Improving the outcomes for cancer survivors in Canada: An interactive approach to competency development using the newly released CANO/ACIO Survivorship Manual

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ABSTRACT
CANO/ACIO has long recognized the important role oncology nurses play in improving outcomes for cancer survivors. To ensure oncology nurses have easy access to the updated evidence, as a basis for their practice, CANO/ACIO undertook the important work of updating the CANO/ACIO self-learning modules on survivorship and creating several new ones. This article highlights the current gaps in care experienced by cancer survivors in the months and years after their cancer treatments are completed and the important contributions that nurses can have in improving the quality of survivorship care. It also provides an interactive approach to competency development using the newly revised and released Pan-Canadian Survivorship Manual.

INTRODUCTION
Approximately 7.1% of the Canadian population, or 2.1 million people, were reported by Stats Canada in 2015 as having been diagnosed with cancer at some point during their lifetime (Public Health Agency of Canada, 2018). As early detection and effectiveness of treatments improve, and as more Canadians live into old age when cancer is more prevalent, we are likely to continue to see the number of cancer survivors in Canada increase (Canadian Cancer Society [CCS], 2020). By the age of 70, one in five Canadians report having been diagnosed with cancer during their lifetime (Public Health Agency of Canada, 2018).

Given the increasing number of Canadian cancer survivors, there is a need to better understand the care experiences and unmet needs of this population. To fill this information gap, the Canadian Partnership Against Cancer (CPAC) collaborated with all 10 Canadian provinces to conduct the Experiences of Cancer Patients in Transition Study (Fitch, Zoomer, Lockwood, et al., 2019). This innovative pan-Canadian survey was completed by more than 13,000 cancer survivors. As the first national survey of its kind, the Transition Study provides foundational information about the difficulties, information requirements, and needs (met and unmet) of cancer patients and survivors across Canada.

CANO/ACIO has long recognized the importance of oncology nurses in improving outcomes for cancer survivors. This recognition was evidenced by the development and release of 11 survivorship learning modules for oncology nurses in 2011. Since then, the body of literature on cancer survivorship care in Canada has evolved considerably. However, as demonstrated by the CPAC Transition Study results, there is urgent need for improvements in survivorship care.

To ensure oncology nurses have easy access to the updated evidence as a basis for their practice, CANO/ACIO undertook the important work of updating the self-learning modules and also creating several new ones. This recently completed work was coordinated and led by CANO/ACIO’s Survivorship Special Interest Group. The new and updated Survivorship Manual is now available in French and English on the CANO/ACIO website for free download to CANO/ACIO members and for a small fee to non-members. The manual is a highly practical and invaluable clinical resource for nurses working at the point of care and for those studying this topic area.

To increase member awareness of this innovative resource, we hosted a workshop about survivorship at the CANO/ACIO annual conference in Winnipeg, Manitoba in October 2019. During this workshop, participants learned about the CPAC Transition Study results and explored the role of the oncology nurse in survivorship. We also introduced the newly revised Survivorship Manual and, in round-table discussions, worked through several case-based scenarios from the Manual. Small group discussions highlighted how oncology nurses could use the manual to better meet the physical and psychosocial needs of cancer survivors, and improve their ability to effectively coordinate care, develop survivorship programs, and enable patient self-management. In this article, we provide an overview of the content shared during the workshop and learnings that emerged from our dialogue.
reported changes in depression, sadness, and loss of interest in daily activities. Changes in sexual intimacy was of greatest concern. Of those who sought help for emotional concerns, about 25% had difficulty obtaining assistance or did not receive it. Ninety-four percent of those with emotional concerns indicated the reason they did not seek help; 22% indicated someone told them it was normal to experience emotional concerns, or they did not want to ask (18%).

Almost half the respondents (44%) experienced at least one practical challenge with 13% experiencing three or more. Twenty-two percent reported challenges returning to work or school, while 21% faced challenges getting to and from appointments and 20% paying for healthcare. Of those who faced practical challenges, returning to work (41%) and getting life insurance (36%) were common issues. Only about a third sought help. Of those who sought help, the largest percent had difficulty obtaining insurance (67%) or paying for healthcare bills (53%). Of those who had concerns, 94% indicated they did not ask for help because they did not want to ask (16%) or they did not know about services available to help them (18%).

The reasons survivors did not ask for help are concerning and have implications for nursing practice. The proportion of individuals expressing concern, but not receiving help, was highest in both emotional and practical domains, ranging from a low of 59% (getting to and from appointments) to a high of 88% (relationships with friends and colleagues). Within the physical domain, across all changes, more than 40% of individuals did not receive help for concerns they experienced. The most frequently cited reasons for not seeking help was that someone had told them what they were experiencing was normal and they did not think anything could be done about it.

Healthcare providers need to be knowledgeable about the potential for issues to arise for survivors and what can be done. Strategies to identify those at risk for experiencing difficulties, if implemented prior to the time of transition, could mitigate challenges or prevent them from emerging later.

This study was undertaken to provide a foundation for action given perspectives of cancer survivors are needed to create services that meet their needs. Many survivors have concerns about physical, emotional, and practical issues; yet, many are not receiving the help they need to reduce suffering related to their concerns. It is imperative we take action to address this reality.

THE IMPORTANCE OF ONCOLOGY NURSES IN CANCER SURVIVORSHIP

Since the emergence of cancer nursing as a specialty in the 1940s, nurses have become increasingly interested in physical, psychosocial and health-related quality of life issues for cancer patients and survivors. More than ever, oncology nurses have an important part to play in survivorship care with a diversity of nursing roles needed in our health system to meet the needs of a growing population of cancer survivors.

One issue that oncology nurses have continued to grapple with is that the definition of survivorship is often tied very narrowly to the transition from specialty oncology to primary care settings (Truant, 2018). This poses several challenges, including a missed opportunity for nurses to identify and begin to address patients’ unmet needs early on in the cancer care pathway. However, oncology nurses are leading the way in developing strategies to integrate survivorship care into various healthcare settings to better support patients through different phases of cancer survivorship. With patients at the crux of everything we do, oncology nurses are optimally positioned to engage patients early on in their cancer journey, as partners in their own care. Recognizing a patient as a survivor from the start can guide nurses to explore survivorship issues with their patients and work together to develop a personalized plan of care that includes the patient’s perspectives and unique needs. This can enhance patient involvement and lead to more individualized care, as well as potentially improve health outcomes and the patient experience (Charalambous et al., 2018).
After primary cancer treatment, models of follow-up care vary greatly. A number of models have evolved over the last decade, including care led by nurses, primary care providers, or oncologists, as well as shared care and survivorship clinics (American Society of Clinical Oncology, 2016; Halpern et al., 2015; Miller et al., 2015). Regardless of the model of follow-up care, transitions in care can be frightening and filled with uncertainty for patients and their families. Follow-up care can bring about several changes including much less interaction with healthcare providers, putting the onus on patients to reach out when concerns arise (Fitch, Zoomer et al., 2019; Thorne & Stajduhar, 2012; Thorne et al., 2014). The results of the CPAC Transitions Study demonstrate the difficulty survivors experience in seeking help with their unmet needs and show that survivors need to be better supported in preparing for life after primary treatment (Fitch, 2019b). Consequently, support during transitions is critical to mitigate challenges and impact the long-term health of survivors. Transitions to survivorship is a key phase where oncology nurses can aid in shaping patients’ experiences with care.

Through ongoing interactions and supportive care interventions, oncology nurses can have a positive impact on the lives of cancer survivors (Charalambous et al., 2018). Several specific strategies to guide nurses in supporting patients through the process of transitioning from treatment to survivorship, and between care providers, are outlined in Unit 2 of the CANO/ACIO Survivorship Manual. These strategies primarily centre on three main tenets:

- disseminating information on cancer treatment and follow-up needs to patients, interdisciplinary care teams, and primary care providers;
- facilitating continuity of care and helping patients navigate transitions across care settings and between care providers; and
- providing opportunities for survivors to engage as active team members in planning their care including acquiring self-management skills that will better enable them to cope with the potential long-term and late effects of cancer and its treatment.

Oncology nurses are critical to ensuring cancer survivors have equitable access to high-quality survivorship care, whether they are delivering care as front-line providers or leading national initiatives aimed at transforming our cancer care system to be more person-centred and responsive to the needs of all patients. Canadian nurses have played a significant role in leading research and generating knowledge in the areas of survivor experiences and outcomes (Fitch, Coronado, et al., 2019; Wilkins & Woodgate, 2011), models of care (Bryant-Lukosius et al., 2015), interventions (Howell et al., 2020), and knowledge to practice (Howard et al., 2014). As we explore new and innovative ways to improve the services and delivery of care to cancer survivors, it will be critical to position oncology nurses in all phases of survivorship care. Nurses are needed not only in specialty cancer treatment settings, but also in primary care settings if we are to deliver the services and patient-centred care required to meet the physical, emotional and practical needs of this growing population.

**INTRODUCING THE UPDATED SURVIVORSHIP MANUAL**

In 2017, a collaboration was launched between the Survivorship-Special Interest Group (SIG) and Canadian nursing experts to update the CANO/ACIO Survivorship Manual and reflect the evolving realities of cancer survivorship. The new manual includes revised versions of the 10 original modules and the addition of two new modules to address specific challenges among adolescent and young adults (AYA), as well as older adults treated for cancer. The 12 modules are now available in French and English for download from the CANO/ACIO website. CANO members may download individual modules or the entire manual for free, with availability for non-members to access the modules for a fee.

The topics of the self-learning modules include:

1. Adult Cancer Survivorship – What We Know
2. Improving Post-Treatment Transitions and Survivorship Care Experiences
3. Managing Late, Long-Term/Persistent Physical Effects of Cancer Treatment
4. Understanding Fear of Recurrence
5. Complementary and Integrative Health
6. Relationships During Cancer Survivorship
7. Sexual Health
8. Psychosocial Distress and Well-Being
9. Returning to Work
10. Risk Reduction Activities
11. Survivorship Issues for Adolescent and Young Adults with Cancer
12. Optimizing Survivorship Care for Older Adults Following Cancer Treatment.

To our knowledge, this is the first bilingual (English, French) resource to guide nurses in addressing cancer survivorship issues. The Survivorship Manual includes an overview of patients’ experiences of living with a cancer diagnosis in Canada and the role of the oncology nurse in meeting the care needs of this population. This resource emphasizes the Canadian context of a universal, publicly funded healthcare system while making efforts to reflect best practices in survivorship care. Each module is introduced with case studies to situate specific challenges in daily nursing practice. We anticipate the Survivorship Manual will be a foundational resource that nurses can use to guide the delivery of high-quality survivorship care.

It is CANO/ACIO’s goal that all Canadian oncology nurses are aware of this resource. This year, CANO/ACIO Chapters will be actively involved in promoting the Survivorship Modules. For sustainability purposes, a dissemination plan will be developed in collaboration with CANO/ACIO Chapters and Survivorship-SIG members. In addition, we are recruiting “Ambassadors” or “Champions” to promote specific modules across clinical settings. Furthermore, we are working to develop webinars in concordance with the different themes from the Survivorship Modules.
WORLD CAFÉ AND CASE BASED SCENARIOS

To highlight the rich and diverse learning experience that could be achieved by using the Survivorship Manual, we utilized the World Café method (www.theworldcafe) to engage with workshop participants. This method allowed us to create a collaborative dialogue about case-based scenarios that mimicked real practice scenarios similar to what participants would encounter in their workplaces. Four tables were organized for this part of the workshop and each table had a facilitator. Each facilitator was given a written description of the World Café approach, principles for successful facilitation, and a case scenario. The case scenarios focused on:

• Cancer Treatment Induced Cognitive Changes
• Return to Work and Fatigue
• Fear of Cancer Recurrence (FCR)
• Transitioning to Survivorship Care.

The workshop attendees were evenly distributed at each table and given 15 minutes to discuss the case scenario. Every 15 minutes, participant groups rotated to the next table, with the facilitators staying at their original table. After one hour, all participants had reviewed and discussed each of the four case scenarios and offered their thoughts regarding each scenario for the following guiding questions:

• What are the key points of information in this case that need to be considered by the nurse?
• What actions might the nurse take in this situation?
• What are the barriers that might need to be managed when trying to support this patient?
• What practice supports would help the nurse to provide high-quality care to this individual?
• How would the nurse’s assessment and intervention differ if the patient was under the age of 30, or over the age of 75?

After all participants had cycled through each table, facilitators shared a summary of discussion that occurred about the case scenarios at their table with the entire participant group. Facilitators paid particular attention to the patterns and insights that came out of the conversation at their table, the diversity of perspectives that were shared, collective discoveries that were made, and ideas about how the Survivorship Manual could be used to overcome barriers to high-quality survivorship care in routine practice.

COGNITIVE CHANGES: AN EXAMPLE OF A CASE BASED SCENARIO TABLE DISCUSSION

The case study of Ms. R., an eighty-one-year old Austrian woman with stage III ovarian cancer, was used to facilitate discussion about cancer treatment-induced cognitive changes.

• Ms. R. received neoadjuvant chemotherapy, robotic surgery, and completed her last cycle of adjuvant chemotherapy four months ago. Ms. R. was an active and independent woman who immigrated from Austria 35 years ago. She is divorced with no children. She has a university education. Her social circle includes a few friends from her years of employment, her family, and friends that she made throughout treatment. During treatment Ms. R. faced various challenges including a decline in her activities of daily living, and a need to increase her dependency on others for transportation, meal preparation, and cleaning services.

• Throughout treatment Ms. R. noticed memory changes that did not directly affect her functioning, but left her self-conscious that friends would notice and worried she would not return to her baseline. She asked, “Is there a point in having a nursing follow-up now that I am all done treatment? Am I taking up the spot of someone who is still sick and really needs the appointment?” Since completion of treatment, she reports that her fatigue has improved, but she only does two hours of volunteering at a time, whereas she used to volunteer for longer shifts before treatment. She is embarrassed that she still relies on a volunteer driver to take her to appointments. She is concerned that her memory is “not what it used to be” but she does not feel the same fog she had during chemotherapy, except on days when she is more tired.

Participants reflected on how cancer treatment-induced cognitive changes in an older adult might shape the survivorship experience. Discussion began with an acknowledgement that cognitive changes due to the cancer experience are real and can be substantial enough to affect everyday life. People may be unable to go back to their school, work, or social activities, or it may take a lot of mental effort to do so. (Ahles et al., 2012; Harada et al., 2013; Harvard Medical School, 2018; Loh et al., 2016).

There were many key points of information in this case-based scenario that the nurse needed to consider. Age, comorbidities, pre-existing cognitive decline, communication with healthcare providers, and navigating the healthcare system may cause and/or contribute to cognitive impairment and, therefore, need to be considered. Comorbidities such as hearing impairment and decreased vision, as well as poorly managed comorbidities can negatively impact cognitive function.

Participants wanted to know more about Ms. R.’s current level of functioning and emotional status (depression versus cognitive changes), specifics about her treatments, (especially drug therapy), stage of her disease, and any disease symptoms. Factors such as distress, fatigue, anemia, depression, insomnia, or hormonal fluctuations may also cause similar symptoms. They were interested in exploring the impact of Ms. R.’s cognitive impairment on her safety. They wanted to know about her living situation. Participants felt that it was important to assess and reassess Ms. R.’s decision-making capacity throughout her cancer experience. It was also important to determine if there is a power of attorney in place. Most importantly, they wanted to know Ms. R.’s priorities.

Participants identified a number of actions that an oncology nurse might take in Ms. R.’s situation. Actions included, but were not limited to...
increasing one’s knowledge about how cancer and its treatment impact cognition, advocating for a geriatric assessment, and conducting a comprehensive assessment using standardized tools such as the Mini-Mental. Nurses can ensure that varied perspectives such as the family physician are captured in the assessment and written information is provided to complement verbal information to facilitate memory. If decision-making capacity is in question, nurses can facilitate referrals to a geriatrician, a clinical ethicist, and/or Social Work. Other referrals might include referral to occupational therapy and community resources. Nurses can have Mrs. R. keep a daily planner or diary to obtain a snapshot of her day. They can encourage her to participate in a support group, engage in activities that help organize one’s day when impaired cognition exists (e.g., keeping a checklist of daily reminders, using sticky notes as reminders, etc.), and do neurobics to improve cognitive function. Examples of neurobics include trying tasks like solving crosswords or puzzles, using word play (such as rhyming), and playing games like Imaginarium. Mrs. R. can be encouraged to plan and prioritize activities.

Several barriers were identified that might need to be managed when trying to support Ms. R. One barrier would be if Ms. R. was not able to attend her follow-up appointments. Other barriers could include lack of support (emotional or practical), Ms. R.’s desire to be independent (she might be reluctant to ask for help or wish to cover up her cognitive status), Ms. R. experiencing depression and possibly withdrawing from family and friends, lack of knowledge related to normal age-related changes (e.g., it is normal to experience cognitive change as one ages), level of academic preparation, diagnosis of cancer, and lack of a comprehensive baseline assessment.

Participants identified several practical supports required by a nurse to provide high-quality care to Ms. R. They identified a key support is having easy access to standardized assessment tools that are short, succinct, relevant, and easy to complete without requiring a lot of time commitment.

The nurse’s assessment and intervention would differ if the patient was under the age of 30. Age can influence what type of care is provided. Specifically, there would be more focus on understanding what is happening because cognitive changes in a younger person would not be considered “normal.” The type of resources needed by a younger person would differ, such as the need for childcare. Cognitive changes might be overlooked in a younger adult if healthcare professionals are not specifically looking for cognitive changes. The type of education sessions and/or support groups would need to be tailored to a younger population. Referral to palliative assessment/palliative care/pain and symptom management team might be delayed because of the younger age. One’s perspective on aging could influence nursing intervention (natural to die at age 88 compared to less than 30). The financial impact might be more significant for a young person still in the workforce compared to an elderly person who is retired.

**CONCLUSION**

To ensure oncology nurses have easy access to the updated evidence as a basis for their practice, CANO/ACIO undertook to update the existing self-learning modules about survivorship and create several new ones.

The new and updated Survivorship Manual is now available in French and English on the CANO/ACIO website for free download to CANO/ACIO members and for a small fee to non-members. The manual is a highly practical and invaluable clinical resource for nurses at the point of care and to those studying this topic area.

**REFERENCES**


