

# UNIT 2

## Models of Care for Follow Up After Treatment for Cancer

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## 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/ACIO 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;  $p \leq 0.001$ ; 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;  $p \leq 0.001$ ) (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:

Model of Care	Advantages	Disadvantages
<b>Oncologist Follow-Up</b>	<ul style="list-style-type: none"> <li>■ Cancer survivors may have a trust relationship with their oncologist</li> </ul>	<ul style="list-style-type: none"> <li>■ Often long waits for appointments related to capacity issues</li> <li>■ In busy practices cancer survivors may not be offered follow-up care</li> </ul>
<b>Primary Care Provider Follow-up</b>	<ul style="list-style-type: none"> <li>■ Convenient</li> <li>■ Provides continuity and a holistic approach to care (i.e. one health care provider who manages the care)</li> </ul>	<ul style="list-style-type: none"> <li>■ 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</li> </ul>

<p><b>Shared Follow-Up</b></p>	<ul style="list-style-type: none"> <li>■ People may feel more secure with oncologist and primary care provider follow-up</li> <li>■ Model works well with the use of a survivorship care plan (see section below)</li> </ul>	<ul style="list-style-type: none"> <li>■ Scheduling of appointments may overlap and routine tests may be missed if communication is not optimum between care providers</li> </ul>
<p><b>Nurse-led Follow-up Clinics</b></p>	<ul style="list-style-type: none"> <li>■ Nurses provide quality follow-up care in collaboration with oncologists</li> <li>■ 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</li> <li>■ Studies have indicated patient satisfaction with this model of care</li> </ul>	<ul style="list-style-type: none"> <li>■ Nurse-led care may not always be desired by the cancer survivor</li> <li>■ Cost effectiveness has not yet been firmly established</li> </ul>
<p><b>Nurse-led Telephone Follow-up</b></p>	<ul style="list-style-type: none"> <li>■ Nurse and cancer survivor “meet” by prescheduled telephone appointment</li> <li>■ Long distance travel is not required to receive followup care</li> </ul>	<ul style="list-style-type: none"> <li>■ Phone assessment is not ideal for diagnosing new concerns</li> <li>■ Nurses must have excellent assessment and triaging skills to determine if the person requires urgent or immediate care based on symptoms</li> <li>■ May require further liaison with primary care provider to assist with new health concerns</li> </ul>
<p><b>Interdisciplinary Survivorship Clinics</b></p>	<ul style="list-style-type: none"> <li>● Opportunity to meet needs from a variety of perspectives including: nurses, dieticians, physicians, social workers, and psychiatrists.</li> <li>■ Focus is on health promotion, risk reduction and prevention of other diseases</li> </ul>	<ul style="list-style-type: none"> <li>■ Those attending the clinic may end up having longer visits due to interdisciplinary nature of clinic</li> </ul>

**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  $\geq 8$ ) (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.

Facilitators	
<b>Recommendations</b>	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).
<b>Stakeholders &amp; Advocacy Groups</b>	As awareness of SCP increases, stakeholders including cancer survivors , primary care providers and advocacy groups will request them as a standard of care.
<b>Evidence</b>	Research demonstrating improved outcomes for patient care associated with the implementation of SCPs.

Barriers	
<b>Lack of Consensus</b>	There is lack of consensus and evidence related to the implementation of SCPs.
<b>Time</b>	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.
<b>Health Human Resources</b>	Human resources are limited. Planning needs to be carried out and resources allocated to ensure SCPs can be developed, implemented and evaluated
<b>Knowledge</b>	Information and clinical practice guidelines are required for practitioners who are developing SCPs. For example practitioners often lack knowledge around employment and insurance issues.
<b>Medical Records</b>	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).

## 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.

SCPs 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](http://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](http://www.jco.org/cgi/content/full/24/18/2917)

American Society of Clinical Oncology (ASCO) recommendations on fertility preservation.

[www.cancer.net](http://www.cancer.net)

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

[www.livestrong.org](http://www.livestrong.org)

Lance Armstrong Foundation

[www.survivorshipguidelines.org](http://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.aicr.org/site/PageServer?pagename=cs_guidelines)

Nutrition guidelines for cancer survivors after treatment.

<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

<http://www.nhmrc.gov.au/publications/subjects/cancer.htm>

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.

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