

# Adult cancer survivorship: Issues and challenges

By Karen Tamlyn-Leaman

## Abstract

*With the growth of the survivorship movement in Canada and the United States, health care providers are being challenged to meet the unique needs of adult cancer survivors. This paper is intended to provide oncology nurses with an overview of adult cancer survivorship and some of the common issues facing adult survivors, as well as implications for oncology nursing practice.*

What is cancer survivorship? Who is considered to be a cancer survivor? This paper is intended to provide an overview of an important emerging area in cancer care: Adult cancer survivorship. First, the concept of adult cancer survivorship will be described, next some of the common issues facing adult survivors are presented, and finally some of the challenges this area presents to oncology nurses will be highlighted. An understanding of survivorship and the challenges associated with it can expand perspectives of the cancer experience and provide nurses with added insight for the care they provide.

## Concept of adult survivorship

Survival rates for persons with cancer are increasing (Halstead & Fernsler, 1994). Approximately one in five cancer patients survived five years post-diagnosis in 1930 (National Coalition for Cancer Survivorship [NCCS]). However in the 1990s that number has increased to one in two, or 50% of cancer patients now survive five years post-diagnosis (Ganz, 1990). These increases are largely due to improvements in screening and early detection techniques, advances in cancer therapies, and developments in supportive care (Berry, D. & Catanzaro, 1992; Hassey Dow, 1991; Loescher, Welch-McCaffrey, Leigh, Hoffman & Meyskens, 1989). The American Cancer Society (ACS) has estimated that there are over eight million people in the United States diagnosed with cancer and five million survive more than five years. In Canada, it is estimated there are at least 500,000 cancer survivors (C. Waters, Health Canada, personal communication, July 26, 1994).

Health professionals are being challenged with the growth of the survivorship movement to view and define cancer survivors in much broader terms than they have in the past. The survivorship



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movement in the U.S. has been growing over the past 10 to 15 years and there are several national and state organizations specifically focused on survivorship issues. Currently in Canada, the only national organization for cancer survivors is the Canadian Breast Cancer Network, which has been formed recently (N. Bourque, personal communication, November 16, 1994). As well, the concept of adult cancer survivorship is receiving more and more attention in the literature.

However, there are inconsistencies in the definition and description of adult survivorship. The traditional medical definition of a cancer survivor is one who has remained free from disease five years or more after diagnosis (Hassey Dow 1990; Hassey Dow 1991; Ruccione & Fergusson, 1984). These people are considered "cured" (Leigh, McCaffrey Boyle, Loescher, & Hoffman, 1993). Many people who have or have had cancer reject this definition of a cancer survivor (Leigh, 1992). Mullan (1990), who was one of the leaders in the survivorship movement in the U.S., stated: "Survival, quite simply, begins when you are told you have cancer... and continues for the rest of your life" (p.1-4). Cancer survivorship has been described by many as a process that begins at diagnosis (Adams, 1991; Gambosia & Ulreich, 1990; Hassey Dow, 1991; Rose, 1989) and consists of stages or "seasons" (Hassey Dow, 1990; Mullan, 1985).

Mullan (1985) identified three seasons of survival. The first season, identified as acute survival, begins at diagnosis. During this season, patients deal with acute side effects of treatment, issues related to their own mortality, and their overriding emotions of fear and anxiety. The second season is extended survival which follows the completion of the initial treatment. In this season, most patients are dealing with the severing of treatment-based supports and fear of recurrence, and are adjusting to physical and psychosocial compromise. The third season, permanent survival, is the stage most frequently associated with "cure". Issues during this season focus around long-term and late effects of cancer treatment, problems with employment and insurance and concerns about reproductive health (Hassey Dow, 1990; Leigh et al., 1993; Mullan, 1985).

## Long-term effects of treatment

Although the process of survival is unique for each individual, there are some common issues which are notable. Because survivorship of adult cancers is a relatively new area of study, accurate information about the long-term or late effects of treatment is limited. Much of what is known has been gained from the experiences of paediatric cancer survivors (Loescher et al., 1989). Furthermore, the newer cancer treatments such as bone marrow transplantation and biological response modifiers offer some patients increased disease-free survival. However, the long-term physical and psychological effects associated with these treatments for adult survivors have yet to be identified (Hassey Dow, 1991).

## LA SURVIVANCE À UN CANCER CHEZ L'ADULTE: PROBLÈMES ET DÉFIS

### ABRÉGÉ

Avec le développement du mouvement des survivants au cancer au Canada et aux États-Unis, les prestataires de soins de santé ont à relever le défi suivant: répondre aux besoins spécifiques des adultes ayant survécu au cancer. Destiné aux infirmières en oncologie, cet article passe en revue les différents aspects de la survivance chez l'adulte. Les divers problèmes rencontrés par les survivants adultes ainsi que les répercussions sur la pratique oncologique y sont aussi abordés.

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There are many potential physical sequelae to the major forms of cancer treatment. Potential long-term and late effects of therapies can range from those that alter activities of daily living to major organic complications or secondary cancers (Hassey Dow, 1991). Alterations in daily living may be manifested by fatigue, arm stiffness, dermatologic problems, dental caries or cataracts (Carnevali & Reiner, 1990; Hassey Dow, 1991). Organic complications may include: Sexual and reproductive functioning alterations, neurologic effects such as neuropathy, vascular effects including lymphedema or cardiomyopathy, pulmonary effects such as fibrosis, urologic effects consisting of chronic cystitis, and gastrointestinal effects such as cirrhosis. The development of second malignancies, especially for those who have received alkylating agents, may be another long-term physical effect of treatment (Carnevali & Reiner, 1990; Hassey Dow, 1991; Loescher et al., 1989). Noteworthy, chemotherapy-related second malignancies account for a very small percentage of mortality figures in long-term survivors of primary cancers (Hassey Dow, 1991; Loescher et al., 1989). In general, the occurrence, frequency and severity of these sequelae depend on many factors such as the type of cancer; the location, size and extent of the primary tumour; intensity and type of treatment; and age and overall health of the patient (Hassey Dow, 1991; Loescher, et al., 1989).

There are many potential chronic psychosocial consequences of surviving cancer. Again, there has been limited research addressing this topic for adult survivors of cancer (Quigley, 1989; Welch-McCaffrey, Hoffman, Leigh, Loescher & Meyskens, 1989). The literature suggests that areas of difficulty may include: Psychosocial effects of the physical alterations (body image and self esteem issues), fear of recurrence, uncertainty about the future, effects on family relationships, social adaptation dilemmas (related to continued social stigma associated with a diagnosis of cancer), re-entry into the workplace, and employment or insurance discrimination (Dudas & Carlson, 1988; Hassey Dow, 1991; Leigh et al., 1993; Quigley, 1989; Welch-McCaffrey, et al., 1989). Many authors propose that these issues and concerns are not being consistently addressed by health care providers (Carter, 1989; Dudas

& Carlson, 1988; Hassey Dow, 1991; Leigh, 1992; Mayer, 1992; Mayer & O'Connor, 1989; Quigley, 1989; Welch-McCaffrey, et al., 1989). Several reasons for this deficit in care have been described and include: Pessimistic attitudes and philosophies toward cancer survivorship, limited exposure to survivors after they have completed treatment by health care providers, low-prioritization of long-term concerns since most health care providers work in acute care settings and have acute care concerns, lack of coordinated care and interdisciplinary collaboration, and scarcity of research findings to support the advantages of rehabilitation interventions (Carnevali & Reiner, 1990; Carter, 1989; Carter, 1993; Dudas & Carlson, 1988; Mayer, 1992; Mayer & O'Connor, 1989).

## Challenges for nursing

Health care providers working in cancer care face tremendous challenges in extending the acute care framework to include care for the growing numbers of adult cancer survivors. Part of this challenge is for health care providers to view cancer as a chronic disease such as cardiac disease (Dudas & Carlson, 1988; Hassey Dow, 1991). Patients with cardiac disease in most parts of Canada have a rehabilitation program initiated at the time of their first myocardial infarction despite the fact that 30% will not survive their convalescent periods (Dietz, 1981). The goal of cardiac rehabilitation, in part, is to reverse or prevent progression caused by the underlying disease process (Mayer, 1992). Is this not what is needed for all survivors of cancer as well? Some suggestions to enhance the concept of cancer as a chronic illness and cancer rehabilitation include: Promoting the positive aspects in cancer care, promoting positive attitudes in nursing students toward cancer care, and promoting positive self-care and independence of patients with cancer (Dudas & Carlson, 1988).

A distinctly different group of health professionals is not required to support patients and their families during survivorship. Rather, what has been proposed is an extension of the treatment/acute-care focus to address survival issues starting at the time of diagnosis and continuing throughout the cancer experience (Welch-McCaffrey, et al., 1989). Nurses in community and ambulatory care settings already

## London's University Hospital announces breakthrough in treating prostate cancer

An international team of scientists and surgeons provided details of the world's first 3D ultrasound-guided cryosurgery prostate procedure at London, Ontario's University Hospital in February.

Cryosurgery, or the freezing of the prostate, is one of the newer treatments for prostate cancer. The problem with the procedure is the difficulty associated with freezing just the prostate with the cancer in it. When other structures immediately adjacent to the prostate are inadvertently frozen, unpleasant and debilitating complications occur for the patient. 3D ultrasound is a more effective technique to visualize what is being frozen.

On December 14, 1994, a procedure was performed during which the entire prostate was frozen with guidance of 3D ultrasound developed at University Hospital, London, and Robarts Research Institute. Subsequent evaluation showed that the entire prostate appears to have been frozen without significant damage either to the urethra, the bladder or the bowel.

In addition to the benefits this new procedure provides for patients, in terms of significantly shorter hospital stay and faster recovery, it has the potential to save the North American health care system between \$250 and \$300 million a year. In Canada, it represents a potential savings of \$25 million.

Prostate cancer is the most prevalent cancer in men, the most frequently diagnosed cancer and the second most frequent cause of death due to cancer in North American men.

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provide care for patients and their families during the different "seasons" of survival. However, how are the specific needs of this growing population to be met? Because this population has not been addressed in nursing research, what information or interventions are helpful to cancer survivors is not known. For example, what information do patients require about the possibility of recurrence, and what signs and symptoms should they report to the physician? When is it best to discuss this? What information is helpful about secondary cancers? Should ongoing psychosocial assessment take place during follow-up appointments in acute-care facilities or in the patient's home or community? What coping strategies are helpful in reducing the stress associated with cancer survival? How can cancer survivors be helped to deal with employment and insurance problems? Do health care professionals know the current resources within the community that could help patients or their family members deal with some of their survivorship concerns? Do health care professionals make the appropriate referrals? Can the role of primary and secondary cancer prevention be extended to meet the specific needs of patients with cancer?

## Recommendations

Some suggestions to address some of these challenges include conducting research studies on the informational needs of adult cancer survivors and including survivors as members of the research team. The development of research studies to examine issues around follow-up care, such as defining the interventions needed by survivors, are also recommended as they may provide direction for enhancing care.

The formation of partnerships between health care professionals and cancer survivors should be sought and encouraged so that

survivorship responsibilities can be shared with the survivorship community (Rowland, 1991). Survivors should be encouraged to form their own self-help and mutual support programs since former patients and current survivors are often seen as the single most valuable means of support for oncology patients (Hassey Dow, 1991). Health care professionals need to support such programs.

Information on available survivor-related resources for patients with cancer and their families should be compiled and updated regularly. This information could be shared with interested patients or family members at the time of diagnosis.

## Final words

Following treatment for cancer, people are faced with the often unexpected challenge of adapting to life after cancer. Nessim (1991) stated the following: "But it wasn't long before I discovered that although I was cancer-free, I certainly wasn't free of cancer. A series of personal incidents revealed that there was more to overcoming this disease than surviving the hardships of treatment. Instead, the end of treatment marked the beginning of a new and unexpected challenge: adapting to life after cancer." (p.xvii)

Do nurses not have a responsibility to prepare patients and families for the experiences they may face in living with and through cancer? Nurses as well as other health care professionals are challenged not only to think about how they can shape care for cancer survivors in the 1990s, but actually translate these thoughts into meaningful actions.

*Note: This paper is adapted from a presentation made at the Eighth International Conference on Cancer Nursing in Vancouver, August 1994.*

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