THE 1999 SCHERING LECTURE

Cancer: The long and winding road

by Trish Picherak

Winner of Schering Lectureship, awarded in Halifax at CANO 1999. Trish's presentation was dedicated to the memory of Dr. Peter Geggie, a friend, colleague, and mentor who helped her on both her personal and professional journeys. Peter was an oncologist at the Tom Baker Cancer Centre in Calgary and died in January 1999.

The connections between information and knowledge and power are observable. "Knowledge is power" is a phrase we are all familiar with. Do we feel more in control when we are knowledgeable? Do we feel powerless when we don't have information or knowledge? Cancer information abounds on the information highway and new information and knowledge is constantly developing. Would you agree that the possession of information and knowledge usually give people experiencing cancer a greater feeling of control? In exploring the links between information, knowledge, and control, I became interested in other factors associated with control.

Prior to resuming my graduate studies, I worked as a director of the national call centre in Regina for the Canadian Cancer Society's Cancer Information Service. I was amazed at the number of long-term survivors of cancer who called looking for cancer related information. I began to realize how few resources, programs, or services were geared to the needs of people for whom cancer is a long-term condition.

Two themes - control and cancer as a long-term condition - converged when I was writing a paper for a course on the biopsychosocial phenomena of cancer, which was the genesis of this presentation. In my presentation, I have tried to weave together theoretical knowledge gained from the literature, experiential knowledge gleaned from my own practice, and the collective knowledge of colleagues in the clinical field.

Cancer, as a chronic condition, is characterized by periods of stable, relative health punctuated with episodic acute morbidity. However, the nursing and health care literature does not fully address the long-term nature of cancer and its effect on individuals, families, and the larger community. In 1997, the National Cancer Institute of Canada (NCIC) reported that the incidence of cancer in Canada would double by the year 2010

(CCS, 1997). Although there has been steady progress in cancer control, the incidence of cancer continues to increase as screening and detection methods improve and the age of the population increases. At the same time, mortality rates are beginning to decline for some cancers, indicating that more and more Canadians will be living with cancer and its effects in the future. Benner and Wrubel (1989) said that in order to meet the challenges of assisting individuals to live with cancer and its effects, nurses need to develop a more complete and comprehensive understanding of the phenomena related to the experience of cancer as a long-term condition.

Originally, the title of my presentation referred to cancer as a chronic disease. But for some, the term chronic may conjure up negative images described as prolonged, unrelenting, static, hopeless, or never-ending. Because our perspective on a situation and how we communicate can influence the message and the interpretation of information, I chose to change the title of my presentation to **Cancer: The long and winding road**. I do not intend to romanticize or sentimentalize cancer, only to frame it in the language of possibility and discovery. Cancer is not just a diagnosis or a disease; it is a journey. We often refer to life as a journey - the road of life and life taking different paths. We can use the same metaphor in talking about the journey that is the cancer experience.

On the cancer journey, the end is not always sign posted. Stops along the way and the milestones are many, the road takes many turns and paths cross. The trail may narrow or become obscured at times. My presentation focuses on the section of the cancer journey bracketed by diagnosis and initial treatment at the beginning and by palliative care and death at the end. Sometimes the distance in between is long and difficult; waiting, wondering what the next bump in the road will be and where and when the journey will end. Cancer, like other long-term conditions, affects individuals, families, and communities. It has physical, emotional, social, and economic implications. In my presentation today, I hope to stimulate anew our role as nurses in this uncertain, yet hopeful midsection of the journey. This presentation focuses on the selected biopsychosocial phenomena of control and the linked phenomena of uncertainty, hope, and spirituality in the context of the experience of cancer as a long-term condition. I will also discuss the implications and possible directions for expert nursing practice.

If we think about cancer as a long-term condition and if we think of the cancer experience as a journey of possibilities and discovery, could it change our nursing practice? Could it change our relationship with our clients or how clients and families respond to cancer? Would it influence how communities respond to individuals with cancer?

Why is reframing the view of cancer as a long-term condition important? Because by acknowledging the section of the journey between diagnosis and death we can see where we have been and where we are going. We can gain perspective. Many individuals diagnosed with cancer, or their families, are not prepared for the reality of the frequently long-term nature of cancer. Expert nursing practice, whether it be in education, administration, research, or in the clinical field, can play a

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central role in illustrating the individual stories of those with cancer and their families, with the goal of positively influencing care and clinical outcomes. In broad terms, the expert nurse has the opportunity to illuminate the collective experience of cancer as a long-term condition through research. Lambert and Lambert (1987) said that, "how a person appraises, describes, and copes with the stress of long-term illness often goes unaddressed in today's health care practice" (p. 527).

Perspectives on chronic illness

Long-term health conditions consume the majority of health care resources today and with advanced, acute care technology and the aging of the population, the impact will accelerate as we enter the next century. In the realm of cancer, in many cases treatment has become more intense and prolonged as second and third and fourth line therapies become available. These changes have created financial, emotional, and psychological strain on families that may extend well beyond the initial crisis of diagnosis.

The long-term nature of cancer may be defined at any point during the cancer journey, from diagnosis to recurrence or progression of disease. Because the experience and needs of those who continue to have cancer and those living with the effects of having had cancer are often similar, I have not

distinguished between them. As a colleague pointed out, cancer is a life-altering event no matter the clinical outcome. Researchers and clinicians have struggled to understand the social and psychological variables that affect disease, but the lack of clarity and common meaning hampers efforts to generate knowledge in this area (Rolland, 1984). For example, the terms cure, metastatic, reoccurrence, and survivor may be used imprecisely or have ambiguous meaning, particularly for the lay public.

Benner and Wrubel (1989) said that, "cancer survivors have not been studied sufficiently to know the impact of surviving cancer on subsequent health, morale, and stress and coping" (p. 285). They go on to say that cure of the disease is not enough; full recovery includes complete reintegration into the community and the ability to once again take up life projects, free of excessive fear. For this reason, it is crucial that health care providers address issues of quality of life for those who survive active treatment and for those who continue to live with cancer. Knowledge of the impact of cancer on survivors can inform nursing in the community, geriatrics, psychiatry, and mental health specialties where long-term effects including loss, grief, and stress may be manifested (Benner & Wrubel).

An example from my practice illustrates the potential effect of cancer as a long-term condition. Cathy was 19 years old, the youngest of four children raised in a close-knit family, when

Abrégé: Le cancer: un long chemin tortueux

Les rapports qu'entretiennent l'information, les connaissances et le pouvoir sont observables. Nos connaissances nous donnent souvent le sentiment de mieux contrôler les choses. L'autoroute de l'information regorge de renseignements sur le cancer, et l'information et les connaissances sont en constante évolution. Tout au long de son exploration des liens existant entre l'information, les connaissances et la maîtrise, l'auteure s'est intéressée à d'autres facteurs associés au phénomène de maîtrise. Cet article avait pour but de concentrer l'attention sur des phénomènes biopsychosociaux sélectionnés de la maîtrise et sur les phénomènes connexes de l'incertitude, de l'espoir et de la spiritualité dans le contexte du vécu du cancer en tant que maladie de longue durée. L'article traite également des répercussions et des orientations possibles pour la pratique spécialisée des soins infirmiers.

Les survivants à long terme sont nombreux à vouloir obtenir de l'information sur le cancer, mais ils ne disposent que de peu de ressources, programmes ou services adéquats. Le cancer se caractérise par des périodes de stabilité où la personne atteinte jouit d'une santé relativement bonne ponctuées d'une morbidité aiguë épisodique. En revanche, les publications en soins infirmiers et en soins de santé ne traitent pas suffisamment de la durée particulièrement longue du cancer et de l'impact de cette dernière sur les personnes atteintes, sur les familles et sur la société. Bien qu'on prévoie que l'incidence du cancer se multipliera par deux d'ici 2010, les taux de mortalité commencent à baisser dans le cas de certains cancers. Il en ressort qu'un nombre toujours croissant de Canadiens et de Canadiennes vivront plus longtemps avec le cancer et les effets de la maladie.

Le cancer n'est pas simplement un diagnostic ou une maladie; il s'agit en fait d'un périple qui comporte son cortège de conséquences physiques, affectives, sociales et économiques. Parmi les personnes diagnostiquées d'un cancer et leurs proches, seul un petit nombre a conscience de la réalité qui veut que le cancer soit fréquemment une maladie de longue durée. La pratique spécialisée des soins infirmiers, qu'il s'agisse des domaines de l'éducation, de l'administration, de la recherche ou de la pratique clinique, peut

jouer un rôle central en illustrant le vécu individuel des personnes vivant avec le cancer et celui de leurs proches, dans le but d'exercer une influence positive sur les soins et sur les résultats cliniques.

Le phénomène de maîtrise est associé à l'image de soi, à la normalité, à l'autonomie et à l'auto-détermination. Les personnes et les familles touchées par un cancer de longue durée recherchent et acceptent la maîtrise et l'autonomie, et participent activement à la prise de décisions. Au cours du traitement, les patients et leurs proches éprouvent une perte de maîtrise dans la vie quotidienne; les horaires, les rôles et le fonctionnement de la famille dépendent de l'horaire des traitements et de la gestion des effets secondaires, avec l'espoir que les choses retourneront à un état "normal" à l'avenir. Des interventions psychologiques qui amènent les gens à découvrir leur propre pouvoir et à mieux se connaître se sont révélées efficaces dans le contrôle des symptômes associés à la thérapie anticancéreuse et à la gestion de la douleur. Les incertitudes qui caractérisent le cancer vu sous l'angle d'une maladie de longue durée, peuvent se traduire par un sentiment d'impuissance. Toutefois, selon son style d'adaptation, la personne atteinte d'une maladie chronique peut voir dans l'incertitude soit un danger soit une occasion favorable. En effet, l'incertitude et l'espoir sont étroitement liés. Chez certaines personnes, le fait de connaître tous les détails peut réduire l'incertitude et nourrir l'espoir, tandis que chez d'autres personnes, l'incertitude doit rester intacte si on veut qu'elles gardent espoir. Il existe aussi des liens étroits entre la spiritualité et l'espoir.

Les infirmières se doivent de voir dans le cancer une maladie de longue durée et de reconnaître les phénomènes associés au cheminement humain. Il faut que les cliniciennes spécialisées dégagent les priorités en matière de recherche afin de pouvoir intégrer à la pratique des résultats de recherche pertinents et de nouvelles connaissances infirmières. En tant qu'infirmières en oncologie, il nous faut privilégier une pratique axée sur la santé, sur la découverte, par les patients, de leurs propres pouvoirs et sur les besoins holistiques de ces derniers et de leur famille.

she was diagnosed with germ cell ovarian cancer. Following removal of both ovaries, Cathy went on to one full year of a gruelling chemotherapy regime which caused significant physical and emotional effects that were distressing to her. When Cathy finally finished her therapy and no remaining cancer could be found, she was given an appointment to return for follow-up in three months. Feeling happy and relieved, Cathy was also fearful of her cancer returning and felt insecure about resuming her regular activities. She called frequently for reassurance. Her life had changed, and the people she had grown to depend on were no longer in her daily landscape. She was thrust back into her "normal life," except she was not the same. Her fertility and identity as a woman had been altered; she had experienced suffering and loss. Primarily my relationship with Cathy focused on the short-term goal of completing treatment, which we hoped would result in cure. As a primary nurse, I viewed her outcome as positive, although I do not know how Cathy viewed it or what she would say about her cancer experience today.

Frank's (1991) book, "At the will of the body," is a moving and eloquent account of his cancer journey starting with a diagnosis of testicular cancer. He describes the pain, fear, and loss he experienced during his journey; a journey which he survived. Frank draws an analogy between his re-entry into normal life where he experienced the stigma, guilt, and shame associated with cancer and began healing and recovery and the story of Jonah being spit out by the whale to continue to live.

Getting a handle on the process

There are a number of multidisciplinary models of chronic illness. Rolland (1984) developed a conceptual model that distinguishes type and phase of illness in the natural history of the disease. The model effectively discriminates between types of chronic illness while providing a common inclusive framework in which to discuss the spectrum of chronic illnesses (Rolland). It compares components of family and individual functioning to the course of the disease at different phases of the illness. The model provides a context in which to compare cancer with other chronic illnesses.

Scott Dorsett's (1991) "Trajectory of recovery" model is specific to cancer as a long-term condition. In the model, recovery is a continuum, separate from but interactive with cancer, whereby each are open and subject to the influence of the other. In this model of nursing, the need for client understanding and control are emphasized and collaboration and co-operation between client, family, and nurse are encouraged (Scott Dorsett).

Cancer is the structure and the trajectory is the process. The individual's trajectory is influenced by the pattern of progression of a specific type of cancer and the host's multiple social and emotional factors. For example, the phenomenon of control and the linked phenomena of powerlessness, uncertainty, and spirituality influence and are influenced by both the disease and the trajectory (Scott Dorsett, 1991).

The cancer trajectory model (Scott Dorsett, 1991) includes "transition points" such as diagnosis, beginning treatment, recurrence, and disease progression. Remission and finishing treatment are also transition points at which many people who have had cancer feel cautiously optimistic, uncertain, and "as if in limbo" (Benner & Wrubel, 1989). They may feel anxious about leaving the environment where they and their disease are accepted and understood and rejoining their previous life, forever changed by their experience. Recurrence may signify the end of a realistic hope for cure and raise the spectre of prolonged life with cancer. The transition point of recurrence

can be described as a crisis of courage. The individual is once again confronted with mortality.

Both Rolland's (1984) model and the Cancer Recovery Model by Scott Dorsett (1991) emphasize the need for a longitudinal trajectory paradigm that focuses on client centred, long-term goals, rather than short-term goals of compliance with treatment and disease remission. "Handle with care," a play about the experiences of women with metastatic breast cancer, was written by Ross Grey, a social scientist from Toronto. One of the characters in the play acknowledges that "the initial diagnosis of cancer is bad, but the second time is worse." She described it as waiting for the bomb to go off.

The long-term effects of breast cancer on women have received significantly more attention than those of other forms of cancer, possibly due to the prevalence of the disease and public profile of the disease in North America (Ferrell, Grant, Funk, Otis-Green, & Garcia, 1998). Ferrell et al. explored the impact of breast cancer on quality of life in the physical, social, psychological, and spiritual domains. In their review of the literature, they found descriptions of many psychological and spiritual concerns related to the breast cancer experience and those concerns persisted in long-term survivors, even in the absence of active cancer. They also found that survivors of breast cancer have a heightened fear of death compared to other cancer diagnoses. Ferrell et al. postulate that this may be because women were more likely to know someone who died of the disease and because of the media attention given to high profile individuals who have died of breast cancer.

The study by Ferrell and colleagues (1998) concluded that women who have survived breast cancer have a need to express their emotions and seek a sense of control. They also have a critical need for psychological and spiritual support. Inattention to unresolved grief and stress may in itself have negative long-term effects on quality of life for cancer survivors (Ferrell et al.; Molassiotis & Morris, 1998).

I wonder if these same findings would be true of individuals experiencing other types of cancer? There is a great deal that is unknown in this regard. There are barriers to learning more about this population of cancer survivors as a whole. Following the acute phase of diagnosis and treatment, most individuals have outpatient or community follow-up. Without follow-up by a multidisciplinary team of oncology specialists, individuals may fall through the cracks. The health care professionals, individual survivor, and family may assume nothing can be done or that the effects are "normal." They assume they have to live with it; that this must be the price for having cancer.

Clinics focusing on the late effects of pediatric cancers are being developed in major Canadian centres. Their focus is wellness, holistic care, and proactive interventions with known effects. Nurses can play a pivotal role in this type of clinic where the interventions are not necessarily medical, but include education, counselling, and linking with other resources and support. We might question whether a similar approach would benefit adults.

One of my colleagues in psychosocial oncology said it succinctly, "Cancer destroys any illusion of being in control." During the cancer experience, individuals are faced with existential questions such as, "Why did I get cancer? Who is in control?" and "Is anyone (even God) in control?" A sense of control can achieve balance, stability, and a feeling of manageability in very uncertain circumstances. For many, taking control is a positive step, the antithesis of being controlled by the cancer. Cancer by its very nature connotes lack of control. It is defined as cells growing out of control, mysteriously and invisibly invading the body, creating havoc in one's own cell reproduction control mechanism (Dollinger, Rosenbaum, & Cable, 1994).

The phenomenon of control is affiliated with self-image, normalcy, autonomy, and self-determination. Individuals and families experiencing cancer as a long-term condition seek and accept control and autonomy, as well as participation in decision making (Bottorff et al., 1998; McWilliam, Stewart, Belle Brown, Desai, & Coderre, 1996). During treatment, individuals and families experience a lack of control in their ordinary lives; schedules, roles, and family functioning revolve around the treatment schedule and management of side effects, with an expectation of returning to "normal" in the future (Benner & Wrubel, 1989). Normal is a subjective and relative state. The image or vision of normal the individual holds influences his or her perspective on hope and faith.

There is evidence in the literature and in clinical practice that, despite having long-term effects of cancer, these individuals do not consider themselves to be ill. They consider themselves as healthy people who have cancer or have had it in the past (Lindsey, 1996; McWilliam et al., 1996; Moch, 1990; Molassiotis & Morris, 1998; Radley & Green, 1987; Tishelman, 1997). This perspective presents an opportunity for nurses to apply the model of health promotion and assist individuals in optimizing their health and ability.

One of my colleagues in pediatric oncology gave the example of a young woman who had received therapy as a child and who as an adult was experiencing very significant sensory and functional limitations, as well as social isolation. The young woman did not see herself as disabled and had not sought any therapy or interventions to deal with her situation. Her primary physician considered the effects normal after cancer treatment. The nurse and multidisciplinary team at the cancer centre planned to focus on helping the young woman optimize her health and providing her with options and opportunities to improve her quality of life; to live her life rather than coping with cancer. There is a delicate balance between helping individuals to see possibilities for change and disrupting their self-image.

In her qualitative research on psychosocial factors contributing to suffering and how suffering undermines the self, Charmaz (1983) found that people with chronic conditions actually suffer a loss of self and that, over time, the accumulation of formerly self-sustaining images results in a diminished self-concept. The very successful Look Good Feel Better program is predicated on the theory that the more normal and attractive a person looks, the better they feel about themselves.

Empowerment

Gibson (1991) found that clients perceived empowerment as "a positive self-concept, personal satisfaction, self-efficacy, a sense of mastery, a sense of control, a sense of connectedness, self-development, a feeling of justice (in that people's choices had been respected), and improved quality of life" (p. 359). In this way, individuals exercise self-reliance and validation of themselves as persons. Those experienced in managing and coping with their cancer may come to feel empowered and recognize themselves as the expert on their own disease (Bottorff et al., 1998; Gibson; Thorne & Robinson, 1988).

The helping, caring nurse-patient relationship becomes the vehicle for patient empowerment according to Miller (1992). Nurses strive to put individuals in the driver's seat when it comes to their condition, helping people to realize that although they may not be in complete control, they can influence their situation. Some of the strategies used are patient education, providing information, counselling and support, and linking individuals with resources. However, often our strategies are focused specifically on the newly diagnosed. We need

strategies and resources that meet the needs specific to individuals as they journey on after diagnosis. Assessing the individual needs of clients and families is essential to ensuring we are attending to the client, meeting people where they are in their experience.

In her editorial on living with chronic illness, Chinn (1996) explicates her belief that nurses and other health care professionals are trapped in the cure frame of reference, influenced by political factors as well as their own self-esteem and self-concept. She calls for a shift in this framework to "the development of viable frameworks that keep the interests, experience, and the voice of the person with chronic illness in the center" (p. vi). Chinn suggested that the focus should be on the philosophic and ethical considerations of the person with a chronic condition, their story, and those most central in their life and their hopes.

Psychological interventions that empower individuals and increase self-awareness have been shown to be effective in symptom control related to cancer therapy and pain management (Frank-Stromberg & Wright, 1984; Simonton & Sherman, 1998). Well-being is also positively influenced by personal control (McWilliam et al., 1996; Mishel, Hostetter, King, & Graham, 1984). The Breast Expressive Supportive Therapy (BEST) study is currently ongoing in several Canadian centres. This study will measure the effects of support group meetings on survival, daily functioning, and quality of life.

Although there is evidence that behavioral interventions such as imagery and expressive supportive therapy can potentiate the immune system and increase survival, there is also contradicting evidence in this area. Research, at this point, is not conclusive (Simonton & Sherman, 1998). It is incumbent upon nurses to develop programs, services, and care plans that reinforce and preserve personal control for individuals and families during the long-term cancer experience (Given & Given, 1984).

Uncertainty and hope

Mishel and Braden (1988) defined uncertainty as "the inability to determine the meaning of events and occurs in a situation where the decision maker is unable to assign definite values to objects and events and/or is unable to accurately predict outcomes" (p. 98). Uncertainties that characterize cancer as a long-term condition, such as stage and type of disease, effectiveness of treatment, treatment toxicity, physical deterioration, disease outcome, and physical and emotional stress on family supports, can promote a sense of powerlessness (Miller, 1992).

The survivors of pediatric cancers have to deal with many uncertainties. There is the threat of secondary cancers, and the potential physical and developmental effects that may not be manifested until later in life. More and more, the focus in pediatric oncology is shifting to the second phase of the cancer journey as increasing numbers of children survive cancer. Somehow, surviving is no longer enough.

The person with a chronic condition may appraise uncertainty as a danger or an opportunity, depending on their coping style. Cancer may give people an opportunity to do things they didn't know they could. Having cancer may diminish their inhibitions, because they feel they have nothing to lose. It may give them more control over their lives; the freedom to accomplish things they otherwise would not have considered.

Mishel et al. (1984) found a significant correlation between uncertainty and pessimism in the diagnostic period, and uncertainty and difficulty adjusting to the diagnosis in women

diagnosed with gynecological cancer. Does uncertainty have different effects during the long-term middle section of the cancer journey? Research into the effect of information on uncertainty is inconclusive. In some studies, detailed information was sought to relieve uncertainty and contribute to a sense of control, while in others information was declined (Mishel et al., 1984). McIntosh (1974) suggested that by declining information individuals were maintaining uncertainty, which allowed them to remain hopeful. Uncertainty and hope are closely related. Being fully informed may alleviate uncertainty while maintaining hope (Cassileth, Zupkis, Sutton-Smith, & March, 1980).

Individuals with cancer express hope differently at various points in the illness trajectory (Miller, 1992). Initially, their hope may focus on the diagnosis; that the cancer has been found early; that there is a cure. In later stages, hope may focus on the ability to endure the treatment without burdening their family and on receiving the understanding and acceptance of friends and colleagues. In the palliative stages, hope may be for relief from suffering, time to attend to unfinished business, forgiveness, and peace. These stages are not experienced as a linear progression, but as complex interactive phenomenon (Benner & Wrubel, 1989; Miller). In the play "Handle with Care," the women described this phenomenon as the 'hierarchy of hope'. One character in the play warns, "don't give me false hope, but don't write me off either."

Nurses have recognized hope as influencing the individual's response to cancer, but there is a need to expand the construct of hope and understand its meaning to the client. Herth (1991) developed an instrument called the Herth Hope Scale which was designed to capture the multidimensional aspects of hope in adults. The instrument was tested with adult cancer patients, the well elderly, well adults, and elderly widows, and results support its use with these populations (Herth). Herth suggests the findings of her study will allow nurse researchers to examine hope in diverse adult populations and to examine the psychosocial, demographic antecedents and correlates of hope. She recommends that the instrument be used to explore the differential effects of chronic versus acute illness on hope, and the impact of hope on adaptation, effectiveness of treatment, and quality of life. Both the individual and family could be evaluated using the scale. Since nurses believe that hope is a factor in the patterned response of individuals and families to cancer, an instrument such as the Herth Hope Scale could potentially enable nurses to assess hope with clients and families and evaluate the effectiveness of hope enhancing strategies (Herth). Hope is contextual and is one of many coping mechanisms.

Spirituality

Spirituality and hope are closely linked. Spirituality can be interpreted as the need for meaning, purpose and fulfillment, the will to live, beliefs, and faith. Health, well-being, and quality of life are influenced by spirituality (Ferrell et al., 1998; Ross, 1995; Soeken & Carson, 1987). In general, there is a paucity of research examining spirituality and its relationship to health. The experience of cancer taxes the individual's physical and emotional coping abilities and there is evidence that the individual's spiritual reserves may be sapped as well (Ross).

The relationship between coping and spirituality can be seen as reciprocal (Ross, 1995). Spiritual well-being is empowering, but the experience of cancer can leave individuals feeling powerless, undermining their self-efficacy, decision-making ability, and efforts to cope with their illness (Miller, 1992; Soeken & Carson, 1987). No longer feeling empowered by God, they may feel unprotected, defenseless, and lacking assurance (Soeken & Carson).

In Ross's (1995) review of the nursing literature on the nurse's role in spiritual care, she found that nurses were aware of clients' spiritual needs and the majority regarded it as their duty to attend to at least some of these needs. However, despite their awareness and sense of duty, it appears that nurses have limited ability to attend to the spiritual needs of their clients (Ross). These results point out a need for research to ascertain how clients perceive nurses could best help them to meet their spiritual needs, to clarify the nurse's role in spiritual care, and to understand how best to teach nurses about spiritual care.

Spirituality is difficult to define; it can have very different meaning and manifestations for individuals depending on their culture, beliefs, and experiences. Even very young children express their spirituality. When describing the spirituality in a young baby she had cared for, one colleague in pediatric oncology described the baby's spirituality as 'shining through' in her response to caregivers. As the baby underwent therapy, her spirituality shone through in her eyes, her mood, and in her ability to sense the environment and affect of the people around her.

In the spiritual domain, it is particularly important that we focus on being, not just doing. The best tool at the disposal of nurses may be the use of self. In the context of a relationship, it can be a means of healing, support, and affirmation of the client as worthy and accepted (Soeken & Carson, 1987).

The Alberta Cancer Board has recently developed the Tapestry residential retreat program for people living the cancer experience. Individuals with cancer and people who are close to them spend several days together exploring the meaning of cancer in their lives. The program is designed to incorporate a holistic approach to the well being of individuals, including their emotional and spiritual needs. The Tapestry program is recognition of the need for individuals experiencing cancer to deal with the meaning of cancer in their life.

Implications for expert nursing practice

Oncology nurses can be very proud of their accomplishments. We have initiated innovative and valuable programs and services, both within the health care system and as members of volunteer organizations and associations such as CANO. But as the nature and treatment of cancer changes, so must our approach to caring for those experiencing cancer, their families, and others in the community. The demographics of the North American population and the rising incidence of cancer indicate that nurse researchers need to make the systematic study of the long-term effects of cancer on individuals and families a priority.

Expert clinicians can be instrumental in identifying research priorities and segments of the population for study. The integration of research findings and new nursing knowledge into practice must be a shared responsibility by all nurses in order to benefit clients and families. Specifically, nurses need to view cancer as a long-term condition and recognize the phenomenon associated with the human journey (Herth, 1991).

As oncology nurses, we need to redirect our focus toward a practice centred on health, empowerment, and the holistic needs of the client and family. What's in it for nurses? The professional satisfaction of providing the holistic care that nurses want to provide and do best. We can dare to hope that we can make a difference too.

What can nurses do to assist those travelling the journey of the cancer experience? We can be present with the individual and family client, offering support, acknowledgement, and compassion. We can support nursing research that will help nurses, their clients, and others to understand cancer as a long-term condition. We need to utilize the research, resources, and

tools that are available to us. Further, we can work within our agencies and organizations to develop and enhance nursing skills and holistic interventions. Your presence and relationship with clients are the most important tools you can use to help others. The interventions in the long and winding journey of cancer are as much about being as they are about doing.

Summary

Control, hope, uncertainty, and spirituality are not new phenomena, but perhaps we can see them in a different light. We still have much to learn about how these phenomena influence and are influenced by the cancer experience. I have asked you to reflect and consider how you, in your own practice, and your nursing colleagues can reframe cancer as a long-term condition. I have asked you to consider how this may change the ways in which you interact with clients and families. How refocusing might affect the care provided to travellers on the trip of a lifetime; the journey of cancer and the impact nursing can have

on that journey. Are we ready to accept the opportunity to be part of someone's story – to journey with them?

In their paper on the myth of control of suffering in palliative care, Gregory and English (1994) concluded that, "Reaching out is accomplished through presence, touch and careful listening" (p 22). People experiencing cancer choose those who will journey with them, offering a privilege of the maximal magnitude.

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