Adult Cancer Survivorship
A Self-Learning Resource for Nurses
Kim Chapman MScN, CON(C), Jennifer Wiernikowski, MN, NP–Adult, CON(C)

Contributors:
Margaret Forbes, RN, MN, NP-Adult, CON(C), Joan Hamilton, MScN,
Lynne Jolicoeur, RN, MScN, CON(C), Dr. Anne Katz, RN, PhD, Virginia Lee, RN, PhD,
Jan Park-Dorsay, RN, MN, NP-Adult, CON(C), Brenda Sabo, RN, PhD,
Lori Santoro, RN, CON(C), Myriam Skrutkowski, RN, MSc, CON(C),
Mary Vachon, RN, PhD, Tracy Soloninka, RN, MS Oncology, CON(C),
Miriam Corne, BScN, MEd, CON(C)

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Table of Contents

04 Purpose
04 Objectives
07 Learning Activities
09 Unit 1 — Adult Cancer Survivorship: What We Know
17 Unit 2 — Models of Care for Patients on Follow-up After Treatment for Cancer
36 Unit 3 — Late Effects of Cancer Treatment
51 Unit 4 — Living with the Fear of Recurrence
67 Unit 5 — Complementary and Integrative Therapies
84 Unit 6 — Relationships
103 Unit 7 — Sexual Health
112 Unit 8 — Psychosocial Health and Well-being
142 Unit 9 — Return to Work
151 Unit 10 — Risk Prevention Activities
173 Unit 11 — Resources and Tools
Definition of Cancer Survivors

Cancer survivors are defined, for the purpose of this self-learning resource, as people who have completed definitive cancer treatment including surgery, radiation therapy, and/or systemic therapy. Extended treatments beyond these modalities (e.g. targeted therapy and hormonal therapy) might be ongoing and people on long term treatments such as these would be considered cancer survivors.

Purpose

The purpose of this resource is to develop and expand nurses’ knowledge in the care of the patients and families surviving cancer. Knowledge will increase awareness of the important role nurses play in cancer survivorship care. Knowledge acquired will promote the integration of concepts and theories of cancer survivorship, thereby facilitating a higher quality of care delivery to patients and families during survivorship. The resource is designed to be a practical clinical resource for the nurse at the point of care.

Objectives

NURSES WILL

- Develop an increased awareness of cancer survivorship, the physical psychosocial and spiritual changes and experiences of cancer and its treatment.
- Enhance their ability to fully assess the needs of cancer survivors and their families.
- Be able to identify the health teaching and health promotion activities that can positively impact cancer survivors and their families as they move towards wellness and possibly reduce the risk of recurrence of their disease.
- Be able to design a care plan for cancer survivors and their families.
- Develop knowledge about the transition cancer survivors go through as they experience the phases of survivorship.
- Acquire knowledge enabling them to provide evidence based cancer survivorship care.
Canadian Association of Nurses in Oncology
Association canadienne des infirmières en oncologie

CANO/ACIO’s Commitment to Developing Excellence in Nursing Education:

In 1984 the Canadian Association of Nurses in Oncology (CANO/ACIO) was established as the first national professional oncology nursing association to support the efforts of Canadian nurses in promoting and developing excellence in oncology nursing. Today, CANO/ACIO remains the national professional association for oncology nursing. It is dedicated to supporting the practice of Oncology Nursing and meeting the health care needs of individuals and families affected by cancer.

Oncology nursing is a specialty area of nursing practice that must be continually supported by additional knowledge and clinical skills. Ongoing education and professional development activities provide opportunities needed for oncology nurses to grow, to enhance their knowledge and practice base, and to support excellence in practice (Standards of Care, Roles in Oncology Nursing and Role Competencies, 2001).

As the professional organization for oncology nursing, CANO/ACIO has set standards and competencies for nursing practice that guide the care we provide to cancer survivors.

Nursing standards describe what nurses do and what nurses are accountable for in practice. They guide the knowledge, skills, judgments, and attitudes that are needed to practice safely (Eifert, 1995; Standards of Care, Roles in Oncology Nursing and Role Competencies, 2001). The standards for oncology nursing practice are based on the Standards of Care to which Canadians with cancer are entitled. The Standards of Care are client-focused statements to ensure that all individuals with a diagnosis of cancer and their families receive the level of care and expertise from the nurses who care for them (Standards of Care, Roles in Oncology Nursing and Role Competencies, 2001).

Nursing competencies are statements, which describe expected performance behavior and reflect the professional attributes required in a given role, situation, and practice setting needed to provide safe and effective practice for the public.

CANO/ACIO is increasingly aware that many patients survive for a long time while living with active disease or live beyond detectable disease with all the long-term physical and psychosocial consequences of therapy. CANO/ACIO is also aware that for a number of cancer survivors, their diagnosis leads to transformation and some experience post-traumatic growth following their cancer diagnosis and treatment. Nurses can make a positive difference in the lives of survivors through ongoing interventions and interactions that influence the patient’s ability to stay healthy and enjoy the highest possible quality of life. It is hoped that this resource will guide nurses in translating cancer survivorship knowledge into practice. It is further hoped that as nurses learn more about their roles in cancer survivorship care, their passion for oncology nursing will be fueled.
Examining the definitions of cancer survivorship is an important consideration. Cancer survivors and their families, health care providers, and professional associations may adopt varying working definitions to guide their work. Broadly defined, the National Cancer Institute defines cancer survivorship in this way:

In cancer, survivorship covers the physical, psychosocial, and economic issues of cancer, from diagnosis until the end of life. It focuses on the health and life of a person with cancer beyond the diagnosis and treatment phases. Survivorship includes issues related to the ability to get health care and follow-up treatment, late effects of treatment, second cancers, and quality of life. Family members, friends, and caregivers are also part of the survivorship experience (NCI, 2010).

For the purposes of the CANO/ACIO Adult Cancer Survivorship: Self-Learning Resource for Nurses, the working definition is very focused. The units included in this resource are crafted according to the notion that cancer survivors are people who have completed definitive cancer treatment including surgery, radiation therapy, and/or systemic therapy. Extended treatments beyond these modalities (e.g. targeted therapy and hormonal therapy) might be ongoing and people on long term treatments such as these would be considered survivors.
Learning Activity:


CANO/ACIO’s Standards for the Specialized Oncology Nurse:

A practice standard (core competency) encompasses the knowledge, skill, judgment, and application necessary for effective practice. A competency describes the behaviors expected of the oncology nurse in meeting the practice standard. Below are the practice standards. Please refer to http://www.cano-acio.ca/conep for the complete list of competencies for each standard.

Practice Standard 1: Comprehensive Health Assessment

The specialized oncology nurse conducts timely and comprehensive assessments of the health and supportive care needs of the individual with cancer and their families across the cancer continuum using a systematic approach that is sensitive to language and culture. The specialized oncology nurse considers the situational context and the needs and responses of the individual and family in determining the scope and depth of assessment.

Practice Standard 2: Supportive and Therapeutic Relationships

The specialized oncology nurse engages in caring and therapeutic relationships with individuals with cancer and their families. These relationships are supportive and sensitive to changing physical and psychosocial-spiritual responses.

Practice Standard 3: Management of Cancer Symptoms and Treatment Side Effects

The specialized oncology nurse integrates and applies knowledge of cancer pathophysiology, disease progression, treatment modalities, treatment side-effects and complications, and symptom problems to assess, plan, implement, and evaluate the outcomes of best practice/evidence-based care and other clinical interventions.

Practice Standard 4: Teaching and Coaching

The specialized oncology nurse prepares individuals with cancer and their families for the many different aspects of the cancer experience providing education, psychosocial-spiritual support, and counseling across the continuum.
Practice Standard 5: Facilitating Continuity of Care/Navigating the System

The specialized oncology nurse promotes and facilitates continuity of care across care settings and between health care providers by sharing information on the individual/family’s current situation, plan of care and goals. The specialized oncology nurse assists the individual/family to navigate the health care system through understanding its structure, system and process, and providing them with strategies to work within that system.

Practice Standard 6: Decision Making and Advocacy

The specialized oncology nurse, in collaboration with other team members of the interprofessional health care team, facilitates self-determination and informed decision making for the individual/family. The specialized oncology nurse advocates on behalf of the individual/family, communicating and documenting their preferred approach to care.

Practice Standard 7: Professional Practice and Leadership

The specialized oncology nurse engages in critical thinking, integrates best practice/evidence-based knowledge, exercises ethical judgment, and advocates for changes when institutional policies fail to meet the needs of oncology patients.

© Practice Standards and Competencies for the Specialized Oncology Nurse, (CANO/ACIO), 2006.
UNIT 1

Adult Cancer Survivorship — What We Know

Kim Chapman RN, MSc(N), CON(C) & Jennifer Wiernikowski RN, MN, NP-Adult CON(C)
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:

<table>
<thead>
<tr>
<th>Phase</th>
<th>Living What’s</th>
<th>Happening</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute</td>
<td>With cancer</td>
<td>Diagnosed, in treatment</td>
</tr>
<tr>
<td>Extended</td>
<td>Through Cancer</td>
<td>Immediately after treatment is completed</td>
</tr>
<tr>
<td>Permanent</td>
<td>Beyond Cancer</td>
<td>Living beyond cancer, more than one year since</td>
</tr>
</tbody>
</table>

(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).


*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.

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**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)
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?
References & Bibliography


Canadian Association of Nurses in Oncology/l’Association Canadienne des Infirmières en Oncologie (CANO) (2001). Standards of Care, Roles in Oncology Nursing and Role Competencies. Ontario: CANO/ACIO.


Center for Disease Control & Prevention.


NCCS Charter (National Cancer Coalition Survivorship).

The Office of Cancer Survivorship (National Cancer Institute, 1996).

UNIT 2

Models of Care for Follow Up After Treatment for Cancer

Margaret Forbes, RN, MN, NP-Adult, CON(C), Lynne Jolicoeur, RN, MScN, CON(C)
Follow up after Cancer Treatment: Quick Overview

- Follow-up care is important to identify any arising health issues, to monitor and address any changes in health which occurred during cancer treatment, to identify cancer recurrence as early as possible, to detect early any other cancers which may occur, and to assess for psychosocial effects.

- Side effects of cancer treatment can present months to years after treatment.

- Nurses have a key role to play in providing follow-up care.

- Follow-up care involves regular medical check-ups.

- Nurses can teach cancer survivors about:
  - Changes that should be shared with their health care provider. It is important for cancer survivors to be aware of changes in their health and report any problems. Many times cancer recurrence is suspected or found by patients between follow-up visits.
  - Topics or issues to be discussed with their health care provider during follow-up care.
  - Emotional responses anticipated following treatment. Anxiety, distress, stress, and/or depression may occur months to years after cancer treatment finishes.

Introduction:

As cancer screening and treatment continues to advance, the number of cancer survivors continues to grow (Rowland, Hewitt & Ganz, 2008). Goals for ongoing care for cancer survivors include management of long term side effects, cancer surveillance for cancer recurrence or secondary malignancies, health promotion/cancer prevention health teaching, and ongoing assessment and intervention related to the psychosocial consequences of living with a cancer diagnosis (Oeffinger & McCabe, 2006). How is this care best provided? In North America follow-up care is generally provided by oncologists and the length of follow-up care is variable depending on the cancer site (Grunfeld et al., 2006). What, then, is the role of the general practitioner (GP) in caring for their patients with cancer? General practitioners are interested in providing follow-up care, but often do not possess the information required about ongoing surveillance for cancer recurrence and management of treatment related side effects, nor is there consistently a formal handover of care from the oncologist (Grunfeld et al. 2006; Oeffinger & McCabe, 2006). Some oncology centres discharge selected patients with cancer back to their family practitioners causing some anxiety for both the patient and their family doctor.
Follow-up care of cancer survivors can be inconsistent if there isn’t a health care provider who is responsible for coordinating the patient care. This can lead to cancer survivor dissatisfaction and an increase in psychological distress during the period of follow-up care (Hewitt, Bamundo, Day & Harvey, 2007; Oeffinger & McCabe). Advanced Practice Nurses specializing in oncology care may be ideally positioned to provide follow-up care.

Understanding the needs of cancer survivors is necessary in order to help them realize their full health potential (Rowland, Hewitt & Ganz, 2008).

Meeting the CANO/AICO Standards and Competencies

Models of cancer care are aligned with Practice Domain Five

Practice Domain 5. Facilitating continuity of care/navigating the system

Practice Standard:

The specialized oncology nurse promotes and facilitates continuity of care across care settings and between health care providers by sharing information on the individual/family’s current situation, plan of care, and goals. The specialized oncology nurse assists the individual/family to navigate the health care system through understanding its structure, system, and process and providing them with strategies to work within that system.

Two relevant competencies for this standard are:

- Facilitating the coordination of care through collaboration with the interprofessional team regarding individual/family goals, needs, plan of care, main concerns, and expectations.
- Applying knowledge to assist the individual/family to navigate the health care system, anticipating gaps and problems they may encounter, and guiding them in approaches to facilitate access to care.

As the cancer survivor moves from treatment to follow-up care, the main care provider may change depending on the model of follow-up care utilized by the centre where the care was received. The nurse plays a pivotal role in assisting the cancer survivor and their family in understanding which aspects of follow-up care are required and how to access it. Coordinating care through interprofessional collaboration assists the patient in the transition between care providers, regardless of which model of care is used. Interprofessional care can help to bridge potential gaps in health care services.

Two examples:

1. The nurse is assessing a cancer survivor during her first follow-up visit after completing chemotherapy for ovarian cancer. The model of care in the organization is to practice shared follow-up care in this group of patients. The nurse spends some time with the cancer survivor and her husband reviewing when to contact her family health team and when to call the cancer care team.
2. The nurse working in a gynecology oncology follow-up clinic meets with a young woman who has completed treatment for cervical cancer over 18 months ago. She presents with significant lymphedema to her left leg. After the clinic the nurse contacts the APN to understand the best approach to care in this situation. The nurse wants to know how to access best practice guidelines/evidence to manage lower limb lymphedema as well as information about the resources available in the local community.

**Literature Review:**

Much of the literature about models of follow-up care and transferring follow-up care has been conducted with patient populations in the context of planning for alternate methods of follow-up, prospective transfer of care, or evaluations of transfer of care programs (Cox et al., 2006; Kelly, Caldwell, & Henshaw, 2006; Koinberg, Langius-Eklof, Holmberg, & Friblund, 2006; Saegrov & Lorensen, 2006; Beaver & Luker, 2005; Miedema, Tatemichi, & MacDonald, 2004; Gaudine, Sturge-Jacobs, & Kennedy, 2003; Brown, Payne, & Royle, 2002; Wong & Chow, 2002; Grunfeld, Fitzpatrick, Mant, Yudkin, & Adewuyi-Dlaton, 1999; Glynne-Jones, Chait, & Thomas, 1997; Grunfeld, Mant, Yudkin, Adewuyi-Dalton, & Cole, 1996).

The purpose of this literature review is to familiarize the nurse with alternatives for follow-up cancer care, the various models of care available, and the issues cancer survivors face in the follow-up phase of cancer care.

**Care Provider and Models of Care:**

Alternatives for managing the growing number of people requiring follow-up care after cancer treatment must be considered and implemented to ensure ongoing needs are being met. In Canada there are several care providers who may provide follow-up care for cancer survivors including: oncologists, surgeons, advanced practice nurses, nurses, general practitioners in oncology, and general practitioners.

A systematic review by Lewis et al. (2009) described nurse-led versus physician-led care for cancer survivors who had completed active treatment for cancer considering the effectiveness and the cost effectiveness of this practice. The review identified four randomized controlled trials (RCTs). It is important to note that assessment of survival and recurrence rates, and psychological morbidity between nurse-led versus physician-led intervention groups were not statistically significant in any of the trials reviewed (Lewis et al.). Two of the four studies showed a statistically significant difference between groups for patient satisfaction. In one study, significantly more patients were able to die at home instead of in hospital or hospice in the nurse-led group (29/72 vs. 14/62; RR 1.78; 95% CI: 1.04-3.06) (Lewis et al.). A significantly greater number of patients identified with the indicators “reassurance” and “being checked” in the physician-led group versus patient-initiated telephone (nurse-led) group for breast cancer follow-up, although this may have been a reflection of the telephone intervention as opposed to the type of health care provider providing the care (reassurance: 20 vs. 3; p ≤ 0.001; being checked: 7 vs. 0; p = 0.003)
(Lewis et al.). In the same study, women followed in the patient-initiated (nurse-led) group found it convenient to initiate their own follow-up care compared to physician-led care (22 vs. 1; p ≤ 0.001) (Lewis et al.). From a resource and economic viewpoint, taking all costs into consideration, nurse-led clinics had a slight advantage over physician-led clinics, although not statistically significant (Lewis et al.). The authors of the systematic review found that the overall quality of all the studies was poor to moderate, with small sample sizes, not representative of all cancer sites, short duration follow-up, economic analyses only partially done, and results poorly reported in some studies (Lewis et al.). Caution must be taken when considering the results of the trials presented in this systematic review, however, this growing body of research provides innovative opportunities for health services researchers and decision makers as they conceptualize and evaluate new models of care delivery for this patient group.

This systematic review highlights that overall, cancer survivors found nurse-led care to be very acceptable, that it is feasible to implement and evaluate nurse-led care models, and that ongoing studies to evaluate the effectiveness and cost-effectiveness of nurse-led follow-up clinics for patients with care are needed (Lewis et al.).

When asked to rate their preference for follow-up care, patients with lung cancer indicated a higher preference for specialist follow-up and nurse-led telephone follow-up, and least preferred GP follow-up care. This was due to the assumed lack of GP expertise in providing follow-up care and for some patients it was about negative experiences related to diagnosis (Cox et al., 2006). Although specialist and nurse-led follow up scenarios both scored highly, preference for specialist follow-up was associated with physicians knowing the patient’s history of cancer. Most patients enjoyed the convenience of telephone follow-up. Nurse led clinics were perceived as being invaluable for support and information.

In a randomized control trial comparing specialist follow-up to GP follow-up, women with breast cancer indicated greater satisfaction with GP follow-up (Grunfeld et al., 1999; Grunfeld et al., 1996). It is important to note that one third of eligible patients did not take part in this study, which may indicate that these women have differing opinions and may prefer specialist follow-up. Similar sampling challenges have also been reported in other discharge studies where up to 50% of eligible participants refused to participate (Brown et al., 2002; Glynne-Jones et al., 1997). Another randomized trial looked at satisfaction between specialist follow-up and patient-initiated follow-up in women diagnosed with low risk breast cancer. The patient-initiated follow-up program consisted of written information on signs and symptoms of recurrence. Patients were advised to contact the Breast Care Nurse by telephone if they had symptoms. Yearly mammograms were conducted, but no follow-ups were planned. Patients in both group reported similar satisfaction levels (Brown et al.).

Understanding the perspective of the primary care provider (e.g. family doctor) is an important consideration in the management of follow-up care for cancer survivors. One study explored follow-up care from the primary care provider (PCP) perspective in a mail-out survey. Half (52%) of the PCP reported feeling comfortable in providing follow-up care to patients diagnosed with breast and colorectal cancer. Forty percent of respondents were
confident they were providing care according to the guideline. More than half of respondents rated the transfer of care from the oncologist to the primary care provider as fair to poor. The most common knowledge gap expressed by the PCP was the uncertainty in the type, frequency and duration of surveillance testing (Nissen et al., 2006).

In a systematic review comparing nurse-led versus conventional physician-led follow-up care for patients with cancer there were no statistically significant differences in survival between the groups (Lewis et al., 2009). Koinberg et al. (2004) found similar findings with overall survival scores being consistent between physician follow-up or follow-up on demand by a breast care nurse for women with breast cancer.

**Summary of Existing Models of Cancer Survivorship Care**

- Oncologist follow-up
- Primary care provider follow-up
- Shared care
- Nurse-led follow-up
- Interdisciplinary survivorship clinics

The following table provides examples of current models of care and care providers. In the future other models of follow-up care for cancer survivors may be introduced. When considering any model of care, the nurse should determine what the advantages and disadvantages may be taking into account the cancer survivor’s perspective. Once the model of care is known, the nurse can assist the cancer survivor in understanding what they can expect at follow-up visits and how to best prepare (see below: Facilitating a Systematic Assessment).

**Examples of Models of Cancer Survivorship Care: Advantages and Disadvantages:**

<table>
<thead>
<tr>
<th>Model of Care</th>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Oncologist Follow-Up</strong></td>
<td>■ Cancer survivors may have a trust relationship with their oncologist&lt;br&gt;■ Often long waits for appointments related to capacity issues&lt;br&gt;■ In busy practices cancer survivors may not be offered follow-up care</td>
<td><strong>Primary Care Provider Follow-up</strong>&lt;br&gt;■ Convenient&lt;br&gt;■ Provides continuity and a holistic approach to care (i.e. one health care provider who manages the care&lt;br&gt;■ Provider may lack confidence in surveillance of recurrence and what tests are routinely ordered in follow-up and require training about aspects of follow-up care</td>
</tr>
<tr>
<td>Shared Follow-Up</td>
<td>People may feel more secure with oncologist and primary care provider follow-up</td>
<td>Scheduling of appointments may overlap and routine tests may be missed if communication is not optimum between care are providers</td>
</tr>
<tr>
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</tr>
<tr>
<td>Nurse-led Follow-up Clinics</td>
<td>Nurses provide quality follow-up care in collaboration with oncologists</td>
<td>Nurse-led care may not always be desired by the cancer survivor</td>
</tr>
<tr>
<td></td>
<td>Nurse-led follow-up clinics create capacity in the system such that oncologists can spend more time with newly diagnosed patients or those with complex medical needs</td>
<td>Cost effectiveness has not yet been firmly established</td>
</tr>
<tr>
<td></td>
<td>Studies have indicated patient satisfaction with this model of care</td>
<td></td>
</tr>
<tr>
<td>Nurse-led Telephone Follow-up</td>
<td>Nurse and cancer survivor &quot;meet&quot; by prescheduled telephone appointment</td>
<td>Phone assessment is not ideal for diagnosing new concerns</td>
</tr>
<tr>
<td></td>
<td>Long distance travel is not required to receive followup care</td>
<td>Nurses must have excellent assessment and triaging skills to determine if the person requires urgent or immediate care based on symptoms</td>
</tr>
<tr>
<td></td>
<td></td>
<td>May require further liaison with primary care provider to assist with new health concerns</td>
</tr>
<tr>
<td>Interdisciplinary Survivorship</td>
<td>Opportunity to meet needs from a variety of perspectives including: nurses, dieticians, physicians, social workers, and psychiatrists.</td>
<td>Those attending the clinic may end up having longer visits due to interdisciplinary nature of clinic</td>
</tr>
<tr>
<td>Clinics</td>
<td>Focus is on health promotion, risk reduction and prevention of other diseases</td>
<td></td>
</tr>
</tbody>
</table>
Regardless of which model of care is utilized to provide follow-up care, the following are valued parts of high quality follow-up care: continuity of care, quality of life, meeting psychosocial/information needs, and utilization of guidelines for follow-up care. There is not yet clear data regarding the cost effectiveness of any one model compared to another.

**Continuity of care:**

Using a focus group approach to collect the viewpoints of women with breast cancer about follow-up care, continuity of care was identified as more important than provider of care (Kelly et al., 2006). The importance of continuity of care was also reported by six women with breast cancer in a phenomenological study (Gaudine et al., 2003). Anxiety was the most significant factor associated with refusal of discharge in a study measuring the effectiveness of a discharge contract in a sample of patients with cancer; however, continuity of care by a consistent care provider was significantly more important to those who refused discharge (Glynne-Jones et al., 1997). Similar findings were reported in focus groups of patients with cancer treated in private or public hospitals in Hong Kong (Wong et al., 2002). As well, participants reported dissatisfaction when they were exposed to a rotation of physicians. Continuity of care continues to pose a challenge in follow-up care for cancer survivors. A systematic review is underway to determine what interventions improve continuity of care and the effectiveness of these interventions in improved follow-up care (Aubin, Giguère, Verreault, Fitch & Kazanjian, 2009).

**Quality of Life:**

Several randomized controlled trials have demonstrated that method of follow-up care does not negatively impact quality of life (Brown et al., 2002; Grunfeld et al., 1996; Grunfeld et al., 2006). Aspects of follow-up care that impact quality of life include a need for better symptom control, rehabilitation services, and emotional support (Saegrov et al., 2006; Wong et al., 2002). Quality of life was improved in a study comparing usual follow-up care versus nurse-led telephone follow-up showing that statistically significantly more patients with lung cancer were able to die at home versus in hospital or hospice (Moore et al., 2002).

**Psychosocial Needs:**

The importance of addressing patients’ psychosocial needs has been reported in many studies (Beaver et al., 2005; Cox et al., 2006; Gaudine et al., 2003; Kelly et al., 2006; Miedema et al., 2004; Saegrov et al., 2006; Wong et al., 2002). Psychosocial Health and well-being will be fully addressed in unit 8. Some of the psychosocial needs arising in follow-up care relate to anxiety and distress about the type of care provider, discharge from specialist care, actual follow-up care appointments, and cancer recurrence.

The model of follow-up care did not impact anxiety scores measured by the Hospital Anxiety and Depression scale (HADS) in two randomized trials (Brown et al., 2002; Grunfeld et al., 1996). Women with breast cancer who were randomized to specialist follow-up care reported
reassurance as an advantage compared to women in the patient initiated follow-up who reported convenience as an advantage (Brown et al.).

In a study measuring the effectiveness of a discharge contract, 56% of those who refused discharge had borderline or possible anxiety (HADS ≥ 8) (Thomas et al., 1997). Participants reported being anxious about discharge from specialist follow-up due to perceived lack of GP skills to detect cancer recurrence and delayed re-entry into specialist care when recurrence was detected (Thomas et al.). When anxiety scores were measured four months post discharge from follow-up care, there was a slight increase in participants with HADS scores greater than eight. Interestingly, participants’ self-report of anxiety was lower than scores measured by the HADS (Thomas et al.). These findings may suggest a need for interventions to address anxiety in patients who resist discharge.

Anxiety around the time of follow-up appointments has been reported by participants in other studies (Gaudine et al. 2003; Glynne-Jones et al., 1997; Miedema et al., 2004; Saegrov et al., 2006; Wong et al., 2002). Participants in four studies reported feeling reassured by negative findings during follow-up appointments (Beaver et al., 2005; Brown et al., 2002; Gaudine et al.; Kelly et al., 2006). In a focus group of women with breast cancer, reassurance that there was no clinical sign of cancer recurrence was vital to maintaining hope (Kelly et al.). Although women were often seen by junior doctors who focused their assessments on the affects of cancer treatment rather than the emotional consequences of cancer, participants were not concerned stating that their need for reassurance was met by being told their cancer had not recurred. The need for reassurance was attributed to anxiety and recommendations were made to integrate interventions on anxiety management into follow-up care (Kelly et al.). In a phenomenological study, women with breast cancer reported that they suffered from the fluctuation between reassurance and anxiety (Gaudine et al.). In an observational study, follow-up appointments were noted to have an optimistic tone and to be focused on short-term concerns, with follow-ups considered as a means of providing reassurance (Beaver et al.).

The most dominant theme that emerged from a qualitative study of patients diagnosed with cancer was the ‘fear of recurrence’ (Miedema et al., 2004). The fear of recurrence permeated all aspects of the participants’ lives regardless of how long ago they had been diagnosed with cancer. Patients with cancer in another study attributed their fear to the perceived inadequacy of the current follow-up approach to detect early recurrences (Wong et al., 2002). In another study, measuring the acceptability of discharge from follow-up, five percent of participants asked to return to hospital based follow-up care due to an unfounded fear of recurrence (Glynne-Jones et al., 1997). (Also see Unit 8: Psychosocial Health and Well Being).

**Information Needs:**

Cancer survivors have varying information needs regarding follow-up care. These include signs and symptoms of recurrence, future treatment options, and how to access supportive care services to discuss feelings (Kelly et. al., 2006; Saegrov et al. 2006). For example, women with breast cancer reported that specialist follow-up care met their information needs.
about cancer treatment and provided networking opportunities with other cancer survivors (Gaudine et al., 2003). Nurses have been identified as being experts in providing invaluable support and information (Cox et al., 2006). The need for structured information provision was identified by some cancer survivors who perceived that doctors were selective in providing information only to more well-educated patients (Wong et al., 2002). The need to clearly communicate about individual patient care information needs between the specialist and the GP was identified (Miedema et al., 2004).

**Guidelines for Follow-Up Care:**

The need for standards, guidelines, or protocols for follow-up cancer care have been identified and are particularly important in the implementation of follow-up approaches that go beyond specialist follow-up (e.g. nurse-led care) (Cox et al., 2006; Gaudine et al., 2003; Miedema et al., 2004; Saegrov et al., 2006; Wong et al., 2002). Participants in one study requested that standards be clearly communicated at the beginning of follow-up care so that expectations about care were clear (Gaudine et al.). One way to communicate this information and to individualize follow-up is through developing survivorship care plans (Earle, 2006; Hewitt et al., 2007). See Survivorship Care Plans below.

**Putting it all Together:**

In summary, the literature shows that cancer survivors are agreeable to follow-up care away from tertiary care settings. Research findings suggest that patients want reassurance that the ability to detect cancer recurrence and the quality of the care they will receive is not compromised when provided outside of the specialist hospital setting. Guidelines or survivorship care plans may be useful tools for primary care providers and cancer survivors in clarifying those necessary components of assessment and intervention (physical and psychosocial) during follow-up.

**Facilitating a Systematic Assessment:**

Cancer survivors should understand the plan for follow-up care and what signs and symptoms require reporting to a health care provider for assessment. Patients should be encouraged to share their survivorship care plan (see below for details) with all their health care providers.

*Assessment Questions For Nurses: the focus of the assessment is to determine if patients understand the proposed plan of follow-up care:*
1. Now that you have completed active treatment, what is your understanding of what happens next?
2. Who will provide follow-up care for you?
3. How often do you need to be seen for follow-up care?
4. What routine blood work and x-ray tests need to be done for you and how often?
5. What will you do if you suspect a new problem?
6. What questions do you have about the proposed plan of follow-up care?
7. What, if anything, would you change about the proposed plan of follow-up care?

**Priority Content for Patient Teaching:**

Depending on the site or type of cancer in question, best practice guidelines, or evidence based guidelines may be available to support follow-up care. The nurse needs to determine which guidelines are utilized by the centre where she/he works and refer to these as a basis for teaching the patient about relevant aspects of follow-up care.

For example, the cancer centre you work in may choose to utilize the *Canadian Medical Journal Association* (CMAJ) clinical practice guidelines for the care and treatment of breast cancer: follow-up after treatment for breast cancer (summary of the 2005 update) for women http://www.cmaj.ca/cgi/reprint/172/10/1319 (Grunfeld, Dhesy & Levine, 2005).

This guideline summary indicates that routine follow-up is required, including history and physical (including information about what needs to be included in a physical examination), and routine annual mammography. The guideline also provides teaching for health care providers related to various post treatment issues such as breast self examination, sexual functioning, body weight management, bone health, cognitive functioning, fatigue, and fertility. Health care providers are to advise women to report new and persistent symptoms without waiting until the next scheduled follow up visit.

**Summary—Models of Follow-Up Care:**

Cancer survivors, their family members and all Canadians dealing with cancer expect that cancer care will be available at the time it is needed. However, growing wait times for cancer assessment, diagnosis, and treatment have been an increasing concern for all.

When follow-up care is provided in a tertiary care setting by specialists (Surgical-Oncologist, Radiation-Oncologist and/or Medical-Oncologist) the demand for follow-up care may far exceed capacity. In addition, other health care providers such as general practitioners, advanced practice nurses, general practitioners in oncology, and others, are under-utilized where follow-up is within their scope of competency and practice. Some cancer centres have implemented alternate models of follow-up care as a pilot project or as standard practice. The assessment questions above may assist patients in understanding the model of care being implemented in their setting so they can be an active partner in directing their follow up care.
Survivorship Care Plans:

Survivorship care plans (SCP) can be used with all cancer survivors regardless of diagnosis or follow-up model used. One of the strong recommendations from the Institute of Medicine (IOM) published in the report From Cancer Patient to Cancer Survivor: Lost in Transition was in favour of implementing survivorship care plans (Hewitt, Greenfield, Stovall, 2006). The IOM subsequently published a second report dedicated to survivorship care planning titled Implementing Cancer Survivorship Care Planning: Workshop Summary (Hewitt & Ganz, 2007). These reports recommend the creation of survivorship care plans (SCP) when cancer treatment ends. The IOM reported that SCP have strong face validity and can reasonably be assumed to improve the care unless and until evidence accumulates to the contrary.

What is the Purpose of Survivorship Care Plans?:

The purpose of SCP is to improve communication between key stakeholders (cancer survivor, interdisciplinary oncology team, and primary care providers) in order to optimize continuity and coordination of care. This is especially needed at transition points such as between the cancer specialist and the health care team coordinating follow-up care.

What are Some of the Characteristics of a Survivorship Care Plan?

Ideally Survivorship Care Plans are:

- Portable documents
- Individualized
- Informative and educational
- Tools that help bridge transition from oncology care to primary care

What Should be Included in Survivorship Care Plans?

Recommendations for the elements to be included in a SCP include those listed below (Hewitt et al, 2006; Hewitt & Ganz, 2007; McCabe & Jacobs, 2008; Ganz & Hahn, 2008).

Recommended Elements of Survivorship Care Plans

- Specific diagnosis: including pathology, stage, and grade
- Treatment summary: includes the details and toxicities of all relevant cancer treatments including surgery, chemotherapy, radiation, targeted therapy
- Identification of actual and potential long term effects of treatment and suggested management.
- Surveillance plan for cancer recurrence: investigations and their frequencies
- Recommendations for screening for secondary and new primary cancers
- Risk reduction/health promotion strategies
In some settings, cancer site specific SCPs have been implemented and focus on screening for disease recurrence. This type of SCP provides recommendations regarding which investigations to perform, at what frequency and patient education guidelines related to symptoms of recurrence (see below). These SCPs are summaries of clinical practice guidelines regarding follow-up care developed for the health care team.

**Improving Care using Survivorship Care Plans: The Link Between SCPs and Clinical Practice Guidelines**

Cancer Survivorship care plans must be based on best evidence. Cancer survivorship is a relatively new domain of research. Clinicians providing survivorship care have limited access to specific clinical practice guidelines (McCabe & Jacobs, 2008). Grunfeld (2006) published a review of the international perspective related to cancer survivorship. In that review a list of relevant clinical practice guidelines is included from a variety of cancer care agencies.

Nurses searching for these types of clinical practice guidelines relevant to survivorship issues could use the following terms to help guide their search:

- Follow-up care (often disease site specific, e.g. Cancer Care Ontario)
- Long-term side effects (side effect specific: e.g. Putting Evidence into Practice (PEP) cards from ONS)
- Supportive care
- Coordination of care

**Barriers and facilitators to Implementation of Survivorship Care Plans:**

Nurses and other disciplines considering implementing SCPs in their clinical settings must have a good understanding of the barriers and facilitators prior to their implementation. The table below provides an overview of some of these considerations.

<table>
<thead>
<tr>
<th>Facilitators</th>
<th>Recommendations</th>
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<tbody>
<tr>
<td>Recommendations</td>
<td>Numerous national and international organizations have recognized the importance of implementing SCP and recommendations for their use. Nurses should reference these agencies when recommending their use in practice. For example: Canadian Partnership Against Cancer (CPAC), The Canadian Association of Nurses in Oncology (CANO/ACIO), Canadian Association of Psychosocial Oncology (CAPO), Institute of Medicine (IOM), Lance Armstrong Foundation (LAF).</td>
</tr>
<tr>
<td>Stakeholders &amp; Advocacy Groups</td>
<td>As awareness of SCP increases, stakeholders including cancer survivors, primary care providers and advocacy groups will request them as a standard of care.</td>
</tr>
<tr>
<td>Evidence</td>
<td>Research demonstrating improved outcomes for patient care associated with the implementation of SCPs.</td>
</tr>
</tbody>
</table>
Barriers

<table>
<thead>
<tr>
<th>Lack of Consensus</th>
<th>There is lack of consensus and evidence related to the implementation of SCPs.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time</td>
<td>Clinicians often support the concept of SCPs however cannot feasibly incorporate their development into a busy clinic setting. There is currently no reimbursement mechanism or workload measurement system to account for longer follow-up visits in which a SCP could be developed.</td>
</tr>
<tr>
<td>Health Human Resources</td>
<td>Human resources are limited. Planning needs to be carried out and resources allocated to ensure SCPs can be developed, implemented and evaluated</td>
</tr>
<tr>
<td>Knowledge</td>
<td>Information and clinical practice guidelines are required for practitioners who are developing SCPs. For example practitioners often lack knowledge around employment and insurance issues.</td>
</tr>
<tr>
<td>Medical Records</td>
<td>Further expansion of electronic medical records is required in order for clinicians to access the necessary information to include in a SCP. Current paper charts and many electronic health records make it difficult to gain a comprehensive picture of the cancer survivor’s experience (e.g. understanding the reason for dose modifications secondary to toxicity can be difficult to find in the health record).</td>
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</table>

Looking to Our Future — Consideration for Research on Survivorship Care Planning:

A comprehensive article was written by Earle (2007), in which a health services research agenda related to survivorship care planning was described. Earle recommended that each element of the SCP be evaluated in order to determine the impact on patient outcomes. Suggestions were made regarding the research method and concepts that could be utilized to evaluate each element of the SCP. If an element of a SCP does not result in improved patient outcomes and substantial resources are needed to support the care plan then it should not be considered for that specific patient population. With this in mind nursing researchers may be well positioned to explore SCPs and their impacts on the cancer system.

SCP could prove to empower and enable cancer survivors to direct their own care by facilitating their understanding of treatment history and actual and potential long-term effects of treatment (Ganz & Hahn, 2008). Conversely, some might argue that a SCP may contribute to anxiety for some cancer survivors (e.g. fear of recurrence, worry about late effects of treatment). Research is needed to determine the impact of SCPs on psychosocial outcomes and to determine who does and who does not benefit from these tools.
Website:

http://www.cancercare.on.ca/cms/One.aspx?portalId=1377&pageId=10186
Examples of evidence based guidelines for cancer care

www.nursingcenter.com/ajncancersurvivors
Report from nursing symposia related to cancer survivorship. Includes resources for care plans such as examples of care plans and reference for guidelines (under resources).

www.jco.org/cgi/content/full/24/18/2917
American Society of Clinical Oncology (ASCO) recommendations on fertility preservation.

www.cancer.net
ASCO people living with cancer. Under survivorship look for ASCO Cancer treatment summaries for examples for care plans.

www.livestrong.org
Lance Armstrong Foundation

www.survivorshipguidelines.org
CureSearch Children’s Oncology Group
Resources relevant to survivorship issues for survivors of childhood, adolescent, and young adult cancers.

http://www.aicr.org/site/PageServer?pagename=cs_guidelines

http://www.livestrongcareplan.org/
A collaborative initiative between Penn Medicine Oncolink and the Lance Armstrong foundation. Patients and or health care providers can enter patient specific information in order to generate a SCP. Note: users need to know detailed information about cancer treatment (including drugs names) in order to complete this on their own

Australian Guidelines by disease site that include recommendations for follow-up care and psychosocial oncology.
Examples of Survivorship Care Plans:

Case Study: Models of Follow-Up Care

N.B. is a 62-year-old male who has completed treatment for colon cancer. Initially diagnosed 6 months ago, he underwent bowel resection for a Stage 1 colon cancer with negative staging tests. He is now returning to the care of his general practitioner but he expresses a lack of confidence in his role and his GP’s role in the follow-up care process.

1. What model of follow-up care is described here?
2. What is the role of the nurse in providing information at time of discharge to N.B. and his family?
3. What information would assist his GP in providing follow-up care?
4. What tool would aid in the transition of care?

Answers:

1. Primary care provider follow-up model
2. N.B and his family require information about:
   a. Frequency of follow-up visits
   b. What the physical examination should entail
   c. Routine diagnostic tests required
   d. When and how to report new symptoms
   e. Coping with transition/readjustment etc.
3. The GP would benefit in receiving information:
   a. Indicated above in (2)
   b. An up-to-date evidence based practice guideline outlining follow-up care for patients with Stage 1 colon cancer
   c. Information about how to work up a suspected recurrence and fast-track referral back to the tertiary center if recurrence is found
4. A survivorship care plan would aid in the transition of care.

Case Study: Survivorship Care Plans

Part I

G.L. is a 69-year-old male, married, retired business executive. G.L. and his wife live in an urban area. His past medical history includes recently diagnosed mild hypertension, treated with a thiazide diuretic, and osteoarthritis treated with NSAIDS. He is a life long non-smoker. He consumes 3-4 alcoholic beverages on most days. G.L. lists golf and fishing as his forms of exercise.
As a result of a routine physical assessment, G.L. learned his PSA score was 4.6. Following referral to an urologist, he was diagnosed with T2a N0 M0 prostate cancer. The pathology was reported as adenocarcinoma, and his Gleason score was 2 + 4.

You are an oncology nurse who has provided care to G.L. during his treatment. He has just completed 30 external beam radiation treatments 3 months ago. He is being treated with anti-androgen therapy, Casodex.

This clinic appointment takes place one month after his last radiation treatment.
BP 142/82        Ht 180.0 cm Wt 104.5 BMI 32.25

His main concerns are:

1. Now that I am finished my radiation, and not coming to the cancer center everyday, who will be monitoring my condition?

2. I’m having more problems with controlling my urination. I feel like I have to go all the time, and I just can’t wait. I’m afraid to go out for a game of golf in case I wet my pants.

3. A guy at work had prostate cancer. His doctor told him if he ever had a really bad back pain, he better get it checked out right away. What does prostate cancer have to do with back pain? I’m confused.

Develop a survivorship care plan to address the issues identified in this case scenario. Include both actual, and potential issues for G.L. Ongoing surveillance, as well as risk prevention activities should be addressed. For examples of survivorship care plans see ‘resource’ section above.

Continue the Survivorship Care Plan Part Two, in Unit 10 “Risk Prevention Activities.”:

Linking Theory to Practice

Now that you have a good understanding of the various models of follow-up care and how to utilize survivorship care plans, subsequent units will provide more practical information to guide development of individualized survivorship care plans based on treatment history, late side effects, coping, and risk reduction activities that may aid in decreasing the risk of cancer recurrence and secondary malignancies.
References:


UNIT 3

Late Effects of Cancer Treatment

Lynne Jolicoeur, RN, MScN, CON(C), Lori Santoro, RN, CON(C), Myriam Skrutkowski, RN, MSc, CON(C)
QUICK OVERVIEW

- Many cancer survivors have a risk of developing late effects or a secondary cancer from cancer treatment received (surgery, systemic cancer therapy, and/or radiation therapy).
- A late effect is defined as a side effect that occurs months to years after a diagnosis of cancer and the completion of treatment, such as chemotherapy, radiation therapy, surgery, or a targeted therapy.
- Although cancer treatments are improving they can still bring late effects. The type of late effect(s) that may develop varies from person to person.
- Long-term side effects or complications differ from late effects of treatment because they begin during treatment and persist beyond the end of treatment.
- Secondary cancers are thought to be a result of previous exposure to chemotherapy and radiation therapy.
- Nursing care involves minimizing risk and facilitating early recognition of the late and long-term effects of cancer and cancer therapy. Treatment of late effects is an important part of cancer care.
- Secondary prevention practices, including lifelong surveillance, risk reduction activities and cancer screening, may reduce the burden of secondary cancers.

INTRODUCTION:

In Canada in 2004, there were an estimated 396,900 male and 456,500 female cancer survivors, for a total of approximately 853,400 Canadians (2.7% overall). This is a 21% increase from the corresponding 679,800 figure reported previously for 1998. The number of people diagnosed with cancer who can expect to survive at least five years is now 60% (National Cancer Institute of Canada, 2004). The growth in the absolute number of cancer survivors presenting with physical complications will continue to increase as a result of improvements in treatment modalities combined with demographic and health trends such as population aging.

Many cancer survivors are at risk for developing some type of late effect from cancer treatment. Late effects, also referred to as delayed effects, can appear months to years after treatment is over. These late consequences of treatment may include secondary cancers, cognitive problems, lymphedema, peripheral neuropathy, and/or cardiovascular conditions. Long-term effects are those side effects or complications of treatment that start during treatment but persist beyond the end of treatment (Eades, Chasen, & Bhargava, 2009). Some cancer survivors may be at risk to have both late effects and long-term effects of the disease and treatments.

Although cancer survivors likely participated in discussions about potential sequelae when treatment decisions were made, they may not recall some or any of that discussion. Nursing care involves minimizing risk and facilitating early recognition of the late and long-term effects of cancer and cancer therapy (Curtiss, Haylock, & Hawkins, 2006). Understanding late effects and educating cancer survivors proactively on effective strategies to manage and minimize the impact of those effects is rapidly becoming a core requirement for nurses and for cancer programs.
By understanding the late effects associated with individual drugs and treatment modalities the nurse can effectively support survivors to implement a survivorship care plan that includes disease-specific follow-up, screening recommendations, and information about possible late effects tailored to each patient.

**Meeting the CANO/ACiO Standards and Competencies:**

**Standards and Competencies relevant to this section:**

Reviewing and using this section in practice, the nurse will be addressing in particular the practice standards of Comprehensive Health Assessment and Teaching and coaching.

**Practice Standard: Comprehensive Health Assessment**

**Competencies:**

Regularly assesses and monitors for potential acute and chronic physical changes to the individual’s response to illness using focused assessment tools.

**Practice Standard: Teaching and Coaching**

**Competencies:**

Facilitates the individual/family’s understanding of the episodic and chronic nature of cancer. Facilitates the development of self-care in order to manage and anticipate the signs and symptoms of disease, side effects of treatments, and symptom identification.

**LITERATURE REVIEW:**

There is a broad range of potential late effects and long-term effects that can vary in severity ranging from mildly unpleasant to very severe (Curtiss, Haylock, & Hawkins, 2006; Eades, Chasen, & Bhargava, 2009). The possible physical and psychosocial sequelae of cancer and its treatments differ according to the age of the cancer survivor, the specific type of cancer, and the cancer treatment regimen received (Curtiss et al., 2006; Eades et al., 2009). Newer therapies such as the molecularly targeted therapies may decrease the burden of physical effects in individual cancer survivors. However, research clearly shows that pre-existing risk factors and specific clinical factors combine to increase a person’s risk of developing late effects or enhancing long-term side effects such as fatigue (Curtiss et al., 2006; Eades et al., 2009).
<table>
<thead>
<tr>
<th>Pre-existing Risk Factors</th>
<th>Specific Clinical Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Age</td>
<td>□ High-dose therapies</td>
</tr>
<tr>
<td>□ Co-morbidities</td>
<td>□ Combination treatment modalities (radiation and chemotherapy)</td>
</tr>
<tr>
<td>□ Heredity</td>
<td>□ Radiotherapy</td>
</tr>
<tr>
<td>□ Lifestyle factors</td>
<td>□ Certain chemotherapy drugs</td>
</tr>
</tbody>
</table>

The acquired physical and functional impairments are often complex for the person with cancer and can be life-threatening, anxiety-provoking, and associated with a negative impact on self-image and self-efficacy (Eades, Chasen, & Bhargava, 2009). Functional difficulties include immobility, incontinence, lymphedema, sleep disturbances, and attention difficulties. The more common long-term side effects or persistent symptoms have been identified as cognitive problems, fatigue, lymphedema, and peripheral neuropathy (Nail, 2001). They vary in terms of the population at risk, presumed causal factors, level of understanding of the natural history of the symptoms, and depth of the research base on preventing or managing the symptoms (Nail, 2001).

Cancer survivors who have experienced organ damage, organ failure, or premature aging due to treatments are likely to live with renal insufficiency, bladder damage, carotid artery disease, cataracts, muscle atrophy, and/or problems with memory and information processing.

Cancer survivors have a 14% higher risk of developing a new cancer, (NCIC, accessed online 2010) also known as a secondary cancer. Secondary cancers are thought to be a result of previous exposure to chemotherapy and radiation therapy. Of the 260,000 10-year cancer survivors in Ontario, second primary malignancies now account for 16% of all cancer incidences in this group (Cancer Care Ontario, accessed online 2010).

**Cognitive changes** include the inability to concentrate, remember or perform complex cognitive activities, or a combination of these. Such changes are most often related to chemotherapy or whole brain radiation (Curtiss, Haylock, & Hawkins, 2006; Muscari, 2006; ManageCRC.com accessed online 2010; Nail, 2001). Cancer survivors may attribute problems in cognition to fatigue, which raises questions about whether or not strategies to prevent or manage fatigue would also improve cognitive function. Emerging literature about the short- and longer-term cognitive impacts of chemotherapy is generating great interest among oncology health care professionals. This body of evidence is dynamic and changing. Other terms used to describe cognitive changes or impairments are chemo brain, chemo clutter, or brain fog (Muscari, 2006). Cognitive changes have been studied most widely in women undergoing treatment for breast cancer, with 17% to 75% reporting symptoms (ManageCRC.com accessed online 2010).
Fatigue is the most commonly reported symptom of cancer and cancer therapy (Gélinas, Fillion, & Fortier, 2004; Barton-Burke, 2006; Eaton & Tipton, 2009). The National Comprehensive Cancer Network (NCCN) defines fatigue as a common, persistent, subjective sense of tiredness related to cancer, or cancer treatment that interferes with usual functioning (2000). The causes of fatigue are varied and include anemia, hypercalcemia, pain, sluggish thyroid gland, depression, poor nutrition, and lack of physical strength (Gélinas, et al., 2004). The NCCN has clinical practice guidelines for nurses that are evidence based (www.nccn.org).

Lymphedema is one of the most widely recognized persistent symptoms and typically occurs secondary to surgical removal of lymph nodes and or radiation therapy to lymph node bearing areas (Golshan & Smith, 2006). Lymphedema is the abnormal accumulation of lymph fluid in the subcutaneous tissue, which can cause excessive swelling mostly in the limbs (Harris, Hugi, Olivotto & Levine, 2001). Untreated, the increased swelling can cause increased functional impairment and risk for recurrent cellulitis (Eaton & Tipton, 2009; Harris et al., 2001).

Peripheral neuropathy is associated with specific drug regimens and dose levels. In follow-up care it is common to hear cancer survivors report numbness and tingling in the hands and feet many years after completing cancer treatment. When the neuropathy involves a sensory component there are safety issues similar to those addressed in the care of people with diabetic neuropathy. (Armstrong, 2005; Curtiss, 2006) Chemotherapy-induced peripheral neuropathy (CIPN) is a quality of life issue for patients and is becoming seen more commonly because of the influx of chemotherapy agents that cause it (Armstrong, 2005; Curtiss, 2006; Eaton & Tipton, 2009)

Summary

All cancer survivors are at risk of experiencing the psychological impact of late effects, such as anxiety, mood changes, depression, coping ability, living with uncertainty, and relationship changes/problems. There is also the social impact, such as the ability to obtain/retain health insurance, and the ability to reintegrate into the work force (availability of work/ability to perform within the job, etc.). Please refer to the Unit 8: Psychosocial Health and Wellbeing and Unit 9: Return to Work for more information.

FACILITATING A SYSTEMATIC ASSESSMENT:

Major Late Physical Effects by Body System

This section of the unit focuses on the major physical late effects. These effects range from specific sequelae such as radiotherapy-induced cataracts to multisystem consequences of chemotherapy-induced premature menopause, including menopausal symptoms, bone loss, and potential cardiovascular effects.
**System Affected** | **Typical Causes** | **Typical Cancers** | **Typical Effects**
--- | --- | --- | ---
**Endocrine** | ■ Radiation to the cranium or nasopharynx - can damage the hypothalamic pituitary axis, causing secondary gonadal failure; also the testis is extremely sensitive.  ■ Chemotherapy (e.g. alkylating agents, especially high-dose cyclophosphamide, cytosine arabinoside, high-dose cisplatin, etoposide)  ■ Hormone therapy  ■ Surgery | Head & Neck  Testicular  Prostate  Gynecological | 1. Thyroid changes  2. Low testosterone  3. Reduced libido  4. Impotence  5. Irregular menses  6. Amenorrhea  7. Premature menopause  8. Azoospermia  9. Osteopenia  10. Osteoporosis  11. Infertility  12. Low levels of some hormones depending on area affected.

Subnormal levels of luteinizing hormone (LH), follicle-stimulating hormone (FSH), and prolactin inhibiting factor have been found in males and females treated for head and neck tumors with 4,000–7,800 cGy of radiation.

Gonadal toxicity may result from surgery, radiotherapy, chemotherapy, and/or hormonal therapy.

Bilateral oophorectomy in premenopausal women leads to abrupt onset of menopause and its associated consequences, including infertility, rapid onset of bone loss, and menopausal symptoms, are typically more severe than with natural menopause.

Pelvic radiotherapy and ovarian ablation with luteinizing hormone releasing hormone agonists have similar consequences to bilateral oophrectomy. Chemotherapy related amenorrhea is prevalent in premenopausal women with breast cancer, and algorithms are available to help predict risk based on age and chemotherapy regimen.

In men, damage to the germinal epithelium of the testis may result from alkylating agents or radiation.

Men treated with androgen-deprivation therapy for prostate cancer experience symptoms of hypogonadism including bone loss, and should be monitored for osteopenia or osteoporosis.

Otto, 2001; Ganz, 2001; Curtiss et al, 2006
<table>
<thead>
<tr>
<th>System Affected</th>
<th>Typical Causes</th>
<th>Typical Cancers</th>
<th>Typical Effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cardiovascular</td>
<td>■ Chemotherapy (e.g. anthracyclines such as doxorubicin, cisplatin, and cyclophosphamide)  ■ Targeted Therapies (e.g. ErbB2)  ■ Radiotherapy to the field encompassing the heart and mediastinum.  ■ People aged 65 or older &amp; those people who received high doses of chemotherapy have a higher risk of heart problems.</td>
<td>Breast  Small-cell lung  Ovarian  Sarcoma  Germ-cell  Hodgkin’s disease</td>
<td>1. Cardiomyopathy  2. Congestive heart failure  3. Acceleration of coronary artery disease  4. Valvular disease  5. Metabolic syndrome  6. Inflammation of the heart muscle.</td>
</tr>
<tr>
<td>Gastrointestinal</td>
<td>■ Radiation (alone or concurrent with chemotherapy) to the pelvis can lead</td>
<td>Colorectal  Gastric  Esophageal  Gynecological</td>
<td>1. Liver toxicity  2. Hepatic fibrosis  3. Cirrhosis  4. Veno-occlusive disease  5. Fistula formation  6. Chronic diarrhea</td>
</tr>
<tr>
<td>Genitourinary</td>
<td>■ Chemotherapy e.g. cyclophosphamide, ifosfamide, and cisplatin  ■ Radiotherapy  ■ Surgery</td>
<td>Genitourinary  Prostate</td>
<td>1. Hemorrhagic cystitis  2. Nephritis  3. Incontinence  4. Impotence  5. Erectile dysfunction  6. Men who had surgery involving removal of lymph nodes near the kidney, bladder, testicles, or rectum may have a risk of infertility.</td>
</tr>
<tr>
<td>Hematological/Immune</td>
<td>Leukemias</td>
<td>1. Cataracts</td>
<td></td>
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<tr>
<td>----------------------</td>
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<td></td>
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<tr>
<td>▪ Allogeneic bone marrow transplant</td>
<td>Lymphomas</td>
<td>2. Hypothyroidism</td>
<td></td>
</tr>
<tr>
<td>▪ Peripheral stem cell transplant</td>
<td>Multiple Myeloma</td>
<td>3. Growth failure</td>
<td></td>
</tr>
<tr>
<td>▪ Chemotherapy</td>
<td></td>
<td>4. Gonadal dysfunction</td>
<td></td>
</tr>
<tr>
<td>▪ Total body irradiation</td>
<td></td>
<td>5. Secondary malignancies</td>
<td></td>
</tr>
<tr>
<td>▪ Radiotherapy</td>
<td></td>
<td>6. Chronic Graft versus Host Disease (GVHD)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>7. Avascular necrosis</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>8. Osteoporosis</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>9. Risk for serious infection for those with splenectomy.</td>
<td></td>
</tr>
<tr>
<td>Lymphatic</td>
<td>Breast</td>
<td>Secondary lymphedema</td>
<td></td>
</tr>
<tr>
<td>▪ Surgery (node dissection)</td>
<td>Head and neck</td>
<td>1. Peripheral lymphedema</td>
<td></td>
</tr>
<tr>
<td>▪ Radiotherapy</td>
<td>GU</td>
<td>2. Trunical lymphedema</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Melanoma</td>
<td>3. Recurrent cellulitis</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Gynecological</td>
<td>4. Erysipelas</td>
<td></td>
</tr>
<tr>
<td>Musculoskeletal</td>
<td>Breast</td>
<td>1. Post mastectomy pain syndrome (PMPS)</td>
<td></td>
</tr>
<tr>
<td>▪ Surgery</td>
<td>Sarcoma (bone and soft tissue cancer)</td>
<td>2. Breast phantom sensations</td>
<td></td>
</tr>
<tr>
<td>▪ Radiotherapy</td>
<td>Lung</td>
<td>3. Impingement syndrome (Frozen shoulder)</td>
<td></td>
</tr>
<tr>
<td>▪ Chemotherapy</td>
<td>Childhood leukemia</td>
<td>4. Risk factors are preoperative psychosocial distress &amp; reconstructive surgery.</td>
<td></td>
</tr>
<tr>
<td>▪ Steroids</td>
<td>Prostate</td>
<td>5. Phantom limb pain due to amputation</td>
<td></td>
</tr>
<tr>
<td>▪ Hormonal therapy (androgen or estrogen suppressants)</td>
<td></td>
<td>6. Post-thoracotomy pain syndrome (occurs in 20-30% of individuals)</td>
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<td></td>
<td></td>
<td>7. Fatigue</td>
<td></td>
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<td></td>
<td></td>
<td>8. Osteoporosis</td>
<td></td>
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<tr>
<td>Neurologic</td>
<td>Pulmonary</td>
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<tr>
<td>--------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------</td>
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<tr>
<td>Chemotherapy: certain agents &amp;/or high doses of certain drugs can cause</td>
<td>Germ cell testicular Breast Lung Genitourinary</td>
<td></td>
<td></td>
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<tr>
<td>neurotoxicity (interferon alpha, platinum compounds (eg. cisplatin,</td>
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<tr>
<td>vinca alkaloids, antimitotics, and taxanes)</td>
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<tr>
<td>Cranial radiotherapy for brain tumours</td>
<td></td>
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<tr>
<td>Primary brain tumour Metastatic disease to the brain Spinal cord</td>
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<td></td>
</tr>
<tr>
<td>Neurologic</td>
<td>Pulmonary</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chemotherapy (e.g. bleomycin, alkylating agents, methotrexate, nitrosourea)</td>
<td>Germ cell testicular Breast Lung Genitourinary</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Radiotherapy to lung fields</td>
<td></td>
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<tr>
<td>Concurrent chemotherapy and radiation therapy</td>
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<tr>
<td>Recurrent respiratory infections in immunosuppressed patients</td>
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<tr>
<td>Bone or Marrow Transplant</td>
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<tr>
<td>Steroids such as prednisone &amp; dexamethasone</td>
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</tr>
</tbody>
</table>

9. Bone and soft tissue cancer survivors may experience physical and psychological effects of losing all or part of a limb, such as phantom limb pain.

References for above tables: Otto, 2001; Ganz, 2001; Curtiss et al, 2006
Late Effects from Surgery:

Late effects from surgery for cancer can vary depending on the surgical site and extent of the procedure. Nurses need to consider adhesions and scaring as well as the impact on body systems related to the site of surgery and what may have been removed in the surgical procedure. Radiation after surgery is common and can impact the long term healing by enhancing scar tissue and causing small visible blood vessels under the skin near the surgical site.

PRIORITY CONTENT FOR PATIENT TEACHING:

Screening for secondary cancer prevention

The prevalence of secondary prevention counseling for cancer survivors is low; this is a missed opportunity to promote healthy behaviours (Sabatino, Coates, Uhler, Pollack, Alley & Zauderer, 2007). With respect to cancer screening in particular, a study of a select group of colorectal cancer patients showed that they were more likely to participate in cancer prevention and cancer screening activities compared to those without a history of cancer (Kunitake, H., Zheng, P., Yothers, G., Land, R.R., Fehrenbacher, L., Giguere, J.K., Wickerham, L., Ganz, P.A., & Ko, C.Y, 2010). Secondary prevention practices, including lifelong surveillance and cancer screening, may reduce the burden of secondary cancers.

Nurses can encourage and educate cancer survivors about the benefits of life-long surveillance. This includes having the person learn how to monitor for new signs or symptoms that may reflect cancer recurrence. Appropriate screening tests are based on type of cancer and cancer treatment:

<table>
<thead>
<tr>
<th>Cancer Survivors</th>
<th>Screening</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treated for thyroid, head, neck, or throat cancer.</td>
<td>Yearly thyroid exam</td>
</tr>
<tr>
<td>Received bleomycin.</td>
<td>Pulmonary Function Testing</td>
</tr>
<tr>
<td>Received treatment that could affect the cardiovascular system.</td>
<td>Cardiac testing such as echocardiogram</td>
</tr>
<tr>
<td>Received radiation to the chest especially at a young age.</td>
<td>Mammogram</td>
</tr>
<tr>
<td>Received treatment that puts them at a higher risk for a second cancer.</td>
<td>Blood testing; CT Scans as appropriate</td>
</tr>
</tbody>
</table>
Received chemotherapy and/or radiation may be at higher risk of dental problems. Chemotherapy may affect tooth enamel. It may also increase the risk of long-term dental problems. High-dose radiation therapy to the head & neck can cause gum disease, change tooth development, & decrease saliva production, resulting in a dry mouth. Treatment history includes the use of bisphosphonates: Risk of osteonecrosis of jaw.

Received steroids may be at an increased risk of eye problems, such as cataracts

Regular check-ups with the dentist.

Regular check-ups with the optometrist or ophthalmologist.

Otto, 2001; Ganz, 2001; Curtiss et al, 2006

Cognitive problems:

- Report any concerns about problems with memory or concentration
- Keep a daytimer to track appointments, medications, and follow-up tests

(Nail, 2001; Muscari, 2006; Vardy et al, 2008; ManageCRC, accessed online 2010)

Fatigue:

- Identify factors which may increase fatigue and modify as needed
- Treatment-related fatigue is not necessarily an indicator of disease progression
- Strategies to cope with fatigue:
  - Energy conservation
  - Distraction
  - Stress management
  - Exercise
- Diary of fatigue levels to evaluate effectiveness of coping strategies

(Nail, 2001; Gélinas et al, 2004; Barton-Burke, 2006, Eaton & Tipton, 2009)

Lymphedema:

- Goals to prevent, manage and treat:
  - Avoid injury and infection to the affected limb
  - Gentle exercise and deep breathing to mobilize lymphatic drainage and flow
  - Maintain a healthy body mass index
  - Use compression garments as appropriate (e.g. arm sleeves, leg stockings)
  - Consider combined decongestive therapy: utilization of manual lymph drainage in combination with compression bandaging to redirecting the lymphatic fluid into functioning vessels and lymph nodes

(Curtiss et al, 2006; Eaton &Tipton, 2009; Harris et. al., 2001; Golshan & Smith, 2006)
Peripheral neuropathy:
- Report persistent symptoms of tingling, numbness or coldness in hands, or feet
- Safety issues: avoid walking barefoot, using care in trimming of fingernails or toenails (Armstrong, 2005; Eaton & Tipton, 2009).

The following teaching content can be provided as appropriate depending on the survivor’s past medical history and previous cancer treatment plan.

Cardiovascular risk:
- Encourage dialogue with the health care provider about having a cardiovascular exam regularly
- Explain to your patient the importance of reporting chest pain
- Explain what type of tests might be done: physical exam, EKG, echocardiography.

Gastrointestinal (GI) risk:
- Consult a dietitian if eating remains a concern
- Teach how to manage chronic diarrhea
- Teach what symptoms to report

Genitourinary (GU) and gynecological risk:
- Encourage discussion on sexual health (refer to Unit 7: Sexual Health for more information)
- Explain the importance of reporting symptoms of dysuria, hematuria, erectile dysfunction, vaginal symptoms, or incontinence
- Review teaching about Kegel exercises to strengthen the pelvic muscles that help to control the flow of urine from the bladder

Endocrine risk:
- Explain that hormone levels can be checked with blood tests, and these should be done regularly if the patient is at risk.

Musculoskeletal risk (bone and joint problems):
- Stay active; participate in regular physical activity
- Do not smoke
- Eat foods rich in calcium
- Limit alcohol intake

Neurological risk:
- Follow-up care should include regular physical exams, hearing tests as appropriate, and x-rays.
- Survivors who experience any cognitive problems should talk with their doctor or nurse.
- Teach about cognitive (thought processes) problems and chemobrain.

Pulmonary risk:
- Explain to your patient the importance of reporting a change in their breathing.
Learning Activity: Case Study

D.A. is a 56 year old woman with breast cancer. Two years ago she was diagnosed with ER/PR +, HER2 neu +, stage II breast cancer. At that time she had a lumpectomy and lymph node dissection followed by radiation, an anthracycline based chemotherapy regimen with herceptin all followed by tamoxifen. She is now being followed every six months by her family physician. She presents with the following concerns:

- SOB with moderate exertion. Prior to her diagnosis she was very active and feels there must be something very wrong with her lungs. She asks you if perhaps her cancer treatment injured her lungs.
- Inability to return to former occupation as nurse as she is just “too tired” to work 12 hour shifts. She also states that she has trouble remembering things and critically thinking through complex patient situations.
- Marital challenges as she states she feels sexually uninterested and has intermittent dyspareunia.
- She had a pelvic fracture after slipping on ice early in the winter and states she does not want to continue taking her tamoxifen. A friend told her that her fall was probably because of “that drug”.
- While in the hospital with her pelvic fracture she had a DVT and continues on low molecular weight heparin (LMWH).

Discussion:

It is critical that you are able to support D.A. in clarifying her concerns and misunderstandings so that together you can effectively work to develop a plan of care to address the challenges she faces.

What late effects need to be identified in the survivorship care plan specific to D.A.’s situation?

Answers:

Her shortness of breath should be carefully assessed to rule out pulmonary embolism or other physical causes such as cancer recurrence and cardiovascular compromise secondary to anthracycline therapy for example.

Her risk of osteoporosis while taking Tamoxifen is actually reduced. If her treatment is switched to an aromatase inhibitor in the future that risk will rise. All women should have a base line bone density test to determine their risk and to use as a comparison to later studies The nurse may talk to her about the increased risk of thrombo embolism while taking Tamoxifen and how her current anticoagulation therapy will impact (reduce) that risk.
Dypareunia (or painful sex) and lack of libido can be addressed in a multi-pronged interdisciplinary approach that includes physical assessment, teaching about non hormonal treatments for dyspareunia and couples counseling. Some women may even need to talk to the oncology team about the risks and benefits of hormone therapy after breast cancer when quality of life is severely impacted.

Many patients describe fatigue after the end of treatment and its intensity and trajectory are variable. By exercising and eating a well balanced diet and minimizing stress where possible she can maximize her energy. In addition refraining from smoking and limiting alcohol can be helpful. Journaling may help her identify ways to conserve energy for high priority activities.

For many reasons a referral to supportive care may be needed; not being able to return to work can cause depression and financial hardships, relationship changes are also a concern.

References:


UNIT 4

Living with the Risk of Recurrence

Lori Santoro, RN, CON(C), Myriam Skrutkowski, RN, MSc, CON(C), Tracy Soloninka, RN, MS Oncology, CON(C)
QUICK OVERVIEW:

- The risk of cancer recurrence is different for each cancer survivor. The type of cancer, the form of treatment, as well as how long it has been since treatment was completed can influence the risk of recurrence.
- Uncertainty of illness in cancer survivors has been described as the “fear of recurrence”. Feelings generated by uncertainty include anxiety, fear, anger, wonder, frustration, helplessness, curiosity, hope, and depression.
- Fear about recurrence is normal and very common amongst cancer survivors, especially during the first several years after completing treatment.
- There are three types of cancer recurrence: local, regional, and distant.
- Cancer survivors may forget that it is still possible to get common physical illnesses like a cough, cold, or a common ache. Most symptoms are not related to cancer. Anytime there is a concern about their health beyond common physical illnesses, cancer survivors should be encouraged to call their health care provider.
- Cancer survivors should be aware of symptoms to report to their primary care provider.
- Many health care providers operate by the “two-week rule”: any pain or symptom that goes away in less than two weeks is not usually something to worry about (www.livestrong.org, 2009).
- If a recurrence of cancer happens, mortality is not imminent. The cancer survivor may require short-term treatment to eliminate the recurrent disease. For others, cancer recurrences become more like a chronic disease that requires treatment intermittently. This allows people with cancer to enjoy good quality of life, control symptoms, and potentially survive longer.
- It is the health care team’s role to help cancer survivors understand what they are experiencing when they present with new symptoms.
- Finding a way to have hope will assist people to begin to think about “living with” cancer, instead of “dying from” it. The process is very individualized.

INTRODUCTION:

For the person dealing with cancer, the flurry of activity surrounding cancer treatment has kept them preoccupied for months and, in some cases, years. The end of cancer treatment often brings a celebration with a sense of relief that treatment is over and hope that the cancer is gone. During recovery, cancer survivors may find the need to transition to a new normal. Cancer survivors often say “life will never be the same after cancer” (From Cancer Patient to Cancer Survivor: Lost in Transition, 2005).

Many cancer survivors struggle with survivorship. They might have felt very cared for and supported along the way through treatment by their health care providers. While undergoing treatment people with cancer feel they are actively fighting their disease. When active
treatment, regular visits and “hands on” care by the health team are finished, people often feel their “safety net” has been lost, they may feel alone, or vulnerable. They may wonder who will give reassurance, provide comfort, answer their questions, and monitor their health. “Fear can be a constant companion. It’s difficult to take charge of your life if you’re always looking over your shoulder” (Magee, Sherri, & Scalzo, 2007, p190).

Fear about recurrence is normal and is very common amongst cancer survivors especially during the first several years after completing treatment. Although the fear does ease with time, it may not go away completely; or it may move to the background of daily life. “The passage of time reinforces the point that life without cancer does exist. It is also important to realize that a recurrence does not mean certain death. Many people who have been dealt a recurrence are alive and well today” (Magee, Sherri, & Scalzo, 2007, p190).

The uncertainty associated with cancer recurrence is an important issue for survivorship. Nurses are ideally situated as members of the healthcare team to provide long-term follow-up and assessment of people with cancer (Curtiss et al. 2006; Boyle, 2006). The nursing care of cancer survivors needs to include comprehensive assessment and evidence-based care plans that focus on the long term physical effects of cancer treatment, identifying cancer recurrence, or the development of secondary cancers as well as the complex psychosocial sequelae of living through life threatening illness (please also see Unit 3: Late Effects of Cancer Treatment and Unit 8: Psychosocial Health and Wellbeing). Nurses should also take the opportunity to focus on risk reduction, cancer prevention, and maximizing well being as part of on-going follow-up (please also see Unit 10: Risk Reduction Activities).

What does recurrence mean?

A recurrence of cancer happens when the treatment given did not kill or remove all of the cancer cells. Often cells that have not been eradicated by treatment are too small to be detected by diagnostic imaging tests. With time, these cells eventually begin to grow and become large enough to be detected clinically or by a diagnostic imaging or laboratory test. Often the health care team will discuss risk of recurrence with cancer survivors. This may be done in broad terms or might include a discussion about the statistics or chances that the cancer may return. Some people find this information reassuring while others find it unsettling or anxiety provoking. Oncology health care teams need to work together to understand how (and if) each patient wants to receive such information.

The use of the term “cured” in relationship to cancer may not hold the same meaning between the health care provider and cancer survivor. The cancer survivor more likely views his/her condition as cured as part of a coping effort instead of in the scientific context, which is based on bio-physiological data. For some cancers, there is a “five-year” period where if there is no sign of recurrence, patients are considered cured. For other cancers, like breast cancer, there is no time frame to say someone is cured (Ganz, 2001; Boyle, 2006).
## Types of Recurrence:

<table>
<thead>
<tr>
<th>Type</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Local recurrence</td>
<td>When the cancer recurs in the site where the cancer started initially.</td>
</tr>
<tr>
<td>Regional recurrence</td>
<td>When the cancer recurs in the lymph nodes near the site of origin.</td>
</tr>
<tr>
<td>Distant recurrence</td>
<td>When the cancer recurs far away from the site of origin, also called metastases. If the cancer metastasizes, it is the same type of cancer as the cancer of origin. For example, breast cancer that has spread to the bones is still breast cancer not bone cancer.</td>
</tr>
</tbody>
</table>

## Cancer Site of Origin and Common Site(s) of Metastasis

<table>
<thead>
<tr>
<th>Cancer Site of Origin</th>
<th>Common Site(s) of Metastasis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bladder</td>
<td>Prostate, uterus, vagina, pelvic wall, abdominal wall</td>
</tr>
<tr>
<td>Bone</td>
<td>Lung, other bones, bone marrow</td>
</tr>
<tr>
<td>Brain</td>
<td>Other parts of the brain, spinal cord</td>
</tr>
<tr>
<td>Breast</td>
<td>Bone, lung, liver, brain, skin</td>
</tr>
<tr>
<td>Cervical</td>
<td>Bladder, rectal wall, liver, GI, lung, pelvic wall</td>
</tr>
<tr>
<td>Colorectal</td>
<td>Liver, lung, bone, brain</td>
</tr>
<tr>
<td>Esophageal</td>
<td>Organs</td>
</tr>
<tr>
<td>Hodgkin's</td>
<td>Lung, liver, bone marrow</td>
</tr>
<tr>
<td>Kidney</td>
<td>Lung, bowel, pancreas</td>
</tr>
<tr>
<td>Laryngeal</td>
<td>Neck, trachea, thyroid, esophagus</td>
</tr>
<tr>
<td>Leukemia</td>
<td>Does not spread</td>
</tr>
<tr>
<td>Liver</td>
<td>Bone, lung</td>
</tr>
<tr>
<td>Lung</td>
<td>Brain, other lung, bone, liver, adrenal gland, kidney</td>
</tr>
<tr>
<td>Melanoma (skin cancer)</td>
<td>Lung, brain, liver, small intestine, bone</td>
</tr>
<tr>
<td>Multiple Myeloma</td>
<td>Bone</td>
</tr>
<tr>
<td>Non Hodgkin’s Lymphoma</td>
<td>Lung, liver, bone marrow</td>
</tr>
<tr>
<td>Non Melanoma Skin Cancer (Basal cell, Squamous cell)</td>
<td>Usually doesn’t spread; brain, lung</td>
</tr>
<tr>
<td>Oral</td>
<td>Neck, lymph nodes, lungs</td>
</tr>
<tr>
<td>Ovarian</td>
<td>Liver, lung, peritoneal carcinomatosis</td>
</tr>
<tr>
<td>Pancreatic</td>
<td>Liver, peritoneal cavity, liver</td>
</tr>
<tr>
<td>Pleural Mesothelioma</td>
<td>Other lung, liver</td>
</tr>
<tr>
<td>Prostate</td>
<td>Bone, liver, lung</td>
</tr>
<tr>
<td>Stomach</td>
<td>Liver</td>
</tr>
<tr>
<td>Testicular</td>
<td>Liver, lung</td>
</tr>
<tr>
<td>Thyroid</td>
<td>Lung, trachea, esophagus, larynx, bone</td>
</tr>
<tr>
<td>Uterine</td>
<td>Bladder, bowel wall, intra-abdominal, inguinal lymph nodes</td>
</tr>
</tbody>
</table>
When Recurrence Happens:

Cancer survivors may face a recurrence during their lifetime and realize that a cure may not be possible. They have already experienced cancer treatment and preparing for treatment again may become difficult depending on past experience. Identifying how a person coped at the time of initial diagnosis can become an early part of the nurse’s assessment. Nurses and other health care providers will need to present a treatment plan that communicates a continued commitment to the cancer survivor while reinforcing hope to help maintain emotional balance. The nurse has a key role in talking to patients about their coping while reinforcing teaching about the disease, treatment, and side effects (Gorman, 2006).

Applying the CANO/ACIO Standards and Competencies

Practice Standard: Comprehensive Health Assessment

Competency:
Regularly assessing and monitoring for potential acute and chronic physical changes to the individual’s response to illness using focused assessment tools.

Practice Standard: Supportive and Therapeutic Relationships

Competency:
Understanding the cancer experience and the different needs, feelings, fears, concerns and losses that the individual/family may encounter as part of the cancer journey and being able to discuss them comfortably with the individual/family.

LITERATURE REVIEW:

There is a growing body of literature to support how implementing certain lifestyle behaviors (e.g. exercise and diet), may be of benefit and possibly prevent a cancer recurrence (refer to Unit 10: Risk Reduction Activities). Nurses have a role in teaching cancer survivors about survivorship and helping them to cope with their fear of recurrence. The literature also supports survivorship care plans that offer information and answer some of the questions that many patients may have after cancer (refer to Unit 2: Models of Care After Treatment for Cancer). Questions that typically surface during recovery and survivorship include:

- How will I know if the cancer comes back?
- Where is the cancer likely to come back?
- Is there anything I can do to prevent the cancer from coming back?
- What tests do I need to ensure the cancer has not recurred?
- How often should I be seen by my doctor?

It is very important for nurses to provide answers to these and other questions. By knowing what to expect after treatment, cancer survivors can be encouraged to make plans, lifestyle changes, and important decisions regarding their health care. This in turn can foster a sense
of control in their cancer survivorship. Healthcare providers have long been challenged to better understand the meaning of the cancer experience for patients (Carroll-Johnson, 2006; Vachon, 2008). Gaining insight into the experience can be facilitated through periodic assessment of uncertainty along the cancer trajectory and promotion of cognitive control (Gil et al, 2006; Penrod, 2001).

For some, fear and anxiety can surface for multiple reasons (e.g. during times of follow-up visits, tests, near anniversary dates, or hearing about someone who has been diagnosed with cancer). Fear can also be an issue when the person experiences lingering treatment side effects or develops delayed treatment effects.

**Uncertainty in Cancer:**

The appraisal of uncertainty about recurrence by cancer survivors can be viewed as either a threat or an opportunity (Lazarus & Folkman, 1984). Viewing uncertainty as a threat may lead to anxiety and worry about one’s health or that the cancer will return. The emotional distress associated with cancer survival has been identified as a consequence of uncertainty (Adams, 1991; Carter, 1993; Cava, 1992; Dow, 1991; Ferrell, Dow, Leigh, Ly, & Gulasekaram 1995; Gambosi & Ulreich, 1990; Mast, 1998; Nelson, 1996; Northouse, 1981).

Uncertainty is defined as a cognitive perceptual state that ranges from a feeling of just less than surety to vagueness; it changes over time and is accompanied by threatening and/or positive emotions (Hilton, 1994). It includes uncertainty generated by the assessment of the individual’s situation and coping responses, as well as how to cope with uncertainty.

Uncertainty is:

- Not being able to foretell the future
- A lack of clarity about the present
- Being in doubt
- Being undecided because things are not definite, clear cut, or determined
- Not being able to rely, count, or depend on someone or something, and
- Having a sense of vagueness about what to do, expect, know, and ask

The role of the nurse in diminishing uncertainty and fostering hope for the future in people with cancer is an area that demands attention (Penrod, 2001; Wonghongkul et al, 2000). Research in nursing and other allied health domains has examined uncertainly and fear of cancer recurrence (Gil et al, 2006; Hilton, 1994; Mishel, 1997). The Mishel Uncertainty in Illness Scale (MUIS) (1981) is the tool used most notably in nursing research to measure uncertainty. A cancer survivorship version (MUIS-S) is applicable for study about knowledge domains related to living with long-term treatment side effects and fears of recurrence (Gil et al., 2006).

In a sample of women who were five to nine years post-treatment for breast cancer, Gil et al., (2006) demonstrated benefits when implementing strategies for uncertainty management.
Strategies included cognitive reframing, problem solving, and providing information about long-term treatment side effects. (Gil et al., 2006).

Cancer survivors may experience a range of feelings associated with fear of recurrence similar to uncertainty, including anxiety, depression, anger, lethargy, disappointment, grief, isolation, and loneliness.

Five issues that contribute to fear of recurrence may include:

- Fear of death
- Fear of dying
- Mortality
- Vulnerability
- Questions about the purpose of life (Shaffer, 2006; Kaye, 1991)

Cancer survivors can put fears to rest and enrich their lives by coming to terms with the issues listed above. Kaye (1991) emphasizes that it helps to create a list of all the things that make a person feel vulnerable. She goes on to say that cancer is only one of many things on the list of vulnerabilities and this realization can help cancer survivors to shift their focus and appreciate that vulnerability is a fact of life for everyone, not just them.

**Facilitating a Systematic Assessment:**

**Signs that a survivor might be experiencing fear of a cancer recurrence:**

- Concern over minor symptoms which may represent cancer recurrence
- Fear of moving forward with life due to the worry of cancer recurrence
- Multiple calls to their health care provider regarding minor symptoms, requiring need for reassurance.

**Questions to assess for fear of recurrence include:**

- How much time do you spend worrying about your cancer coming back?
- How much time do you spend during the day thinking about your cancer coming back?
- How much time do you spend at night thinking about your cancer coming back?
- Describe your sleep patterns.
- Describe your appetite? Are you eating well? Do you have days when you don’t feel hungry?
- How is your social life? How much time do you spend with family and friends?
- Are you spending quality time with friends and family or are you withdrawing from them?
- What activities do you enjoy these days? Has your enjoyment in them decreased recently?
- How is work/school? Do you have any issues functioning at work such as concentration?
- Describe a health issue that is worrying you now.
- How might we be able to help you manage your worries?
Priority content for Interventions and Patient Teaching:

Symptoms that cancer survivors should report to their health care provider include:

- Return of the cancer symptoms (e.g. a lump or new growth at the original cancer site)
- New or unusual pain that seems unrelated to an injury and does not go away
- Unintentional weight loss
- Bleeding or unexplained bruising
- A rash or allergic reaction, such as swelling, severe itching, or wheezing
- Chills or fevers
- New onset of headaches
- New shortness of breath
- Persistent cough
- Hematochezia
- Hematuria
- New masses or skin changes
- New nausea, vomiting, diarrhea, loss of appetite, or trouble swallowing
- Profound fatigue
- Swelling in an arm or leg
- Unusual symptoms that just can’t be explained

(American Cancer Society, 2009)

It is recommended that the person with cancer talk with their health care provider about symptoms. Together, they might identify some of the reasons for the fears or uncertainty and try to decide if they are realistic or not. For example, a person with cancer may be worried about information that someone else has told them that is not accurate.

One suggestion that might be helpful when dealing with new symptoms that are unlikely to prove cancer related is to wait a few days and observe without panicking. If the symptoms continue, then call the health care provider; try to avoid assuming the cancer has returned unless there is evidence that there is cause for concern.

When to refer a cancer survivor for psycho-social support

When the fear of cancer recurrence is interfering significantly with quality of life, cancer survivors should be encouraged to seek professional support through social workers, psychologists, psychiatrists, mental health nurses, or spiritual care workers. The nurse can normalize the need for a referral by informing the cancer survivor that many people feel overwhelmed and struggle with their fears after cancer treatment.

Talking about uncertainty and fear of cancer recurrence and seeking support can be very helpful. Offering a comment such as:
I hear you say that you are feeling very overwhelmed with worry about the possibility of your cancer coming back. It sounds like this is interfering with your ability to enjoy your everyday life. Many people experience this. Often talking to someone can be very helpful and provide ways to cope with this fear. I can arrange for someone to call you or give you a name and number of someone to talk to. What do you think about this idea?

**How to help cancer survivors cope with the stresses of cancer and find balance in life**

To deal with fear of recurrence, it is useful to assist the cancer survivor to recognize it and gradually to learn ways to control it. Some teaching strategies that nurses may be able to implement with cancer survivors include the following:

- Suggest that the person with cancer increases their awareness of when they experience the fear of recurrence by keeping track of the times and situations in which it occurs.
- Observe for patterns such as:
  - Does it happen only in medical settings?
  - Are there certain times of the day?
  - What triggers the fear of recurrence: reading or watching (TV, movies) something that refers to cancer?
  - Encourage patients to talk specifically about what they fear about recurrence (death, more treatment, a particular side effect) in order for the health care team to provide focused support.

Fear of recurrence can also be expressed in positive ways. Although cancer survivors may find that they no longer have control over their body or daily life, it may be possible to find ways for them experience control in many parts of their lives:

- Attending regular medical follow-up appointments.
- Some people find it helpful to join a support group and talk to others who have lived the cancer experience.
- Some cancer survivors may benefit from counseling. The person may request that the nurse or health care provider refer the person to a social worker, psychologist, psychiatrist, or another helping professional.
- Looking for information and seeking support.
- Adopting new risk reducing behaviors such as an exercise routine, healthy eating habits, and cancer screening programs.
- Physical and other stress reducing activities, such as yoga, meditation, or tai-chi.

As a survivor author Ronnie Kaye suggests that as normal check ups come and go fear and apprehension will likely begin to wane until it reaches manageable levels or even disappears (Kaye, 1991).
Cancer as a chronic illness

Depending on the type of cancer, the nurse may consider a discussion with cancer survivors about the concept of “cancer as a chronic disease” (Curtiss, 2006; Rowland et al, 2001). It is important to clarify whether there is agreement in the point of view between the cancer survivor and the health care professional. Many types of cancer, which were once considered terminal, are now thought of as chronic, and are similar to other chronic illnesses (Rowland et al, 2001). In addition, some types of cancer might present with periodic relapses and remissions. The cancer condition meets the criteria of chronic illness, as defined by the 1956 Commission on Chronic Illness, if a long period of observation, supervision, or care is required (Strauss et al. 1984).

Follow-up visits

Follow-up care allows cancer survivors to have their health monitored as well as their issues and concerns addressed. Recommendations for cancer follow-up care vary for the different types of cancer. People diagnosed with cancer may have several health care providers involved in their care. The goal generally is for cancer survivors to see at least one health care provider every three to four months during the first few years after cancer treatment is completed and then once or twice a year thereafter (refer to Unit 2: Models of Care for Follow Up After Treatment for Cancer).

The following should be included at a follow-up visit by the health care provider:

- Update history (physical, family/social, medication)
- Assess and address any lingering treatment related side effects or any late effects that may have developed (refer also to Unit 3: Late Effects of Cancer Treatment)
- Assess for signs of a recurrence and perform a physical exam. Depending on the type of cancer, blood work, diagnostic imaging, or other investigations may be required

Although many health care providers monitor their patients at different time intervals, there are attempts to set more formalized follow-up guidelines both provincially and nationally.

The role of the nurse:

- Understand that issues for cancer survivors will vary depending on their type and stage of cancer, age, life circumstances, family history etc.
- Remember that people will experience cancer differently. Some will recover faster (both physically and emotionally) than others
- Assess cancer survivors and their families for fear of a recurrence on an ongoing basis and refer them to supportive care practitioners as appropriate
- Listen for cues that fear of cancer recurrence is a concern
- Validate the person’s feelings
- Provide information on what to expect physically and emotionally after cancer treatment
● Help cancer survivors be aware of the normal follow up recommendations specific to them - individualize the cancer survivorship care plan (see unit 2: Models of care/survivorship care plans)
● Encourage cancer survivors to attend follow-up appointments and participate in recommended surveillance and screening
● Advocate for cancer survivors so that their concerns are heard

Nurses support and advocate for cancer survivors to:

● Acknowledge their fears
● Know that they are not alone
● Seek help/ talk about their fears to family, friends, and professionals; join a support group, etc.
● Learn what they can about their disease, recovery and what they can do to stay well.
● Learn what resources are available to provide support and ease recovery
● Take control of what they can such as lifestyle behaviors such as healthy eating, regular exercise, quality sleep, stress management, smoking cessation, and limiting alcohol consumption (see Unit 10: Risk Reduction Activities)
● Offer support when a cancer recurrence does occur.

Please refer to Unit 8: Psychosocial Health and Wellbeing for more information.

Learning Activities: Case Studies

A.J. is a 45-year-old woman who was diagnosed two years ago with Stage 3 breast cancer. Her treatment plan consisted of neo adjuvant (pre-op) chemotherapy surgery (lumpectomy), followed by radiation therapy. She is now taking hormone therapy. A.J. is married with good support from her husband. They have two children, a 21-year-old daughter and an 18-year-old son. A.J. has worked as a social worker for 15 years at a local community clinic. She took care of her father when he was diagnosed with lung cancer. Her father died of lung cancer three years ago.

During her treatment for breast cancer A.J. experienced an episode of febrile neutropenia and on going struggles with nausea related to chemotherapy. She managed her nausea with anti-emetics and mitigated the risk of further febrile neutropenia through self-administered granulocyte colony stimulating factors (G-CSF) injections. She remained calm during her treatments of chemotherapy and radiotherapy. She seldom requested assistance.

Four months after the end of her treatment, the nurse did a follow-up telephone call. A.J. reported that she cries often, has ongoing fatigue, sleeps eleven hours every night, and is trying to adjust emotionally to all that has happened. She acknowledged that only after her treatment ended did she begin to grieve her losses, including her father’s death, and her own challenges related to her own cancer diagnosis. She identified that she has always tried to remain strong for her family and friends but now has no energy to do anything that she was
used to doing. She shared that she does not wish to return to her work because she fears talking to clients who might have a cancer diagnosis. In six months she will start back to work on a part time basis. She has a follow-up appointment with her oncologist in two months and is very fearful that test results will show that her cancer has returned.

- What are some interventions that might have been offered to help her deal with fears related to cancer recurrence?
- What are some interventions that you might wish to consider during the telephone call?

### J.A.’s Story

J.A. is a 43-year-old woman who has Stage 3, lymph node negative, estrogen receptor negative, HER2 negative, BRCA 1 positive breast cancer. She was treated with a mastectomy, chemotherapy, radiation therapy, prophylactic bilateral oopherectomy, and a prophylactic contra lateral mastectomy. She was not a candidate for breast reconstruction due to pre-existing medical conditions. She is left to wear bilateral prostheses. She is disappointed by this and has tried to rationalize that, “this is just how it has to be”. All through her journey J.A. has reached out to her nurse for information and support. She has also accessed support from a social worker.

J.A. has remained very anxious through every step of her breast cancer experience. She worries about her cancer coming back every day. She has tried several medications for her anxiety/depression and she is not able to tolerate them. J.A. is 9 months from completing chemotherapy and 3 months since her last surgery. She has developed an over-riding concern regarding every symptom or discomfort that she feels. This is disrupting her sleep and has become all-consuming.

J.A. is planning to return to work very soon. She had just started a new job a week prior to her diagnosis. Therefore, she has no sick benefits and she has mounting stress about financial issues.

While trying to strengthen and recondition herself by using her treadmill she has noticed she has low back/pelvis pain. It has been lingering for a month now. She saw her primary health care provider and is now being sent for a bone scan. She calls the nurse in a state of panic. She is afraid that the bone scan may show that her cancer has returned. She says that maybe it is from her intense workouts. She wonders if she really needs the bone scan but in the same breath says if she doesn’t have the scan she will drive herself crazy with the fear of the unknown.

- What questions would you consider in your assessment when you speak to J.A.?
- What are some interventions that can be provided at the time that treatment ends?
- What outcomes would you expect from your interventions?
Discussion about A.J.’s Story

Interventions to offer to prepare A.J. for dealing with fear of recurrence:

- Assess how A.J. is dealing with her father’s death
- Assess her coping abilities/strategies
- Assess family support
- Assess family members’ reaction to cancer diagnosis
- Education on expected late effects, (e.g. fatigue, psychological distress, lymphedema)
- Education on coping with uncertainty, (e.g. fear of recurrence and illness worry, especially at time of follow-up visits)
- Foster hope and sense of control

Possible interventions during your telephone call with A.J.:

- Explore her symptoms (e.g. fatigue, emotional distress, loss of control etc.)
- Acknowledge that she has losses to deal with that she might not have had time to deal with in the past
- Acknowledge that she needs time to adjust to her situation
- Assist her to identify goals that can reduce her uncertainty and increase her sense of control (e.g. keep a diary, reconcile her fears, find time for bereavement, continue follow-up visits)
- Remind to continue regular follow-up appointments with medical doctor
- Explore concerns of family members

Discussion about J.A.’s story:

Interventions to offer at the end of treatment:

- Assess J.A.’s coping abilities
- Assess her family support
- Encourage attendance to the survivorship program after treatment
- Ensure she has a copy of the booklet *Getting Back on Track – Life after Treatment* with follow-up guidelines available at her centre
- Ensure she is aware of the programs and services available to her
- Encourage her to continue getting support with the social worker
- Discuss with J.A. perhaps the need for a referral to a psychiatrist to discuss her anxiety as well as her inability to tolerate the medications tried by her GP
- Encourage her to attend follow up appointments with her doctors as scheduled and as needed.
- Education on expected late effects, e.g. fatigue, psychological distress
- Education on coping with uncertainty, e.g. fear of recurrence and illness worry, especially at time of follow-up visits
- Foster hope and sense of control
Interventions to consider during your call with her:

- Acknowledge J.A.’s feelings and worry.
- Assess J.A.’s current physical symptoms. Although it is important to help her cope with her anxiety and not create alarm, she may require assessment to rule out metastases as a cause for her pelvic/low back pain. Consider her risk of recurrence based on her original breast cancer presentation and the time since treatment when determining her current risk of cancer returning and craft a plan to evaluate the pain. A bone scan may be needed which could show both cancer and non cancer related causes for the pain.
- Ask if she has any questions related to her situation. Don’t offer more answers that she is prepared for.
- Assess her coping strategies both past and present.
- Assess her sleep, appetite, ability to carry on with her usual routine, etc. Are things being impacted as a result of this new situation and how?
- Explore ideas around improving sleep, appetite, and coping.
- Explore her concerns about returning to work and what it might mean to her and her family (assuming she has a family)

REFERENCES


American Cancer Society, 2009.


Quick Overview

- In the literature, CAM refers to Complementary and Alternative Medicine. Recently this widely recognized phrase has been slightly changed to Complementary and Integrative Medicine. Throughout this chapter the acronym CAM will be used to denote this growing domain of treatments.

- Complementary therapies are generally described as unconventional treatment modalities and approaches that are (usually) nonsurgical and non-pharmaceutical but have known efficacy used with mainstream care (i.e., scientifically based care). Alternative therapies are generally described as therapies or approaches which replace or are used instead of traditional, mainstream treatment and have not been scientifically proven. Alternative therapies frequently do not have a scientific basis and sometimes have even been disproved (Society of Integrative Medicine (SIO), 2009; National Center for Complementary Medicine (NCCAM), 2010). That being said, it is really the intent with which the therapy is used that defines it. For example, high dose vitamin C infusions are complementary therapy when used in conjunction with “traditional” or “conventional” therapies. They are alternative therapy if used “instead” of “traditional” or “conventional” therapies.

- The term “integrative medicine” has been gaining acceptance in medical academia. In essence, Integrative Oncology is the use of conventional and complementary therapies together.

- The NCCAM developed a classification system to make sense of the many therapies available. The categories are: biologically based practices, energy medicine, whole medical systems, mind-body medicine, manipulation, and body-based practices.

- While there is much to learn about these therapies, over the last decade research has improved our understanding about the safety and efficacy of CAM.

- Studies show that cancer survivors need more information and support from health care providers to make decisions about their use of CAM, especially when using CAM alongside their conventional cancer treatment (2009, www.bccancer.bc.ca/cameo).

- The Office of Cancer Complementary and Alternative Medicine (OCCAM) and NCCAM web sites are two of several great resources. Both sites offer a multitude of information for the public and health care providers on current research findings. CANO/ACIO is developing a section about CAM on its web site for people with cancer.

- Nurses have an important role in educating and supporting cancer survivors in considering or utilizing CAM.

Applying the CANO/ACIO Standards

Many people use complementary or alternative therapies throughout their active phase of cancer treatment and beyond. Nurses have varying levels of knowledge about the use of CAM in the setting of cancer survivorship.
Applying the CANO/ACIO Standards

Practice Standard: Comprehensive Health Assessment

The standard states, “The specialized oncology nurse conducts timely and comprehensive assessments of the health and supportive care needs of the individual with cancer and their families across the cancer continuum using a systematic approach that is sensitive to language and culture. The specialized oncology nurse considers the situational context and the needs and responses of the individual and family in determining the scope and depth of assessment” (CANO/ACIO, 2006).

How can you meet the standard?

There are a number of ways to meet the standard. For the purposes of this section, the focus will be on the competency that is “assessing the patient’s use of and response to complementary and alternative health care (CAHC) practices throughout the cancer trajectory.”

Example

M.B. is being seen today in the follow-up clinic. It has been six months since M.B. finished her cancer treatment. The competency would direct the nurse’s assessment to focus specifically on learning from M.B. if she uses CAM and if she does, how it impacts her life. It is important for the nurse to think about the types of questions to ask M.B. to explore her use of complementary and/or alternative therapies and their impact on her. Refer ways to assess if cancer survivors are using CAM (later in this section). Assessment specific to CAM is covered later in this section.

LITERATURE REVIEW

A quick synopsis of the literature

- Many people affected by cancer use complementary therapies. A much smaller number of people use alternative therapies.
- Our knowledge and understanding about CAM is evolving.
- The evidence to support CAM use ranges from non-existent to fairly high.

Prevalence of CAM Use among People Affected by Cancer

The literature identifies that CAM use ranges from 10% to greater than 60% in patients with cancer, depending on the definition used (Adams, Sibbritt, Easthope, & Young, 2003; Chrystal, Allan, Forgeson, & Isaacs, 2003; Navo et al., 2004; Weiger et al., 2002; Yates et al., 2005). Yates and colleagues (2005) found in their survey of seventeen American Community Clinical Oncology Program affiliates that as many as 91% of people with cancer reported using at least one form of CAM, including practices such as prayer. More recently,
the Complementary Medicine Education and Outcomes Program (CAMEO) web site reports that up to 80% of patients diagnosed with cancer use CAM, yet most make decisions about integration of their therapies into their conventional treatment plan and care without the knowledge or support from their health care providers.

**Current Understanding of CAM**

CAM is an evolving area. This literature review captures what we presently know. However, it is important for nurses to stay current with the literature.

**Historical Perspective**

The National Institute of Health in the United States established the National Center for Complementary and Alternative Medicine (NCCAM) out of concern for safety and efficacy of use of CAM. The NCCAM focuses on research (pharmacologic studies; evaluation of CAM practices), research training, and communications. Its aim is to ensure the safety and efficacy of natural products.

The NCCAM defines CAM as a “diverse medical and health care systems, practices, and products that are not presently considered to be part of conventional medicine. Conventional medicine is medicine as practiced by holders of MD or Doctor of osteopathy, DO degrees and by their allied health professionals, such as physical therapists, psychologists, and registered nurses. Some health care providers practice both CAM and conventional medicine. Alternative refers to therapies used in place of conventional medical treatments. While some scientific evidence exists regarding some CAM therapies, for most there are key questions that are yet to be answered through well-designed scientific studies—questions such as whether these therapies are safe and whether they work for the diseases or medical conditions for which they are used. The list of what is considered to be CAM changes continually, as those therapies that are proven to be safe and effective become adopted into conventional health care and as new approaches to health care emerge.” (Taken from http://nccam.nih.gov/health/whatiscam/ January 30, 2010).

**OCCAM is the section of NCCAM that specifically focuses on CAM in the oncology setting.**

**Evolving Perspective**

The term *integrative medicine* has been gaining acceptance in medical academia. The Consortium of Academic Health Centers for Integrative Medicine (November 2009) defines integrative medicine as “the practice of medicine that reaffirms the importance of the relationship between practitioner and patient, focuses on the whole person, is informed by evidence, and makes use of all appropriate therapeutic approaches, healthcare professionals, and disciplines to achieve optimal health and healing.” (Taken from http://www.imconsortium.org/faq/home.html, June 5, 2010).
Specific to the area of cancer, The Society for Integrative Oncology (SIO) emerged as an international organization focused on encouraging scientific evaluation, dissemination of evidence-based information, and appropriate clinical integration of complementary therapies. The SIO’s website address is http://www.IntegrativeOnc.org. The SIO is comprised of leading oncologists and oncology professionals from major cancer centers and organizations. The SIO focuses on the promotion of quality research and appropriate application of useful, adjunctive complementary modalities.

“Integrative oncology has been specifically described as both a science and a philosophy that focuses on the complex health of people with cancer and proposes an array of approaches to accompany the conventional therapies of surgery, chemotherapy, molecular therapeutics, and radiotherapy to facilitate health.” (SIO, 2009, accessed August 17, 2010).

Defining CAM

NCCAM and the SIO agree that there is an essential difference between “complementary” and “alternative” therapies.

- **Complementary therapies** — unconventional treatment modalities and approaches that are nonsurgical and non-pharmaceutical but have known efficacy used with mainstream care

- **Alternative therapies** — replace/used instead of traditional mainstream (scientifically based) treatment and have not been scientifically proven, frequently do not have a scientific basis, and sometimes have even been disproved.

(NCCAM, 2010; SIO, 2009)

The intent with which the therapy is used defines it as either complementary or alternative.

It’s important to realize that what is considered alternative medicine today may be considered complementary therapy tomorrow as more approaches/treatments undergo study and move into mainstream. What is now known is that when an alternative medicine therapy is used in addition to conventional therapy, it’s called complementary. When complementary therapy is used in addition to conventional treatment, it is called integrative medicine.

Evidence to Support CAM Use in Cancer Care

The Society of Integrative Oncology (2009) published an article that evaluates the current level of evidence regarding complementary therapies in the care of patients dealing with cancer. The review, helpful in making evidence-based treatment decisions in integrative oncology can be found at http://www.IntegrativeOnc.org.
Classification of Complementary Approaches

NCCAM developed a classification system to make sense of the many therapies available. The distinctions between classifications aren’t always clear-cut and some classifications use techniques from more than one category.

The following chart captures key points about each of the classifications of complementary approaches. It is important to appreciate that the research in this area is limited or in many cases non-existent, but growing.

<table>
<thead>
<tr>
<th>Classification</th>
<th>Key Practice Points</th>
</tr>
</thead>
</table>
| Biologically based practices         | ▪ Use of substances found in nature, such as herbs, foods, and vitamins. It is important to keep in mind the potential natural products are not without side effects.  
▪ Examples include: herbal products, dietary supplements, vitamins, other dietary supplements, other so-called natural but as yet scientifically unproven therapies such as shark cartilage to treat cancer.  
▪ Examples of herbs include ginseng, ginkgo and Echinacea.  
▪ A few more examples of herbs and botanicals and their potential impact:   
  ▪ St John’s Wort could inhibit effect of indinavir  
  ▪ Kava Kava is potentially toxic to liver  
  ▪ Chapperal tea can lead to liver failure  
▪ Examples of dietary supplements include selenium, glucosamine  
▪ There is a growing body of evidence about the role of Vitamin D in primary cancer prevention and cancer recurrence.  
▪ Mega vitamins – there is no scientific evidence of their benefit; they can cause health problems.  
▪ Individual dietary supplementation has not been shown to prevent cancer or cancer recurrence.  
▪ Although some botanicals have beneficial effects, studies indicate that misuse of herbs can be detrimental e.g., ginger, ginseng, and garlic have antiplatelet effects. Mildly estrogenic botanicals such as red clover and soy may stimulate hormonal sensitive cancers. |
| Energy medicine                      | ▪ Therapies based on the manipulation of bioenergy fields to restore balance in one’s energy force. The belief is that when the energy flow in the body is blocked or unbalanced one can become sick.  
▪ The energy flow has been called chi, prana, and life force.  
▪ The mechanism of action is not fully understood; benefits vary from person to person.  
▪ They may reduce stress and have a modest effect on pain relief but no evidence that they have any antitumor effects.  
▪ Examples include: Magnetic field therapy, Reiki, Healing/Therapeutic Touch, qi gong. |
### Classification

| Whole Medical Systems (Ancient medical systems) | \- Whole medical systems are built upon complete systems of theory and practice. They are not a single practice (such as massage) or remedy but many practices focused on a philosophy such as energy fields in the body or the power of nature. Examples include: homeopathic medicine, naturopathic medicine, traditional Chinese medicine, and Ayurvedic medicine.  

\- Ancient healing systems generally evolved apart from and earlier than the conventional Western medical approach used in the United States and Canada. They include ayurveda from India and traditional Chinese medicine.  

\- Homeopathy is an approach that uses minute doses of a substance that causes symptoms to stimulate the body's self-healing response.  

\- Naturopathy is an approach that focuses on noninvasive treatments to help the body do its own healing. It uses a variety of practices, such as massage, acupuncture, herbal remedies, exercise, and lifestyle counseling.  

\- Traditional Chinese medicine.  

\- Ayurvedic medicine. |

| Mind-body techniques | \- Use of a variety of techniques designed to enhance the mind’s capacity to affect bodily function and symptoms.  

\- Examples include: meditation, guided imagery, expressive arts (music therapy, art therapy, dance therapy), prayer, and relaxation  

\- Some techniques that were considered CAM in the past have become mainstream such as patient support groups and cognitive-behavioral therapy.  

\- Evidence shows the benefit of support groups, supportive/expressive therapy, cognitive-behavioral therapy, and cognitive-behavioral stress management (Deng et al., 2009).  

\- A meta analysis of 116 studies revealed that mind-body therapies decrease anxiety, depression, and mood disturbance in some patients diagnosed with cancer and improve coping skills. If cancer survivors want to really benefit from mind body therapies they need to practice them regularly (Wesa et al., 2008).  

\- Controlled trials have shown emotional and physiologic benefits by reducing anxiety, stress, depression, and pain (Wesa et al., 2008)  

\- The ASIST technique and the Prayer Wheel are two practices which some people may use to help them find a peace and calmness in dealing with their illnesses. These two types of therapies are described by Vachon (2002). |
## Manipulation and body-based practice

- Practices based on manipulation and/or movement of one or more parts of the body.
- Examples include: massage, reflexology, exercise, chiropractic, and osteopathic manipulation.
- Massage Therapy — Recommended by SIO as part of a multimodality treatment approach in patients experiencing anxiety or pain. Generally used for patients with normal blood counts. Not recommended to be used immediately post surgery. Reported to provide symptom relief for 48 hours or more (Wesa et al., 2008). Refer to the SIO article authored by Deng et al. (2009) for a detailed discussion of massage therapy.

## Classification Key Practice Points

### Manipulation and body-based practices

- Physical Activity and Exercise — There is good evidence that regular physical activity and exercise improve quality of life, decrease fatigue, improve physical functioning, improve emotional well being, and provide health-related benefits such as cardiovascular fitness, muscular strength, body composition, and physical functioning. Research has shown that cancer survivors significantly improve lifestyle behaviours when provided with sequentially tailored sessions on how to improve diet, and increase physical fitness. See Unit 10 “Risk Reduction Activities”

- Acupuncture — It is a component of traditional Chinese medicine that is based on the understanding that the body contains vertical meridians (qi flow). It involves using special needles to unblock meridians in the body. A systematic review of the literature reported that acupuncture is safe when performed by qualified practitioners (Deng, 2009). Multiple well designed studies support the use of acupuncture for immediate nausea. Research has shown that acupuncture may help lessen xerostomia, improve post op bowel function, decrease vasomotor symptoms, minimize depression and fatigue. The SIO (2009) strongly recommends acupuncture as a complementary therapy as a way of managing poorly controlled symptoms such as pain and chemotherapy induced nausea and vomiting. The SIO (2009) cautions that while the value of acupuncture in treating dyspnea, fatigue, chemotherapy induced neuropathy, or hot flashes has not been established, there is anecdotal experience suggesting it to be useful. It is important to appreciate that acupuncture is not without risk such as infection from inadequately sterilized equipment, injury to internal organs (pneumothorax, spinal cord injuries, hepatitis), and contact dermatitis (Eliopoulos, 1999).
Facilitating a Systematic Assessment

Based on observational studies and case studies, the SIO strongly recommends that health care providers explore the use of complementary and alternative therapies as a routine part of initial and ongoing assessment. Health care providers should also seek to understand the reasons for CAM use and explore their own personal beliefs (Bell, 2010).

Assessment of the use of CAM by cancer survivors

It’s not uncommon for cancer survivors to use CAM but not disclose it to their health care providers. In fact, the literature indicates that as many as 50% of patients using CAM do not disclose its use (Bell, 2010; Deng, 2009).

People do not disclose using CAM because they

- may feel embarrassed
- worry about their health care provider’s reaction
- were not asked about CAM by their health care provider
- their health care provider did not seem interested
- did not see it as being relevant
- believed that their health care provider would not be informed about CAM or be helpful to them (Bell, 2010; Deng, 2009)

One of the first steps in assessing CAM use is to ask a cancer survivor if he/she is using CAM. Asking about CAM use conveys acceptance of the topic, demonstrates that it is important to talk about CAM and that the nurse is interested in this aspect of his/her health care.

The nursing assessment is guided by understanding the underlying reasons the cancer survivor may have chosen to use CAM. Some of the reasons people use CAM during cancer survivorship may be:

- To relieve the long-term side effects associated with taking systemic cancer therapy
- To take an active role in improving their health and wellness
- To attempt to prevent the cancer from recurring

Some people choose CAM because they prefer alternative theories of health and disease to the medical model.
Ways to assess if Cancer Survivors are using CAM (conducting an integrative assessment)

Ask the cancer survivor:

- Directly if he/she uses CAM: For example, “In addition to your prescription medications, do you use any other medicines, herbs, vitamins, etc.?” How you ask about CAM use may determine the person’s response. The literature suggests that when the word “alternative” is used people are more likely to withhold information (related to fear of disapproval, etc.) (Bell, 2010; Deng, 2009).
- If cancer survivors are concerned about the possibility of recurrence ask if they are doing anything specific to prevent the cancer from returning. The nurse may say “Some people take extra vitamins and minerals, or use herbs to help prevent their cancer from coming back. Since you finished your cancer treatment have you been taking any vitamins, minerals, or herbs?”
- About their nutrition: Gaining insight into the nutritional intake may offer information about CAM use.
- About their activity level: Is he/she doing Tai Chi? Yoga? Qi Gong? These types of activities help increase understanding about the person’s thoughts and beliefs about CAM. Ask, “Are you involved in an exercise program?” Explore the nature of the exercise program. (Refer to Unit 10: Risk Reduction Activities for more information about diet and exercise).
- About their use of complementary, alternative, and integrative therapies
- Knowing the reasons why people use CAM, tailor your assessment to focus on the possible reasons for CAM use such as, “Are you using any herbs, vitamins, or other such substances to help you prevent the cancer from returning?”

Priority Content for Intervention and Patient Teaching

How can Nurses Support Cancer Survivors Considering the Use of/or Using CAM?

- Use a non-judgmental approach to build trust and encourage discussion about use of CAM.
- Assess the person’s CAM practice or lack thereof and determine if there are information needs. Remember to build this into the nursing assessment at each visit.
- Educate that mind-body modalities are recommended as part of a multidisciplinary approach for reducing anxiety, mood disturbance, and chronic pain and improving quality of life (SIO, 2009)
- Address information needs with the aim to support the decision making process so that benefits of CAM can be maximized and truly do complement conventional medicine.
Discuss with the cancer survivor the timing of CAM use. For example, some complementary therapies may be safe to use after cancer treatment, but not during treatment.

Be prepared to provide education if a particular form of CAM is deemed unsafe.

Inform the physician about concerns you may have about your patient’s use of CAM.

Be able to share reliable, credible resources about CAM with cancer survivors. See below for a list of some of the available resources.

Refer to other trained professionals as appropriate.

Nurses should optimize side effect management as often CAM is used by cancer survivors as a means of treating side effects.

How can nurses find time to discuss CAM with cancer survivors?

Include a question about CAM in the survivorship assessment tool that is used for comprehensive assessment of cancer survivors.

Ask cancer survivors to provide a list of all the therapies they use (e.g. over-the-counter medications, herbal therapies, massage therapy)

Take advantage of “teachable moments”, for example if a cancer survivor’s openly discusses CAM; this is an opportunity to explore the topic further.

Resources

Groups and Programs in Canada

CANO/ACIO CAM SIG

The Canadian Association of Nurses in Oncology has a Special Interest Group (SIG) specifically about CAM. Any CANO/ACIO member may become a member of the SIG.

Complementary and Alternative Medicine Education and Outcomes (CAMEO) Program

The CAMEO Program is a combined research initiative of the BC Cancer Agency and the University Of British Columbia School of Nursing designed to evaluate the impact of evidence-based education and decision support related to complementary and alternative medicine (CAM) for people living with cancer as well as cancer health professionals. (Taken from the BC Cancer Agency website at www.bccancer.bc.ca/RES/ResearchPrograms/cameo/default.htm Accessed June 5, 2010). CAMEO is located at the Vancouver Centre of the BC Cancer Agency, and officially opened in the summer of 2008. More information about the program and the work being done can be accessed at www.bccancer.bc.ca/RES/ResearchPrograms/cameo/default.htm.
Online Resources

There are many websites that provide information about CAM (see below). The list is not intended to be an exhaustive one of existing web sites but a starting point.

When visiting any CAM web site for information explores the following questions:

- Is the organization that sponsors the site credible?
- What is the purpose of the site?
- What is the site’s source of information?
- Who is providing information for the site?
- Who funds the site (any biases or conflicts; product web site)?
- How frequently is the site up-dated?
- Are (randomized) clinical trials about CAM reported on the site?

Canadian Web Sites

- CAMline - [www.camline.ca](http://www.camline.ca) — Health Canada’s natural health product directorate. Provides up-to-date, evidence based reviews of natural health products and complementary and alternative therapies geared to health care professionals.
- Cancer Care Ontario’s web site - [www.cancercare.on.ca](http://www.cancercare.on.ca) — makes available their position paper about complementary therapies.
- The BC Cancer Agency web site (CAMEO) — [http://www.bccancer.bc.ca/RES/ResearchPrograms/cameo/default.htm](http://www.bccancer.bc.ca/RES/ResearchPrograms/cameo/default.htm) — provides reliable, valid information about CAM.
- The Canadian Association of Nurses in Oncology (CANO/ACIO) web site’s section on CAM for patients — [www.cano-acio.ca](http://www.cano-acio.ca) — this portion of the CANO/ACIO web site provides basic information for patients about CAM.
- The Canadian Cancer Society — [www.cancer.ca](http://www.cancer.ca) — has great patient information about CAM topics such as finding information, evaluating the information, talking to your doctor, making the right decision, choosing a practitioner, natural health products regulations, therapies that may help, and suggested links.
Other Web Sites

- **American Botanical Council** — [www.herbalgram.org](http://www.herbalgram.org)
- **National Center for Complementary and Alternative Medicine** — [www.nccam.nih.gov](http://www.nccam.nih.gov)
  This site offers Research-based information on treatments and conditions.
  OCCAM was established in October 1998. Its purpose is to coordinate and enhance the activities of the National Cancer Institute (NCI) in the area of complementary and alternative medicine (CAM). OCCAM offers a wealth of credible information on its website about health (About CAM, CAM therapies), research (Clinical trials and other research), and its activities related to the National Cancer Institute. Information is provided for health professionals and patients. You will also find OCCAM’s newsletter on the web site. The newsletter NCI CAM News contains information on the National Cancer Institute’s latest CAM activities. Featured in the newsletter are things such as highlights of NCI-sponsored CAM research, resources for researchers, and upcoming meetings and lectures.
- **Natural Medicines Comprehensive Database** — [www.naturaldatabase.com](http://www.naturaldatabase.com).
- **The American Cancer Society** — [www.cancer.org](http://www.cancer.org)
  has information about the different aspects of CAM on its website, their patient focused information guides patients in the safe use of CAM and explores how, if, CAM may help them. They cover topics such as: learning about new cancer treatments, learning about new ways to prevent cancer, complementary and alternative methods for cancer management, guidelines for using complementary and alternative methods, and the placebo effect. They have great sections on “What questions should I ask about complementary and alternative methods that I might be thinking about using?” and “How can I spot fraud and questionable treatments?”
- **The Cochrane Review Organization** — [www.cochrane.org/index2.htm](http://www.cochrane.org/index2.htm).
- **The Memorial Sloan Kettering web site** — [www.mskcc.org/aboutherbs](http://www.mskcc.org/aboutherbs)
  The Memorial Sloan – Kettering Cancer Center’s “About Herbs” is an excellent resource for physicians and patients. It contains continually updated monographs of over 232 botanical and nutritional supplements.
  The Office of Cancer Complementary and Alternative Medicine (OCCAM) coordinates and enhances the activities of the National Cancer Institute (NCI) in the arena of complementary and alternative medicine (CAM). Their website contains a range of up-to-date, credible information about CAM, NCI CAM related activities in the areas of research, health information, etc. Here are a few of the resources on CAM for cancer:
  - [www.cancer.gov/cam/health_index.html](http://www.cancer.gov/cam/health_index.html) patient health information home page
  - [www.cancer.gov/cam/health_camaz.html](http://www.cancer.gov/cam/health_camaz.html) CAM A-Z list of fact sheets and publications on CAM modalities
- **University of Texas M. D. Anderson Cancer Center Complementary/Integrative Medicine Education Resources** — [http://www.mdanderson.org/CIMER](http://www.mdanderson.org/CIMER)
  Offers an educational program for patients and health care professionals.
Are you thinking about Practicing CAM? Do you already practice CAM?

The Canadian Nurses Association (CNA) has the following statement about nurses and CAM:

“Nurses practicing complementary therapies must do so in context of a nursing framework, and there must be evidence of the nursing process of assessment, planning, intervention, and evaluation.”

Find out more by visiting the CNA web site (www.cna-nurses.ca/cna), Nurse One (www.nurseone.ca) or calling CNA.

Learning Activities to Expand Nurses’ Understanding of CAM

1. Identify the following as conventional, complementary, alternative, or a combination of approaches.
   a. Nurse provides aromatherapy to a person with cancer following surgery to help lessen their discomfort.
   b. Person with cancer takes a special diet to treat cancer instead of undergoing surgery, radiation or chemotherapy.
   d. Person with cancer receiving chemotherapy has massage therapy weekly.
   e. Cancer survivor uses only shark cartilage to treat his cancer.

2. M.G. asks you about taking shark cartilage to prevent his cancer from returning now that his chemotherapy is finished. Describe how you would respond to M.G.’s question.

3. R.C. is a 43 year old woman who was diagnosed with Stage 3 colon cancer. She finished her adjuvant treatment approximately ten months ago. She tolerated her chemotherapy with relatively few side effects and no side effects which were greater than Grade 2 toxicity (National Cancer Toxicity Grading Scale, 2006). She presents now with acute abdominal pain, nausea, ascites, and jaundice. She reports weight loss of about 5 kg since finishing her chemotherapy. R.C. undergoes management of her symptoms and investigation of the cause(s) of her symptoms. Investigation reveals disease recurrence. R.C. asks you if you think that her recurrence is due to the different herbs and substances that she has tried since finishing her chemotherapy. Describe how you would respond to R.C.

Answers

1. (a) Nurse uses aromatherapy to lessen a person’s discomfort following surgery. Integrative
   (b) Person takes a special diet to treat cancer instead of undergoing surgery, radiation or chemotherapy. Alternative
   (c) Person undergoes surgery for treatment of gastric cancer. Conventional
   (d) Person receiving chemotherapy has massage therapy weekly. Integrative
   (e) Cancer survivor uses only shark cartilage to treat his cancer. Alternative
2. Acknowledge and explore M.G.’s concern about recurrence. Discuss the pros and cons of using shark cartilage. If you are not familiar with shark cartilage, refer M.G. to a pharmacist or dietitian knowledgeable about use of shark cartilage.

3. Apply the CANO/ACIO comprehensive health assessment competency of assessing the person’s use of CAM with aim to better understand what she used, why she used it, and how it may be impacting her today. Approach R.C. in a non-judgmental way.

References


Canadian Association of Nurses in Oncology/l’Association Canadienne des Infirmières en Oncologie (CANO) (2001). Standards of Care, Roles in Oncology Nursing and Role Competencies. Ontario: CANO/ACIO.


UNIT 6

Relationships

Joan Hamilton, MScN
Quick Overview

- For many cancer survivors and their family members, health care providers become an important support and social network. As a cancer survivor transitions to follow-up care, he/she and their family lose this regular support.
- Partners and family members of cancer survivors may have different expectations of when the person with cancer should be “back to normal”.
- Family members sometimes tire of extra roles and responsibilities, of ongoing strain, of nothing being “normal”.
- Some cancer survivors feel pressure to return to their roles as quickly as possible so as to ease the burden of others and give a sense of things being “normal”.
- Partners and family members may demonstrate overprotective behaviours and may want to hold their loved one back from resuming activities.
- Cancer survivors who are unpartnered have different challenges. Although many have close family and friends, support is not the same as having a partner. Many single people have concerns and fears around re-entering the dating scene.
- Same sex couples should have the same opportunity of discussing their couple concerns as others.
- Cancer survivors have learned through diagnosis and treatment that some family and friends have either pleasantly surprised, or disappointed them in terms of their understanding and support throughout the cancer experience. As cancer survivors move back into social activities and the workplace, they may again experience different reactions from friends, acquaintances, and co-workers.
- A person can have a partner and many friends and family and still feel very alone during and after an experience like cancer. It is important not to assume that relationships are fulfilling.
- Many couples who start the cancer journey with a solid relationship and good communication patterns, move into cancer survivorship with the same solid relationship.
- Couples who start the cancer journey with a poor quality relationship tend to continue having challenges throughout the cancer experience and beyond.
- Some couples start the cancer journey with a good relationship, but the distress of the diagnosis on one or both can greatly impact the quality of the relationship as they move along the cancer continuum.
- Fears and concerns about prognosis, recurrence and uncertainty in the future can create emotional distancing within a couple or family.
- Partners may want to protect each other from the distress (e.g. fears, anxieties) they are feeling so that they do not share their worries with each other. This lack of sharing limits the support they would commonly provide to each other.
- Physical and body image changes and changes in body functioning can greatly impact a couple’s sexual, intimate, and emotional relationships.
Introduction

People with cancer, their partners, and families are not necessarily aware of or prepared for the many challenges they can face adjusting to a "new normal", as they transition from treatment to recovery and cancer survivorship.

As a person completes treatment and begins the transition from active care to recovery to follow-up care, many relationships inevitably change. The cancer survivor and family leave the social network of the health care team who have provided safety and support and an understanding of the cancer experience. The completion of treatment often signifies the expectation that life should return to "normal" when in fact, the road to recovery may take to months to years, and some may not recover. Different expectations about when a person should be ‘back in the swing of things’ creates strain within a family. Many cancer survivors and their partners find that life will never be the same, in some or many aspects. The "new normal" that evolves can bring many relationship challenges to couples, family, friends, co-workers, and those who are unpartnered.

Cancer survivors, their partners and families, need to be prepared for possible new imbalances now that the focus is on recovery, not treatment. They should be aware of the issues of cancer survivorship that they may encounter as many family, friends, and co-workers no longer consider them to be "sick". Providing this information is part of the role of the nurse. Nurses can assist cancer survivors, their partners, and families to:

• sort out issues that are preventing a smooth adjustment
• help people with their ongoing feelings of distress, fears, intimacy issues
• assist in establishing new and relevant relationships with health professionals and others (i.e. support group)
• assist in examining and attempting to improve the quality of their relationships.

Cancer can change what is meaningful in life. Some cancer survivors experience a shift in values and what is important to them, and change life goals accordingly. For others, cancer becomes the focus of life and their lifework. Others want life to return as much as possible to what it was before diagnosis. When one person experiences a shift in what is meaningful, it usually impacts the partner, family, and other relationships.

Applying the CANO/ACIO Standards

The CANO/ACIO standards and competencies indicate that the specialized oncology nurse provides follow-up care and continues to explore the changes and challenges. With the transition from active to follow-up care, when immediate side effects have lessened, there is opportunity to help the person with cancer, their partner and family identify changes and challenges to determine what information and assistance they may need.
CANO/ACIO Standards and Competencies Relevant to this Section

In providing care around relationship issues in cancer survivorship, the nurse will be addressing several practice standards and related competencies. The following highlight the standards with some of the most relevant competencies.

Practice Standard: Comprehensive Health Assessment:

Conduct a systematic, comprehensive psychosocial, spiritual, and cultural assessment that includes the individual/family’s response to cancer, their main concerns, feelings, fears, goals, and understanding of prognosis. Assess the individual/family’s financial, social, and practical concerns that may impact their cancer experience. Explore and document the impact and meaning of illness on the individual/family and their support systems.

Practice Standard: Supportive and Therapeutic Relationships:

Understand the cancer experience and the different needs, feelings, fears, concerns, and losses that the individual/family may encounter as part of the cancer journey. Apply knowledge of family dynamics and disease adaptation to support the individual/family’s adjustment to managing and living with the uncertainties of cancer. Assist the individual/family to maintain/establish relationships with individuals or groups who have significant meaning to them over time. Identify individuals and families that require supportive, psychosocial, and spiritual care and refer in a timely manner.

Practice Standard: Teaching and Coaching:

Assess the individual’s understanding of common psychological reactions and responses to the cancer experience and providing information about effective coping mechanisms. Identify limitations in the nurses’ own skill and knowledge base and referring to others when appropriate. Assisting the individual/family to identify and build on their existing strengths when confronting new information and situations.

Practice Standard: Facilitating Continuity of Care/Navigating the System

Apply knowledge of the individual/family’s changing needs as they move across the cancer care continuum, supporting them through the transitions. Initiate, advocate, and mobilize agency and community resources. Apply knowledge of the impact of cancer on the individual/family roles and relationships, facilitating role redefinition, and adaptation. Instruct the individual/family about the appropriate person to contact for concerns and problems. Advise the individual/family concerning survivorship issues and the resources available to support them.
Literature Review

It is well recognized that the cancer journey not only impacts the person with cancer but also the partner, the couple as a unit, family members, the family unit, friends, the social network, and co-workers. As cancer survivorship is a relatively new concept in oncology, information is lacking on the stressors, resources, meaning, and quality of life reported by survivors and family caregivers and the interrelationship between survivors' and family caregivers' quality of life (Mellon, Northouse & Weiss, 2006, p. 120).

The following selected literature review contains examples of literature and research about relationships. See Unit 8: Psychosocial Health and Well Being for content related to reactions and responses to cancer and treatment. The impact on sexuality of cancer survivors and their partners is discussed in Unit 7: Sexual Health. Cancer survivor’s relationships with co-workers are addressed in other sections of this module.

Health Care Team Relationship

For many people with cancer and their family members, health care providers become an important support and social network through treatment. As a person with cancer transitions to follow-up care, the cancer survivor and their family lose this regular comfortable support (Mitchell, 2006).

Family Relationship

“Cancer has been described as a family disease (Boyle, 2003b; Moulton, 2000; Rowland et al., 2001). Considered “secondary survivors”, families have unique issues and provocations as they cope with life after cancer (Boyle et al., 2000; Mellon, 2002). Families must integrate and synthesize information often of a secondhand nature, monitor, and supervise ongoing care requirements, and worry in isolation about what the future holds. Guilt may prevail. For example, family members may ask themselves questions such as: Could I have recognized the symptoms earlier?; Should I have forced him to go to the doctor even though he resisted?; or How could I have been so consumed with the kids that I did not see his weight loss? These enduring feelings of guilt can plague families for a long time. Families of cancer survivors experienced feelings of frustration, isolation, confusion, and tiredness in response to the competing demands of providing usual family care in conjunction with the accommodating survivor needs “More in-depth investigation of family issues during survivorship is required because the future portends the addition, rather than the detraction, of care giving expectations that are imposed on families” (Carroll-Johnson, 2006, p. 37).
Studies with breast cancer survivors have demonstrated that their partners and other family members (e.g. children) can experience a variety of emotional and psychological changes (e.g. anxiety, uncertainty, depression, fear, symptoms of post traumatic stress syndrome, and avoidance) (Segrin, Badger et al. 2007). Some family members report higher levels of distress than that of the cancer survivor. The distress experienced by some breast cancer survivors (e.g. depression, anxiety) impacts on the distress of family members, particularly if the breast cancer survivors’ reactions are visible to others. Family members (i.e. daughters) may experience the same or similar symptoms as the person with cancer. (Segrin, Badger et al, 2007).

In a study by Mellon, Northouse & Weiss (2006) cancer survivors and their family caregivers between one and six years post treatment, were interviewed about quality of life, stressors such as fear of recurrence, family stressors, and family hardiness. The results of this study found that, “cancer survivors reported significantly higher quality of life, less fear of cancer recurrence, and more support than their family caregivers. The strongest predictors for cancer survivors’ quality of life were family stressors, social support, positive meaning of the illness, and employment status. Whereas the strongest predictors for family caregivers’ quality of life were fear of recurrence and social support. Both the survivor’s and family caregiver’s quality of life independently contributed to the other’s quality of life” (Mellon, Northouse & Weiss, 2006, p. 120). The authors reported that some family caregivers may be more susceptible to fear of recurrence because they have had little contact with health professionals and fewer opportunities to ask questions or get information. In their discussion, Mellon, Northouse & Weiss (2006) stress the importance of including family caregivers in the different aspects of cancer care.

Tension and disruption can occur when a cancer survivor is ready to leave the cancer journey behind and the family is not (Australian Government National Health and Medical Research Council, 2003). Family members may be perceived as demonstrating overprotective behaviours, resulting in the cancer survivor feeling resentful. On the other hand, family members may want to get back to some semblance of “normal” and the cancer survivor may not be ready or able to move on (Mitchell, 2006). The cancer survivor may feel frightened, feel anxious, may not want to move on from the cancer experience, or may be reevaluating life priorities. If cancer survivors do not feel that those they feel closest to understand what they need and what they are going through, they may look to those with similar issues and needs for support and understanding. They may seek out other cancer survivors or support groups where they feel understood and accepted. (Australian Government National Health and Medical Research Council, 2003).

Family members do not generally know how to be supportive in discussing cancer or responding to the thoughts, feelings, and behaviors of the person with cancer (Lewis, 2006). During treatment for cancer, the roles, and responsibilities within relationships are often adjusted as the person with cancer may not be able to perform his or her usual functions. With the completion of treatment, some family members want and expect duties to be reallocated immediately, even when the recovering family member is not ready. Others may find that they enjoy new responsibilities and do not want to give up a role they have taken on (Fergus & Gray, 2009).
For partners or family members who are performing care giving duties for their loved one during treatment for cancer, the relationships may change. A variety of challenges including aspects of emotional, psychological, sexual, intimate, and social relationships may be experienced (Segrin, Badger et al, 2007).

**Children’s Reactions**

Most of the studies examining children’s reactions to cancer in the family do not extend past two years of diagnosis. If a parent is diagnosed with cancer, children are often distressed about their parent’s health as well as their own sense of security (Lewis, 2006). Some children think more negatively of themselves and have a poorer self-esteem, than their peers with parents not diagnosed with cancer. When a parent experiences cancer, the quality of their parenting may be affected and they may not know how to help their distressed child (Lewis, 2006). A variety of studies examining the emotional and psychological impact of cancer on the person with cancer and family members suggests that adolescent girls may be at increased risk of adjustment issues (Segrin, Badger et al., 2007).

**Couple Relationships**

Couples experience many different stressors, changes, and challenges in their relationship during and after cancer treatment. These changes and disruptions range from practical, financial, parenting, and emotional distancing (i.e. avoiding conversations, lack of sharing feelings and fears), to changes in intimacy and sexual activity, mutual support, and planning for the future (Fergus & Gray, 2009; Holmberg et al., 2001; Sormanti & Layser, 2000).

Many couples adjust well to a diagnosis of cancer and its treatment and may find that the relationship remains close and stable. These couples are able to use their strengths to remain open and honest, to share couple concerns, and to continue to be each other’s main support (Badr, Acitelli et al., 2008; Sormanti & Layser, 2000). Some couples feel they have grown emotionally closer, their relationship has improved, and that they are more intimate (Dorval, Guay et al. 2005; Manne & Badr, 2004).

For other couples experiencing cancer, the relationship becomes strained and emotionally distant. Attempting to protect each from their feelings, fears, and concerns they may avoid or pretend that nothing is wrong. These couples may not engage in the difficult conversations of such topics as prognosis, fears of dying, and living with an uncertain future. Emotional isolation may be experienced as they try to manage their own emotions and the emotions of their partner (Skerrett, 2003, Badr, Acitelli et al., 2008; Fergus & Gray, 2009).

Couple relationships can change because one or both experience emotional and psychological distress. This decreases the quality of their relationship. Some couples blame their break up on the stress of the cancer experience (Badr, Acitelli et al., 2008).
The term ‘relationship talk’ describes a couple ‘talking about the nature and state of one’s relationship, what one needs from the relationship and the relationship implications of a shared stressor’ (Badr, Acitelli et al., 2008, p 64.) Badr and colleagues (2008) evaluated lung cancer patients and their partners three and six months post treatment and reported that patients and partners who had more relationship talk experienced less distress and greater marital adjustment over time. The more satisfied the person was with the relationship talk, the less distress they experienced. Over time, partners had less distress than patients with more communication about their couple relationship. The work of Badr and colleagues (2008) stressed the need for couple-focused interventions emphasizing communication and relationship needs of both.

Most couples, no matter how high functioning, have been challenged with the demands of cancer and its treatment. Fergus & Gray (2009) describes how ‘even high functioning couples may be thrown off course as they struggle to meet the demands of illness amidst the disruption it causes in the relationship’ (p. 1113).

Studies have demonstrated that one person’s distress can influence those who they are close to. If one partner is anxious, this can contribute to the other partner becoming anxious, even if they are not facing the same threat (Segrin, Badger, et al, 2007). Evidence suggests that levels of psychological distress are similar in both the cancer survivors and their caregivers (Kim, Kashy, et al., 2008). Kim and colleagues (2008) found that “each person’s psychological distress is the strongest predictor of their own quality of life, the partner’s distress, and the (dis)similarity in distress of the couple also play significant roles in one’s quality of life” (p. 203).

The support of a partner is paramount in a cancer survivor’s adjustment super ceding other family members’ and friends’ support (Fergus & Gray, 2009). This provides rationale for the importance of helping a couple to identify stresses and problems within their relationship and to address the issues as a couple. Hodgkinson, Butow, et al., (2007) found that the quality of the couple relationship may greatly impact on the distress and needs of both the cancer survivor and his/her partner.

In a longitudinal study of breast cancer patients and comparison controls that aimed to determine whether a breast cancer diagnosis, personal assertiveness, and partners’ relationship focused coping were sources of variation in relationship satisfaction over time it was found that relationship problems were not necessarily dependent on a breast cancer diagnosis. Those who were more assertive about their own needs and who had partners that were focused on maintaining/growing the relationship were more satisfied in both groups. The authors felt that for those who already find it hard to express their feelings and who feel tension when they open up about their emotions, a breast cancer diagnosis may increase the risk of relationship dissatisfaction. Additionally it was recognized that the relationship focused coping of the partner was very important (Hinnen, Hagedoorn, et al, 2008, p. 750).
Partners of cancer survivors provide support to their mate, but they too need support for years after the diagnosis and treatment of cancer (Hodgkinson, Butow, et al., 2007). Anxiety demonstrated by partners of women with breast cancer negatively impacts the breast cancer woman’s quality of life (Segrin, Badger, et al., 2007). As there is some evidence to suggest that partners do not always share openly in front of their loved one, conducting an assessment separately may provide more open honest information from the partner. In a study of women with breast cancer, Segrin, Badger, et al., (2007) found that both breast cancer survivors and their partners experienced anxiety while going through treatment. The partner’s anxiety influenced the anxiety of the woman with breast cancer. The partner’s anxiety was associated with the woman’s well-being (e.g., depression, fatigue, and symptoms management). A partner’s ability to cope with distress, or get help with their distress benefited both partners in terms of helping partner anxiety and impacting the quality of their relationship (Segrin, Badger, et al., 2007). In a study with cancer survivors and their partners, Hodgkinson, Butow, et al., (2007) reported that “higher distress in partners was correlated with higher distress in survivors and higher need in partners was correlated with higher need in survivors” (p. 412). The reactions of one partner affect the reactions of the other (Dorval, Guay et al. 2005).

The quality and satisfaction of a couple’s relationship may change over time. One partner (commonly the healthy one), takes on roles and responsibilities of the other and the other partner (the person with cancer), is released of his or her usual duties. The flexibility of ‘give and take’ may no longer be available, adding pressure to the healthy partner. This division is commonly not easy for either (Kuijer, Buunk, et al. 2004). With completion of cancer treatment, the healthy partner may be ready and waiting for the recovering partner to begin taking over some responsibilities. The recovering partner may not yet feel ready. This can cause ongoing tension (Fergus & Gray, 2009; Kuijer, Buunk, et al 2004).

Cancer and cancer treatment can cause changes in sexual functioning, body image, and a couple’s sexual routine. The changes can greatly impact a couple’s emotional, intimate, and sexual relationship, causing frustration and dissatisfaction for both. These difficulties or changes in sexual performance can affect feelings of intimacy and confidence. They can impact emotional closeness which can cause strain, tension, and resentment within the relationship (Fergus & Gray, 2009; Holmberg, Scott et al, 2001). See Unit 7: Sexual Health for further information.

**Being Unpartnered**

Holmberg, Scott et al, (2001) found that single women were angrier, sad, and hurt related to their experience of cancer. These findings suggest that unpartnered women may face more difficulty than those of partnered women.
People with cancer who do not have a partner may have different or more complex issues than those with a partner. The timing of when to tell a potential partner of the cancer, and when to show them body changes are issues (Holmberg, Scott et al, 2001). Body image and self-esteem changes impact initiating a relationship. Some people with cancer feel that the cancer labels them, and that changes to their bodies may limit their chances of having new sexual relationships. (Australian Government National Health and Medical Research Council, 2003).

Facilitating a Comprehensive Assessment

As the transition to recovery and cancer survivorship becomes imminent, it is important for the nurse to explore and discuss the following with cancer survivors, partners, and families:

- different challenges that they may face;
- different ways to remain open and honest with each other;
- ways to maintain respect for each other’s thoughts and feelings; and
- the identification of resources that are available to them now, and in the future.

The nurse can normalize that many couples and families need assistance in adjusting once cancer treatment is complete. It is important for the nurse to prepare the person with cancer, their partner, and family members for the upcoming change in their relationships with the cancer care team. This is often a big adjustment and a sense of loss for cancer survivor and their family.

Suggested Opening Statement and Questions:

- "For many people, the diagnosis and treatment of cancer changes the relationships with their partner, family members, friends, or co-workers. Some relationships are better, some are more challenging. How have things been for you?"
- "What types of changes have you experienced?"
- "How do you think things will change now that you have completed treatment?"

Questions to ask the cancer survivor:

- How are you finding things with family members / friends / your partner?
- Who do you lean on for support?
- Do you find that some people treat you differently? How upsetting is this for you?
- Sometimes when cancer treatment is over, some family members are anxious for everything to get “back to normal”. Many people who have had cancer say that the old normal is just not possible. What has your experience been like?

Questions to ask the cancer survivor, couple and family:

- How have things changed for you as a couple (within your family) through all of this?
- In what ways has cancer brought you closer together? In what ways has it pushed you apart?
Are you the type of family that usually shares feelings with each other?
What are members of your family saying or doing that are helpful? Not helpful?
Sometimes, the whole experience of cancer has caused strain and tension within the family. How is your family doing?
Do you or anyone in your family have questions about your cancer and the future (risk of it coming back, worries about you dying)?
Having a family meet with a health care provider to ask some general questions can sometimes help open up a discussion within the family. Would a family meeting be helpful in your family's situation?
After the experience of cancer, some people want to put the experience behind them and move on, close the cancer chapter of their life. For others, cancer continues to be a big focus in their lives, not something that they want to move past. Where would you say you fit in this? Where would you say your partner/family fits with this? In what ways does this difference in your thinking cause any problems or tension?

Questions to ask a Couple

Would you say you were emotionally close before all this started? How about now?
Many couples need some help talking about certain things. Would you like to see someone who may be able to help you open up more to each other?
How did you show affection for each other before your experience with cancer (hugging, cuddling, holding hands) Has this changed? Why do you think this has changed? Do you miss being affectionate?
How comfortable are you talking about changes in your appearance, how your body works, and how that affects things sexually?
How much of a concern are these changes for both of you? How much have you talked to each other about these changes?
How would you like to see your relationship improve?
Many couples find that they need some help reconnecting after treatment. Would you like to see someone?

Questions to ask the partner of the cancer survivor

How openly can you talk with your partner about changes, fears, and concerns in your relationship?
What kind of care taking, if any did you provide for your partner when s/he was having cancer treatment? What was that like for you? How has doing that care taking for him/her changed your relationship?
In what ways does your partner look different now? How this change affected how you feel about him/her?
Questions to ask an unpartnered cancer survivor

- We know that often, individuals who do not have a steady partner have different concerns and issues than people with a steady partner. How are you finding things?
- Who do you rely on for support?
- What concerns do you have as a single person?
- Some of the big concerns that have been identified for single people are concerns such as:
  - When should I consider dating?
  - When do I tell a potential partner I had cancer?
  - How will they react to my body?
  - Will I totally scare them off?
  - How will the sex part work?
  - Have you been thinking about any of these things?

Priority Content for Patient Teaching

- Couple/family relationships may change with the completion of cancer treatment. Sometimes responses of family members/partners are supportive and comforting, sometimes not. Some family members don’t know how to react, what to do, or what to say to the cancer survivor, and need guidance.
- Recovery is usually slower than everyone wants it to be. Some family members will expect a return to a “normal” routine right after completion of cancer treatment, others may demonstrate protective behaviours for a long time.
- The experience of cancer impacts everyone differently. For some people, having cancer changes them as a person. It changes their values, their outlook on life and what is important, what they want in a relationship. These changes can create changes in relationships.
- Some cancer survivors find that it is the people around them who change. Their partner / family members / friends change what they talk to them about, and how they are included. Sometimes these changes create tension or strain. Sometimes relationships don’t survive these changes.
- Everyone deals with cancer in their family in their own way, and it can be well into recovery before loved ones really begin to treat the cancer survivor as ‘normal’ or they can begin to plan for the future.
- If family members or friends have not been able to support the cancer survivor through their illness as they may have wanted, they experience feelings of guilt or worry about reconnecting (now that treatment is over and everything appears back to “normal”). Ironically, it is the cancer survivor who may put others at ease, to make the first move at reconnecting the relationship.
Couples

- As the cancer journey moves into cancer survivorship, many couples find that they haven’t spent a lot of time on their relationship. They haven’t talked to each other about what they are scared of, how they have felt, how they are feeling, and plans for the future. If a couple hasn’t been able to be affectionate, to cuddle, to share intimate moments, it can take some time to get back on track with their relationship. Some couples need help reconnecting in certain ways.

- If a cancer survivor or their partner is finding it hard to adjust to physical, sexual, intimate, emotional, or body changes, it is important that they not wait long before seeking help. Changes and challenges need to be addressed sooner rather than later; relationships may diminish in quality over time with feelings of anger, resentment, and bitterness. Don’t put off getting help for your patient.

- If one partner continues to experience distress into cancer survivorship (related to fears, worries, uncertainty) it inevitably impacts upon the distress of the other person in the relationship and the quality of the relationship.

- Some types of cancer and cancer treatment result in bodily changes that impact upon the spontaneity and satisfaction with intimacy, and sexual activity. Finding a compromise can often take motivation and frank discussion. Often a health care provider can provide useful guidance and suggestions.

- Often, as cancer treatment comes to an end, partners are excited to move on, leave the illness behind, and “get back to normal”. The cancer survivor may not be in the same space. They may feel anxious that cancer treatment has stopped. They may not feel ready to move on and may be still in the cancer frame of mind. Couples often need some help working on this imbalance.

Being Unpartnered

- Being single can be very difficult through cancer treatment and cancer survivorship.
- Supportive friends can be wonderful but are not the same as having a steady partner.

Counseling

- Many people find that they benefit from some professional help as they move to a new normal after cancer. Some people may find that a non-partial listener helps them sort out changes in their relationships. Very often, couples or families need help to start talking, or they need help keeping the conversation going. Some couples or families may need specific guidance in addressing their issues. Some people benefit from learning the right questions to ask. Some couples require assistance in learning about how to express themselves or how to work things out.
Examples of Nursing Interventions

- Along with the cancer survivor, many family members need ongoing reassurance that frequent ongoing monitoring of the cancer survivor’s situation is no longer needed. Feelings of ‘being abandoned’ by the health care team can be normalized. The nurse can provide specific directions on who to call for what concerns as they are being transitioned from the cancer care program to cancer survivorship.

- It is helpful to provide opportunities for partners and family members to ask questions and discuss “hard conversations” (e.g. fear of recurrence, prognosis, worries about dying) when the family is all together.

- Normalize how difficult moving forward form the cancer experience can be for the cancer survivor, their partner, and family members with the many changes and challenges. Explain that couples/families may benefit from professional help with being open and honest with each other and knowing how to address all the changes that have occurred (in their relationships, family life, feelings, and fears), and how to now move forward.

- Encourage family members not to demonstrate protective behaviours towards the cancer survivor related to discussions of normal daily life. It is helpful for the partner/family to understand that the cancer survivor needs to be involved with the ups and downs of family life; it helps them to integrate back into everyday living.

- When the cancer survivor is ready to begin resuming normal activities, talk about it as a couple/family so that everyone is aware of the plan.

- Encourage family members to talk about what they are feeling and discuss concerns as their loved one transitions from the sick role.

- For some family members, they can hardly wait to give back certain responsibilities that they have taken on throughout the illness. They may want to give them back too soon, or all at once. Explain that recovery is gradual, that everything cannot get back to normal all at once.

- For other family members, it is hard for them to give up the extra responsibilities. Assist family members in understanding the reasons behind the cancer survivor needing to gradually participate in family life as before.

- When the cancer survivor continues to live with limitations or consequences of the cancer or treatment, help the family sort out roles and responsibilities or link the family with someone who can guide them.

Relationship with Partner

- Normalize that some couples need time to get to know each other again when the couple no longer has to have the cancer as a focus of their lives.

- Normalize that many couples benefit from professional help to reconnect emotionally, intimately, and sexually.
Normalize that the cancer journey commonly changes both the cancer survivor and their partner, by creating new or different feelings, new and different ideas, and sometimes different values and beliefs. Inform the couple that as they move into cancer survivorship, there will be less and less focus on the cancer experience. Explore where their relationship is, what feelings each of them have, in what ways things changed in terms of how they are communicating and what they are sharing with each other.

Consider seeing the couple separately and together. When separate, ask each how they feel the other is doing, and if they have any concerns about well-being. Ask about changes they are experiencing in their couple relationship. With the partner, ask about changes of feelings due to changes in appearance and body functioning, and if anything has changed because of being in the care giving role. With the cancer survivor away from their partner, it gives them an opportunity to share information and concerns about their body image changes that they feel uncomfortable sharing when their partner is present.

Explore how the cancer survivor is feeling about their body, their self confidence, and how this impacts their relationship with their partner.

Normalize changes a cancer survivor may be feeling (e.g. feeling less sexually attractive; less interested in sexual activity; less sexually aroused; less of a woman or man).

**Being Unpartnered**

Normalize and acknowledge the unique challenges of trying to find a new partner. When do they tell a potential partner? How much of their story do they tell? When do they show them the changes in their body? Should they tell the person as soon as they meet, or wait until they know there may be something to the relationship?

Provide detailed information about psychosocial resources that are available.

**Resources**

Encourage your agency to maintain a list of counselors (public and private) who can address different issues.

If couple/family counselors are not available in your area, provide written material of and accessible relevant written materials. These materials will not replace a counselor, but they may help normalize and validate a cancer survivor’s or couple’s experience and may facilitate discussion. Some people like to have resources to read and research.
Learning Activity:

C.R., 46, completed her cancer treatment 6 weeks ago and is in for her first follow-up visit. Her husband F.R. is with her. To date, her visits have focused on the discussion and management of physical side effects. With many of these now resolving, you observe today that she has been able to move her focus away from physical symptoms and describe how her cancer journey has impacted her psychologically. You describe some of the emotional changes she may experience as she moves from being a cancer patient to being a cancer survivor. She asks what else she may need to know as she shifts to what she is calling a 'survivor state of mind'.

Realizing you have limited time remaining in the clinic visit, what information do you think may be important to introduce to C.R. and F.R. to help normalize some of the challenges they may experience as a couple and family?

- Partner and family members may all have different expectations of how a survivor moves from ‘being sick’ or ‘being a patient’ to getting back into normal life.
- Some may expect the survivor to be completely back to normal and to move along now as if nothing has changed. Some may be overprotective and some partners and family members may believe that all their lives have changed forever and nothing will ever be the same.
- Explain to family that recovery may take weeks to months with gradual improvement. Acknowledge that this gradual recovery have be hard or frustrating for everyone, especially as everyone is eager for things to get back to some kind of normal.
- If the survivor’s cancer has not been openly discussed (follow-up, risk of recurrence, changes in how survivor looks) and spoken or unspoken worries about ‘are you going to die?’ have not been addressed, this can cause strain, tension, uncertainty, worries, and the inability to have open honest communication within a family members. The impact can seep into different aspects of life. This can be a hard discussion and survivors may need help from a health care provider with planning or wording of such a discussion. Adults and children tend to cope better when they are informed.
- Reassure family members that ‘if anything changes from what I have told you, I will let you know’.
- Different couples/families can experience different stresses, stains and challenges in their relationships and in home life as the person who has had cancer moves back into their normal life. Some couples and families talk about what is distressing them and are able to resolve issues. For other couples and families, stress, resentment, and anger can build and people remain silent. If couples and families are feeling stressed, things are not getting better and people are unable to talk, get help. Suggest resources.
- It is important for couples to talk to each other about their fears around the future, fear of dying, changes in appearance, bodily changes, other changes, and other worries. Lack of openness about these issues can cause ongoing strain and stress and can impact the couple’s sexual, intimate, and emotional relationship. May need professional help to start talking, to keep talking, or both. Discuss available resources in cancer program.
• Discuss the different psychosocial resources available in cancer program, different written resources, and the types of health professional they may seek out in their own community. Normalize the need for these services by clarifying that resources are available because of the many different challenges survivorship can create in relationships and many cancer survivors and their partners seek such support.

• For survivors who are unpartnered there are different challenges. It is always important to seek out additional support from the supportive care team which may include psychologists and social workers who can help craft a meaningful care plan for unpartnered patients.

Selected Resources

For Nurses


For Cancer Survivors, Partners and Families

[www.cancerhelp.org](http://www.cancerhelp.org) Patient Information Coping with Emotions


University of Texas, MD Anderson Cancer Center. [www.mdanderson.org/patient-and-cancer-information/index.html](http://www.mdanderson.org/patient-and-cancer-information/index.html) Patient and Cancer Information Cancer Survivorship Health and Well-Being After Cancer. On line information to read but on that page you can also print off or read from a booklet called Survivorship: Living with, Through and Beyond Cancer (see Psychological, social, emotional, and spiritual impacts of cancer).

National Coalition for Cancer Survivorship (www.canceradvocacy.org) Find a Resource Cancer Survivor Toolkit Special Topics Living beyond Cancer including; Intimacy, Family Communication, Emotional Aspects of Cancer (audio or written presentation).

References

Australian Government National Health and Medical Research Council (2003). *Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer.*


UNIT 7
Sexual Health
Dr. Anne Katz, RN, PhD
Quick Overview text box.

- Up to 80% of cancer survivors will experience some alterations in sexual functioning as part of the cancer trajectory.
- It is important for the nurse to recognize that sexual challenges are present at all stages of cancer and to offer assessment and assistance where needed.
- It is most common for cancer survivors and their partners to seek help when treatment is complete and life goes back to ‘normal’.
- Sexuality is very much a cancer survivorship issue.

Introduction

All people are sexual beings from birth to death. Awareness of one’s sexual self begins in early childhood and is maintained despite illness, relationship status, or actual sexual activity. Cancer and its treatments pose a significant threat to a person’s sexual self-image as well as to how they are able to express their sexuality.

Up to 80% of cancer survivors will experience some alterations in sexual functioning as part of the cancer trajectory (Meyerowitz, Desmond, Rowland, Wyatt, & Ganz, 1999); whether they choose to seek help for this is variable. It is important for the nurse to recognize that sexual challenges are present at all stages of the cancer experience and to offer assessment and assistance where needed (Rolland, 2005). Alterations to sexuality and sexual functioning can occur anywhere along the cancer trajectory, from diagnosis to end of life. It is most common for cancer survivors and partners to seek help when treatment is complete and life goes back to ‘normal’, thus sexuality is an important cancer survivorship issue.

Link to relevant CANO/ACIO Standards

Attending the sexual health needs of the cancer survivor and partner is relevant to many of the CANO/ACIO Standards of Care including: individualized and holistic care; family centered care; and supportive and therapeutic relationships. For the specialized oncology nurse refer to the Standards and Competencies for the Specialized Nurse Domain #1 Comprehensive Health Assessment; Domain #3 Management of Cancer Symptoms and Treatment of Side Effects; and Domain #4 Teaching and Coaching.

Literature Review

Changes to Sexual Functioning and Sexuality

Alterations to sexual functioning and sexuality most commonly manifest in the following ways: body image issues, changes to sexual anatomy, alterations in physiological functioning, and emotional responses to these changes. The following discussion will briefly highlight some of the most important issues; more in-depth explanations are found in the resources presented at the end of this section.
Body Image Issues

Treatment for cancer usually involves some combination of surgery, radiation therapy, chemotherapy, and endocrine manipulation (Katz, 2007). Any and all of these may impact on body image. The presence of scars as well as weight gain or loss may profoundly alter the way a person sees themselves as a sexual being. The area around a scar may feel numb or be hyper-sensitive to touch. Skin changes as a result of radiation therapy may have similar results. No matter how much reassurance the person receives from their partner, their sexual self image may be altered and they may be reluctant to appear naked in front of their partner or may avoid sexual touching (Schover et al., 1995).

Any and all kinds of surgery may affect body image even though it may seem minor. For example, women who have lumpectomy rather than mastectomy may experience alterations to their body image because of the scar that remains on the breast or because the shape of the breast is different.

Changes to Sexual Anatomy

The surgical removal of body parts or organs that directly affect sexual functioning include mastectomy, radical prostatectomy, and hysterectomy. Other surgeries close to the pelvic area (such as the rectum) may also interrupt blood or nerve supply to the area and thus affect sexual functioning. After radical prostatectomy, many men find that their penis undergoes shrinkage as a result of lack of blood flow from nocturnal erections (Munding, Wessells, & Dalkin, 2001).

Alterations in Physiological Function

After surgery, scar tissue in the area of the surgery may alter various phases of the sexual response cycle. For example, some women find that after hysterectomy their orgasms feel different, usually as a result of the loss of contractions of the uterus during the contraction phase of orgasm (Gruhmann, Robertson, Hacker, & Sommer, 2001). Women who have been treated for breast cancer may need to take hormone manipulating medications such as aromatase inhibitors; these are known to cause vaginal dryness that causes pain with intercourse (dyspareunia) and often leads to lack of interest in sex (lack of libido) because the woman is fearful about experiencing pain (Bentrem & Jordan, 2002). Similarly, men with advanced prostate cancer may need to take androgen deprivation therapy which leads to significant loss of libido and this has been shown to impact negatively on the intimate relationship (Navon & Morag, 2003).
Emotional Responses

Many couples do not anticipate what it means to deal with something that previously was natural and spontaneous. Some couples find it difficult to talk about what has happened to their sex life and may drift apart. Others are able to deal effectively with this change and seek help or find other ways to maintain intimacy in the relationship. There is no right or wrong way to deal with sexual changes after cancer but it is important that cancer survivors and their partners are aware that sexual changes are likely to occur and how to access resources to help them cope. (Refer to Unit 6: Relationships and Unit 8: Psychosocial Health and Wellbeing for more information about emotional responses.)

Fertility

Many of the treatments for cancer can affect fertility. This is of special importance when a child, adolescent, or young adult is treated for cancer. In males, the testicles (and hence sperm production) are more susceptible to damage before puberty so a man who was treated for cancer in childhood may be infertile (Lambert & Fisch, 2007). When cancer is diagnosed after puberty, it is advised that all young men have sperm frozen and stored for future use. This is a difficult decision for the young man and his parents as the decision has to be made when the cancer survivor and family are in shock about the diagnosis (Schover, Brey, Lichtin, Lipschults & Jeha, 2002).

There are fewer options for fertility preservation in young women. After puberty the ovary is susceptible to damage from both chemotherapy and radiation. Shielding the ovaries or moving them out of the field of radiation does help to prevent damage. The only proven method of preserving fertility in women is to harvest eggs which are then fertilized by the partner’s sperm and the resultant embryos are frozen for implantation at a future date. This option is not available to adolescents who are not partnered. Freezing unfertilized eggs or ovarian tissue remains experimental (Davis, 2006).

Understanding the impacts of cancer and cancer treatment on fertility is important for the nurse in the setting of cancer survivorship. In this course of the cancer experience cancer survivors and their partners may be living with the reality of never conceiving a child together. They may be experiencing continued disappointment, grief or distress. It is important to be considering this within the nursing assessment and exploring it appropriately. Some individuals or couples may need focused counseling in follow up and referrals to supportive care practitioners may be indicated.

It is important for couples to know that assuming that the person who has had cancer is infertile may result in an unexpected pregnancy. Some cancer survivors may not use condoms for contraceptive purposes and this puts them at risk for acquiring sexually transmitted infections.
Facilitating a Systematic Assessment

As a holistic care provider who sees cancer survivors and their partners over time, the nurse is ideally situated to assess for sexual problems related to the cancer and/or its treatment and to make suggestions to help with identified problems. This is certainly within the scope of nursing practice however many nurses state that they do not feel comfortable discussing this with patients (Magnan, Reynolds, & Galvin, 2005). Others state that they do not know enough about the topic and so do not assess their patients.

The resources provided in this unit will provide the factual content to enable the nurse to provide the answers to most questions that cancer survivors will ask. Increasing personal comfort with talking about the topic may be challenging, but may improve with experience.

It is vital that an assessment of sexual functioning and any difficulties encountered be done at regular intervals during treatment and follow-up. There are a number of ways to assess sexuality and sexual functioning in the cancer survivor. The two models described below are simple to use and easy to remember.

The PLISSIT Model (Annon, 1974) is a 4-level model that suggests deepening levels of enquiry and assessment.

The first level is that of permission. Using a non-threatening opening question or suggestion, the nurse indicates to the cancer survivor that he/she is willing to listen to any sexual concerns. A statement such as “Many men who have been treated for prostate cancer experience some degree of difficulty achieving or maintaining an erection. I can provide you with information that you may find useful if you have any questions about this or anything else.”

The second level is that of limited information. All nurses should be able to give this kind of information when working with cancer survivors in their area of practice. An example of this level of assessment/intervention is: “The vaginal dryness you describe since starting on tamoxifen is quite common. There are a number of things that can help, starting with a vaginal moisturizer such as Replens®. You may also want to use a lubricant such as Astroglide® for sexual activity”.

The third level of this model is specific suggestion; this requires a more in-depth knowledge of sexuality and cancer but most expert nurses should be able to provide this level of assessment/intervention. A statement such as “Because you did not have a nerve-sparing procedure when they removed your prostate, the oral medications used to treat erectile dysfunction will not work. You will have to consider more mechanical or invasive methods such as the vacuum pump or penile self-injection”.

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The final level, **intensive therapy**, is best left to a sexuality counselor/therapist or specialist. It is important for the nurse to know about the local resources available to cancer survivors with concerns about sexuality. For example there may be resources such as sexuality counseling, sexuality clinics, and pelvic physiotherapy to name a few.

The second model, the **BETTER model** (Mick, Hughes and Cohen, 2003) was developed for use in oncology settings. It is similar to the PLISSIT Model in that the first level of intervention involves bringing up the topic (B). The second letter (E) involves explaining that sexuality is part of quality of life, and cancer survivors should be aware that they can talk about this with the nurse. The nurse should then tell (T) the cancer survivor that appropriate resources will be found to address their concerns and that while the timing (T) may not be appropriate now, they can ask for information at any time. Cancer survivors should be educated (E) about the sexual side effects of their treatment and finally, a record (R) should be made in the chart to report that this topic has been discussed.

A more detailed discussion about assessment of sexuality can be found in the text *Breaking the Silence on Cancer and Sexuality: A Handbook for Health Care Providers* by Anne Katz RN PhD (Oncology Nursing Society, 2007).

**Priority Content for Patient Teaching**

Many cancer survivors who experience sexual difficulties do not know where to go for help. The nurse may be the first and only person to ask about this important part of life and must be prepared to help the cancer survivor find the help that they need and want. When a problem is identified, nurses should have on hand the names and contact information for sexuality counselors or therapists, marital and family therapists, or psychosocial clinicians who may be able to help.

**Additional Resources**

**WEBSITES**

Website from the UK. Information for patients and their partners.

[http://www.cancer.org/docroot/MIT/MIT_7_1x_SexualityforWomenandTheirPartners.asp](http://www.cancer.org/docroot/MIT/MIT_7_1x_SexualityforWomenandTheirPartners.asp)
American Cancer Society website. For women.

[http://www.cancer.org/docroot/MIT/MIT_7_1x_SexualityforMenandTheirPartners.asp](http://www.cancer.org/docroot/MIT/MIT_7_1x_SexualityforMenandTheirPartners.asp)
American Cancer Society. For men.

Mayo Clinic.
BOOKS


The following books and articles will be helpful for nurses who want to learn more about the topic of cancer and sexuality.


Case Study

J.P. is 54-year-old. Three weeks ago she was diagnosed with breast cancer after a routine screening mammogram. She was scheduled for a lumpectomy and will have radiation after that. You see J.P. in follow up when she returns to see the surgeon who performed the lumpectomy. She is alone and very upset. J.P. tells you that her husband has barely made eye contact with her since the surgery and appears to be withdrawing. He has not touched her at all since the surgery and they used to have a very active and satisfying sex life. J.P. is feeling very much alone and is worried that, “there is something very wrong” with her husband’s reactions following her breast surgery. She is not sure how she will manage to get through the radiation therapy without him.

Apply either the PLISSIT or BETTER Model to suggest a statement or question to begin your interaction with Jill.

What further questions should you ask?

What advice can you give J.P. at this time?

Who is the best resource to refer J.P. to and when is an appropriate time to make the referral?

Answers

J.P.’s husband’s response is not unusual and may be his way of coping with the new circumstances of their life. There is no right or wrong way to cope. He may not actually be withdrawing but rather trying to find a new way of coping with the situation. He would likely benefit from some counseling on his own as well as some couples’ counseling.

It would be helpful to ask J.P. what her expectations of her husband are and how he is meeting or failing these expectations. Assessing her other means of support would also be important at this time. It would also be helpful to explore what kind of touching she is referring to. She may mean sexual touching of her breasts or she may mean that he avoids any kind of physical contact with her, including hugging or holding her hand when she needs it.

A referral to a social worker as soon as possible is a good place to start. This professional will be able to identify other resources that may be needed to help this couple to deal with their coping and adaptation. A referral to a support group may also be useful.
References


UNIT 8

Psychosocial Health and Well-being

Virginia Lee, RN, PhD, Brenda Sabo, RN, PhD, Myriam Skrutkowski, RN, MSc, CON(C), Mary Vachon, RN, PhD
You gain strength, courage, and confidence by every experience in which you really stop to look fear in the face. ~Eleanor Roosevelt

Quick Overview

• Distress has become a more widely accepted and less embarrassing term than depression, anxiety, or other psychiatric or psychological terms (National Comprehensive Cancer Network, 2007).
• Vulnerability to emotional distress following cancer has been consistently shown to predict poorer adjustment.
• Although symptoms may overlap, it is important for nurses to recognize that depression and grief are not the same.
• Cancer patients frequently report that spirituality and religion are important in helping them to cope with and adjust to the cancer experience (Edser & May, 2007)
• The ability to find meaning and the occurrence of post traumatic growth are very individualized processes that may or may not occur over time.

INTRODUCTION

The psychological distress of dealing with temporary or permanent health effects from a diagnosis of cancer and its treatment carries a significant burden for many patients and families. Challenges related to stigma, disability, long term fatigue, chronic pain, work and leisure, and the financial costs associated with cancer treatment and management may occur in isolation or be compounded by pre-existing psychosocial issues.

This chapter is designed to enhance the oncology nurse’s understanding of psychosocial and spiritual health issues among cancer patients and their families. Case studies are provided to support learning. Completion of the case studies and a review of the literature will provide nurses with:

1. A basic understanding of common psychological effects of cancer and the transition to survivorship. These effects include depression, grief and loss, anxiety, and Post Traumatic Stress Disorder (PTSD).
2. Knowledge on the roles of spirituality, religion, and meaning-making in the transition process.
3. An understanding of the concept of Post Traumatic Growth.
4. Helpful tools and guiding questions to support patients and families as they begin the process of creating meaning from the cancer journey to survivorship.
5. Resources are provided at the end of the chapter for individuals interested in learning more about psychosocial/spiritual health and well being.
What Do Oncology Nurses Offer?

Nurses are uniquely situated to recognize distress and offer timely support to the patient and family. Oncology nurses promote continuity of care by virtue of their specialized knowledge base and skills that can holistically, and at times simultaneously, address the psychosocial, physical, and/or social concerns of the patient. For example, a nurse can change a wound dressing while discussing with the patient his fear of recurrence of cancer and its potential impact on his children and family. Oncology nurses also promote continuity of care because they work in a multidisciplinary milieu in which they can refer patients who require more specialized, in-depth assessment, or treatment to other professionals and support services.

Applying the CANO/ACIO Standards and Competencies

Reviewing and using this section in practice, the nurse will be addressing in particular the following competencies:

1. Standard Practice: Comprehensive Health Assessment Relevant Competencies
   a. Conduct a comprehensive psychosocial, spiritual, and cultural assessment that includes the individual/family’s response to cancer, main concerns, feelings, fears, goals, and understanding of prognosis
   b. Screen for psychosocial and spiritual distress using validated tools
   c. Explore and document the impact and meaning of illness on the individual/family and their support systems (take into account present life circumstances and view of quality of life)
   d. Assess and respect individual/family religious and spiritual practices/resources
   e. Assess and respect cultural influences
   f. Assess individual/family financial, Social, and practice concerns that may impact cancer experience
   g. Assess individual/family’s mental health needs including therapies and outcomes (if relevant)
2. Standard Practice: Supportive and therapeutic relationships Relevant Competencies
   a. Apply supportive care strategies and best practice/evidence-based psychosocial care interventions within the scope of practice to facilitate effective coping
   b. Identify individuals/families that require supportive, psychosocial and spiritual care and refer them in a timely manner

What Happens When We Don’t Meet Patients’ Psychosocial Needs?

Research has shown that psychological and social stressors (e.g. depression, lack of social support, limited coping capabilities, low socio-economic status) have been associated with increased morbidity, mortality, and decreased quality of life (Adler & Page, 2008; Carroll-Johnson, Gorman, & Bush, 2006; Kielcolt-Glaser, McGuire, Robles, & Glaser, 2002). Further compounding the problem of survivorship for many patients and their families is living with
the uncertainty of recurrence which may be expressed as fear, anxiety, and/or emotional ups and downs (Gaudine, Sturge-Jacobs, & Kennedy, 2003; Mishel, 1997; Nelson, 1995). Grief and loss must also be acknowledged as a component of transitioning to survivorship. The broad array of feelings and behaviours common after a loss, such as the death of a loved one, may also be experienced in direct response to other losses such as: the loss of a breast, the loss of original hopes and dreams, loss of social support, etc.

**FACT:** Approximately 80% of cancer survivors may experience rates of psychological distress, anxiety, depression, and diminished quality of life similar to that of the general population, however a significant number of cancer survivors may have difficulty transitioning, and/or adjusting to the role of survivor (Alfano & Rowland, 2006)

**LITERATURE REVIEW**

**What do we mean by psychological distress?**

Distress has become a more widely accepted and less embarrassing term than depression, anxiety, or other psychiatric or psychological terms (National Comprehensive Cancer Network, 2007), within the context of cancer.

Distress has been defined as “a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and treatment (National Comprehensive Cancer Network, 2009, DIS-2.).

**Did you know that 18% to 43% of cancer survivors may experience significant distress requiring professional intervention?** (Vachon, Lancee, & Conway, 1990; Zabora, BrintzenhofeSzoc, & Curbow, 2001)

The experience of distress is variable ranging from sadness and a sense of feeling vulnerable to profound depression. Distress can occur at any point along the cancer continuum (NCCN, 2009). Heightened distress has been associated with negative outcomes and frequently goes unrecognized or untreated (Fallowfield, Ratcliffe, Jenkins, & Saul, 2001).

Negative outcomes include:

- Decreased treatment adherence
- Decreased satisfaction with care
- Decreased quality of life
- Decreased survival

**Depression**

Depression is a disease (e.g. psychiatric mood disorder) and a collection of symptoms influenced by biological (e.g. multiple sclerosis, cancer, cardiac disease), social and interpersonal stressors (e.g. sense of belonging, social support, conflict, loneliness) (Hagerty, 1999).
It is characterized by sadness beyond that considered within the normal range of emotions and which permeates all aspects of the individual’s life (Walsh, 1998). Depression may be primary (exist alone) or secondary (associated with other disease states).

**Common symptoms (DSM-IV)**

Clinical depression is evidenced by the individual experiencing, for at least two weeks, a depressed mood and loss of interest or pleasure in activities usually enjoyed. In addition to these symptoms, the individual must have at least four of the common symptoms listed below:

**COMMON SYMPTOMS**

<table>
<thead>
<tr>
<th>Depressed mood</th>
<th>Psychomotor retardation or agitation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Difficulty sleeping*</td>
<td>Suicidal ideation</td>
</tr>
<tr>
<td>Guilt &amp; worthlessness</td>
<td>Hopelessness (considered a key symptom)</td>
</tr>
<tr>
<td>Lack of interest</td>
<td>Decreased libido</td>
</tr>
<tr>
<td>Decreased energy*</td>
<td>Diurnal variation</td>
</tr>
<tr>
<td>Inability to concentrate</td>
<td></td>
</tr>
<tr>
<td>Poor appetite*</td>
<td></td>
</tr>
</tbody>
</table>

* indicates vegetative symptoms

It is sometimes suggested that the vegetative symptoms noted above be replaced with the Endicott Criteria, as the vegetative symptoms might be reflective of disease or treatment side effects.

**ENDICOTT CRITERIA**

<table>
<thead>
<tr>
<th>Social withdrawal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depressed appearance</td>
</tr>
<tr>
<td>Diminished reactivity</td>
</tr>
<tr>
<td>Pessimism</td>
</tr>
</tbody>
</table>

It is important to take into account the following RISK FACTORS when considering depression:

- Severity of illness
- Stressful life events
- Prior history of depression or family history of depression
- Medications, and
- Socio-economic pressures
The Prevalence of Depression

The prevalence of depression among survivors has been estimated to range from 0-38% for major depression and from 0-58% for depression spectrum syndromes (Massie, 2004). This wide variability may be attributed in part to how researchers define depression. Although depression is considered to be the most common mood disorder associated with cancer, it can be alleviated with appropriate and timely intervention. Unfortunately, an all too common belief held by many health care professionals is that “depression is normal for the patient” (Carroll-Johnson, Gorman & Bush, 2006, p.241).

Reflecting on your own practice you may now think you have fallen into the same belief pattern, perhaps overlooking depressive symptoms in cancer survivors for whom you provide care. You are not alone! Lack of comfort, familiarity and skill in identifying major depression is not an uncommon concern among nurses who may frequently underestimate the level of depressive symptoms among those experiencing moderate to severe depression (Valente & Saunders, 2005). Nurses frequently rely on crying, depressed mood, and vegetative symptoms such as insomnia, fatigue, anorexia, and constipation to inform their assessment. In the patient with cancer and/or survivor population such symptoms are not good indicators of depression (Carroll-Johnson, Gorman & Bush, 2006) as they may often manifest as the side effects of treatment.

Vulnerability to emotional distress following cancer has been consistently shown to predict poorer adjustment.

Symptoms of depression are more likely to be associated with the following cancers: oropharyngeal (22%-57%), pancreatic (33%-50%), breast (1.5%-46%), lung (11%-44%) (Massie, 2004). Factors negatively impacting adjustment include:

- a past history of depression,
- co-morbidities,
- low socio-economic status,
- lack of social supports,
- persistent side effects of treatment and cancer,
- coping style, and
- multiple life stressors (Alfano & Rowland, 2006)

Differentiating between Depression and Grief

Common symptoms present in both depression and grief are: intense sadness, sleep disturbance, and appetite disturbance. While clinically depressed individuals experience feelings of worthlessness and lack of self-esteem, individuals who are grieving, generally do not perceive themselves as less of a person because of the loss (Worden, 2001).
Grief

Although symptoms may overlap, it is important for nurses to recognize that depression and grief are not the same. “While the world may look poor and empty for those experiencing grief, the person feels poor and empty in depression” (Worden, 2001, p.22). It is also important to understand that in addition to experiencing grief, an individual may also have a major depressive disorder, post traumatic grief disorder or other psychiatric diagnosis.

Recent research on complicated or prolonged grief disorder (PGD) has found a set of risk factors and clinical correlates of PGD including a history of childhood separation anxiety, controlling parents, parental abuse, or death, a close kinship relationship to the deceased (e.g., parents), insecure attachment styles, marital supportiveness, and dependency and lack of preparation for the death—all suggesting that attachment issues are salient in creating a vulnerability to PGD (Priggerson et al, 2009).

In the context of a cancer experience, the survivor may be focused on her/his grief experienced as the result of illness; or the illness experience may lead to re-visiting previous unresolved grief. This might be more apt to occur if there have been any of the pre-existing issues referred to above. For example, a woman in her 40’s was diagnosed with breast cancer. The diagnosis brought back memories of her mother’s death from breast cancer when she was 17 years and that of her father’s death from colon cancer two years later. The memories triggered her to revisit the grief she experienced from their loss. A woman, who had an abusive and controlling mother and had a strong positive bond with her father who died, had great feelings of abandonment when she felt that her family, friends, and health care professionals were not being as supportive to her as she would have liked when she was going through her cancer treatment. Her early feelings of abandonment were triggered. While it was difficult to cope during treatment her abandonment and grief issues surfaced when she completed treatment and did not have the support provided through regular contact with staff during treatment.

Grief may focus on a loss in the past (loss orientation) or the present and future (restoration orientation) (Stroebe & Schut, 1995). This is also referred to as the two track model of bereavement in which track one focuses on the bereaved person’s bio-psychosocial functioning and track two concerns the individual’s ongoing relationship to the range of memories, images, thoughts, and feeling states associated with the deceased (Rubin et al, 2009).

The individual may move back and forth in an effort to confront or avoid the loss. For example, a woman may grieve the loss of her breast, imagine having it back, and recognize that it was necessary to have her breast removed in order to improve her chances of survival.
Grief may be immediate, delayed, or chronic. One might also experience anticipatory grief at the thought of death. Survivors dealing with a diagnosis of advanced or metastatic disease may grieve for their life as they had known it and may grieve for what they may not experience in the future if they die of their disease, for example not being able to see a child graduate, get married, or have a child. For some survivors, even with a good prognosis, there may be an experience of grief as they feel the “death of a dream” of life as they may have anticipated it.

Nurses should keep in mind that not all individuals experience the same intensity of grief in response to the current diagnosis or past losses which may be triggered while dealing with survivorship. There is no right or wrong way, nurses must, therefore, take care not to stereotype the grief response of patients or family members. Our personal values and beliefs may influence our interpretation of another individual’s grief.

**Anxiety**

Anxiety is an emotional or physiological response to known or unknown causes that may range from a normal reaction to extreme dysfunction (American Psychiatric Association, 2000)

Anxiety is a broad term referring to a group of illnesses including

- generalized anxiety disorders (GAD),
- phobias,
- panic disorders,
- post traumatic stress disorder (PTSD), and
- obsessive-compulsive disorders (OCD).

GAD has been defined as an “uncontrollable disposition to worry about one’s welfare and that of one’s immediate kin” (Akiskal, 2007).

Anxiety in cancer survivors is attributed to the treatment experience and its associated adverse effects (Amir & Ramati, 2002) and/or the fear of recurrence (Vachon et al, 1989, 1990, 1991; Sanson-Fisher, 2000). Anxiety is sometimes difficult to assess in the cancer population. Stark and colleagues (2002) found that 48% of a sample population with a variety of cancer diagnoses had an anxiety disorder when assessed by questionnaire. However, when reassessed by diagnostic interview only 18% of the group fulfilled the criteria for anxiety disorders. (For further discussion on anxiety and fear of recurrence see Unit 4: Living with the Risk of Recurrence).
Post Traumatic Stress Disorder

Post traumatic stress disorder (PTSD) occurs when an individual is “unable to reconcile the shock of a traumatic event with core beliefs about one’s self and the world” (Jim & Jacobsen, 2008, p.414).

As the brain becomes overwhelmed with the information (thoughts, memories, and images) from the traumatic event core beliefs (e.g. people are innately good, self in control, self as invulnerable to death or disease, the world as just) are shattered. Symptoms emerge out of the struggle to integrate trauma related information with core beliefs and are believed to initially serve an adaptive function to help integrate the impact of cancer (Creamer, Burgess, & Pattison, 1992; Horowitz, 1992). For example:

- intrusive thoughts (e.g. involuntary, recurrent or distressing thoughts, or dreams about the cancer) help maintain cancer-related information in active memory for cognitive processing and integration
- avoidant behaviors (e.g. emotional numbness, efforts to suppress, or avoid cancer reminders) keep threatening thoughts out of consciousness to regulate against emotional distress
- a state of hyper-vigilance over physical symptoms maintains a state of watchfulness and preparedness for signs of advancing disease and trouble

The movement back and forth between intrusive memories and avoidance are theorized to be normative efforts to process the traumatic information, make sense of it and integrate it into existing beliefs. When integration fails and movement between memories and avoidance becomes chronic (i.e. symptoms persist more than one month), the individual is said to be experiencing PTSD (American Psychiatric Association, 2000).

It is estimated that 16% to 28% of cancer survivors experience intrusive thoughts following treatment completion and 15% to 34% experience high levels of avoidance after treatment (Jim & Jacobsen, 2008).

A study of long-term breast cancer survivors found that 18% of women had full PTSD and 58% experienced partial PTSD (two out of three PTSD symptom groups) (Amir & Ramati, 2002). Women who were the least ill when receiving chemotherapy were more at risk of PTSD symptoms when examined up to 60-months after treatment. The authors of the study hypothesized that a diagnosis of an early cancer stage and the healthier a woman’s perception of herself, the more difficulty she had in accepting the need for chemotherapy (Amir & Ramati, 2002). Symptoms of post traumatic stress have been associated with greater depression symptoms and decreased quality of life.
Experiencing a diagnosis of cancer, investigational work-ups, and/or treatment may also lead to patients re-experiencing trauma from the past such as sexual abuse. A recent Canadian study using regional data from Manitoba and Saskatchewan drawn from the 2005 Canadian Community Health Survey found childhood sexual abuse was associated with 49% higher odds of developing cancer when adjusted for age, sex, and race. The odds were 47% increased when adjusted for the risk factors of childhood stressors, adult health behaviors, and adult socio-economic status (Fuller-Thomson & Brennenstuhl, 2009).

Spirituality and Survivorship (adapted from Vachon 2008a)

Spirituality involves both faith and meaning (Breitbart, 2002), an attempt to make contact with or become aware of the “deep knowing” of our being (Cunningham, 2002).

Spirituality has been defined as “the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred.” (Puchalski et al, 2009).

This is often expressed as a relationship with God, but it can be about nature, art, music, family, or community—whatever beliefs and values give a person a sense of meaning and purpose in life”(Puchalski & Romer, 2000,p.129). It may emerge from religious belief or it may have no relationship at all to organized religion. Although universal consensus does not exist about a precise definition of spirituality, commonalities among the various definitions can be found, including ways to find connectedness, direction, transcendence, meaning, and purpose (Reynolds, 2006).

Religion is an expression of spirituality and can be understood as the values, beliefs, and practices that people adopt to meet spiritual needs (Taylor, 2006; Highfield, 2000). Religion is defined as an organized system of beliefs, practices, rituals, and symbols designed to facilitate closeness to the sacred or transcendent God, higher power, or ultimate truth or reality (Koenig, McCullough, Larson, 2001).

Cancer patients frequently report that spirituality and religion are important in helping them to cope with and adjust to the cancer experience (Edser & May, 2007)

A meta-analysis of fifteen qualitative studies of women with breast cancer from ethnically and culturally diverse groups including Asian American, Aboriginal, Hispanic, and African American women (Howard, Balneaves, Bottorff, 2007) found that spirituality was an important theme. Reliance upon reflection and spirituality appeared to increase when cancer entered these women's lives, as illustrated by a greater reliance on prayer, meditation, church attendance, and consultation with spiritual leaders. Spirituality played a significant part in helping women deal with their thoughts of mortality, and helped them cope. In Edser and
May’s study (2007) of community cancer support group participants, associations were noted among self-help attitudes, proactive self help, and spirituality. Spirituality was reported to be more than just a coping mechanism, but an active, dynamic response and a positive psychological outcome. They note that it is the integration of spiritual life that is the crucial variable in assessing spirituality and argue for a conceptualization of spirituality as a “will to meaning.”

Some cancer survivors find their disease results in spiritual transformation. Hirshberg and Barasch (1995) noted that some type of spiritual experience or awakening was common to long-term survivors diagnosed with incurable disease and who had exceeded their initial prognosis of survival time.

**Meaning-making**

The process of meaning making is a very individualized process. It is unknown when or how quickly people reach a sense of meaning in the aftermath of cancer.

**Meaning-making** is the ability to find a sense of order and purpose in life in the aftermath of a life threatening event (Park & Folkman, 1997; Park, 2010; Taylor, 1995; Thompson & Janigian, 1988).

- A sense of order in life derives from deeply held beliefs about the controllability, predictability, and fairness in the world (Janoff-Bulman, 1989, 1992).
- A sense of purpose in life derives from having important goals that directs one’s behaviours and actions (Park & Folkman, 1997; Thompson & Janigian, 1988).

Today’s medical and technological advances are making it possible for more people to live longer with cancer (Canadian Cancer Society, 2009). However, survival without purpose in living can exacerbate psychological suffering. For many, the cancer experience forces an abrupt confrontation with one’s mortality and other related existential issues (Leung & Esplen, 2010; Lovgren, Hamberg, & Tishelman, 2010; Sand, Olsson, & Strang, 2009). Having a sense of meaning in life is important for cancer survivors because the lack of meaning has been associated with interference with the ability to cope with cancer treatment; block re-engagement in life, increase a sense of demoralization, futility, and powerlessness; and increase suicidal ideation and desire for hastened death (Breitbart, Rosenfeld, Pessin, et al., 2000; Kissane, Clarke, & Street, 2001; McClain, Rosenfeld, & Breitbart, 2003; Wilson, Chochinov, McPherson, C.J., et al., 2007). Having a sense of meaning has also been shown to buffer the physical adverse effects from cancer-related symptoms such as pain and fatigue (Barkwell, 1991; Lundstrom, Furst, Friedrichsen, & Strang, 2009; Simonelli, Fowler, Maxwell, & Anderson, 2008; Thompson, 2007).
Cancer survivors enter into a constant struggle to balance a new reality characterized by an acute awareness of the fragility of life and the threat of imminent death (Halstead & Hull, 2001; La Cour, Johannessen, & Josephsson, 2009; Sand, Ilsson, & Strang, 2009).

The emotionally and intellectually challenging process of searching for meaning is considered necessary to reconstruct a life schema that can restore a sense of equilibrium (Park & Folkman, 1997; Taylor, 2000; Thompson & Janigian, 1988). However, there is great variability in the prevalence and pattern of searching for meaning (Kernan & Lepore, 2009). The ability to find meaning does not always lead to an end to distress, but can lead to a more balanced perspective of life that positive and negative aspects can co-exist in the aftermath of cancer (Folkman, 1997; Folkman & Greer, 2000; Kagawa-Singer, 1993).

During the search for meaning, thoughts, feelings, and behaviors may be weighted heavily by concerns about one’s mortality and uncertainty about the future (Lee, et al., 2004; Sand, et al., 2009; Weisman & Worden, 1976-77). In addition, individuals may feel a sense of disintegration or disconnect with oneself and with others (Mount, Boston, & Cohen, 2007). Individuals may become immobilized with regards to caring for their self, or lack the motivation to participate in social activities with family and friends.

Over time, individuals learn to balance “living with a new normal” in the face of future uncertainty (Kvåle, 2007; Sand, Ollson & Strang, 2009). Individuals may retain a sense of integrity and self-worth but accept a more vulnerable self, and pursue personally relevant goals knowing that the world is less predictable and less controllable. Many cancer survivors become more purposeful and decisive in their behaviors for example, participating only in activities that they want to not because they are expected to (Lovgren et al, 2010).

Research is still under way to understand how individuals make meaning of their cancer experience to result in psychological adjustment and adaptation. However, studies have consistently found that patients benefited from engaging in supportive social networks, environments, or activities that facilitate self-disclosure and self reflection (Neimeyer, 2004). Other strategies that have been found to be beneficial to help individuals begin to find meaning in their situation is to help patients identify realistic, short term, achievable goals, or to focus on finding something of value in the present moment. One such strategy is the use of the Meaning-Making Intervention (see Appendix 1).
Post Traumatic Growth

Post-traumatic growth in the context of cancer is a burgeoning new concept that has emerged over the last three decades (Jim & Jacobsen, 2008).

Post traumatic growth (PTG) has been defined as the “positive psychological change experienced as a result of the struggle with highly challenging life circumstances” (Tedeschi & Calhoun, 2004).

For PTG to occur the individual must have been exposed to an ‘extremely undesirable event’, have time to process and recover from the event and make meaning from the experience (Bellizzi, 2004). Individuals are able to change the meaning of the traumatic event to maintain positive beliefs about the self and world within which they live.

Post traumatic growth has been reported in three specific life domains among cancer survivors:

Commonly Reported Benefits of Cancer (Jim & Jacobsen, 2008, p.416)

| Social resources | Deeper love for spouse and family  
|                 | Improved relationships with family & friends  
|                 | Increased time and effort invested in relationships  

| Personal resources | Better outlook on life  
|                   | Greater satisfaction with religion  
|                   | Increased compassion, sympathy, and more concern for others  

| Coping skills | Greater acceptance of circumstances  
|              | Learning to take things as they come  
|              | More effective coping with stress  

Post traumatic growth is associated with the survivor’s perceived threat of death (Lechner, Zakowski, Antoni, et al 2003; Cordova, Cunningham, Carlson, et al, 2001), concerns about recurrence (Bower, Meyerowitz, Desmond, et al 2005), and perceived stressfulness of cancer (Sears, Stanton & Danoff-Burg, 2003; Cordova, Gliese-Davis, Golant, et al, 2007). While perceived threat is required to support growth too much may overwhelm the cancer survivor’s impeding growth.
The most frequently identified predictors of PTG in the research literature include:

- younger age
- ethnic and/or visible minorities
- perceived social support
- greater emotional and cognitive processing
- positive reframing (Jim & Jacobsen, 2008)

### FACILITATING A SYSTEMATIC ASSESSMENT

#### Screening and assessment

The aim of screening is to distinguish those individuals who probably have psychosocial distress and offer help where help is wanted from those who are coping as well as can be expected given their particular situation.

When a reliable screening tool has been used and significant clinical psychological distress identified, it should be followed by a more thorough diagnostic evaluation or assessment to accurately determine if clinical depression is present. If you are unsure if the patient or family member is experiencing depression or significant distress do not hesitate to refer to a professional (e.g. a member of the psychosocial oncology team such as Advanced Practice Nurses, psychologists, psychiatrists, chaplains, or social workers) for further assessment.

#### Cross-cultural perspectives in psychosocial oncology

Culture significantly contributes to

- the beliefs and attitudes held about the meaning of health, illness, and cancer
- how an individual understands the experience with cancer
- what and how information is communicated among family members as well as with health professionals
- decision-making patterns that affect their health and way of life.

In this era of increasing immigration and globalization of the world, it is important to be aware of cross-cultural and intra-cultural differences. The health care provider is in a unique position to learn about how culture may influence a patient’s psychological response to their experience with cancer, and subsequently enhance the effectiveness of interventions by offering culturally sensitive care.
Screening for distress

The National Comprehensive Cancer Network Distress Management Panel published guidelines in 2007 that include the use of the Distress Thermometer tool and its accompanying problem list (NCCN, 2007). Tools such as this have made it easier to screen patients for distress arising from emotional, spiritual, or religious concerns, family or practical issues, or physical problems. It is now proposed as the 6th vital sign (Canadian Partnership Against Cancer [CPAC]). To date, only 36.5% of Canadian cancer centers screen for distress (Vodermaier & Linden, 2008). Consensus-based guidelines developed by the Distress Management Panel of NCCN recommend screening all patients regularly for psychosocial distress as a part of routine cancer care including follow up care (Distress Management Clinical Practice Guidelines, 2003). A Pan-Canadian initiative, CPAC (Canadian Partnership Against Cancer), is currently underway in 5 sites across Canada to evaluate a standardized approach to screening for distress. Under the auspices of CPAC, the following tools are being used: Distress Thermometer, Edmonton Screening Assessment System (ESAS), and the Canadian Problem Checklist.

Assessment

Differentiating between Depression and Grief

<table>
<thead>
<tr>
<th>DEPRESSION</th>
<th>GRIEF</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intense sadness for at least 14 days, which persists over time</td>
<td>Intense sadness may come and go in waves</td>
</tr>
<tr>
<td>Sleep disturbance</td>
<td>Sleep disturbance</td>
</tr>
<tr>
<td>Loss of appetite</td>
<td>Loss of appetite</td>
</tr>
<tr>
<td>Guilt (general overall sense of)</td>
<td>Guilt (related to specific aspect of loss rather than overall sense of)</td>
</tr>
<tr>
<td>Worthlessness (lack of self esteem)</td>
<td>Usually normal self esteem and sense of worth</td>
</tr>
<tr>
<td>Disturbed body image</td>
<td>Usually normal body image</td>
</tr>
<tr>
<td>Hopelessness</td>
<td>Can still experience some pleasure in life (e.g. visits from grandchildren)</td>
</tr>
<tr>
<td>Finds no pleasure in any aspect of life</td>
<td>Maintains hope for some aspects of life</td>
</tr>
<tr>
<td>Active desire for early death</td>
<td>Can work through some issues</td>
</tr>
<tr>
<td>Thoughts of suicide</td>
<td>Social withdrawal usually temporary</td>
</tr>
<tr>
<td></td>
<td>Yearning for the deceased</td>
</tr>
</tbody>
</table>
Factors that influence the mourning process (how one works through grief) include:

- who the person was in relationship to the bereaved,
- nature of the relationship,
- how the individual died,
- prior experiences of loss,
- personal characteristics (e.g. age, gender, coping style, beliefs and values),
- social (e.g. support network, role, religion/spirituality),
- life stressors (e.g. financial burden) (Worden, 2001),
- attachment issues,
- early childhood issues of abuse, attachment, and loss (Priggerson et al, 2009),
- the illness and death experience of the person who died and how this relates to the survivor’s present and anticipated experience.

Symptoms of anxiety include

- arousal,
- vigilance,
- tension,
- irritability,
- non-restful sleep, and
- gastro-intestinal disorders,
- Anxious patients may also have great difficulty in anticipating or dealing with chemotherapy, radiotherapy, hormonal manipulation, or other therapies.

Increased risk factors for PTSD among cancer survivors
(Amir & Ramati, 2002; Jim & Jacobsen, 2008)

- Being female,
- Younger,
- Less educated,
- Having a lower income,
- Fewer social and emotional supports,
- A prior history of trauma, and
- Difficult interactions with medical staff.
Questions to Explore Meaning and Spirituality in Cancer Survivors (Vachon, 2008a)

1. What gives this person’s life meaning?
2. Is the individual questioning the meaning of her/his life?
3. How are previous beliefs either sustaining them or causing them challenges during their cancer or survivorship experience?
4. What are the person’s values and how might they be affected by the diagnosis?
5. What are the person’s goals in life and how will cancer affect these goals?
6. Is the person interconnected with others and how are these relationships being affected?
7. What is happening to the person’s sense of self, self image, self esteem, and ability to perform usual roles in life?
8. Does the sense of meaning come from spiritual roots? Do they serve as a source of support or stress? Do they have any important religious or spiritual beliefs?

PRIORITY CONTENT FOR PATIENT TEACHING …

Inform patients and family that:

• Feelings of sadness, depression, or anxiety are common when someone is affected by cancer
• While most individuals are able to manage or cope well, others may have difficulty with the ability to cope and make decisions related to their diagnosis and treatment
• Warn patients that medications such as steroids may cause unexpected psychological symptoms such as anxiety, angry outbursts, feelings of depression, and tearful outbursts
• If they experience any of the following symptoms, then it is important to report them to the nurse or other health team member:
  o Heart palpitations, sweating, dizziness,
  o Fear of losing control, fears about the future,
  o Persistent worry, recurrent thoughts about diagnosis and treatment
  o Difficulty concentrating,
  o Change in behavior, functioning, roles,
  o Three of the following six physical symptoms associated with GAD:
    □ Restlessness
    □ Concentration difficulties
    □ Easily fatigued
    □ Irritability
    □ Muscle tension
    □ Sleep disturbance
• There are ways to manage their symptoms and there are resources available for them
• There will be good days and there will be bad days, but personally fulfilling moments can co-occur alongside the distressing side of living with cancer (Folkman & Greer, 2000).
Your role as an oncology nurse

- Nurses are available to help survivors find meaning in their situation
- Ask questions, e.g. “You seem worried today, have you been feeling more anxious lately?”
- Use life narrative approach that provides a way to view life from another vantage point and reduces distress levels
  - Ask “Can you tell me your story, what is important to you?” offers a way to share personal emotions and feelings with you (sometimes family) (Neimeyer, 2004)
  - Keep a personal journal to chronicle what has happened, what is happening, and record thoughts about what may happen,
  - Review past photos of oneself throughout the cancer journey that become a testament of the person’s strengths and capacities to arrive at where they are currently,
  - Write a letter to oneself to motivate and be one’s own cheerleader.
  - Use the lifeline exercise and offer to review it with the patient (see Appendix 1).
- Act as a facilitator: assists the person to put their thoughts and feelings about what is happening to them into words. You facilitate this process of adjustment through your caring and listening.
- Offer information and counseling to family members; inform the family where they can get assistance at any point.
  - For Depression: It is sometimes difficult to decide when to refer for depression because it is normal to have some feelings of normal sadness in response to a diagnosis of depression. A rule of thumb is that if this sadness persists beyond two weeks, health care professionals should suspect depression and treat aggressively, especially if core symptoms of depression are present. These include helplessness, hopelessness, poor self-esteem, feelings of guilt, or worthlessness, and suicidal ideation (Lovejoy et al, 2000; Bronheim et al, 1998; Vachon, 2006)
  - For Grief Work: If nurses feel that patients are spending a lot of time discussing the losses they are experiencing as a result of their diagnosis or treatment, including the loss of fertility, then it is appropriate to refer the person to a mental health practitioner.

If survivors would like to spend time discussing feelings related to previous losses, such as a mother’s death from cancer when one is now facing the diagnosis, then it might be helpful to help the patient to discuss the person who died.

A helpful exercise for people who are having trouble with unresolved issues with grief is to suggest they write a letter to the deceased expressing unresolved feelings, regrets, unexpressed feelings, then get a new piece of paper, empty one’s mind and let the deceased write back to them. If a person has no belief in an afterlife, then it can be suggested that she/he imagine what the deceased would say.
Case example to support creation of meaning from the cancer experience

J.C. is a 52-year-old single woman who was referred for crisis intervention because she was not coping as well as expected following her diagnosis and treatment for early ovarian and uterine cancers. As a survivor, she felt she had coped well during her treatment but less so now. Since she seemed to have many questions about her diagnosis she was encouraged to take some time to think, gather information about her diagnosis and undertake the lifeline exercise reflecting on its meaning at this point in her life (see Appendix 1 on Meaning-Making Intervention for information about the lifeline).

She returned quite surprised to have “begun to connect the dots”. When she was 22 J.C. had a mastectomy and implants for large benign breast cysts. She did not feel she understood what was happening at that time nor did she have any supports thus she was left to deal with the situation on her own. For at least 20 years after that time she engaged in self destructive behavior. With the help of a psychiatrist she was able to see that her behavior and feelings were reflective of PTSD. She stopped her destructive behaviour with this insight. Her diagnosis of gynecological cancers was a shock. She had gone for a hysterectomy for what was perceived to be a benign condition. When she found she had cancer she was quickly referred to a cancer centre. Her oncologist mentioned that more surgery might be indicated for staging purposes. All she could think of was “no more surgery”. She got through her treatment with the help of family and friends. Doing the lifeline exercise allowed her to see how this surgery had reactivated the earlier issues. She was unconscious of the connection until she began the exercise. She was able to reflect upon how she had opened to help at this point in a way she never had before and how she took control over the aspects of her disease she could control. She was pleased to re-evaluate her response to treatment using the concept of post traumatic growth (approval for inclusion of this personal story has been given by the patient).

Learning Activities: Case Studies

1. R.J.’s Story

R.J. is a 50-year-old male diagnosed with Stage II prostate cancer two years ago. He declined a radical prostatectomy at that time opting for radiation brachytherapy (radioactive seeding). His wife expressed concerns after hearing him comment “I would rather die than wear a diaper!”

R.J. has been married for 25 years and is the father of two adult sons, 19 and 21 years. Both boys live with their parents. They were unaware that their father had cancer until 3 months ago. R.J.’s parents are both deceased (within the past 5 years) – his mother as a result of breast cancer at age 70 and his father from prostate cancer at 78 years of age. R.J. has a brother 53 and a sister 57. His sister was diagnosed with breast cancer at 50 (Ductal Carcinoma in Situ). She is currently in good health. R.J. continues to work as an IT specialist managing a staff of 38 for a large advertising/public relations firm.
Recently R.J. and his wife were in clinic for follow-up. While he was out of the room his wife mentioned that R.J. continues to remain uncommunicative about his cancer experience and at times appears ‘distant’ and ‘cold’. Lately he has begun purchasing what he refers to as ‘toys’ without any discussion. His most recent acquisitions included a red BMW convertible and a Harley Davidson. When she questioned him about the purchases he responded with “what difference does it make. Remember what the urologist told me – ‘you will likely die of cancer not old age!’ I may as well begin enjoying myself while I can.” (While her memory of this comment is unclear, R.J. is adamant the oncologist made this statement). Feelings of hopelessness, lack of self worth, and low self esteem continue.

1. What possible psychosocial concerns are occurring?

2. How would you begin to explore R.J.’s loss for a future?

3. What intervention(s) would you consider and why?

2. J.M.’s story

J.M. is a 27-year-old woman with multiple myeloma undergoing chemotherapy. Usually talkative and social, she has recently become quiet and emotionally fragile. Her boyfriend of three years broke up with her after she was admitted for treatment. In researching the disease on the internet, she has become overwhelmed with the poor prognosis. In addition, the patient across the hall died last night, and she overheard the family crying. In conversation with the nurse, she said “I hate it here. I just don’t know why all this is happening to me. We were talking of marriage. We wanted to buy a home on the lake. I wanted kids. Now I’m told that even if I survive, the chemo will leave me sterile. Maybe it would be better if I just died quickly like that guy.”

Some questions to ask on this case might be:

1. Is J.M. spiritual? How would you find out or open the topic of conversation with her?
2. What spiritual issues are being expressed here?
3. What is this person’s picture of life?
4. How would you respond to this patient?

Discussion about Cases

1. RJ’s Story

• What possible psychosocial concerns are occurring? Examples may include the following and should not be considered all inclusive:
  • grief (associated with loss, e.g., future)
  • body image issues (e.g. sense of masculinity, manliness, sexuality)
  • psychological distress
  • challenges adjusting to living with cancer (e.g., meaning, purpose, uncertainty/fear)
• What intervention(s) would you consider and why?
  • Screening for distress may be a helpful first step (e.g., Distress Thermometer, ESAS)
    a. Assess level of distress and determine the need for specialist intervention (e.g. referral to member of the psychosocial oncology team)
    b. If ESAS score is 0-4, nurse can work with RJ
  • Try out the meaning making intervention
  • Assess RJ’s wife for emotional/psychological distress

• Consider trying out the three basic skills to help in moving patients through the dark journeys:
  a. Attending to feelings — Ask survivors to name the dark feelings and not judge them as good or bad but simply present.
  b. Befriending Feelings — Teach to tolerate and accept feelings by breathing through them. Breathing, relaxation exercises, meditation and prayer examples of strategies.
  c. Surrendering to the suffering — Evokes wisdom, compassion & courage. Worst form of despair happens when survivors feel that pain was purposeless (Platek, 2008)

• May want to consider exploring RJ’s understanding of cancer and its meaning for him.
  o How does he see his future unfolding
    When he looks in the mirror, who does he see

2. J.M.’s Story

1. Offering a statement that reflects how she is feeling may open the door to further communication: For example, you could say, “You have been through so much lately. Life is unfair and you feel like giving up. But you are still here. What keeps you going? What do you believe in that continues to give you strength? “

2. The loss of connection to her boy friend of three years and the loss to social connections (if she is less talkative and isolated), and loss of connection to herself (i.e. not recognizing who she is anymore given that her future plans have been uprooted). Explore any unexpressed anger and normalize this feeling, give appropriate outlet (e.g. writing a letter, journaling, audiotaping, art, etc)

3. Ask JM to describe further how she had envisioned her life to unfold. What has she lost? what can she retain from her hopes and dreams? Use the lifeline exercise with her.

Additional Resources

American Psychosocial Oncology Society http://www.apos-society.org 4 free lectures on using the Distress Thermometer

Canadian Association of Psychosocial Oncology: http://www.capo.ca/eng/index.asp

Canadian Mental Health Association: http://www.cmha.ca/bins/index.asp
Canadian Partnership Against Cancer: [http://www.partnershipagainstcancer.ca/progress2009_release](http://www.partnershipagainstcancer.ca/progress2009_release)

Cancer Net: [http://www.cancer.net/patient/Survivorship](http://www.cancer.net/patient/Survivorship)

Lance Armstrong Foundation: [http://www.livestrong.org/site/c.khLXK1PxHmF/b.2660611/k.BCED/Home.htm](http://www.livestrong.org/site/c.khLXK1PxHmF/b.2660611/k.BCED/Home.htm)


Princess Margaret Hospital Breast Cancer Survivorship Program: [http://www.survivorship.ca/](http://www.survivorship.ca/)

**References**


Cunningham AJ. Bringing spirituality into your healing journey. Toronto: Key Porter Books Ltd; 2002.


**Reading Resources**


**Grief:**


**Spirituality**:


The following exercise may be printed out and given to the patient to complete on their own, with the nurse or with another health care provider.


The search for meaning is asking questions about the personal importance of a life event, such as cancer, to give it purpose and to place it within one’s total life pattern. Finding meaning can help put your life back on the path to self-realization or becoming the best you can be. Here is one way to find meaning in what has happened to you.

A. Learn about transitions.

Transitions are moves from one life event to the next. They occur in three phases:

<table>
<thead>
<tr>
<th>Phase</th>
<th>What is Taking Place</th>
</tr>
</thead>
<tbody>
<tr>
<td>Phase One (An Ending)</td>
<td>When you recognize what you have lost through the cancer experience</td>
</tr>
<tr>
<td>Phase Two (A Neutral Zone)</td>
<td>When you feel disconnected from the past and present, and uncertain about the future</td>
</tr>
<tr>
<td>Phase Three (A New Beginning)</td>
<td>When you find a new normal and recognize new opportunities and priorities</td>
</tr>
</tbody>
</table>

B. Use the Lifeline exercise.

Step 1. Acknowledge the present. Draw a single line to symbolize your “Lifeline”. Draw a circle on the line to represent where you are in your life now. Since the diagnosis of cancer, think about what has changed, what has not changed, what feels out of control, what is still in your control, what have you lost, what have you gained? Tell your story to a friend, write it down in a special journal, or speak it out loud to yourself.

Step 2. Contemplate the Past. Your ability to get to this point is a testament of your resilience. Think of pivotal life events (positive or negative) before your cancer diagnosis, and add them to the left of your lifeline. Think of how you coped with those events. Identify what strengths helped you live through those events. Can these strengths help you to cope with your present experience with cancer? Would you do things differently today?

Step 3. Live the present, for the future. Wisdom is being able to make important life decisions in the face of uncertainty. Think of your life goals and priorities, and add them to the right of your lifeline. Think of what would allow you to look back on a life with least regret. What is important for you to accomplish today? In the next week? The next month? The next year?
UNIT 9

Returning to Work

Margaret Forbes, MN, NP-Adult, CON(C), Miriam Corne, BScN, MEd, CON(C)
Quick Overview

Work is an essential part of life for many people. A diagnosis of cancer may impact the cancer survivor’s ability to continue working. Once cancer treatments are completed, some survivors find it difficult to return to work at full capacity depending on physical and emotional limitations. This can impact finances and ultimately personal and family needs. This is a significant but often overlooked stressor for cancer survivors. Health care providers are often asked by employers to provide assessments of the cancer survivor’s functional status to facilitate a return to work. Nurses are well positioned to provide input and assist with this aspect of survivorship care.

Introduction

Work fills an important need for many survivors of cancer including fulfilling financial and social needs and is often regarded as an important psychological step to recovery (Maunsell et al., 2004). For many, working includes not only a regular source of income but also health benefits that may not be covered during treatment and recovery from cancer. Up to forty percent of people with cancer stop working while receiving treatment (Short, Vasey & Tunceli, 2005). Therefore, the decision to return to work may be influenced by the need to regain regular income and access to health benefits (Maunsell et al., 2004). Additionally for many, work is how a person defines themselves and is part of a social support network (deBoer, Taskila, Ojajärvi, vanDijk & Verbeek, 2009). Being able to return to work after cancer treatment often indicates to the survivors, their families, and work colleagues that recovery from cancer is possible and life is returning to normal (deBoer et al., 2009).

For cancer survivors who are self-employed or who have been unable to continue with regular employment during treatment, a referral to a social worker can provide information regarding income replacement, health and life insurance, finding a new job, and employment discrimination.

Cancer survivors often experience ongoing physical, psychological, and social problems (e.g. pain, cognitive changes, depression, anxiety, fatigue) at the completion of treatment that may become chronic issues (deBoer et. al., 2009). Working with their health care professionals, cancer survivors can discuss return to work plans keeping in mind the functional and, at times, the emotional restrictions that may be present. Often employers are willing to accommodate graduated return to work programs to assist with integration back into the workplace. Although employers are not permitted to inquire about medical history, a medical certificate can be requested to ascertain the employee’s ability to function at work.

There are support services that can facilitate optimal functioning at work. For example a physiotherapist or occupational therapist can provide exercises to reduce pain, increase range of motion, improve fatigue, and recommend modifications that will maximize independence. An ergonomics assessment may provide information on how to modify the workspace to accommodate any functional changes (e.g. persons with lymphedema).
Cancer survivors who are self-employed may face unique challenges especially if they are unable to continue working in their business due to functional limitations. These individuals often have to consider giving up their business and finding other suitable work. The financial and emotional impact of “losing” a business can be a significant blow (CBCN, 2010).

**CANO/ACIO’s Standard for the Specialized Oncology Nurse**

**Practice Standard 6: Decision Making and Advocacy**

The specialized oncology nurse, in collaboration with other team members of the interprofessional health care team, facilitates self-determination and informed decision making for the individual/family. The specialized oncology nurse advocates on behalf of the individual/family, communicating and documenting their preferred approach to care.

**Literature Review**

As treatment for cancer improves, people are surviving for many years after the diagnosis and treatment of cancer (Rowland, Hewitt & Ganz, 2006). About half of the survivors of cancer are less than 65-year-old; thus actively part of the workforce (deBoer, Taskila, Ojajärvi, vanDijk & Verbeek, 2009). Improved cancer survival rates have been predicted to improve the return to work rate of people with cancer (Nachreiner et al., 2007). The capacity to return to work has a great influence on quality of life and financial well-being. The decision of whether or not to return to work affects not only the cancer survivor but also their family and society in general (Lee et al., 2008). Cancer survivors may experience physical or psychological effects after treatment ends that can impact the ability to return to work, thus understanding the impact of long term effects is important (deBoer et al., 2009). (See Unit 3: Late Effects of Cancer Treatment).

A cohort study of 1,433 cancer survivors found that those with haematological malignancies were less likely to return to work while those with breast or prostate cancer were more likely to return to work (Short, Vassey & Tunceli, 2005). This study showed that 20% of cancer survivors report cancer-related disabilities and that more than 50% of those who return to work quit within a year. The highest rates of disability or quitting work were noted among cancer survivors who had cancers of the head and neck, central nervous system, and those with Stage IV blood and lymph malignancies (Short, Vassey & Tunceli, 2005).

A population based retrospective cohort study of 646 women with breast cancer showed that they were slightly more likely than age-matched cohorts never diagnosed with cancer to not be working three years after diagnosis (Drolet et al., 2005). Older age, union membership, cancer recurrence and women with an annual income of less than $20,000 increased the likelihood of these women in not working (Drolet et al., 2005). Two smaller studies comparing women with breast cancer against matched cohorts found that fatigue and cognitive changes were more prevalent in the cancer survivor group (Calvio, Peugeot, Bruns, Todd & Feuerstein, 2010; Hansen, Feuerstein, Calvio, & Olsen, 2008).
A pilot study found that factors that aided a smooth return to work after a cancer diagnosis included job flexibility, co-worker, and supervisor support, health care provider support as well as limited physical effect from the cancer and cancer treatments (Nachreiner et al., 2005).

A population-based cross-sectional survey of 1,511 long-term survivors of prostate, endometrial cancer, non-Hodgkin’s lymphoma, and Hodgkin’s lymphoma from the Netherlands explored the prevalence of employment issues in those who were long-term cancer survivors (Mols, Thong, Vreugdenhil & van de Poll-France, 2009). Forty-nine percent were working in their jobs without any limitations, while 17% worked fewer hours and 34% stopped working or retired due to their cancer diagnosis. In this study, it is important to note that after excluding those who didn’t have a job prior to their cancer diagnosis, only 403 survivors remained (Mols et al., 2005) with their pre-diagnosis employers.

Physical limitations, functional, and cognitive changes can impact the ability to remain employed after a cancer diagnosis in individuals who experienced childhood acute lymphoblastic leukemia (ALL) (Mody et al., 2007). 4,151 cancer survivors identified through the Childhood Cancer Survivor Study (CCSS) were matched with siblings who did not have cancer, and compared to their siblings, cancer survivors of childhood ALL experienced lower rates of employment, health insurance, graduation from college, and marriage than their siblings (p<0.001). When compared to their siblings, the survivors also experienced adverse cognitive and functional impairment, physical limitations, and adverse mental health (p<0.001) (Mody et al., 2007). Another study considering the same population (CCSS) found that cancer survivors of childhood cancers are often unemployed due to health limitations or inability to remain employed. Their findings recommend that vocational assistance may be a helpful strategy for this group (Kirchoff et al., 2010).

A comprehensive report by the Canadian Breast Cancer Network (2010) indicated that 80% of women diagnosed with breast cancer in Canada experienced a financial impact with long-term financial consequences for both breast cancer patients and their families. On average, the patient household experienced a 10% drop in annual income with 44% of respondents depleting their savings and retirement funds, while 27% took on debt to cover treatment costs. The report also determined that Employment Insurance benefits covered only 15 weeks of the average treatment length of 38 weeks, thus adding to the financial burden. The diagnosis and treatment of breast cancer caused a significant disruption in labour force participation. Of the 81% of respondents who were employed in salaried jobs at the time of diagnosis, 16% had their jobs terminated while undergoing treatment and 17% were unable to return to their previous job with the same title and salary. Over one-fifth (21%) of respondents reported returning to work before they were fully able due to financial pressure (accessed www.cbcn.ca ). This report indicated that women with breast cancer continued to experience unexpected hurdles when re-entering the workforce and it is likely that many other people with cancer have similar experiences.
This brief review has identified that approximately half of the people diagnosed with cancer are able to return to their jobs post-treatment (Mols et al., 2009; Drolet et al., 2005). At times those who are close to retirement age when cancer treatments are completed retire (Drolet et al., 2005). Long-term side effects may impact the cancer survivor’s ability to function in, or return to their pre-diagnosis job capacity (Mody et al, 2007). Physical and psychological changes are often the limiting factors. Supportive services and physical rehabilitation programs aimed at maximizing physical and psychological functioning would likely improve cancer survivors’ ability to function to their pre-diagnosis standards within their jobs (Short, Vasey & Tunceli, 2005; Nachreiner et al., 2005). Additionally vocational counseling and employment support services may assist transition back to work (Short, Vasey & Moran, 2008).

Facilitating a Systematic Assessment

Here are some common questions a nurse can ask a cancer survivor to assess readiness for returning to work.

1. How would you know if you are ready to return to work?
2. How does your financial situation impact your decision to return to work? Do you need to return to work for financial reasons?
3. How has your diagnosis and treatment affected the work you want to do?
4. How many hours of uninterrupted sleep do you have in a night?
5. What affects your energy level?
6. How is your concentration (short term memory)? If your concentration is affected please give an example.

Nurses and health care team members can assist cancer survivors by ensuring physical dysfunction and cognitive changes are dealt with as effectively as possible. Some strategies to consider are:

- Encourage regular exercise during treatment, during the follow-up period, and ongoing to decrease the risk of long-term physical dysfunction and increase sense of well-being
- Cancer survivors with functional changes will likely benefit from some form of rehabilitation or physiotherapy
- Survivors with chronic pain could be referred to pain and symptom management services to identify strategies for dealing with pain more effectively
- Psychiatric services and/or cognitive behavioural therapy may benefit those who have psychological or cognitive changes
- Social workers may be able to assist patients in vocational counselling and financial counselling
- Partner with the family doctor to ensure there is no duplication of services
Priority Content for Intervention and Patient Teaching

Here are some common questions that cancer survivors may ask nurses related to returning to work:

1. How long are people with cancer usually off work for?
2. What will happen if my insurer thinks I’m ready and I don’t think I am?
3. Who will decide when I can go back to work?
4. Can I return to my prior job? If not, what are my options?
5. How will I know if I am physically and psychologically ready to return to work?

By having answers to these questions, nurses can help cancer survivors plan for their return to work.

Here are some suggestions for cancer survivors recommended by Maureen Robinson (Vocational Rehabilitation Counselor, BC Cancer Agency; see website below in Resource section) as they prepare to return to work:

- ask your family doctor or oncologist to give you an estimate of when you might be able to return to work and any limitations you might have
- ask your employer and/or union representative how returning to work is coordinated
- if you are unable to return to your former job due to limitations, you can inquire regarding modifications to the job or if another job is available that you can do
- if you have long-term disability through an insurance company you will want to determine if the plan includes rehabilitation
- if you are on Canada Pension Plan disability find out if they are able to provide return to work top up benefits and vocational rehab
- know your Human Rights; contact the human rights coalition within your province or the Ministry of Labour for advice

Learning Activity: Case Study

M.N. is a 46-year-old man who has completed treatment using high dose interferon for melanoma of his right shoulder that had spread to one lymph node. Not only has he had a wide excision of the melanoma, but he also had a radical auxiliary node dissection. Since completing his induction therapy, he continues to feel quite fatigued. M.N. has just begun maintenance dosing of the interferon and his oncologist has indicated that if he feels well enough he could return to work, as side effects from maintenance therapy are not as significant. He will still require monthly follow-up at the cancer centre while on treatment. Functionally M.N. has noted difficulty experiencing full range of motion of his right arm and at times it seems that when he lifts objects more than 10lbs that he might drop them.
He expresses his concern to you about returning to his job at the factory due to the repetitive nature of his work on the assembly line and the requirement to be lifting items that can weigh up to 15 lbs each. He is also worried about his fatigue level. His major concern is being able to provide for his family. Although his wife works outside the home, it is his wages that bring in the bulk of the family income as well as a full benefit plan for his family (wife and 3 children). He feels that if he doesn’t get back to work soon, that he might be at risk for losing his job.

1. Explain how you might facilitate an assessment of M.N. that will provide you with information to devise a return to work plan.
2. What resources would you recommend to M.N.?

**Answers to Case Study**

1. In coordination with the oncologist facilitate a functional inquiry along with a focused physical assessment of musculoskeletal and neurological testing of M.N.’s upper body with specific attention to his right arm and shoulder. The functional inquiry would provide information about M.N. ability to carry out normal ADLs while the physical assessment would inform you about physical limitations. Findings may suggest that occupational therapy or physiotherapy may be helpful to regaining full function. He may require teaching on how to manage fatigue. Oncology nurses can provide this information, or if there are fatigue management services within your facility you may refer him there.

2. Other resources may include referral to social work for a vocation assessment and/or a financial assessment. You may want to refer him to website that provides information about returning to work. (See website below:  http://www.bccancer.bc.ca/PPI/copingwithcancer/emotional/Work+Related+Issues.htm.)

3. Periodic reassessment at follow-up visits to ensure M.N. is tolerating his return to work.

**Resources**

When looking for resources for cancer survivors, consider that several provincial cancer-related websites have begun to develop web pages and programs that may assist cancer survivors returning to work. These websites may have information that may be applicable to people anywhere in Canada, however nurses may have to search provincial sites for appropriate information.

For example, CancerCareManitoba is starting a program in the fall of 2010 called “Moving Forward After Cancer Treatment” which will assist patients with survivorship issues, and specifically returning to work. Another example is from the BC Cancer Agency which provides concrete advice about returning to work (see link below):

http://www.bccancer.bc.ca/PPI/copingwithcancer/emotional/Work+Related+Issues.htm
This website includes information on the following topics:

1. Disclosing your cancer experience at work
2. Returning to work and long term disability forms
3. Things to consider when returning to work
4. Returning to work checklist
5. The emotional impact of returning to work

RESOURCES and REFERENCES:

*Getting Back on Track: Life After Treatment* (Breast Cancer Centre of Hope, Winnipeg, Manitoba).

*Coping with Financial Concerns When you have Breast Cancer* (Willow Breast Cancer Support Canada).

*Life After Cancer* (Canadian Cancer Society).


www.cancerandcareers.org resources providing tools for employees with cancer.


UNIT 10
Risk Reduction Activities

Jan Park-Dorsay, RN, MN, NP-Adult, CON(C)
Quick Overview

- Compared with previous decades, cancer survivors can expect to live longer than their predecessors, necessitating a long term health promotion plan.
- In addition, cancer survivors die of non-cancer causes at a higher rate than persons in the general population.
- Many cancer survivors will spontaneously initiate positive behavioural changes, however, many do not. It is important that oncology nurses have the competencies to assess survivors' readiness for making a behavioural change and provide the necessary information about how to reduce risks of cancer recurrence and co-morbid health conditions.
- There is a significant body of knowledge that when cancer survivors modify behaviours related to exercise, nutrition, smoking cessation, and alcohol intake they can reduce the risk of recurrence of certain types of cancer and the development of co-morbidities that may impact on the quality of their lives and or life expectancy.
- The application of a specific theory helps to guide the use of risk reduction interventions. The Transtheoretical Model (TTM) can be used by nurses to assess cancer survivors' readiness for change, and to offer targeted interventions to support the adoption of risk prevention activities in the areas of exercise, nutrition, smoking cessation, and alcohol intake.

Learning Objectives

By the completion of this module, nurses will:

- Understand the evidence-based rationale for promoting risk reduction behaviours in the areas of exercise, nutrition, smoking cessation, and alcohol intake for cancer survivors.
- Be able to apply the Transtheoretical Model (TTM) to assessing and intervening with cancer survivors in making behavioural changes for cancer recurrence and co-morbidity risk prevention.
- Be aware of resources for cancer survivors to assist them in making risk reduction behavioural changes.

Meeting the CANO/ACIO Standards and Competencies for the Specialized Oncology Nurse:

Reviewing and using this section in practice, the nurse will be addressing in particular: Practice Standard: Teaching and Coaching. The standard states that the specialized oncology nurse prepares individuals with cancer and their families for the many different aspects of the cancer experience providing education, psychosocial-spiritual support, and counseling across the continuum.
Relevant Competencies:

- assisting the individual/family to understand the importance of adopting healthy lifestyle behaviors to optimize treatment outcomes
- providing relevant information/education at the appropriate times to through the cancer experience related to recovery, rehabilitation, and survivorship

Literature Review

The August 2008 issue of Seminars in Oncology Nursing is devoted to the health promotion of cancer survivors. Guest Editor, Deborah Mayer states, “We have come a long way to treating the disease, but we need to realize we are not yet actively promoting the health of the cancer survivor.” (p. 143). Health encompasses the physical, mental, spiritual, and social well-being of survivors. This module will focus on the following selected health promotion topics including exercise, nutrition, smoking cessation, and alcohol intake. Please refer to Unit 8: Psychosocial Health and Well-being for content on Psychosocial and issues.

Roland (2008) outlines seven compelling reasons why health promotion is an important role for nurses. These reasons are:

- The population of cancer survivors is growing.
- Cancer survivors can expect to live longer than their predecessors, necessitating a long term health promotion plan.
- Cancer survivors tend to be older, and be at risk of other co-morbidities.
- Cancer and treatment for cancer have the potential to affect every aspect of a cancer survivor’s life.
- The risk of recurrence or multiple cancers heightens the need for screening and surveillance.
- Competing health conditions may be potentially life threatening if left untreated.
- Cancer may represent a “teachable moment” creating an opportunity for oncology nurses to help cancer survivors identify make lifestyle changes promoting health.

The National Centre for Health Statistics concluded that there is overwhelming evidence that cancer patients die of non-cancer causes at a higher rate than persons in the general population (Brown, Brauner & Minnotte, 1993). A substantial proportion of cancer survivors spontaneously initiate positive behavioural changes, however, many do not. Males and those with less education, people over the age of 65, or who live in urban areas are less likely to either initiate healthful changes in behaviour, or maintain them. (Demark-Wahnefried, Aziz, Rowland & Pinto, 2005). The number of studies reporting on health promotion for cancer survivors is limited, and the sample sizes tend to be small. In spite of the state of the evidence, enough is known about the issues cancer survivors face to direct oncology nurses to guide cancer survivors towards healthy lifestyles and away from illness.
Theories used in Health Promotion with Cancer Survivors

Researchers and clinicians have used a variety of theories in designing and evaluating health promotion interventions with cancer survivors. The application of a specific theory helps to guide assessment and the use of interventions and contributes to the growing body of evidence in this area of study. Pinto and Floyd (2008) have reviewed theories used in 21 randomized clinical trials promoting healthy behaviour change in adult cancer survivors. The theories identified in their search included:

1. The Transtheoretical Model
2. Motivational Interviewing
3. Social Learning and Cognitive Theories
4. Theory of Planned Behaviour
5. Cognitive Behaviour Theory
6. Others

Refer to Pinto & Floyd (2008) for a discussion of the above theories.

A Focus on The Transtheoretical Model (TTM)

The Transtheoretical Model (TTM) has been found to be effective in improving fitness, improving general health, reducing fatigue, and smoking cessation (Pinto and Floyd, 2008). Developed by Prochaska & DiClimente (1983), TTM targets both cognition and behavioural changes. Survivors are assisted in making healthy lifestyle changes by weighing the pros and cons, or evaluating the risks and benefits involved in making a change.

Use of the Transtheoretical Model provides the nurse with a framework for assessing cancer survivors’ readiness for making behavioural changes. TTM-based interventions tailor nursing recommendations based on the cancer survivor’s readiness for change. The following chart summarizes the five stages of change in the TTM. The stages are cyclic, not linear. The cancer survivor may move into and out of stages, or relapse and start at stage one several times before maintaining the change.

<table>
<thead>
<tr>
<th>TTM Stage</th>
<th>Survivor Behaviour</th>
<th>Nursing Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Pre-contemplation</td>
<td>○ Not considering making a change within the next six months.</td>
<td>○ Provide education about the risks and benefits of making a change.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Empower cancer survivors by emphasizing free choice.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Assist cancer survivors to self-explore feelings about unhealthy choices and re-evaluate prospects of change.</td>
</tr>
</tbody>
</table>
2. Contemplation

- Intending to make a change within the next six months.
- More conscious of the benefits, but aware of unwanted consequences (e.g. Cost, time constraints).
- May present as ambivalent, "procrastination".
- Health education and reinforcement of the benefits of the change.
- Openly discuss strategies to deal with possible negative consequences.

<table>
<thead>
<tr>
<th>TTM Stage</th>
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</thead>
<tbody>
<tr>
<td>3. Preparation</td>
<td>Ready to make the change within the next 30 days.</td>
<td>Offer social support. Make referrals to appropriate resources. Encourage and empower cancer survivor that they have the ability to make the change.</td>
</tr>
<tr>
<td>4. Action</td>
<td>Made specific changes to their lifestyle. The potential for relapse is high in this stage.</td>
<td>More frequent contact with the cancer survivor to help reinforce the positive lifestyle change and help problem solve obstacles to maintenance. Reinforce the long term benefits.</td>
</tr>
<tr>
<td>5. Maintenance</td>
<td>Working to prevent a relapse. Feels more confident about changes, may be a role model for others.</td>
<td>Less frequent contact, may be over the phone. Continue to reinforce benefits of the change. Discuss potential &quot;triggers&quot; that could invite a relapse.</td>
</tr>
</tbody>
</table>

(Pinto & Floyd, 2008; Singer, 2007)
Exercise

A growing body of evidence indicates that exercise has a positive effect on body composition, physical functioning, oxygen capacity, cardio-respiratory fitness, muscle strength, flexibility, pain, compromised mood, quality of life, fatigue, and other impairments related to cancer and its treatment (Schwartz, 2008). In a systematic review and meta-analysis by McNeely et al. (2006) the authors concluded that, “exercise is an effective intervention to improve quality of life (QOL), cardio-respiratory fitness, physical functioning, and fatigue in breast cancer patients and survivors” (p. 40). These positive results were similar to those reported elsewhere with other populations of cancer survivors (Schmitz, Holtzman, Courneya et al., 2005). Perhaps even more importantly, it has been suggested that exercise may reduce risk of cancer recurrence (Holmes, Chen, Feskanich, et al., 2005) and reduce the risk of developing cancer (Martinez, 2005; Moore, Park, & Tsuda, 1998). A recent systematic review conducted by Barbaric, Brooks, Moore and Cheifetz (2010) concluded that “there appears to be a trend toward increased survival among patients diagnosed with breast and colorectal cancer who participate in greater levels of physical activity.” (p. 31). The National Cancer Institute (NCI) website concisely reviews key points from studies on the relationship between exercise and cancer. Cancer survivors report both interest in and the belief that they can participate in exercise. (Cheifetz & Park Dorsay, 2007).

Currently, cancer survivors and health care providers lack knowledge about the benefits of exercise, how to exercise safely, efficiently, and effectively. “To date, there are no evidence-based cancer-specific guidelines for exercise …. until there are guidelines, clinicians who may be hesitant to prescribe exercise for their patients need to consider the potential harm from inactivity compared with the short- and long-term benefits on health.” (Schwartz, 2008). Benefits of exercise have been demonstrated in exercising independently in the home, as well as in supervised settings.

Nutrition

Comprehensive care of cancer survivors includes nutritional interventions targeting both cancer and co-morbidities. Cancer survivors may be ready to adopt healthy lifestyle behaviours. Nurses need to be aware of current literature and guidelines to in order to help cancer survivors make the best nutritional choices. (Toles & Demark- Wahnefried, 2008).

Traditionally, weight loss and cancer cachexia have been the areas of interest with respect to nutrition and cancer survivors. Cancer survivors who are under nourished or cachexic are often fatigued and experience poor quality of life (Toles & Demark- Wahnefried, 2008). For these cancer survivors, a referral to a registered dietician is important. The texture and temperature of foods may need to be modified based on difficulties with chewing or swallowing. Cancer survivors’ senses of taste and smell may be altered in response to treatment. The goal for cancer survivors with a low body mass index (BMI) is to take in
more energy than is used in activity. Nutritional counseling goes hand in hand with energy conservation and counseling about exercise and activity. The American Cancer Society last updated their guidelines on nutrition and physical activity in 2006.

Recently, researchers have been focusing on increased BMI and increased risk of developing cancer, cancer survivorship, and cancer recurrence. Approximately 70% of breast and prostate cancer survivors have increased BMI. “There is compelling evidence to support weight control efforts in this (cancer survivor) population.” (Demark-Wahnefried et al., 2005, p. 5815). Toles and Demark-Wahnefried (2008) systematically reviewed studies related to diet and cancer survivorship following the publication of the ACS 2006 guidelines. They report that:

- Cancer survivors with increased BMI have a greater risk of cancer recurrence and mortality than survivors of normal BMI (non-hodgkin’s lymphoma, multiple myeloma, gastrointestinal, kidney, breast, gynecological, and prostate cancers).
- Increased BMI at time of diagnosis is associated with poorer outcomes (breast, prostate cancers).
- BMI greater than 35 strongly associated with recurrent colon cancer, colon cancer mortality
- Not enough is known about increased BMI after diagnosis and morbidity and mortality
- Increased BMI increases the risk of developing, or having poorly managed co-morbidities, for example, cardiovascular disease, diabetes, metabolic syndrome

### Smoking Cessation

The following comment, or something similar, about a cancer survivor who smokes is not true. “Well, the horse is out of the gate, so no point in quitting smoking now.” Improved diagnosis and treatments for cancer have resulted in longer survival rates for certain types of cancer. Preventing cancer survivors from starting or returning to smoking and helping others to quit is increasingly important (De Moor, Elder, and Emmons, 2008).

### The Risks

After a cancer diagnosis smoking is particularly harmful (De Moor et al., 2008). Adult survivors who continue to smoke after their diagnosis with cancer have the following risks:

- A poorer response to treatment
- Experience more toxicities and complications of treatment
- Increased risk of developing a second primary cancer
- Lower rates of survival than people who stop smoking
The Benefits

There are health benefits of quitting smoking for all people, regardless of diagnosis, age, or gender. The benefits increase the longer someone abstains from smoking.

Benefits of not smoking include:

<table>
<thead>
<tr>
<th>Timeframe from smoking cessation</th>
<th>Physiologic Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>8 hours</td>
<td>carbon monoxide levels drop, oxygen levels in the blood return to normal limits.</td>
</tr>
<tr>
<td>72 hours</td>
<td>breathing becomes easier, lung capacity increases</td>
</tr>
<tr>
<td>2 weeks to 3 months</td>
<td>circulation improves, lung functioning increases up to 30%</td>
</tr>
<tr>
<td>6 months</td>
<td>coughing, fatigue, and shortness of breath improve</td>
</tr>
<tr>
<td>10 years</td>
<td>risk of dying from lung cancer is cut in one half</td>
</tr>
<tr>
<td>15 years</td>
<td>risk of dying of a heart attack equals a person who never smoked</td>
</tr>
</tbody>
</table>

Alcohol Intake

According to the Centre for Addiction and Mental Health (2007). “While many people have a sense of the risks of heavy drinking, and may be aware of problems such as drinking and driving, the link between drinking and cancer is less familiar to the general public (Giesbrecht et al. 2000; Anglin et al. 2005). Media coverage on the protective effects that alcohol can have on cardiovascular disease rarely mentions that alcohol consumption also increases the risk of cancer and other chronic diseases” (p. 1).

Research still needs to be done to provide further evidence of the impact of alcohol on cancer-specific morbidity and mortality. Regardless, the available and extensive international research that focuses on specific cancers can be used as the basis for prevention initiatives. (CAMH, 2007). As cited in the CAMH 2007 document, alcohol has been labeled as a carcinogen by both the International Agency for Research on Cancer (IARC 1988) and the US National Toxicology Program (2005). Research has shown that this association includes the risk of breast cancer, liver cancer, head and neck cancer, and cancers of the rectum and colon. Some studies have demonstrated increased risk with increased alcohol consumption on stomach, lung, ovary, and prostate cancers but, on balance, the body of scientific evidence has been inconclusive.
Key Points for Practice: Exercise

It is important for nurses to educate cancer survivors about the definitions of activity and exercise.

1. **Physical activity**: skeletal muscle contraction resulting in bodily movement that requires energy use.
   a. Physical activity can be thought of as energy expenditure throughout the day, for example, walking up and down stairs, shopping, and house cleaning.

   b. Physical exercise (exercise training): a form of physical activity that is planned and performed with the goal of achieving/preserving physical fitness. Physical exercise results in increased heart rate.

   For some cancer survivors who have not been regular exercisers, or who are de-conditioned as a result of cancer or its treatments, walking around the block may raise their heart rates sufficiently to be considered exercise. The goal then is to gradually increase physical activity to the point of exercise: physical activity that is planned and performed with the goal of achieving/preserving physical fitness.

**Helping Cancer Survivors to Incorporate Exercise into a Healthy Lifestyle: Applying the TTM Model**

Nurses need to incorporate exercise into cancer survivorship care plans with the same priority as other nursing interventions. This includes applying a specific theoretical model, for example the TTM in the creation of cancer survivor self selected exercise goals, exercise counseling, and evaluation of interventions targeted at increasing exercise. In addition to educating cancer survivors about the benefits of exercise, nurses can demonstrate understanding, and help develop strategies to manage challenges to exercise. Challenges may include: embarrassment about exercising in public related to body image issues, fatigue, fear of experiencing pain or side effects, never having exercised/not knowing what to expect, lack finances related to inability to work.
<table>
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<tr>
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</thead>
<tbody>
<tr>
<td>1. Pre-contemplation</td>
<td>- Not considering making a change within the next six months.</td>
<td>- Provide education about the risks and benefits of exercising/not exercising.</td>
</tr>
<tr>
<td></td>
<td>- May lack information, may have attempted to exercise 30 min 3-5 times weekly, not been successful and now feels discouraged.</td>
<td>- Empower cancer survivor by emphasizing free choice.</td>
</tr>
<tr>
<td></td>
<td>- Avoids talking about exercise or thinking about risk behaviours (sedentary lifestyle).</td>
<td>- Assist cancer survivors to self-explore feelings about unhealthy choices and re-evaluate prospects of exercising.</td>
</tr>
<tr>
<td></td>
<td>- Assessment question: When was the last time you thought about starting an exercise program?</td>
<td></td>
</tr>
<tr>
<td>2. Contemplation</td>
<td>- Intending to make a change within the next 6 months.</td>
<td>- Health education and reinforcement of the benefits of exercising 30 min. 3-5 times a week.</td>
</tr>
<tr>
<td></td>
<td>- More conscious of the benefits, but aware of unwanted negative</td>
<td>- Openly discuss strategies to deal with possible negative consequences (e.g. sore muscles from prolonged inactivity).</td>
</tr>
<tr>
<td></td>
<td>- May present as ambivalent, “procrastination.”</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Assessment question:</strong> What is the biggest barrier to starting an exercise program at this point in time?</td>
<td></td>
</tr>
<tr>
<td>TTM Stage</td>
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</tr>
</tbody>
</table>
| **3. Preparation** | • Ready to start exercising within the next 30 days.  
• Have a plan (joined the gym).  
**Assessment questions:**  
*When is your appointment with the personal fitness trainer at the gym?*  
*What can I do, if anything to help you get started at the gym?* | • Offer social support.  
• Make referrals to appropriate resources (eg. Assist with health clearance for exercise facility).  
• Encourage and empower cancer survivor that they have the ability to start exercising. |
| **4. Action** | • Exercising for 30 min 3-5 days most weeks for less than 6 months. Made specific changes to their lifestyle.  
• The potential for relapse is high in this stage.  
**Assessment question:**  
*Now that you are exercising 3-5 times a week, you must be noticing changes in how you are feeling. Please tell me about them.* | • More frequent contact with the cancer survivor to help reinforce the positive lifestyle change and help problem solve obstacles to maintenance.  
• Reinforce the long term benefits of exercise (eg maintenance of a normal BMI). |
| **5. Maintenance** | • Regularly exercising for more than 6 months.  
• Working to prevent a relapse.  
• Feels more confident about changes, may be a role model for others.  
**Assessment question:**  
*You recently started back on chemotherapy. How difficult has it been for you to maintain your exercise program?* | • Less frequent contact, may be over the phone.  
• Continue to reinforce benefits of exercise.  
• Discuss potential “triggers” that could invite a relapse (eg. Vacation, relapse of disease). |

(Pinto & Floyd, 2008; Singer, 2007)
Cancer survivors should always consult with their oncologist or primary health care provider before beginning an exercise program.

**Tips for starting an exercise program**

1. Exercise every other day
   - Start slowly and gradually, increasing exercise to tolerance
   - Gradually increase exercise to 30 min every day
   - Combine both aerobic and strength training with stretching to increase flexibility
   - Exercise at a moderate intensity, 50-75% of predicted maximum heart rate
   (Schwartz, 2008)

**Exercise Safety**

Safety is a priority for cancer survivors who are exercising. Cancer survivors need to be educated about the contraindications to exercise. They are:

a. Shortness of breath with minimal exertion or at rest
b. Unrelieved bone or any pain
c. Extreme fatigue
d. Severe muscle wasting
e. Dizziness
f. Anemia: recommend minimal exertion with hemoglobin less than 80 g/L
g. Thrombocytopenia: minimal exertion with platelet less than 50 (X10 g/L)
h. Absolute neutrophils ≤1.0 (x10 g/L)
i. Fever of 380C or greater
j. Severe nausea and vomiting, potential for electrolyte imbalance (Na\(^+\) and K\(^+\))
   (Courneya, 2000)

**Exercise Counseling**

Jones et al. (2004) investigated the effects of an Oncologist’s counseling to exercise on self-reported exercise behavior in newly diagnosed breast cancer survivors (N=450).

In this randomized controlled trial, participants were divided into three groups: usual care (no exercise counseling), counseling to exercise only, and counseling to exercise and referral. Oncologists were trained to provide a 30 second exercise counseling script. Participants correctly recalled exercise counseling from 41% to 77%.

- Those who received exercise counseling only were significantly more active than those who did not.
- Those who recalled receiving exercise counseling (correctly or incorrectly) were significantly more active than those who did not recall exercise counseling.

Nurses are in a prime position to provide exercise counseling to cancer survivors. Exercise counseling can take as little as 30 seconds to provide, and can be incorporated into the initial encounter and each follow-up visit.
The exercise counseling script

“Recent research has shown that some of the side effects you may experience during treatment may be controlled with a modest exercise program. I recommend trying to exercise 20-30 minutes every day at a moderate intensity. Even less may be beneficial, but try to do something everyday. Exercises such as brisk walking will meet these requirements.” (Jones et al, 2004).

Key Points for Practice: Nutrition

Nurses can teach cancer survivors that gradual weight reduction may have a significant, positive impact on managing hypertension, elevated blood glucose levels, hyperlipidemia, pain, and improve physical functioning. Cardiovascular disease is the leading cause of deaths in Canada, and cancer survivors benefit from an assessment and interventions to reduce their risk of developing this significant co-morbidity.

What is BMI?

The distinction between overweight and obesity is made on the basis of the body mass index (BMI). The BMI is the most practical way to evaluate the degree of excess weight. It is calculated from the weight and square of the height as follows:

\[
\text{BMI} = \frac{\text{body weight (in kg)}}{\text{height (in meters)}^2}
\]

The BMI can also be obtained from a nomogram, a table, or a calculator. Many web sites provide online tools to help calculate BMI, [click here](#) for an example from the National Institutes for Health.

Classification of BMI — The recommended classifications for BMI adopted by the National Institute of Health (NIH) and World Health Organization (WHO) and endorsed by most expert groups are:

- Underweight — BMI < 18.5 kg/m2
- Normal weight — BMI ≥ 18.5 to 24.9 kg/m2
- Overweight — BMI ≥ 25.0 to 29.9 kg/m2
- Class I obesity — BMI = 30.0 to 34.9 kg/m2
- Class II obesity — BMI = 35.0 to 39.9 kg/m2
- Class III obesity — BMI ≥ 40 kg/m2. This type of obesity is also referred to as severe, extreme, or morbid obesity.
Helping Cancer Survivors Attain or Maintain a Healthy BMI

Cancer survivors should always talk with their oncologist or primary health care provider before starting a weight reduction or exercise program.

Nurses can role model healthy lifestyle behaviors by maintaining a normal BMI themselves.

The goal would be to lose no more than 1 kg per week. Encourage the intake of a well-balanced diet; increase the intake of low fat, plant-based foods, while limiting animal-based foods, especially red meats.

Encourage exercise and activity. Decreasing BMI will require lifestyle changes of both increased exercise (expenditure of energy) and decreased energy intake.

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<tbody>
<tr>
<td>1. Pre-contemplation</td>
<td>○ Not considering making a change within the next six months.</td>
<td>○ Provide education about the risks and benefits of weight reduction.</td>
</tr>
<tr>
<td></td>
<td>○ May lack information, may have attempted to loose weight, not been successful and now feels discouraged.</td>
<td>○ Empower cancer survivor by emphasizing free choice.</td>
</tr>
<tr>
<td></td>
<td>○ Avoids talking about weight loss or thinking about risk behaviours.</td>
<td>○ Assist cancer survivors to self-explore feelings about unhealthy choices and re-evaluate prospects of weight reduction.</td>
</tr>
<tr>
<td>2. Contemplation</td>
<td>○ Intending to make a change within the next six months.</td>
<td>○ Health education and reinforcement of the benefits of changing</td>
</tr>
<tr>
<td></td>
<td>○ More conscious of the benefits, but aware of unwanted consequences (eg. Cost, time constraints).</td>
<td></td>
</tr>
<tr>
<td></td>
<td>○ May present as ambivalent, &quot;procrastination.&quot;</td>
<td></td>
</tr>
</tbody>
</table>

Assessment question: What is the biggest barrier to changing your eating behaviours at this point in time?
<table>
<thead>
<tr>
<th>TTM Stage</th>
<th>Survivor Behaviour</th>
<th>Nursing Intervention</th>
</tr>
</thead>
</table>
| **3. Preparation** | ○ Ready to start changing eating behaviours within the next 30 days.  
○ Have a plan (joined a weight loss program, joined a gym). | ○ Offer social support.  
○ Make referrals to appropriate resources (e.g. registered dietician, certified fitness trainer).  
○ Encourage and empower cancer survivor that they have the ability to start loosing weight. |

Assessment question: When is your appointment with the dietician at the clinic?  
What can I do, if anything to help you start your weight reduction program? |

| **4. Action** | ○ Exercising for 30 min 3-5 days most weeks for less than six months.  
Made specific changes to their lifestyle.  
○ The potential for relapse is high in this stage. | ○ More frequent contact with the cancer survivor to help reinforce the positive lifestyle change and help problem solve obstacles to maintenance.  
○ Reinforce the long-term benefits of exercise (e.g. maintenance of a normal BMI). |

Assessment question: Now that you have lost 5 kg, you must be noticing changes in how you are feeling. Please tell me about them. |
### Key Points for Practice: Smoking Cessation

#### Helping Cancer Survivors Quit or Not Return to Smoking

In their systematic review of smoking cessation and prevention studies with cancer survivors, De Moor et al. (2008) outline characteristics of effective smoking prevention programs:

- Emphasis on the unique health risks and vulnerability to tobacco-related health problems of cancer survivors
- Goals are set for abstaining from tobacco
- Regular reinforcement of the importance of abstaining from tobacco
- Use of a theoretical framework to design interventions
- Combining pharmacologic (nicotine replacement) with behavioural strategies
- High intensity support over multiple session
- Focus on strategies for making healthy life style choices and avoiding high risk behaviours

#### Assessment:

Prior to offering an intervention to help a cancer survivor quit or not return to smoking, the nurse can use the TTM as a framework to assess readiness to make the behavioural changes.

<table>
<thead>
<tr>
<th>5. Maintenance</th>
<th>○ Regularly exercising for more than six months.</th>
<th>○ Less frequent contact, may be over the phone.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>○ Working to prevent a relapse.</td>
<td>○ Continue to reinforce benefits of exercise.</td>
</tr>
<tr>
<td></td>
<td>○ Feels more confident about changes, may be a role model for others.</td>
<td>○ Discuss potential “triggers” that could invite a relapse (eg. Vacation, relapse of disease).</td>
</tr>
</tbody>
</table>

Assessment question: You talked about going on a cruise to celebrate your one year anniversary of finishing radiation. Have you thought about how you will make health food choices while you are on vacation?

(Pinto & Floyd, 2008; Singer, 2007)
When did you last think about quitting smoking? Pre-contemplation
When you think about quitting, what holds you back? Contemplation
What date have you chosen as “quit day”? Preparation
You’ve been smoke free for two weeks. That is quite an accomplishment! How does it make you feel? Action
What advice would you offer other cancer survivors who want to quit smoking like you did? Maintenance

For cancer survivors who smoke, it is important for nurses to offer at least a brief intervention to help them to quit. The diagnosis of cancer is a high risk time for former smokers to relapse, and a key time for nurses to reinforce the importance of abstaining from smoking. The United States Public Health Service 5A's approach to tobacco use in the clinical setting is an important resource for oncology nurses. The 5A's are:

- **Ask**: ask and document each person’s tobacco use at each clinical encounter
- **Advise**: in a clear, strong, and personalized manner, urge all smokers to quit
- **Assess**: evaluate the person’s stage of readiness to make a change within the next 30 days (Apply TTM framework)
- **Assist**: if the person is willing to make an attempt to quit, provide resources, help
- **Arrange**: schedule close follow-up, reinforce success, or intervene if relapsed

(summarized from De Moor et al, 2008)

One of the resources nurses can offer cancer survivors is information about smokers’ quit lines. A survey conducted to evaluate the effectiveness of a smoker’s helpline in Ontario reported on callers 28 days after they talked with a quit specialist. Thirty nine percent of callers reported they had made a quit attempt. Thirty one percent set a quit date, and 65% had cut down on the number of cigarettes smoked (Health Canada, 2005). This link lists “Quit Lines” by province.

**Key Points for Practice: Alcohol Intake**

How is alcohol intake described?

One of the methodological challenges related to the research on the increased risks of certain types of cancers and alcohol intake is the description of alcohol intake. Different international studies describe low, moderate, and heavy alcohol intake differently. According to Dufour (1999), in Canada, moderate drinking for both males and females is described as:

- Two alcoholic drinks per day or nine drinks per week
- One alcoholic drink consists of five ounces of wine, one and one half ounces of a spirit, or 12 ounces of beer
Assessment:

The assessment of alcohol use/misuse may follow a different order than that of other risk reduction behaviours. Prior to using the TTM framework, the nurse can use the CAGE Questionnaire (Ewing, 1984) as a screening tool to determine if it is appropriate to further assess and offer interventions to quit or modify alcohol intake. The CAGE Questionnaire is a very brief, non-confrontational tool frequently used in primary care settings to screen for alcohol overuse. It takes less than one minute to complete. The cancer survivor can complete a paper and pencil version, or it can be done as part of the nurse-cancer survivor interview. It has been tested for validity and reliability. The CAGE Questionnaire is not a diagnostic tool. Answering more than two out of the four questions as “yes” does not diagnose a person with alcoholism. However, answering “yes” to two questions directs the nurse to further explore the potential for alcohol misuse.

CAGE Questionnaire

- Have you ever felt that you should CUT down on your drinking?
- Have people ANNOYed you by criticizing your drinking?
- Have you ever felt bad or GUILTY about your drinking?
- Have you ever had a drink first thing in the morning to steady your nerves or get rid of a hangover (EYE opener)?

Helping Cancer Survivors Make Informed Choices about Alcohol Intake

Brief interventions have been demonstrated to reduce high risk alcohol intake. Brief interventions are a useful strategy nurses can use to help cancer survivors modify their drinking behaviours. (CAMH, 2007). The 5 A’s Framework used to help smokers quit, can be applied to helping cancer survivors modify their drinking behaviours.

- **Ask:** ask and document each person’s alcohol use at each clinical encounter
- **Advise:** in a clear, strong and personalized manner, urge cancer survivors to cut down or quit drinking alcohol if they are more than moderate drinkers
- **Assess:** evaluate the person’s stage of readiness to make a change within the next 30 days (Apply TTM framework)
- **Assist:** if the person is willing to make an attempt to cut down or quit provide resources
- **Arrange:** schedule close follow-up, reinforce success or intervene if relapsed

(modified from De Moor et al, 2008)
Tips to Offer Cancer Survivors Cut Down or Eliminate Alcohol

Review:
How much is a drink?
A drink is:
1. one 350 mL (12 oz) bottle of beer (5% alcohol)
2. one 145 mL (5 oz) glass of wine (12% alcohol)
3. one 45 mL (1.5 oz) shot of spirits (40% alcohol)

Drinking more than 3.5 drinks a day can double or even triple the risk of developing cancer. (Canadian Cancer Society, 2010)

If the cancer survivor chooses to drink alcohol, limit the amount consumed. One alcoholic drink a day for women and less than two drinks a day for men is recommended. According to the literature, even one drink a day on average can increase the risk of breast cancer.

Practical tips include:

5. Try not to start drinking alcohol if you are thirsty instead quench your thirst with water or another non-alcoholic drink first.
6. Avoid salty snacks such as potato chips and nuts while drinking alcohol because these make you thirstier.
7. Have some non-alcoholic or low-alcoholic drinks during the evening.
8. Space out your drinks about an hour apart.
9. Always have a glass or bottle of water with you as well as your alcoholic drink.
10. Think about the strength of your drink. Choose beer or wine that contains less alcohol.

(Canadian Cancer Society, 2010)

This link is an excellent resource for survivors who are thinking about limiting the amount of alcohol they consume, or eliminating alcohol from their lifestyle. This National Institutes of Health resource provides a self-assessment guide consistent with the TTM to help survivors gauge their readiness to make a change with respect to alcohol intake. Tips for cutting down or eliminating alcohol intake are provided.

Learning Activity: Case Study

Part Two

Note: This is a continuation of the case study you first read in Unit 2: Models of Care for Follow Up After Cancer Treatment and the survivorship care plan that was developed for G.L. G.L is now 71-year-old and two years post external beam radiation treatment and androgen suppressant therapy for T2a N0 M0 adenocarcinoma of the prostate. His Gleason score was 2 + 4.
G.L. continues to be treated for hypertension with thiazide diuretic and a beta blocker. He is awaiting bilateral knee replacements for osteoarthritis. He is a life long non-smoker. He consumes 3-4 alcoholic beverages on most days. G.L. leads a sedentary lifestyle. He stopped playing golf after his treatment, fearing the embarrassment of urinary incontinence while on the course.

You are a nurse who has provided care to G.L. during and following his treatment. He is now coming to the clinic every six months. G.L. tells you that it is “too difficult” to see his primary care provider on a regular basis.

PSA 0.1         BP 154/88      Ht 179.0  Wt 114.0  BMI 35.2

G.L. main concerns are:

- “I’d like to be more active, but I’ve gained so much weight, and I’m so short of breath when I do the tiniest activity. It’s an effort to do almost anything.”
- “My wife is only 65-year-old. She still looks healthy and pretty. We used to be really close, do lots of things together. I have trouble getting an erection. I tell her I’m just tired, but honestly, I just can’t do it.”
- “That guy at work with prostate cancer he slipped on the ice and broke his wrist. And now I hear he broke his hip! I’d like to be more active, but not if my bones are going to break like a china tea cup!”

Develop a survivorship care plan to address risk reduction issues identified in this case scenario. Provide examples of questions you would use, applying the TTM to assess G.L. readiness to make behavioural changes. Include both actual and potential issues for G.L. Part One and Part Two of the survivorship care plan should address actual and potential issues specific to G.L. Ongoing surveillance, as well as risk prevention activities should be addressed.

Discussion of case study:

Risk reduction issues include
- increased BMI (Class II Obesity)
- sedentary lifestyle
- increased alcohol intake

Health conditions G.L. is at risk for include
- cardiovascular disease: stage two hypertension in spite of treatment
- depression: withdrawing from social interactions related to urinary incontinence, fears of recurrence/complications of disease (pathologic fracture), marital issues related to ED
- excessive ETOH use: as above, self medicating for pain while awaiting hip replacements for osteoarthritis
- type two diabetes: age (72), increased BMI, ETOH use
- metastases from prostate cancer
References


UNIT 11

Resources and Tools
There are many credible, reliable, and informative resources available to help you learn about survivorship and expand your knowledge base about survivorship. This section will highlight some of the available resources. Keep in mind, resources keep changing and evolving. This section will help you get started. Let’s start by looking at some of the resources available to you the health care professional. We will then explore great resources that you can recommend to your patients.

**Health Care Professional Resources**

For more information about cancer survivorship issues, visit the following sites:

- [National Cancer Institute’s survivorship research section](#)
- [National Coalition for Cancer Survivorship](#)
- [CDC’s survivorship efforts](#)
- [American Society of Clinical Oncology (ASCO)](#) – you can download forms (ASCO Treatment Summaries) to fill out about what treatment(s) your patient received and outline the schedule for follow-up care.
- [Institute of Medicine Report on Survivorship](#): This 2005 national American report provides information about the challenges that survivors face.

**Patient Resources**

- [Canadian Cancer Society links about survivorship](#)
- [Cancer Net](#) offers a wide range of information to help patients transition to survivorship.
  The site covers topics such as:
  - Finishing Treatment—What Comes Next
  - ASCO Treatment Summaries
  - Keeping a Personal Medical Record
  - Terms to Know
  - Managing side effects
  - Late effects
- [Caring Voices](#)
  - Caring Voices, an online community of support for cancer survivors, is an initiative of the Princess Margaret Hospital, in Toronto, Ontario.

Caring Voices is a national platform that offers online access to current educational resources, peer support, and advice and education from health care and community experts.

Cancer survivors can access Caring Voices from across the country and registered members can take part in real time chats, including several scheduled monthly events and discussions with other cancer survivors, members of the cancer community and health care professionals.
Meeting the CANO/ACIO Standards and Competencies

Reviewing and using this section in practice, the nurse will be addressing the following standard domains:

- Standard Practice Teaching and Coaching
- Standard Practice Facilitating Continuity of Care/Navigating The System
Adult Cancer Survivorship
A Self-Learning Resource for Nurses
Kim Chapman MScN, CON(C), Jennifer Wiernikowski, MN, NP-Adult, CON(C)

Contributors:
Margaret Forbes, RN, MN, NP-Adult, CON(C),
Joan Hamilton, MScN,
Lynne Jolicoeur, RN, MScN, CON(C),
Dr. Anne Katz, RN, PhD, Virginia Lee, RN, PhD,
Jan Park-Dorsay, RN, MN, NP-Adult, CON(C),
Brenda Sabo, RN, PhD,
Lori Santoro, RN, CON(C),
Myriam Skrutkowski, RN, MSc, CON(C),
Mary Vachon, RN, PhD
Tracy Soloninka, RN, MS Oncology, CON(C)
Miriam Corne, BScN, MEd, CON(C)