

Empowering Oncology Nurses through Knowledge and Practice to Improve Transitions Following Treatment and Survivorship Care

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Received: June 22, 2021; Accepted: June 28, 2021; Published: August 27, 2021

ABSTRACT

Following cancer treatment, individuals can be left with physical, emotional, and practical consequences which influence their quality of life. Cancer survivors frequently require added knowledge and skills to handle the demands of everyday living after treatment. Oncology nurses are in an ideal position to address the needs of cancer survivors. This article describes an online interactive workshop for oncology nurses to introduce Canadian data on unmet needs of cancer survivors, highlight the contribution oncology nurses can make to survivorship

care, and introduce a self-learning resource for survivor care. Didactic presentations and small group discussions were used and feedback from participants was positive. Online learning can be an effective approach for learning with international nursing colleagues and could be utilized for nurses with limited access to cancer nursing education.

Key words: Cancer survivors, interactive online learning, oncology nursing role in survivorship, survivorship

Introduction

The cadre of cancer survivors is growing and anticipated to exceed 20 million worldwide by 2025.^[1,2] A diagnosis of cancer and its treatment can leave survivors with physical, emotional, and practical consequences which influence their quality of life.^[3,4] For many, living with the aftermath of treatment can be likened to living with the ongoing impact of a chronic illness.^[5,6] Frequently, individuals require added knowledge and skill to handle the demands

of everyday living after treatment for cancer. Oncology nurses are in an ideal position to address the needs of cancer survivors and prepare them for the transition to the posttreatment phase of their experience with cancer.

This article is based on an interactive workshop provided for the International Cancer Nursing Conference held virtually in February 2021. The purpose of the workshop was to share the results of a national survivor study

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Cite this article as: Watson L, Maheu C, Champ S, Fitch MI. Empowering Oncology Nurses through Knowledge and Practice to Improve Transitions Following Treatment and Survivorship Care. *Asia Pac J Oncol Nurs* 2021;8:555-9.

Access this article online

Quick Response Code:



Website: www.apjon.org

DOI:
10.4103/apjon.apjon-215

completed in Canada and explore the role oncology nurses could play in high-quality survivorship care. We also wanted to profile a new resource for oncology nurses regarding survivorship care which had been developed by the Canadian Association of Nurses in Oncology (CANO/ACIO). We included both didactic presentations and interactive discussions about survivor case studies. Below, we will highlight the content shared at the workshop and the resulting feedback from participants.

Didactic Presentation: Understanding the Experience of Canadian Cancer Survivors

With the growing cadre of cancer survivors, understanding the nature and impact of consequences from the diagnosis and treatment is growing, and survivorship support is being seen as an imperative for oncology nurses.^[7-10] Although not all survivors experience challenges at the time of treatment completion, a sizeable proportion have ongoing difficulties and report profound effects on their quality of life.^[3,4]

Planning of survivorship care in our country required a deeper understanding of the experiences of survivors as they transition from the completion of their primary cancer treatment into the survivorship phase of their journey. In 2017, the Canadian Partnership Against Cancer undertook a national survey to understand the experiences of cancer survivors 1–3 years following treatment. The intent was to provide the basis for actionable recommendations on integrating cancer survivorship care, ultimately improving the experiences of survivors.

The full description and rationale for the transitions survey is reported in a previous publication.^[11] In brief, the survey, Experience of Cancer Patients in Transition Study, was mailed to a randomly selected sample of 40,790 cancer survivors from across ten Canadian provinces. The eligibility criteria included adult survivors (age 30+ years) of breast, prostate, colorectal, or melanoma diseases with no metastatic spread, and selected hematological (e.g., Hodgkin's lymphoma, diffuse B-cell lymphoma, acute myelogenous leukemia, and acute lymphocytic leukemia) cancers, as well as adolescents and young adults (AYAs, 18–29 years) with all nonmetastatic cancer types except testes, where metastatic disease was included. These groups were most apt to be followed in community settings by primary care teams.

A total of 13,258 individuals responded to the survey, 20% of whom were AYAs.^[11] Most were breast (28%), prostate (23%), and colorectal (20%) survivors. Sixty percent were 65+ years. Similar patterns existed for the adult and for the AYA groups. The most prevalent concerns reported

by respondents were fatigue (67%) in the physical domain and anxiety/worry/fear of cancer returning (68%) in the emotional domain. Twenty-two percent reported concerns about worry regarding return to work or school.

Despite having concerns, many respondents did not seek help (ranged from 85% to 37% across concerns).^[11] When asked about the reasons for not seeking help with a concern, the most frequent reason given was, “someone told me it was normal and I didn't think anything could be done about it” (50.9% for physical, 33.7% for emotional, and 21.5% for practical). The other frequently cited reasons included, “I did not want to ask,” “I was embarrassed,” and “I did not know services were available to help me.”

For those individuals who did seek help, many reported difficulties in finding relevant assistance (ranged from 21% to 65%).^[11] Difficulties happened most frequently for psychosocial and practical concerns. Furthermore, many individuals were not able to differentiate whether their physical symptoms were because of their cancer treatment or from other chronic diseases escalating after the cancer treatment. Some thought their physical issues were simply a result of getting older.

These findings have implications for oncology nurses. Identifying cancer survivors who have concerns and assisting them to connect with relevant resources is critically important. As well, it is important to discuss expectations about survivorship and help the individual understand what might happen and make them aware that there are interventions that can assist them. They do not have to suffer on their own.

The Important Role Oncology Nurses Play in High-Quality Survivorship Care

During diagnosis and treatment, patients are focused on the immediate tasks of grasping the implications of their cancer diagnosis, making treatment decisions, getting through treatment, dealing with anxiety and all the uncertainties, and managing side effects. Despite looking forward to the end of treatment, all these demands leave little room for patients to contemplate life after cancer treatment or understand the long-term implications of cancer. In addition, the end of primary cancer treatment brings forth new challenges for many as they work to adjust to living with changes from the disease and treatment.^[12,13]

As a basis for practice, oncology nurses need to understand the experiences of cancer survivors and the substantial impacts on quality of life which can occur from issues such as fatigue, cognitive changes, lymphedema, pain, emotional distress, impact on work, and financial challenges.

Distress can emerge from living with uncertainty, finding “a new normal,” fear of recurrence, and returning to work or school. Many survivors face significant financial challenges and are more vulnerable to health-related issues than are their healthy counterparts.^[14]

Oncology nurses play an important role in preparing patients for the transition to survivorship and living life after cancer treatment (CANO/ACIO Survivorship Modules available on the CANO/ACIO website, www.cano-acio.ca). This role can include actions such as:

- Reviewing survivorship care plans with patients as they approach the end of their primary treatment
- Educating patients and family members about what to expect and what they can do to manage any late, long-term, and persistent effects and the surveillance plans
- Facilitating engagement in self-management of long-term effects
- Helping patients set appropriate expectations
- Assisting patients and their caregivers to become better equipped to navigate the primary and cancer systems, and advocate for themselves
- Coordinating care between the cancer professionals and the community care team.

Dialogue about Case Studies

After an overview of the transitions study data and the role oncology nurses can play in survivorship phase, workshop attendees were divided into groups for small group discussions lead by a member of our team. Each group reviewed a different case study that reflected a common survivor challenge: transitioning to survivorship, fear of recurrence, returning to work, and cognitive impairment [case studies in Appendix 1]. The subsequent discussions focused on the context and influencing factors in the survivor situation and how oncology nurses would assess and intervene. Information about appropriate interventions for each of the case studies is depicted in the modules (see CANO/ACIO website for access to modules).

In reporting back to the large group of workshop attendees after the case study review and small group discussions, the following insights were shared.

Patterns and insights regarding survivorship care around the world

Dealing with the aftermath of cancer can be likened to dealing with posttraumatic stress for some individuals; there is little understanding about survivor needs or available resources to support survivors in many countries; often, there is little information available about survivor experiences; social media is gaining in potential both for

harm and for offering ways to support survivors; in many settings, community-based advocacy groups are supporting survivors.

Diversity in perspectives about survivors and oncology nurses

The focus on survivorship varies around the world; high-resource countries have a more concerted focus on survivorship, whereas middle-to-low-resource countries are focusing more heavily on the development of palliative care programs (many cancers are diagnosed late and facilities for treatment can be scarce); resources for survivorship and survivorship care models are diverse; some cancer teams follow survivors in the cancer centers while others transition survivors back to primary care settings; nurses are not often able to access programs about cancer nursing care; very few opportunities exist to learn about cancer survivorship for nurses; in some countries, financial issues are a real concern as patients are responsible for paying for their own treatments.

Collective discoveries

When working with survivors, it is important to assess the full context including the family situation; providing information and support about survivorship is clearly a nursing role but can be challenging if there is no education about it for the nurses themselves; there is a need to support family caregivers as well as the survivors.

Survivorship Self-learning Resource for Nurses

The CANO/ACIO recently revised a self-learning resource for oncology nurses regarding survivorship. The resource is a revision of a 2011 resource and includes current evidence regarding cancer survivorship [table of contents in Appendix 1]. In addition to covering evidence for practice regarding physical, emotional, and practical concerns held by survivors, new material has been added on the care of AYAs and older adults with cancer. The 12 modules in this resource are available from the CANO/ACIO website for free to CANO/ACIO members. Workshop participants were offered access to these modules for free. Otherwise, the modules can be accessed by all for a limited fee or free for nurses in low-to-middle-income countries.

Discussion

Lessons learned and recommendations

The workshop was offered through a virtual platform and provided the opportunity to engage with colleagues in various parts of the world. In turn, this approach facilitated

learning about survivorship issues in various countries and understanding more about the variation which currently exists for this phase of cancer care. The participants engaged actively in the small group breakout room discussions leveraging ideas from each other's experiences. Although capacity and knowledge of survivorship care varied across participants, a common thread was recognizing the need for broad access to more oncology-specific education for nurses who care for cancer patients regardless of the phase of their cancer trajectory. Although the transitions study and the survivorship modules originated in the Canadian context, there was agreement about the value added internationally by such digital learning resources.

Overall, the session ran smoothly and there was opportunity for visual and vocal interaction by participants. The virtual nature of the workshop highlighted the incredible opportunity to offer high-quality live interactive learning opportunities across international boundaries, which holds the potential to transform access to such learning activities in low- and middle-income countries. Although this workshop was offered virtually due to the global coronavirus disease 2019 (COVID-19) pandemic, the success of this international interactive workshop could be used to develop other virtual oncology nursing education opportunities that span international borders.

Conclusions

The survivor cadre is growing, albeit at different rates in different parts of the world. Oncology nurses are in ideal positions to assist individuals who have undergone cancer treatment to prepare for and transition successfully to the survivorship phase of their cancer journey. To engage in supporting cancer survivors, nurses themselves would benefit from opportunities to learn more about the survivorship experience and its implication on the long-term quality of life of cancer survivors. In addition, nurses would be best served to learn more on best available evidence to guide their practice in providing long-term surveillance and health maintenance throughout the continuum of cancer care with survivors.

Financial support and sponsorship

Nil.

Conflicts of interest

All authors were workshop leaders and were all involved in writing portions of the self-learning resource for

survivorship introduced during workshop; the resource is an education product of the CANO/ACIO. The corresponding author, Prof. Margaret I Fitch, is the editorial board member of the journal.

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Appendix

Appendix 1: Case studies utilized at workshop (see Canadian Association of Nurses in Oncology website for access to the learning modules and information about interventions for these types of situations)

Transitioning to survivorship

Kim is a 46-year-old patient with right breast cancer, Stage 2, T2N1M0, invasive ductal carcinoma, 3/10 lymph nodes positive, ER and PR positive, and HER2 negative. She underwent a right lumpectomy and axillary node dissection and completed 6 cycles of FEC-D chemotherapy and 25 fractions of radiation. She started tamoxifen 3 months ago and presents in your follow-up clinic today. The plan for hormonal therapy is to complete 5 years of tamoxifen and to consider extended therapy afterward. She had a routine mammogram this morning. She is married with a 10-year-old daughter. She works as a sales representative in a retail clothing store and is currently on disability leave. You met Kim before and know that her sister who lives in a different country has been also recently diagnosed with breast cancer and their mother died of endometrial cancer 5 years ago. Due to volume in your facility, the operational leadership is encouraging clinical teams to consider transitioning low-risk breast cancer patients back to their family physician for follow-up care, and your team had identified Kim as a patient who may be appropriate for transition back to primary care.

You see Kim today in clinic and you noticed on her ESASr form that she rated fatigue 7/10, anxiety 8/10, depression 5/10, and well-being 6/10. The rest of the scores are noncontributory or equal or below scoring of 3. On the Canadian problem checklist, she indicated concerns about work/school, fears/worries, frustration/anger, feeling a burden to others, worry about family/friends, understanding illness and treatment, talking with the health care team, knowing about available resources, and concentration/memory.

Fear of recurrence

Mr. Charles is a 70-year-old man who completed treatment for prostate cancer 5 years ago. His oncology team believes that he has a low risk of recurrence, therefore he is being transferred from tertiary care to primary care. During his meeting with the oncology nurse, to discuss transfer of care, he was highly anxious and pleaded to continue seeing his oncologist regularly. Mr. C believes that his cancer is dormant and could return at any time, therefore he believes it is essential to remain on guard to catch it quickly for when the cancer returns. Mr. C lost his wife to cancer 10 years ago and he is worried that his adult children will lose another parent to cancer.

Mrs. Duff is a 34-year-old woman who completed her breast cancer treatment 2 years ago. She reported feeling shocked when diagnosed given her young age. Mrs. Duff wanted to focus on her career and then have children with her husband but found herself unable to fulfill her plans given her cancer treatment. Mrs. Duff hopes to move on from her cancer experience but feels unable to plan her future because cancer could always come back. Mrs. Duff reported having weekly panic attacks when thinking about cancer. She has since been avoiding going to her physician's office because she is worried that it will remind her of cancer, she will lose control, and have another panic attack. Mrs. Duff does not allow herself to think about cancer, as soon as the thought pops up, she distracts herself using social media.

Return to work

Sally has completed surgery, radiation, and chemotherapy for breast cancer 6 months ago. She previously worked as a clerk in an office. She has been off work for 18 months and is receiving long-term disability benefits. She reports her greatest concern is returning to her work because she has lymphedema which causes her arm to swell up making extensive keyboarding difficult. She reports that her work is stressful particularly related to multitasking and that she is accountable to many staff members. She is fearful that stress is not good for her health. As well, she is having some difficulty sleeping and thus feels tired. She shares feeling exhausted after doing simple housework like preparing dinner. She is unsure about her ability to work and her readiness to return to work. She works for a large company and has been informed that her job is available to her for now.

Cognitive impairment

Ms. Reid is an 81-year-old woman who comes for a follow-up visit. You have been following her for the last 18 months, beginning at the time of her diagnosis of Stage III ovarian cancer, followed by neoadjuvant chemotherapy, robotic surgery, and adjuvant chemotherapy. She has a history of a remote early-stage breast cancer and treated hypertension.

You know her to be an active and independent woman who emigrated from Austria 35 years ago. She is divorced with no children. She has a university education. While her social circle has become progressively smaller since her retirement a decade ago, she has kept socially active by volunteering and by chatting with acquaintances. Throughout treatment, she made friends with other cancer patients in waiting rooms and support groups.

During these months, you have seen her face various challenges. She was independent in her ADLs prior to starting treatment, but during therapy, she reluctantly began to rely on support services for the first time in her life: transportation help, delivered meals, and cleaning services. Throughout treatment, she 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 completed her last cycle of chemotherapy 4 months ago. When you greet her at the beginning of the appointment, she describes that she experiences fatigue but has noticed that it is improving. Ms. R's memory is also "not what it used to be," but she does not feel the same fog she had during chemotherapy, except on days she is more tired. Ms. R describes that she was able to return to volunteering now that her immune system has improved after chemotherapy, although she only does two hours at a time now, whereas she used to volunteer for longer shifts.

ER: Estrogen receptor, PR: Progesterone receptor, HER2: Human epidermal growth factor receptor 2, FEC-D: Fluorouracil epirubicin cyclophosphamide-docetaxel, ESASr: Edmonton Symptom Assessment System-revised, ADL: Activities of daily living

CANO/ACIO Adult Cancer Survivorship Modules – A self-learning resource for nurses (can be found at <https://www.cano-acio.ca>)