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Integrating primary care providers through the seasons of survivorship

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ABSTRACT

Traditionally, the role of primary care providers (PCPs) across the cancer care trajectory has focused on prevention and early detection. In combination with screening initiatives, new and evolving treatment approaches have contributed to significant improvements in survival in a number of cancer types. For Canadian cancer survivors, the 5-year survival rate is now better than it was a decade ago, and the survivor population is expected to reach 2 million by 2031. Notwithstanding those improvements, many cancer survivors experience late and long-term effects, and comorbid conditions have been noted to be increasing in prevalence for this vulnerable population. In view of those observations, and considering the anticipated shortage of oncology providers, increasing reliance is being placed on the primary care workforce for the provision of survivorship care. Despite the willingness of PCPs to engage in that role, further substantial efforts to elucidate the landscape of high-quality, sustainable, and comprehensive survivorship care delivery within primary care are required.

The present article offers an overview of the integration of PCPs into survivorship care provision. More specifically, it outlines known barriers and potential solutions in five categories:

- Survivorship care coordination
- Knowledge of survivorship
- PCP-led clinical environments
- Models of survivorship care
- Health policy and organizational advocacy

Key Words Survivorship, primary care providers, education

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INTRODUCTION

Traditionally, the role of primary care providers (PCPs) across the cancer care trajectory has focused predominantly on prevention and early detection[1]. New treatment modalities have contributed to impressive achievements in oncology: the 5-year survival rate for cancer survivors is now better than it was a decade ago, and the survivor population is expected to reach 2 million by 2031[2]. Notwithstanding those triumphs, many cancer survivors experience distressing aftereffects[3], and comorbid conditions are increasing in the survivor population[4]. In view of those observations, and considering the anticipated shortage of oncology providers[5], reliance is increasingly being placed on PCPs for survivorship care provision[6]. However, further efforts to elucidate the landscape of high-quality, sustainable, and comprehensive survivorship care delivery within primary care are required[7,8].

The present article offers an overview of the integration of PCPs into survivorship care provision. More specifically, it outlines known barriers and potential solutions in five categories:

- Survivorship care coordination
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- Health policy and organizational advocacy

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BARRIERS AND POTENTIAL SOLUTIONS

Survivorship Care Coordination

In the first decade of the 2000s, the U.S. Institute of Medicine's *Lost in Transition* report promoted the value of PCPs in the delivery of comprehensive follow-up care to cancer survivors and recommended the provision of survivorship care plans (SCPs) to the primary care workforce for patients who had reached treatment completion[9]. To date, deficits in survivorship care coordination remain unresolved, including suboptimal communication between oncology providers and PCPs[10] and poorly defined PCP roles in survivorship care delivery[11]. Moreover, current evidence appears divided on the question of whether SCPs are beneficial to PCPs[12].

With respect to communication, evidence has revealed mutual communication gaps between oncology providers and PCPs[13]. Those communication issues might be influenced in part by organizational culture, institutional practice preferences, financial incentives, and availability of management support[14]. Communication issues can also arise because of poor role definition for PCPs in cancer care[1,11]. In a study from Easley *et al.*[11], health care providers were asked to describe what the role of PCPs in cancer care provision should be. Respondents—including PCPs, surgeons, medical and radiation oncologists, and general practitioners in oncology (GPOs)—described that role as "quarterback" or team leader responsible for cancer care coordination, provision of psychosocial support, and management of comorbid conditions, which differed greatly from the actual PCP role. Expectations concerning the survivorship care provider role also differ between patients, PCPs, and oncologists[1]. Thus, further research exploration is warranted to better define the roles taken by PCPs in survivorship.

Lastly, PCPs appear to value SCPs, indicating their usefulness in providing information about cancer regimens, late and long-term effects, and follow-up care recommendations. The SCP is also viewed as a helpful tool to improve care coordination with the oncology workforce[15,16]. Notwithstanding those benefits, concerns about cost-effectiveness and resource limitations have been described as barriers to SCP implementation[17]. Perhaps of even greater importance, current evidence to demonstrate that SCPs improve the survivorship care delivered by PCPs and the health outcomes of cancer survivors is lacking[18]. Future work in this area should go beyond the aim of providing SCPs to PCPs and should focus on the identification of actionable cancer follow-up information that can be readily integrated into primary care practice, which might in turn lead to improved patient outcomes[19].

Knowledge of Survivorship

Previous studies have shown that PCPs follow patients during active treatment as well as after treatment completion[7,20]. Ensuring that PCPs have core competencies in survivorship, which in part comprise surveillance for recurrence, screening, management of late and long-term effects, and health promotion interventions, cannot be overstated[21] (Table I). However, PCPs are often unaware of the specific concerns and surveillance needs of cancer survivors[22,23]. Moreover, previous studies suggest that PCPs have low levels of confidence about survivorship care provision, reporting lack of knowledge as a key factor[23–26]. Educating the primary care workforce about survivorship should therefore take upmost precedence[6].

In recent years, commendable initiatives have been developed to make survivorship training and educational resources available to PCPs. Online platforms such as British Columbia's Family Practice Oncology Network (http://www.bccancer.bc.ca/health-professionals/networks/family-practice-oncology-network), which houses information about online and in-person training opportunities and resources, could serve as an excellent source for PCPs. Other examples of useful online resources include those from Cancer Care Ontario (https://archive.cancercare.on.ca/toolbox/qualityguidelines/clin-program/survivorship) and CancerCare Manitoba (https://www.cancercare.mb.ca/For-Health-Professionals/follow-up-care-resources), which host repositories of select survivorship care recommendations. Nonetheless, current resources remain sparse, and further implementation of survivorship education at the postgraduate and continuing medical education levels is critical[6].

Programs should put emphasis on describing the key providers involved in survivorship care delivery and foster a culture of collaboration through educational interspecialty offerings. Interspecialty education, which can improve communication and collaboration between providers, benefiting patient safety, cost of care, and resource management, could help to close care coordination gaps between oncologists and PCPs[27,28]. An innovative example is Moving Forward After Cancer: A Learning Suite for Family Medicine and Oncology Postgraduate Trainees (https://www.cpd-umanitoba.com/courses/moving-forward-after-cancer), designed to communicate, to an audience of postgraduate family medicine and oncology trainees, best practices in the transition of cancer patients to primary care. Other selected educational resources are listed in Table II.

Universities and professional associations across Canada should partner to develop and disseminate standardized evidence-based survivorship education programs. Those activities should be integrated into residency curricula and continuing medical education activities for PCPs in active practice. Lastly, in addition to providing expert survivorship content, the proposed programs should be embedded into established social cognitive frameworks that promote tangible changes in the clinical behaviours of PCPs, which might lead to enhanced survivorship care delivery[29].

PCP-Led Clinical Environments

Several factors have been reported as hindrances to the provision by PCPs of comprehensive care to cancer survivors. First, on treatment completion, PCPs report inadequate receipt of information from oncology providers[7,8]. Second, the primary care workforce values provision of survivorship guidelines to steer their care[30]. Considerable progress has been made in developing survivorship guidelines for PCPs, such as those for breast[31], colorectal[32], prostate[33], and head-and-neck cancers[34]. Although being exhaustive in survivorship information that was not readily available

TABLE I Core competencies[a]

Topic	Competencies
Survivorship	■ Demonstrate how to obtain a cancer and cancer treatment history and how to interpret the health implications of that history. ■ Differentiate the common uses of the terms personal cure, disease-free survival, overall survival, survivorship, and cancer survivor, and how they affect clinical approaches and policymaking. ■ Identify incidence and prevalence of cancer survivorship overall and differences by age and sex.
Surveillance	■ Understand the risk of new primary cancers and local or metastatic recurrences, and the temporal pattern of recurrences of specific primary cancers. ■ Be aware of available surveillance methods (for example, history and physical examination; imaging studies; bloodwork, including tumour markers) and if applicable, the sensitivity and specificity in detecting recurrences and their cost-effectiveness. ■ Be familiar with data about the effect of surveillance and early detection of recurrences on overall survival. ■ Recognize treatment options and their effectiveness in the event of a new primary cancer and local or metastatic recurrences.
Long-term and late effects	■ Be aware of potential consequences of cancer treatment in various age groups, to include the effects on cardiopulmonary, skeletal, gastrointestinal, respiratory, and endocrine systems, and sexual function and fertility. ■ Appropriately assess cancer survivors for late and long-term effects of treatment, to include surgery, radiation, chemotherapy, hormonal treatments, immunotherapy, and targeted therapies. ■ Assess the interplay between late and long-term effects and other comorbid medical conditions. ■ Be aware of best practices in symptom management and rehabilitation.
Health promotion and disease prevention	■ Demonstrate knowledge that cancer survivors are at increased risk for comorbid health conditions. ■ Be able to screen, counsel, and provide referrals to programs for smoking cessation, weight management, physical activity, sexual rehabilitation, and other lifestyle habits. ■ Encourage cancer survivors to establish a relationship with a primary care provider to receive age- and risk-based screening and non-cancer disease management.
Psychosocial care	■ Be aware of the psychological, social, economic, and spiritual impacts of cancer and its treatments in various age groups. ■ Be able to identify problems in psychosocial well-being in the post-treatment period. ■ Be able to evaluate the contributions of disease and treatment features to problems in psychosocial well-being. ■ Be aware of best practices in the psychosocial care of cancer survivors, and be able to make appropriate referrals.
Childhood and adolescent-and-young-adult (AYA) cancer survivors	■ Recognize that childhood and AYA cancer survivors are a growing population with significant rates of premature mortality, chronic morbidities, and second malignant neoplasms. ■ Be aware of the recommendations from the U.S. Institute of Medicine about risk-based follow-up care for all survivors of childhood and AYA cancer. ■ Be familiar with the long-term surveillance guidelines based on exposures from the U.S. Children's Oncology Group. ■ Be able to provide childhood and AYA cancer survivors with appropriate risk-based care. ■ Recognize that requests for, and use and discussion of, cancer survivorship care plans with survivors can facilitate the delivery of evidence-based or best-practice follow-up care.
Older adult cancer survivors	■ Understand the demographics of cancer survivorship and aging, with the recognition that most cancer survivors are older adults. ■ Recognize the anticipated workforce shortage to care for the growing number of older cancer survivors, and the need for geriatric competence embedded in all disciplines of health care. ■ Understand that care of the older cancer survivor is driven by a patient-centred approach guided by the patient's functional rather than chronologic age and taking into account their values and preferences. ■ Consider that the increasing association of aging with poverty and social isolation requires unique approaches in terms of assistance, transportation, navigation, and other means to deliver proper cancer and survivorship care.
Caregivers of cancer survivors	■ Recognize that most survivors receive important care and support from informal caregivers. Those individuals, commonly family members, are often key to the optimal health and well-being of the survivor. ■ Be aware that informal cancer caregivers are at risk for depression and caregiving burden. Furthermore, because most cancer survivors are older adults, their caregivers could also be older and have their own health problems. ■ Recognize the importance of acknowledging the role of and providing support to caregivers through appropriate mental health referrals and use of programs to help them to manage caregiver burden as needed.
Communication and coordination of care	■ Understand and recognize various care models for delivery and coordination of post-treatment care of survivors. ■ Be able to provide a facilitated transition from oncology to primary care, coordinated shared care, and advance care planning that includes a patient-centred discussion and written documentation. ■ Communicate with other health care professionals to facilitate coordination of care among providers.

TABLE II Selected education resources and tools for primary care providers (PCPs)

Canadian Association of General Practitioners in Oncology (CAGPO)
■ CAGPO holds an annual conference that covers the latest oncology care topics and cancer-related symptom management overviews. Speakers include general practitioners in oncology (GPOs), medical and radiation oncologists, hematologists, and PCPs. Web site: http://www.cagpo.ca
■ CAGPO also offers a self-directed learning program comprising a series of cancer cases targeting PCPs and GPOs. Web site: http://cagpo.ca/cases
Cancer Care Ontario (CCO)
■ Online resource offering a cancer survivorship evidence-based series developed by experts selected by CCO and in partnership with the Program in Evidence-Based Care. Web site: https://archive.cancercare.on.ca/toolbox/qualityguidelines/clin-program/survivorship/
BC Cancer
■ Online resource dedicated to empowering PCPs to care for cancer patients through resource provision and education. Web site: http://www.bccancer.bc.ca/health-professionals/networks/family-practice-oncology-network
CancerCare Manitoba
■ Online resource providing care guidelines by disease site group and referral forms for cancer care (within Manitoba). Web site: https://www.cancercare.mb.ca/For-Health-Professionals/referral-guidelines-for-physicians
Foundation for Medical Practice Education and McMaster University collaboration
■ Offers Practice Based Small Group (PBSG) Learning Program designed to promote reflective practice in PCPs. Selected PBSG modules are specifically dedicated to cancer care. Web site: https://www.fmpe.org/en/programs/practice-based-small-group-pbsg-learning-program
American Society of Clinical Oncology (ASCO)
■ ASCO's online introductory course offers an overview of best practices and relevant topics pertaining to survivorship care. Web site: https://university.asco.org/survivorship-program
■ ASCO also hosts a repository of tools and resources entitled *The Survivorship Care Compendium* to support providers in their delivery of survivorship care. Web site: https://www.asco.org/practice-guidelines/cancer-care-initiatives/prevention-survivorship/survivorship/survivorship-compendium
Cancer Survivorship E-Learning Series
■ Online resource offering a series of survivorship educational modules. Modules include presentations by physicians, experts, and cancer survivors. Web site: http://cancersurvivorshipcentereducation.org
UpToDate
■ Online resource providing summarized content of evidence-based survivorship care recommendations developed by experts. Content can be found using "cancer survivorship" key words in search bar. Web site: https://www.uptodate.com/contents/search

[a] Reprinted from Shapiro *et al.*[21], with permission.

prior, many of the guideline recommendations are not currently supported by strong evidence[6]. Similarly, given the rapid advances in the field of oncology, the long-term sequelae of newer cancer agents are currently unknown[35]. Third, a recent study published by Rubinstein *et al.* suggests that the absence of cancer survivorship as a distinct clinical category (comparable to diabetes and chronic obstructive pulmonary disease) might be a barrier to the provision of comprehensive survivorship care in primary care settings. In the absence of such recognition, survivorship care remains poorly defined, likely contributing to the lack of actionable care strategies and follow-up algorithms geared to PCPs for the optimal follow-up of cancer survivors[19]. Lastly, current health information systems might not be adequately suited to the implementation of population-level survivorship interventions[19]. Further measures to identify actionable interventions in survivorship care should therefore be prioritized and serve to inform the provision of care to cancer survivors. Additionally, together with identification of actionable interventions, endorsement of survivorship as a distinct category and optimization of current information systems might facilitate the implementation of high-quality survivorship provision by the primary care workforce[19].

Models of Survivorship Care

Since about 2010 or so, numerous models for the provision of survivorship care have been developed[36], including risk-stratification and chronic care models, to name a few. In risk-stratification models, a shared-care approach between oncology and primary care is adopted based on patients having been categorized into low-, moderate-, or high-risk categories[37]. Chronic care models for survivorship delivery draw from previously described care models for chronic diseases such as congestive heart failure and diabetes[38], which promote self-management interventions. Despite the significant work accomplished to create and evaluate the implementation of those various models, evidence about their effectiveness is scant[35]. No universal model of survivorship care exists, because such care must

be adapted to targeted survivors, the local context, and available resources. Nonetheless, existing models for survivorship share one commonality: they include primary care professionals as key providers of survivorship care, reinforcing the importance of strategic interventions to optimize the integration of PCPs into the follow-up care of cancer survivors (Figure 1).

Many cancer survivors also have common comorbid conditions alongside specific physical and psychosocial needs such as pain, peripheral neuropathy, lymphedema, social role disruption, and fear of recurrence, among others. Comprehensive survivorship care could be optimally provided using an interdisciplinary primary care team approach comprising social services, psychology, nutrition, and other allied health professionals. Interdisciplinary teams are being increasingly relied on for the delivery of primary care[39]. An interdisciplinary primary care team approach might be favoured by patients and providers[40,41], could help to improve health outcomes and management of chronic diseases[42,43], and might enhance quality of care and resource use while lessening care fragmentation[40]. Moreover, the inclusion of GPOs, also called onco-generalists, in interdisciplinary primary care teams could help to broaden the receptivity of oncologists for transitioning patients to primary care and optimize collaborations between involved providers[6]. The GPOs might also serve as survivorship expert resources to PCPs, contributing to survivorship knowledge enhancement for interdisciplinary primary care teams by actively participating in teaching activities[6].

Health Policy and Organizational Advocacy

Key actions from policymakers and advocacy stakeholders are required to support the integration of PCPs into survivorship care delivery. First, health-governing agencies must invest in awareness campaigns promoting the value of PCPs in survivorship care provision at the population level. Although cancer survivors identify the PCP as one of their survivorship providers (namely, for help with fear of recurrence and adjustment to their "new normal" after treatment[44,45]), their confidence in the competency of the PCP to provide cancer-specific follow-up care appears low[46]. Moreover, given that follow-up care was traditionally entrusted to oncology specialists, some cancer survivors might be unaware of PCP contributions to survivorship care delivery[46]. A better understanding by cancer survivors of the PCP's expected role might bolster the integration of these important providers into survivorship care provision.

Second, given that PCPs report the value of guidelines as tools in survivorship care provision[7], optimization of current guidelines to reflect high-quality evidence-based interventions in the primary care setting are warranted[6]. Endorsement of survivorship as a distinct clinical category, together with utilization of data from electronic medical records, could aid in such guideline optimization. It could also facilitate the creation of electronic medical record–based decision aids and reminders to guide PCPs and promote a comprehensive approach to cancer survivors, which is particularly important for survivors presenting with comorbid conditions[19]. Additionally, a statement of financial compensation to PCPs for survivorship care provision, as for other interventions performed throughout the cancer continuum (such as screening for cancers), could give much-needed recognition and visibility to survivorship care within primary care settings[19].

Finally, advocacy for research funding to pursue rigorous evaluation of survivorship care models that go beyond quality-of-care outcomes to include assessment of program structure; access to psychosocial, fertility, and rehabilitation services; and cost analysis outcomes are compulsory to elucidate programs capable of providing comprehensive high-quality survivorship care that is resource-effective and financially sustainable[47]. All the foregoing actions are of paramount importance to optimize PCP-led survivorship care delivery[19].

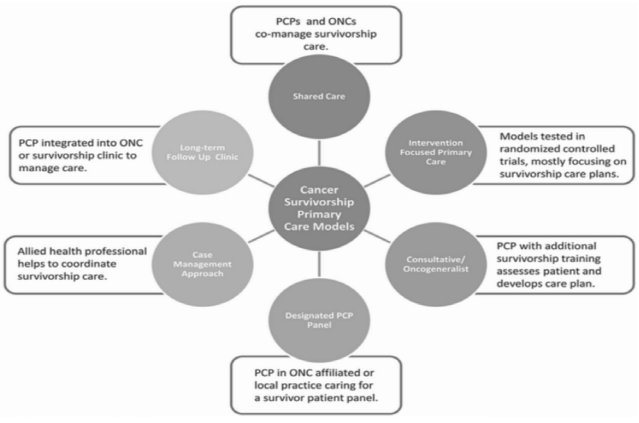

FIGURE 1 Models of care. Reproduced from Nekhlyudov *et al.*[6], with permission of Lancet Publishing Group in the format journal or magazine via Copyright Clearance Center. PCP = primary care provider; ONC = oncologist.

SUMMARY

Primary care providers play a key role in the care of cancer survivors. Despite significant advances, further extensive work is required to pave the road toward optimal integration of the primary care workforce into survivorship care delivery. Pressing investments from academic institutions and professional associations to create and disseminate standardized survivorship education across Canada are warranted. Recognition of survivorship as a distinct clinical category by policymakers and key stakeholders is compulsory: such validation will ultimately ensure the establishment of high-quality and sustainable survivorship care delivery in primary care.

Key Points

- Primary care providers are key players in survivorship care delivery.
- The development of evidenced-based survivorship education programs is a priority agenda item for the optimal care of cancer survivors.
- The endorsement of survivorship as a distinct clinical category by policymakers is critical to the establishment of high-quality and sustainable survivorship care provision by the primary care workforce.

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CONFLICT OF INTEREST DISCLOSURES
We have read and understood *Current Oncology*'s policy on disclosing conflicts of interest, and we declare that we have none.

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