

UNIT 1

Adult Cancer Survivorship — What We Know

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Approximately 45% of men and 40% of women may develop cancer in their lifetime. One in four Canadians will die of the disease. Nearly two-thirds of all Canadians diagnosed with cancer can expect to live five years or more beyond their original diagnosis (Canadian Cancer Society's Steering Committee, 2009). Once considered a death sentence, cancer has now become a chronic disease for many Canadians. Biomedical and technical advances in conjunction with early detection have contributed to longer survival.

Although healthcare professionals have begun to recognize, acknowledge and treat the psychological, emotional, social, and spiritual effects of cancer at diagnosis and active treatment, less attention has been afforded the effects of survivorship. Cancer survivors and their families are discharged from the safety net of the cancer system and are expected to return to their 'normal' routine of daily life. Within each of the self learning modules included in this resource you will find a brief literature review, collectively these highlight how challenging it is for some cancer survivors to return to that 'normal' routine.

Who is a Cancer Survivor?

There is no single definition of cancer survivor or cancer survivorship. Surviving cancer or "survivorship" has been defined in different ways. People with cancer and health care professionals may differ in their definitions.

People with cancer tend to define cancer survivorship as being free of disease after the completion of treatment; cancer survivorship starts upon completion of treatment (Lesley Washington: Cancer survivorship workshop, 2008).

Health Care Professionals more commonly define cancer survivorship as a process of living with, through, and beyond cancer. Based on this definition, cancer survivorship begins at diagnosis. This definition accounts for people who continue to have treatment to either reduce risk of recurrence or to manage the cancer as a chronic illness. For example:

"From the moment of diagnosis and for the remainder of life, an individual diagnosed with cancer is a survivor"—NCCS Charter (National Cancer Coalition Survivorship)

"Cancer survivors are people who have been diagnosed with cancer and those people in their lives who are affected by the diagnosis, including family members, friends, and caregivers." (Center for Disease Control & Prevention)

The American Office of Cancer Survivorship (National Cancer Institute, 1996) has defined a cancer survivor this way, "an individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life. Family members, friends, and caregivers are also impacted by the survivorship experience and are therefore included in this definition." To learn more about what the Office of Cancer Survivorship has to say about survivorship go to <http://dccps.ncis.nih.gov.ocs>.

Phases of survivorship have also been described;

Phase	Living What's	Happening
Acute	With cancer	Diagnosed, in treatment
Extended	Through Cancer	Immediately after treatment is completed
Permanent	Beyond Cancer	Living beyond cancer, more than one year since

(Modified from Mullan, 1985).

Cancer can also be viewed through the lens of “meaning-making”. Perspectives of cancer survivorship have been described in various ways. For example cancer as a “non-issue”; minimization and denial of cancer; cancer as a definition of self; cancer as a turning point; and, cancer as a spiritually transformative experience (Vachon, 2001).

People with cancer travel different journeys. While there are some similarities, differences exist because people are individuals. Some of the literature has discussed the following cancer trajectories for people living with cancer:

- Live free of cancer for many years
- Live cancer free for years then die quickly of late recurrence
- Live cancer free from the initial disease but going on to develop a secondary cancer
- Live with intermittent periods of active disease
- Live with persistent disease
- Live after expected death

What drives trends in cancer survivorship?

- Better prevention, improved screening & earlier detection, lifestyle; infection control; regulation; screening (e.g. include mammography for breast cancer the Pap test for cervical cancer, and Fecal Occult Blood testing and colonoscopy for colorectal cancer).
- Improvements in cancer treatment.
- More effective treatment of side effects and comprehensive supportive care make it increasingly likely that people can successfully complete treatment with minimal reductions in dose or intensity of therapy, minimal interruptions, and improved tolerance.
- The development of targeted therapies which effectively kill cancer while minimizing side effects may be less toxic than standard therapy. Examples include image guided surgery, Intensity Modulated Radiation Therapy (IMRT), molecular/biologic systemic therapies.
- Population-based disease prevention and management such as evidence based practice guidelines and protocols, measurement of quality indicators, shorter knowledge transfer gap in use of evidence.

Why is it important for us to talk to people with cancer about cancer survivorship?

People with cancer want to know “what comes next” after completing treatment. Talking about survivorship helps some people adjust to and live with uncertainty. Talking about survivorship issues helps people feel less anxious, less ambivalent, even less frightened at the completion of active treatment. Many people often feel anxious at the end of treatment because their “safety net” of support from regular and frequent contact with the health care team ends. What are the issues that survivors may deal with as they complete treatment? Some people may experience physical problems (immediate or long-term), have difficulty returning to work or experience discrimination at work, experience sexual and/or relationship problems, express fertility concerns, fear of recurrence, or feel like their social network has changed or be inadequate.

We know that fear of recurrence is common among most cancer survivors. Many people find it hard to know what is “normal” after cancer which can lead a person to over-interpret the significance of minor physical problems and be unsure about what needs to be reported to the doctor or health care team. Oncology nurses can help people deal with their fear of recurrence by reviewing information with them about risk of recurrence and how lifestyle choices may impact that risk going forward. Nurses assist people treated for cancer and their family in adjusting to the uncertainty of survivorship. Helping redefine “normal,” and discussing the importance of routine follow-up visits is an important nursing role. For people with cancer taking long term oral medications to help reduce the risk of cancer recurrence, the nurse plays a vital role in ensuring there are no barriers to taking medications as prescribed. (More information is available about issues related to fear of recurrence in Unit 4.)

Relationships can undergo changes when cancer is diagnosed. Relationship problems that may have been ignored before cancer can surface. Some families and friends may become closer, while others become more distant. Some families and friends may have exhausted their ability to be supportive. It’s important to realize that the entire family is changed by the cancer experience, but the family may not recognize these changes. See also Unit 6 for more information about relationships and cancer survivorship.

The State of Cancer Survivorship in Canada:

In 2010 when this module was developed the picture of cancer survivorship looked like this:

- Varied definitions and perspectives of “survivors” and “survivorship”.
- Increasing awareness that many people survive a long time living with disease or living beyond detectable disease.

- A lack of Canadian data about cancer survivors, their needs, and gaps in care.
- Cancer survivors express concern about cancer recurrence, the development of second cancers, and treatment related late effects (e.g. the development of chronic co-morbidities affecting quality of life and mortality).
- Survivorship care is a neglected phase of the cancer care trajectory.
- A lack of clarity and little consistency across provinces, organizations, and programs about the type and nature of survivorship programs required.
- Agreement that cancer survivorship urgently requires national attention and coordination.
- A lack of coordinated commitment to taking action to address survivorship issues.

A group of researchers in British Columbia conducted an environmental scan as part of a larger survivorship project by the Cancer Journey Action Group of the Canadian Partnership Against Cancer (CPAC). The survivorship project aimed to move a national cancer survivorship agenda in Canada forward. The scan consisted of both a literature search as well as individual interviews with 47 key informants with a threefold purpose:

1. To explore the nature of and extent to which cancer survivorship conceptualization, research and practice is undertaken in Canada,
2. To identify some of the key Canadian contributors to cancer survivorship undertakings, and
3. To identify resources from the literature that may prove useful in future cancer survivorship efforts in Canada.

You can find the full report on the Canadian Partnership Against Cancer web site, <http://www.partnershipagainstcancer.ca/index.html>.

Who is The Canadian Partnership Against Cancer (CPAC)?

CPAC is an independent organization funded by the federal government to accelerate action on cancer control for all Canadians. “We are a partnership of cancer experts, charitable organizations, governments, patients and survivors, determined to bring change to the cancer control domain. We work together to stimulate generation of new knowledge and accelerate the implementation of existing knowledge about cancer control across Canada.” (Accessed from the CPAC web site June 5, 2010) CPAC evolved from the Canadian Strategy for Cancer Control (CSCC). The CSCC drafted Canada’s first national cancer control plan and advocated successfully for its funding.

Key Pieces of Work to Date: Understanding Cancer Survivorship Beyond Canada

Cancer survivorship emerged a number of years ago as a priority concept within cancer care in the United States and a number of key documents were produced. The Institute of Medicine (IOM) produced a document titled *Ensuring Quality Cancer Care* (1999) focused on ensuring quality cancer care. Key messages from that work included the fact that high quality care results in improved outcomes for people treated for cancer. The IOM went on to say, “Continued follow-up should include basic standards of care that address the specific needs of the long-term survivor” (IOM, 1999). Other key documents from the IOM include *Childhood Cancer Survivorship: Improving Care and Quality of Life* (2003), *Meeting the Psychosocial Needs of Women with Breast Cancer* (2004), *From Cancer Patient to Cancer Survivor: Lost in Transition* (2005), *Caring for the Whole Patient* (2007).

From Cancer Patient to Cancer Survivor: Lost in Transition advocated for the development of a formal care plan for cancer survivors that integrates, within one document, key treatment-relevant variables, exposures, late-effect risks, and management and follow-up.

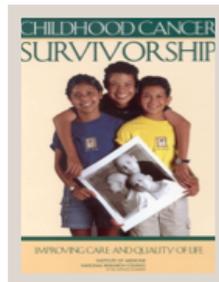
<http://video.google.com/videoplay?docid=5016792703273138301#>.

Caring for the Whole Patient focused on the emotional and social issues that people with cancer often encounter during survivorship which may greatly affect their well-being.



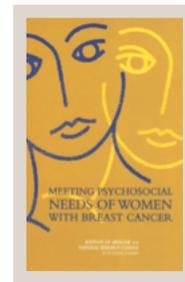
From Cancer Patient to Cancer Survivor: Improving Care and Quality of Life

(2003)



Childhood Cancer Survivorship: Improving Care and Quality of Life

(2004)



Meeting the Psychosocial Needs of Women with Breast Cancer

(2005)

Meeting the CANO/ACIO Standards and Competencies:

Reviewing and using this section in practice, the nurse will be addressing practice domain number six decision making and advocacy.

Competency—advocating for the individual/family’s wishes and decisions when developing the inter-professional plan of care.

Recognizing your patient as a cancer survivor focuses your assessment so that you explore survivorship issues with your patient and their family. You learn through your assessment what survivorship issues are important to them and you share this information with the team. This helps to shape the patient’s care plan.

For example, you discover that your patient wants to return to work upon completion of treatment. As a result, the care plan now includes interventions to help facilitate re-entry into the workforce such as referral to the social worker and teaching about transitioning back into the workforce.

Competency—documenting the individual’s goals and preferences for decision making and the processes used to arrive at these decisions.

Your documentation reflects your patient’s desire to return to work as soon as possible after completing treatment (goal) and includes his desire to be directly involved in any decision making related to this goal. Documentation includes his reasons for returning to work as soon as possible after completion of treatment (financial and social).

Another practice standard which would apply to this section is practice domain number seven, professional practice and leadership.

Learning about survivorship prepares you to care for patients after the completion of cancer treatment. By reading this module and becoming better informed about survivorship you are meeting the competencies within this practice standard.

Suggested Learning Activities:

1. Read the Institute of Medicine (IOM) reports and access IOM fact sheets on survivorship by [clicking here](#), watch the [IOM video](#).
2. Reflect on your current practice. What competencies are you already meeting in your practice based on having a broad understanding of the current status of cancer survivorship? How might you change your practice having learned more about cancer survivorship in this unit?

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