancers, e.g. prostate and breast cancer. The information age has provided an important medium for nurses in providing support and education.

Today, more than 400 million people are users of the Internet and the number is expected to continue to increase (Anon., 2001). We cannot ignore the change. As McIntosh and Rizzo noted in their presentation on "Face to face with technology: Implications for nursing practice," nurses must learn to manage technology - or they will end up being managed by technology.

It seems apparent that we are undergoing some form of health care revolution in each of our countries. I am not an authority on your system, but I believe we have some similarities. Yesterday, the newspaper reported that health care costs will rise 6 to 9% a year over the next decade. In his presentation, Stratford noted that Canada will reinvent the health system. We too are evaluating changes for our system. In the USA, we are facing the challenges of a managed care environment, hospital closings, shifts in health care delivery from the hospital to the outpatient setting and to the home with more acutely ill patients in these environments, elimination of registered nurse positions and their replacement with unlicensed assistive personnel, the replacement of specialty care by primary care, changing roles, and lack of qualified or experienced nurses for oncology care.

What is most alarming for nurses around the world is the nursing shortage. Nursing shortages exist nearly everywhere - it is one of the greatest challenges of this century. We are seeing more migration of nurses as they seek higher salaries and better working conditions. For example, in the United Kingdom where there is an acute nursing shortage, the number of overseas nurses coming to the UK has risen by 48% in 12 months. Most recruits are from South Africa, Australia, the Philippines, New Zealand, and the West Indies (WHO, 2000).

You must be just as concerned in your country. Nurses under the age of 35 decreased by 21% between 1994 and 1999. And your nurses are getting older, with 43 being the average age of a Canadian registered nurse (SEW News, 2000). We heard from several presenters that the nursing school enrollment has dropped and by 2011 there will be a shortage of 113,000 nurses. We also have a shortage of nurses and physicians. As I age, I wonder who will take care of me. At a recent worldwide conference, Judith Oulton, executive director of the International Council of Nurses (ICN), noted that this century will see the rise of a global professional nurse, an individual qualified to provide services anywhere. As the recruitment and retention crisis expands, the nursing profession must act. Our education systems must act. And as a cancer nurse, no matter where you work and no matter at what level, you can be a collective part of the tapestry of cancer nursing by being a mentor. I would venture to say that each of you in this room has mentored another nurse. Sometimes you did it without even knowing you did it. In my brief observations over the past two days, I have witnessed or heard stories of mentorship. Even some interesting recruitment stories! On Monday, Leahy and colleagues described their initiatives to prepare inexperienced nurses in the specialty of oncology. One aspect was a mentorship program where every nurse who comes to the centre is connected with a mentor. Fitzsimmons reminded us that "caring leadership" is a key to recruitment and retention. I would challenge you to make a concerted effort to serve as a mentor. By nurturing, by influencing, the life of one nurse, the lives of many people are affected.

As we weave, we must not forget the warps of nursing that permit us to each provide a weft of thread for our tapestry. Our foundations guide what we can and must do. Our foundation is nursing and care.

Nurses are the largest health care provider group in virtually all countries. Even though we encounter nursing shortages, there are 11 million working nurses around the world and 80% of all primary health care is delivered by nurses (ICN, 2000).

Nurses improve the quality of care in hospitals. Research has shown that when you have more nurses you will have shorter lengths of stay, lower costs, and fewer complications (Prescott, 1993). A higher ratio of nurses to patients in hospitals revealed six fewer deaths per 1,000 patients than hospitals with fewer RNs (Hartz et al., 1989).

We have seen a change in what consumers think about nurses. Consumers have confidence in nurses. A recent poll of the public indicated that 86% were willing to go to an advanced practice nurse for basic health care. Nurses are respected more than any other health care provider and the majority of Americans indicated that registered nurses are not given responsibilities equal to their abilities (Brown & Grimes, 1993), and the primary care provided by nurse practitioners is equivalent or superior to that provided by physicians (U.S. Congress, 1986).

Diversity in nurses' roles can strengthen our tapestry, as each role provides different stitches to provide a unique pattern and story. I believe the diversity in roles is exciting. No longer is it just hospital nursing, but we have moved care to a variety of settings. We have heard many papers describing creativity in education, nursing roles in the community, the nurse researchers who are providing tools, instruments, and evidence for our practice. We have heard discussions about the various advanced practice roles and primary nursing. When I was perusing the Canadian Nurses Association (CNA) website related to issues and trends in Canadian nursing, I came across several interesting papers. Suggestions for the community nurse, advanced

practice nurse, and even the nurse entrepreneur; all excellent resources. These diverse roles are strengthening the tapestry.

Those of us who entered the nursing profession entered with a caring spirit. No matter what path you take during your nursing career, I do not believe that the pattern of caring disappears.

I noted in a recent article (Yarbro, 1998) that this is a time, the beginning of a new century, when numerous authors are writing about the future of everything. And nursing is no exception. Some are optimistic, some are pessimistic. I am an optimist. I believe that the dramatic changes taking place present many opportunities for nurses in this millennium. Yes, we need to improve our nursing education system to meet the changing environment of the future. Yes, we need to reach consensus about our various nursing roles and the appropriate education and training for these roles. Yes, we need to be proactive rather than always complaining. We need to support our peers and work collaboratively with our physician colleagues. Yes, we need to inform the public about who and what we are. In an eloquent article, Kitson (1997), noted that as nurses we need new metaphors and new images to communicate our essence. She suggested a slogan, "We will be there for you." I have no doubt that we will be there for our patients, no matter what happens. I believe that we are changing the concept of the nurse that is held by the public. Our image is changing.

"Nurses always there for you" was the slogan for International Nurses Day. On Monday, we heard the CNA slogan for 2001 nurses week: "Nurses: Champions for Health." Your president challenged you to "Honk, raise your voices to what you have accomplished. Be the voice of cancer nursing in Canada."

Janes and Robinson reminded us on Monday that cancer nurses

can make a difference, when they so eloquently and creatively reminded us that cancer is an uninvited guest to the family, and children need to be a part of the picture early. We must make the children a part of the collective work of our cancer nursing tapestry.

The presentations over the last three days are a clear indication that we are making a difference in cancer patient care in palliative care, symptom management, patient education, the treatment settings such as radiation therapy, bone marrow transplant, pediatric oncology, and even developing creative programs in urgent care and the community. The strength of nursing research has been a strong thread throughout the conference. It is up to us to show that we make a difference, that we are cost-effective, that we provide quality care.

We are "the continuous thread of patient care." We leave this conference and will return to our settings, hopefully with renewed commitment, energy, excitement to continue the tapestry we are creating. The individual contributions at this conference are the collective work of art that is creating and will continue to create the tapestry of cancer nursing.

As nurses and citizens of the world, we are creating the future by what we do or do not do today. All of us look with pride on the tapestry of nursing created by our predecessors. Let each of us, in the small weft we weave into our own part of the tapestry, always remember that those who follow will look someday at what we have done. May they see no imperfection in our work, be it ever so tiny. The tapestry we weave for our world of the 21st century is bound only by our visions, our values, our resources, and our imaginations. ♦

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