

Rapid Synthesis

Identifying Educational Approaches and Resources to Support Seamless Transitions Between Cancer Programs and Primary Care

27 January 2021



HEALTH FORUM

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Rapid Synthesis:
Identifying Educational Approaches and Resources to Support Seamless Transitions Between
Cancer Programs and Primary Care
60-day response

27 January 2021

*Identifying Educational Approaches and Resources to Support Seamless Transitions
Between Cancer Programs and Primary Care*

McMaster Health Forum

The McMaster Health Forum's goal is to generate action on the pressing health-system issues of our time, based on the best available research evidence and systematically elicited citizen values and stakeholder insights. We aim to strengthen health systems – locally, nationally, and internationally – and get the right programs, services and drugs to the people who need them.

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Timeline

Rapid syntheses can be requested in a three-, 10-, 30-, 60- or 90-business-day timeframe. This synthesis was prepared over a 60-business-day timeframe. An overview of what can be provided and what cannot be provided in each of the different timelines is provided on McMaster Health Forum's Rapid Response program webpage (www.mcmasterforum.org/find-evidence/rapid-response).

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Conflict of interest

The authors declare that they have no professional or commercial interests relevant to the rapid synthesis. The funder played no role in the identification, selection, assessment, synthesis or presentation of the research evidence profiled in the rapid synthesis.

Merit review

The rapid synthesis was reviewed by a small number of policymakers, stakeholders and researchers in order to ensure its scientific rigour and system relevance.

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KEY MESSAGES

Questions

- What cancer-survivorship educational approaches and resources for primary-care providers and for patients, caregivers and their families support seamless transitions between cancer programs and primary care to enable high-quality, long-term survivorship care closer to home (e.g., integration of cancer into chronic-disease management resources and long-term survivorship care)?
- What cancer-survivorship educational content and resources are available in Canadian provincial and territorial health systems?

Why the issue is important

- There has been a rise in cancer diagnoses with an estimated 225,800 new cancer cases in 2020, in addition to an increased five-year net survival rate of any type of cancer in Canada.
- The number of people living with cancer or transitioning out of the cancer system into survivorship care will continue to increase.
- In follow-up care, survivors require supports for symptom management, psychosocial needs, lifestyle behaviour changes, and various physical and practical functional challenges.
- It is important to identify existing educational content and resources for primary-care providers and for patients and their families/caregivers to inform and guide expectations surrounding the transition to survivorship, facilitate effective communication and cooperation, and improve planning to reduce barriers and unmet needs for all stakeholders involved.

What we found

- We conducted a synthesis of research evidence that describes transition supports and approaches from cancer care to primary care for survivors, caregivers and their families, as well as a system analysis of Canadian provincial and territorial health systems about key features of cancer-survivorship educational content and resources.
- For the synthesis of research evidence, we identified 44 systematic reviews, in addition to 19 primary studies that provide insights about the questions in relation to the Canadian context, where we identified seven types of educational approaches or resources to support cancer transitions: 1) communication strategies; 2) skills training; 3) system-navigation supports; 4) self-management supports; 5) electronic and mobile health technologies; 6) multifaceted transition interventions; and 7) care models that include transition supports.
- While there is limited evidence on the effectiveness of approaches to support seamless transitions, key themes emerged in the literature when describing how the seven approaches can support care transitions, such as: 1) improving communication and information flow; 2) increasing patient and healthcare-provider capacity; and 3) improving coordination and health-systems navigation.
- Specific to enabling high-quality, long-term survivorship care closer to home, knowledge-related barriers, communication, and coordination continue to hinder primary-care providers in delivering effective survivorship care.
- When identifying and considering educational approaches to enable high-quality, long-term survivorship care closer to home, three key aspects emerged from the literature: 1) the different structures and efficacy of survivorship-care models; 2) communication strategies to eliminate patient-provider barriers; and 3) self-management strategies to build survivors' capacity to overcome challenges.
- We identified cancer-survivorship educational content and resources that are available in Canadian provincial and territorial health systems, such as key features of programs that are designed to meet a variety of needs for patients and their caregivers/families (in general and for specific patient populations), and for primary-care providers.
- All of the provinces and most of the territories had information on educational content and resources related to survivorship for patients, families and primary-care providers in various formats (e.g., online and/or in-person programs and workshops, online evidence-based tools and websites) with some distinguishing differences in cancer survivorship and cancer care transition programs.

QUESTIONS

- 1) What cancer-survivorship educational approaches and resources for primary-care providers and for patients, caregivers and their families support seamless transitions between cancer programs and primary care to enable high-quality, long-term survivorship care closer to home (e.g., integration of cancer into chronic-disease management resources and long-term survivorship care)?
- 2) What cancer-survivorship educational content and resources are available in Canadian provincial and territorial health systems?

WHY THE ISSUE IS IMPORTANT

The number of new cancer cases has continued to rise across Canada, with an estimated 225,800 new cancer cases and approximately 83,300 cancer deaths in 2020.(1) It is estimated that nearly one in two Canadians will develop some form of cancer over their lifetimes.(2) The burden that increased cancer prevalence has placed on health systems in Canada has been compounded by the growing aging population, and by improvements in cancer-treatment efficacy. Canada has experienced a demographic shift wherein there are now more persons aged 65 years and older than children under 15, and projections estimate that the 65 years and older age group will more than double, from 4.2 million in 2003-2007, to 9.4 million in 2028-2032.(3) The incidence of cancer increases with age; the majority (90%) of cancer diagnoses in Canada occur among those who are over the age of 50.(2) Additionally, advances in cancer detection and treatment have significantly improved the likelihood of cancer survival. The average five-year net survival rate for people diagnosed with any type of cancer in Canada is 63%.(2) All of these factors suggest that the number of people living with cancer or transitioning out of the cancer system into survivorship care will continue to increase.

In supporting the growing number of individuals transitioning to survivorship care, there is a need to improve the coordination between cancer care and the primary- and community-care sectors. In many jurisdictions across Canada, the provision of cancer services operates using a parallel cancer sub-system, which has limited overlap or integration with primary and community care.(4) The fragmented nature of this care transition is not sustainable and creates numerous challenges for both patients and primary-care providers.(5)

For patients, the skewed balance toward disease treatment within many cancer sub-systems often means that many individuals will transition back into the broader health system without accessing the full range of necessary supports.(6) The transition in care following treatment into survivorship requires survivors and their families to adjust how they interact with the healthcare system. Often, patients are not prepared for what to expect when treatment is over, and the abrupt end to frequent contact with their care team can lead to

Box 1: Background to the rapid synthesis

This rapid synthesis mobilizes both global and local research evidence about a question submitted to the McMaster Health Forum's Rapid Response program. Whenever possible, the rapid synthesis summarizes research evidence drawn from systematic reviews of the research literature and occasionally from single research studies. A systematic review is a summary of studies addressing a clearly formulated question that uses systematic and explicit methods to identify, select and appraise research studies, and to synthesize data from the included studies. The rapid synthesis does not contain recommendations, which would have required the authors to make judgments based on their personal values and preferences.

Rapid syntheses can be requested in a three-, 10-, 30-, 60- or 90-business-day timeframe. An overview of what can be provided and what cannot be provided in each of these timelines is provided on the McMaster Health Forum's Rapid Response program webpage (www.mcmasterforum.org/find-evidence/rapid-response).

This rapid synthesis was prepared over a 60-business-day timeframe and involved four steps:

- 1) submission of a question from a policymaker or stakeholder (in this case, the Canadian Partnership Against Cancer);
- 2) identifying, selecting, appraising and synthesizing relevant research evidence about the question;
- 3) drafting the rapid synthesis in such a way as to present concisely and in accessible language the research evidence; and
- 4) finalizing the rapid synthesis based on the input of at least two merit reviewers.

feelings of anxiety and abandonment (e.g., fear that they are not being cared for or are receiving suboptimal care).(5) Survivors and their families can also experience confusion surrounding which health systems or services to access for which problems, and at what times.(5) Additionally, there is a discrepancy between what individuals need following cancer treatment and what primary- and community-care services currently provide.(7) In follow-up care, survivors require supports for symptom management, psychosocial needs, lifestyle behaviour changes, and various physical and practical functional challenges.(5; 7-11) These needs are not always effectively accounted for. For primary-care providers, challenges in providing optimal transitional and survivorship care stem from poor coordination and communication across providers (including poor information flow),(5; 8) a lack of speciality training in how to provide effective and person-centred follow-up care,(12) and a lack of clarity about roles and responsibilities (e.g., in the management of late/long-term side effects).(5; 8; 12)

Additional supports are required to meet the needs of cancer survivors in this transition, as well as to enhance the capacity of primary- and community-care sectors in providing optimal care during and beyond the care transition. It is important to identify existing educational content and resources for primary-care providers and for patients and their families/caregivers to inform and guide expectations surrounding the transition to survivorship, facilitate effective communication and cooperation, and improve planning to reduce barriers and unmet needs for all stakeholders involved.

WHAT WE FOUND

We conducted a synthesis of the evidence that we identified from our searches in Box 2 to inform question 1. In reviewing evidence in relation to question 1, we sought to include documents that provide evidence that supports transitions from cancer care to primary care for survivors, caregivers and their families. Within this scope, we included resources that support shared-care approaches between cancer care and primary care for cancer survivors. For question 2, we conducted a system analysis by hand searching government and stakeholder websites in Canadian provincial and territorial health systems for documents that describe features of cancer-survivorship educational content and resources. Our findings for each question are presented below.

Question 1 - What cancer-survivorship educational approaches and resources for primary-care providers and for patients, caregivers and their families support seamless transitions between cancer programs and primary care to enable high-quality, long-term survivorship care closer to home (e.g., integration of cancer into chronic-disease management resources and long-term survivorship care)?

We identified 45 systematic reviews, of which 14 are of high methodological quality,(9; 13-25) 26 are medium quality (12; 26-50) and five are low quality.(51-55) We also identified 19 primary studies that provide insights about the question in relation to the Canadian context.(10-11; 56-72)

We summarize the key findings from these documents in Table 1 according to the following seven types of educational approaches or resources to support transitions that were identified in the literature:

- 1) communication strategies;
- 2) skills training;
- 3) system-navigation supports;
- 4) self-management supports;
- 5) electronic and mobile health technologies;
- 6) multifaceted transition interventions; and
- 7) care models that include transition supports.

In addition, we summarize the key findings from Table 1 in relation to information specific to transitions and to survivorship, and highlight themes in each of these areas across the seven areas highlighted above.

Box 2: Identification, selection and synthesis of research evidence

We identified research evidence (systematic reviews and primary studies) by searching Health Systems Evidence (in November 2020) (www.healthsystemsevidence.org) and PubMed (in December 2020). In Health Systems Evidence, we searched for transition in the open search combined with search filters for disease type (cancer) and type of document (overviews of systematic reviews, systematic reviews of effects, systematic reviews addressing other questions, economic evaluations and costing studies). In Health Systems evidence, we also conducted a search without an open search term, applying the following filters: disease type (cancer), sector (primary care) and type of document (overviews of systematic reviews, systematic reviews of effects, systematic reviews addressing other questions, economic evaluations and costing studies). In PubMed, we used the search string Transition* AND primary care AND survivor* AND cancer AND Canada. We also hand searched the systematic reviews that were included in a previous Evidence Brief produced by the McMaster Health Forum (Optimizing Patient and Family Transitions from Cancer Treatment to Primary- and Community-care Supports in Canada, March 2018).

We supplemented these searches with hand searches of government agencies, cancer-care agencies and system-level primary-care network in each provincial and territorial health system in Canada.

The results from the searches were assessed by one reviewer for inclusion. A document was included if it fit within the scope of the questions posed for the rapid synthesis.

For each systematic review we included in the synthesis, we documented the focus of the review, key findings, last year the literature was searched (as an indicator of how recently it was conducted), methodological quality using the AMSTAR quality appraisal tool (see the Appendix for more detail), and the proportion of the included studies that were conducted in Canada. For primary research (if included), we documented the focus of the study, methods used, a description of the sample, the jurisdiction(s) studied, key features of the intervention, and key findings. We then used this extracted information to develop a synthesis of the key findings from the included reviews and primary studies.

Key findings related to educational approaches and resources supporting seamless transitions

Among the included systematic reviews, there was consensus that there is limited evidence on the effectiveness of cancer-transition approaches. Programs and interventions are largely heterogenous, and it is often unclear which specific approaches that support transitions are most effective. However, key themes emerged in the literature on how the seven types of educational approaches or resources can either directly or indirectly support seamless cancer care transitions, such as: 1) improving communication and information flow; 2) increasing patient and healthcare-provider capacity; and 3) improving coordination and health-systems navigation. The following information is categorized into the three themes, where key outcomes and barriers related to the identified types of educational approaches or resources that support seamless cancer transitions are described in detail.

Improving communication and information flow

Communication strategies and interventions that aimed to improve information flow targeted both doctor-patient communication and communication between doctors. There was evidence to suggest that clinicians face many communication challenges with patients at the threshold of cancer survivorship. As such, much of the educational content in this area focused on approaches to mitigate these challenges. These approaches centred on identifying and cultivating the necessary skills among healthcare providers to lead effective, contextual and sensitive conversations with their patients.(27; 56)

Communication skills training (CST) was a commonly cited tool for building these skills among healthcare providers involved in cancer care.(22) CST targeting primary-care patients (including cancer patients) was also found to be an effective approach in increasing patients' total level of active participation in healthcare interactions.(42)

Additionally, patient-held records were found to be associated with psychological benefits and practical benefits to patients (not specific to cancer patients), including empowerment through the ability to be actively involved in their care and the capability to track their own health information.(51)

Electronic health and mobile health technologies were often employed in doctor-patient communication. The literature broadly described electronic health technologies as the use of information and communication-based technologies (e.g., telephones, patient monitoring devices, and other wireless devices).(48) One example is the use of technological communication and support in cancer follow-up care (e.g., telephone or electronic symptom reporting).(25; 32; 57) These intervention types were often valued among patients in terms of convenience; however, they presented some barriers for both patients and providers relating to increased workloads and difficulties in accessing or using technologies. Relating to communication between doctors in transitions, interactive communication (i.e., timely, two-way exchange of pertinent clinical information) between collaborating primary-care physicians and specialists was found to be associated with positive outcomes for patients receiving ambulatory care (including cancer patients).(41)

Increasing patient and healthcare-provider capacity

Beyond communication skills training, some additional approaches were identified for increasing patient and healthcare-provider capacity in healthcare transitions. Health information-technology applications that support patient-centred care (e.g., decision supports, telemedicine, tools for patient self-management) were found to have a positive effect on compliance with standards of care, use of healthcare resources, provider responsiveness to individual patient needs, and shared decision-making in the patient-clinician context.(14) Potential barriers to the utilization of this technology include poor usability and issues with access.(14) One review also provided evidence for the initiation of positive behaviour change among cancer survivors using telephone interventions.(30) To increase the capacity of healthcare providers in the post-treatment follow-up of cancer survivors, several clinical practice guidelines recommended that members of survivorship-care teams be provided with ongoing education opportunities.(50)

Improving coordination and health systems navigation

Regarding improving coordination and health-systems navigation, most of the literature focused on evaluating the effectiveness of specific transition interventions or models. Some of the research focused on examining the role of various healthcare providers during transition periods. For example, one review examining the role of different providers in leading follow-up care in the post-surgical (for colorectal cancer patients) or post-treatment (for breast cancer patients) time periods determined that primary care and nurse-led care were equivalent models.(13) In another review, transitional care led by clinical nurse specialists was found to be effective in reducing patient mortality following cancer surgery compared to usual care.(55) Shared-care models, where follow-up care was provided by both the specialist oncologist and the primary-care provider, were recommended for high-risk cancer survivors (e.g., those with long-term co-morbid illnesses, persistent side effects, receiving hormonal treatments).(47; 58) Three studies of multifaceted transition interventions (e.g., involving transition clinics, survivorship care plans, patient education materials) for cancer survivors (breast and colorectal cancer) transitioning from oncologist-led clinics to primary-care providers reported positive outcomes for patients. These positive outcomes included improved coordination, continuity of care and self-management, as well as lower healthcare utilization.(58-60)

Patient-navigation programs were a commonly cited tool for helping patients navigate the care transition. However, because interventions and their components varied significantly, the literature did not provide definitive statements about the effectiveness of specific navigation intervention activities. Despite this, across numerous reviews, patient navigation was found to be associated with various positive outcomes for patients with cancer (e.g., attendance to care events, adherence to follow-up treatment, process measures, positive psychosocial and quality of life benefits, enabling culturally competent patient-provider communication).(15; 27; 35; 46). Patient navigators were commonly recruited and trained within the community and were culturally aligned with the patient population.(27; 46)

Cancer-survivorship-care plans were also widely cited as a resource to help cancer patients manage the transition from active treatment into follow-up.(34; 50; 61-63) However, evidence for their efficacy was mixed due to heterogeneity in design, delivery and outcome measures. Some positive outcomes reported to be associated with survivorship-care plans for cancer survivors included fewer unmet needs(34) and improved adherence to guidelines.(61) Cancer survivorship-care plans were sometimes designed with specific components for primary-care physicians.(62; 64) One study reported that family physicians considered physician-tailored survivorship-care plans helpful as they felt more engaged with transition care.(62)

Key findings related to educational approaches and resources enabling high-quality, long-term survivorship care closer to home

Many studies made apparent that cancer survivors continue to experience various physical, emotional and practical unmet needs throughout survivorship. Additionally, the capacity of primary-care providers in delivering effective survivorship care continues to be hindered by knowledge-related barriers, as well as barriers in communication and coordination (including a lack of clarity about roles and responsibilities).

Overall, when identifying and considering educational approaches to enable high-quality, long-term survivorship care closer to home, three key aspects emerged from the literature: 1) the different structures and efficacy of survivorship-care models; 2) communication strategies to eliminate patient-provider barriers; and 3) self-management strategies to build survivors' capacity to overcome challenges. The following research evidence was synthesized into these three aspects, while describing key outcomes and challenges related to the types of educational approaches or resources for each aspect.

Different structures and efficacy of survivorship-care models

There was substantial variation among cancer survivorship-care models (e.g., content, timing, intensity, format), and the evidence from these models was limited, particularly regarding potential advantages of

different models and effects on survivors' health outcomes. For the post-primary treatment follow-up of cancer survivors, models of care generally included: 1) survivorship clinics; 2) shared care between oncologists and primary-care physicians; 3) nurse-led survivorship care; and 4) multidisciplinary models of care.(36; 40; 57) Some reviews compared the efficacy of different models of survivorship care. One review comparing oncologist-led follow-up and physician- or nurse-led follow-up reported no differences in quality of life or disease recurrence outcomes among patients; however, more positive outcomes were associated with nurse-led follow-up (e.g., higher scores for emotional functioning, less psychological distress).(40) Further, another review concluded that nurse-led breast cancer follow-up contributed positively to quality of life among patients, as well as to significant improvements in certain symptoms (e.g., constipation, nausea, pain).(36) Evidence suggested that patients recognize the benefits of family physician involvement in cancer follow-up care, and desire their involvement in the management and coordination aspects of their care, as well as in providing emotional and social support. However, numerous barriers were cited by both patients (e.g., poor communication, poor access to facilities, negative perceptions about the quality of primary care) and primary-care physicians (e.g., miscommunication, lack of training, uncertainty about roles) in establishing an effective care relationship.(12; 19; 65; 66)

Communication strategies to eliminate patient-provider barriers

To eliminate the barriers preventing effective patient-provider relationships in survivorship, several communication strategies were suggested. For example, to reduce the confusion about roles and responsibilities among physicians in providing follow-up care, it is suggested that communication be enhanced between primary- and tertiary-care providers, and that electronic medical records be used.(12) In improving the provision of patient support, computer-mediated communication strategies (e.g., email, videoconferencing, social support groups) used by a variety of healthcare professionals have been found to produce positive effects for cancer patients (e.g., increasing access to healthcare, allowing more time to formulate questions/responses).(49) Evidence also highlighted a specific gap in care for adult childhood cancer survivors; provider communication about late effects was found to be insufficient, preventing survivors from engaging in late effects detection and communication.(65) It is suggested that communication strategies in this area be improved across the cancer care continuum.(65)

Self-management strategies to build survivor capacity

Self-management interventions for cancer patients and survivors varied substantially in design (e.g., content, format, delivery, population), in measured outcomes and in efficacy. Therefore, overarching conclusions as to the components or elements of self-management interventions for this patient population could not be drawn. Some common positive outcomes reported across reviews and studies of different self-management types (e.g., group-based, educational, psycho-educational, health-coaching, multidimensional) include improved physical activity/function,(39; 44) improved quality of life,(18; 23; 39; 44) and improved management of cancer symptom clusters (e.g., physical, cognitive/psychosocial, fatigue).(16; 18; 23; 40) However, these positive outcomes must be interpreted cautiously as there was often conflicting evidence. There was evidence to suggest that electronic and mobile health applications can support self-management for chronic diseases (including cancer), as well as facilitate connections (e.g., between doctors, doctor-patient, between patients) and produce other positive effects (e.g., for health behaviours, perceived social support, knowledge/clinical outcomes).(48)

Table 1: Key findings from systematic reviews (n=45) and primary studies (n=19)

Type of educational approach or resource to support transitions	Key findings in relation to supporting seamless transitions		Key findings about enabling high-quality, long-term survivorship care closer to home
	Key findings from systematic reviews and primary studies for primary-care providers	Key findings from systematic reviews and primary studies for patients, caregivers and their families	
Communication strategies	<ul style="list-style-type: none"> • Evidence suggests that clinicians face many communication challenges (with patients) at the threshold of cancer survivorship (transition from primary treatment into aftercare), and recommendations for mitigating challenges were identified in the following areas: 1) attending to patient cues; 2) addressing avoidance; 3) demonstrating sensitivity to context; 4) managing relationships; 5) surfacing patient anxieties; and 6) clarifying roles and responsibilities (56) • Delivering culturally competent patient-provider communication in cancer management was found to be associated with the following: <ul style="list-style-type: none"> ○ Healthcare-provider skills, including avoiding stereotyping and generalizations when managing patient care, building critical skills in maneuvering the initial medical encounter, gaining patient trust, engaging with patients' extended families, and addressing patients appropriately according to their cultural preference (27) ○ Personal characteristics and attitudes of healthcare providers, such as demonstrating respect for cultural diversity and patients' cultural values (27) 	<ul style="list-style-type: none"> • Patient-held records are used across healthcare systems and are designed to facilitate communication between patients and health professionals • There was evidence to suggest that patients value having personal records to track health, remember events and share information (51) <ul style="list-style-type: none"> ○ Patient-held records were found to be associated with psychological benefits for patients (not specific to cancer patients), including empowerment through the ability to be actively involved in care and the ability to ask questions and challenge assumptions (51) ○ In some cases, patients viewed the use of patient-held records as the allocation of unwanted responsibility, which is a barrier to uptake (51) 	<ul style="list-style-type: none"> • The use of computer-mediated communication strategies (e.g., email, videoconferencing, social support groups, multifaceted interventions) by a variety of healthcare professionals were seen to produce positive effects for patients (including cancer patients) when used for providing patient support; examples of positive effects include increasing access to healthcare, allowing more time for formulating questions/responses, and saving travel time/expenses (49) <ul style="list-style-type: none"> ○ Increased workload for patients and providers was cited as a potential barrier to uptake across communication strategies (due to technical difficulty)(49) • Results of one study indicated that patient-provider communication (between adult childhood cancer survivors and long-term follow-up healthcare professionals) was influenced by the relationship between the patient and provider (65) <ul style="list-style-type: none"> ○ Cancer survivors were reluctant to seek care and discuss late effects with their provider when a foundation of trust was not previously built; however, providers reported a lack of time to build positive patient-provider relations in the transition period (from pediatric to adult healthcare) (65) ○ Provider communication about late effects was found to be insufficient for adult childhood cancer survivors (along the cancer care continuum), which can prevent survivors from engaging in late-effects prevention,

	<ul style="list-style-type: none"> ○ Cultural awareness, including self-awareness (e.g., provider’s own culture, cultural beliefs, health belief systems, spirituality and cultural assumptions, personal biases) and interpersonal awareness (e.g., inherent patient-provider power differences, potential differences in cultures) (27) ● Interactive communication (i.e., timely, two-way exchange of pertinent clinical information) between collaborating primary-care physicians and specialists was found to be associated with positive outcomes for patients (including cancer patients) receiving ambulatory care; compared to studies that did not include interventions to enhance the quality of information exchange, studies that did include these interventions had larger effects on patient outcomes (41) 		<p>detection and communication; it was suggested that communication strategies in this area be improved (65)</p>
<p>Skills training</p>	<ul style="list-style-type: none"> ● Practice facilitation in the primary-care setting showed a beneficial effect on chronic-disease (including cancer) process (e.g., screening, diagnosis, clinical process) and outcome (e.g., laboratory results, blood pressure, hospitalization) measures (45) ○ Communication skills training (CST) interventions that aimed to improve the general communication skills of healthcare professionals (HCPs) involved in cancer care (e.g., doctors, nurses, allied healthcare professionals) were associated with an increased likelihood of using open-ended questions and of demonstrating empathy toward patients, and a decreased likelihood of giving only the facts without individualizing responses to patients’ 	<ul style="list-style-type: none"> ● Relating to communication behaviour outcomes, CST targeting primary-care patients (including cancer patients) was found to be an effective approach in increasing patients’ total level of active participation in healthcare interactions (42); expressing concerns was the communication behaviour with the most significant difference in favour of CST ○ CST was not found to be associated with longer patient visits, but trained patients often received more information within visits (42) ○ CST was not associated with improved treatment outcomes, health or psychosocial well-being (42) 	<ul style="list-style-type: none"> ● Health coaching interventions that aim to grow capacity among cancer survivors were not found to be associated with self-efficacy, but were found to be associated with improved mood, physical activity and quality of life among survivors (44)

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	<p>emotions (among HCPs post-intervention) (22)</p> <ul style="list-style-type: none"> ○ There was no evidence to support differences in other HCP communication skills (e.g., negotiation, clarifying or summarizing information) resulting from CST interventions (22) 		
<p>System-navigation supports</p>	<ul style="list-style-type: none"> ● Transitional care (TC) interventions initiated within the hospital setting for patients with chronic diseases were associated with positive outcomes, including: <ul style="list-style-type: none"> ○ Psychosocial outcomes: high patient confidence in managing their conditions and/or understanding their medical regimen, improvements in post-discharge quality of life and patient satisfaction (compared with usual care) (19) ○ Healthcare-utilization outcomes: lower mortality rate post-discharge, lower re-admission rate, lower emergency-department visit rate (20) ● Transitional care led by clinical nurse specialists was found to be effective in reducing patient mortality following cancer surgery compared to usual care (55) 	<ul style="list-style-type: none"> ● Evidence remains mixed on the effectiveness of patient navigation, because of the heterogeneity of patient-navigation programs in both design and reported outcomes ● The literature did not provide definitive statements about the effectiveness of specific navigation intervention activities <ul style="list-style-type: none"> ○ Patient navigation was found to be effective in promoting attendance to care events and adherence to cancer-care follow-up treatment (15) ○ Patient navigation supporting chronically ill older adults through healthcare transitions (post-acute care period) was seen to have positive economic, psychosocial and quality of life benefits,(35) but some studies in this area reported no effect ○ Compared to usual care, several studies in cancer prevention/management reported a statistically significant positive effect for one or more outcome (e.g., patient-oriented, surrogate outcomes, process measures) when patient-navigator programs were used for people with chronic diseases (including cancer)(46) ○ Within healthcare systems, patient navigation was a commonly cited organizational strategy for enabling culturally competent patient-provider communication in cancer management (27) 	<ul style="list-style-type: none"> ● A prominent theme throughout the literature was exploring the outcomes and impacts associated with cancer follow-up care led by different healthcare providers <ul style="list-style-type: none"> ○ Nurse-led breast cancer follow-up has become increasingly common ○ One review found that nurse-led interventions in the follow-up stage of breast cancer contributed positively to quality of life among patients, led to significant improvements in certain symptoms (e.g., constipation, nausea, pain), and yielded higher satisfaction levels than hospital clinics (36) <ul style="list-style-type: none"> ▪ Some barriers identified in the delivery of effective survivorship care by nurses include a lack of knowledge, support, awareness and resources relating to cancer-survivorship care, as well as barriers at the practice setting level, such as lack of care structure, demanding workload, clinic workflow and competing priorities (67) ○ Patients broadly recognize the benefits of family-physician involvement in follow-up care (e.g., greater trust, convenience, continuity of care) and desire their involvement specifically in the management/coordination and reporting aspects of care, as well as providing emotional and social support ○ However, patients also cited numerous barriers to engaging family physicians for follow-up care (e.g., lack of solid relationship, poor communication and coordination, poor

			<p>access to facilities, negative perceptions about the quality/efficiency of primary care versus secondary care)(12; 19; 65; 66)</p> <ul style="list-style-type: none"> ▪ Some barriers in the provision of cancer follow-up/survivorship care cited by primary-care physicians include miscommunication, loss of contact with patients, uncertainty of roles, and lack of training ▪ Suggested mitigating factors include enhancing communication between primary- and tertiary-care providers and the use of electronic medical records(12) <ul style="list-style-type: none"> ○ Comparing non-specialist (i.e., general practitioner, nurse) to specialist-led follow-up for cancer care yielded very low certainty evidence, and it was uncertain how this strategy affected overall survival, time to detection of recurrence, or cost ○ Results also revealed that non-specialist versus specialist-led follow-up may make little to no difference to anxiety (at 12 months), and it is more certain that it has little or no effect on depression (at 12 months) (21)
<p>Self-management supports</p>	<ul style="list-style-type: none"> • Cancer-survivorship care plans were sometimes designed with specific components for primary-care physicians,(62; 64) such as digital information on clinical practice guidelines, symptom management and community resources for their patients (62) <ul style="list-style-type: none"> ○ One study reported that family physicians considered physician-tailored survivorship care plans helpful as they felt more engaged with transition care ○ Family physicians also expressed the need for succinct instructions, printable checklists and validated patient-scored instruments to 	<ul style="list-style-type: none"> • Survivorship care plans were widely cited as a resource to help cancer patients manage the transition from active treatment into follow-up,(34; 50; 61-63) and evidence for their efficacy was mixed (and sometimes conflicting) given the heterogeneity in their design, delivery and outcome measures <ul style="list-style-type: none"> ○ Some studies indicated that cancer patients explicitly expressed the desire for survivorship care plans during the transition phase (or just before) (62; 63; 66) and that among cancer patients who received survivorship care plans, satisfaction with care plans was high and accompanied by positive feelings toward the survivorship-care plans (34; 62) ○ Commonly included elements of survivorship care plans for patients were information on a patient’s medical history and cancer therapy,(61; 	<ul style="list-style-type: none"> • Self-management interventions/support for cancer patients and survivors varied substantially in design (e.g., content, format, length, delivery), in measured outcomes (e.g., knowledge, skills, bio-psychosocial markers of health, positive social networks) and in efficacy, and, as a result, overarching conclusions about the components or elements of self-management interventions for this patient population could not be drawn since very few studies used the same combinations of core elements, and among those that did, results were conflicting <ul style="list-style-type: none"> ○ One review indicated that group-based self-management programs for patients with cancer were found to improve physical function, but no significant results were found relating to an association between

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	<p>improve clinic visits during and beyond the transition period (from active treatment into follow-up care)(62)</p> <ul style="list-style-type: none"> • To prepare providers for the post-treatment follow-up of cancer survivors, several clinical practice guidelines recommended that members of survivorship-care teams be provided with ongoing education opportunities (50) 	<p>62; 64) follow-up guidelines (including visit reminders) tailored to patients,(61; 62; 64) information on symptoms/side effects,(50; 62; 64) key contact numbers and program information,(62) and information on available community resources (62)</p> <ul style="list-style-type: none"> ○ Some positive outcomes reported to be associated with survivorship-care plans for cancer survivors include fewer unmet needs (34) and improved adherence to guidelines (61) ○ Key barriers to the uptake of survivorship-care plans include the resource-intensive nature of their development (e.g., time required and associated costs to the healthcare system),(34; 68) as well as potential distress that may arise for some patients (e.g., unwanted responsibility) (34) • One review evaluated the impact of post-treatment self-management guidelines for prostate cancer survivors and found that patients were satisfied with the guidelines, and that most patients preferred receiving the information before their last appointment, and to receive information in multiple formats (e.g., internet-based, paper-based) and in combination with an in-person educational visit with their healthcare provider (69) 	<p>group-based self-management and quality-of-life or physical-activity-level outcomes (39)</p> <ul style="list-style-type: none"> ○ One review suggested that self-management education interventions to support patients with cancer improve symptoms of fatigue, pain, anxiety, emotional distress and quality of life (40) ○ One review suggested a promising role for psycho-educational interventions (e.g., progressive muscle relaxation, meditation, social support, educational components) delivered during or post-active treatment, in managing cancer symptom clusters (e.g., physical, cognitive/psychological, fatigue) (16) ○ One review reported that self-management interventions for cancer survivors (who completed primary treatment) had no statistically significant effects on anxiety, depression and self-efficacy, but had a significant medium effect on health-related quality of life, and a large effect on fatigue (borderline significance)(23) • Spirituality and addressing stigma were identified as key components for cancer-recovery interventions for Indigenous survivors, and interventions should focus on re-integrating survivors back into families and communities to enhance quality of life and create support networks (29) <ul style="list-style-type: none"> ○ Patient navigators were cited as a potential avenue for additional support/supportive care coordination (29) • One review provided evidence of a significant positive impact of physical-activity interventions post-cancer treatment on upper- and lower-body strength, lean body mass, overall quality of life, fatigue, immune parameters (e.g., neutrophil count, NK cell activity), pain, and general symptoms and side effects (53)
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<p>Electronic and mobile health technologies</p>	<ul style="list-style-type: none"> • Patients reported satisfaction with the use of technological support (e.g., telephone calls) in cancer follow-up care,(25; 32; 57) and, in some cases, this type of intervention was preferred <ul style="list-style-type: none"> ○ Across various telephone intervention types (e.g., telephone follow-up in lieu of routine hospital follow-up, telephone interventions for treatment, side effect monitoring and toxicity management, supplementary psycho-educational telephone interventions), evidence suggested that cancer patients valued telephone-based interventions in terms of convenience (e.g., facilitating personal organization, time/travel savings, overcoming participant restrictions), and reported positive personal experiences with these interventions (e.g., acceptance/appreciation of calls, perceptions of intervention helpfulness/usefulness)(25) ○ One review provided evidence for the initiation of behaviour change among cancer survivors (e.g., physical activity, diet, weight control) using telephone interventions (30) • Some studies indicated that monitoring symptoms in cancer follow-up care using a telephone system yielded the reporting of more severe symptoms when compared to nurse-assisted programs (32) • Electronic symptom-reporting systems (e.g., conducted with patient at clinic, summary of reported symptoms made available to physicians) between patients and providers (not specific to cancer care) were found to be effective in 	<ul style="list-style-type: none"> • In one review, telehealth interventions for family caregivers (not specific to cancer) were found to be associated with an improvement across various caregiver outcomes including psychological health, social support, coping, communication, cost-saving, physical health and productivity (33) 	<ul style="list-style-type: none"> • One review found that the application of electronic and mobile health technologies in the management of chronic diseases (including cancer) can have significant positive effects on health behaviours, perceived social support and knowledge, and clinical outcomes; there was also evidence to suggest that these internet-based applications can support self-management/care and facilitate connections (e.g., doctors with other doctors, doctors and patients, patients with other patients) (48) <ul style="list-style-type: none"> ○ There are socio-technical factors that affect the usability and uptake of these technologies (e.g., access to technology/internet, implementation may require changes to individual job design and/or clinical pathways) as well as user errors that can arise in human-computer interaction; it is widely suggested that effective electronica and mobile health technologies must be accessible and easy to use (48)
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	<p>identifying and prompting discussion of troublesome symptoms (in consultations), and showed positive outcomes for patient symptom distress, symptom management and health-related quality of life (17)</p> <ul style="list-style-type: none"> • Health information-technology applications that support patient-centred care (e.g., decision supports, telemedicine, tools for patient self-management) were found to have a positive effect on compliance with standards of care, use of healthcare resources, provider responsiveness to individual patient needs/preferences, and shared decision-making in the patient-clinician context (14) <ul style="list-style-type: none"> ○ Barriers to the utilization of health information-technology applications include poor usability and issues with access due to factors such as age, socio-economic status and education; barriers cited by physicians include concerns of added work, issues with implementation and concerns about confidentiality (14) ○ High satisfaction, usefulness and efficiency are factors reported to enable the use of health information technology (14) 		
<p>Multifaceted transition interventions</p>	<ul style="list-style-type: none"> • No evidence from systematic reviews or primary studies was identified 	<ul style="list-style-type: none"> • A study of a multifaceted transition intervention for breast cancer survivors transitioning from oncologist-led clinics to primary-care providers (Well Follow-Up Care Initiative, Ontario, Canada) indicated that compared to the control group, those in the transition intervention group reported lower hospitalization rates, cancer clinic visits and appointments with specialist oncologists, with similar frequency of primary-care visits, and the intervention group was also associated with lower costs to the healthcare system (60) 	<ul style="list-style-type: none"> • One review reported that multidisciplinary interventions that aim to enhance the return-to-work (RTW) process for cancer patients, in which vocational counselling, patient education/counselling, biofeedback-assisted behavioural training and/or physical exercises were combined, led to higher RTW rates than usual care (24) • There was evidence to suggest that multidimensional home-based survivorship programs may increase breast-cancer specific

		<ul style="list-style-type: none"> ○ The transition intervention involved survivorship care plans, patient-education materials, direct transition to primary care and stepped approach for transition clinics, with an average 25 months of follow-up (60) ● A study of a province-wide, multifaceted transition program for colorectal cancer survivors transitioning from oncologist-led clinics to primary-care providers (Moving Forward after Cancer, Manitoba, Canada) indicated that patients reported improved coordination, continuity in their care, and self-management due to the transition program ● The program involved a transitional clinic and a survivorship-care plan (developed with the patient and community-care provider collectively)(59) <ul style="list-style-type: none"> ○ The implementation (in the primary-care workflow) of the program/survivorship-care plan was cited to be facilitated by a standardized template integrated into the Electronic Medical Record (EMR)(59) 	<p>quality of life and global quality of life immediately following the intervention, and may decrease anxiety, insomnia and fatigue among survivors immediately following the intervention (18)</p> <ul style="list-style-type: none"> ● Some studies of multidimensional rehabilitation programs (physical and psychosocial interventions aimed at enhancing the knowledge, coping behaviour, self-efficacy and quality of life among cancer survivors) reported physical and psychosocial benefits among cancer survivors; however, evidence was limited (9)
<p>Care models that include transition supports</p>	<ul style="list-style-type: none"> ● A review of care models that aim to improve the coordination of cancer treatment between primary-care and oncology-care providers found that primary-care and nurse-led care were equivalent models in the post-surgical period for patients with colorectal cancer, and following treatment in patients with breast cancer (13) ● A review examining patients who live with cancer and one or more additional long-term illness (i.e., comorbid illness) suggested that to reduce the pressure on primary care in providing follow-up and support to this patient group, there is a need for a shared-care model (involving oncologists) or supported self-management (47) 	<ul style="list-style-type: none"> ● A review of three intervention models (case management, shared care, interdisciplinary teams) that aim to improve the continuity of cancer care on healthcare-provider, patient and process outcomes reported that no significant difference in patient health-related outcomes was found between patients who received interventions versus usual care (28) ● Regional Cancer Centres (RCCs) in Ontario, Canada reported three main models (direct to primary care, transition clinics, shared care) of follow-up care to support the transition of breast cancer survivors to primary care ● These care models and the resources they provided were associated with a sense of preparedness for the care transition among survivors (58) <ul style="list-style-type: none"> ○ The direct to primary care model transitions breast cancer survivors directly to their primary-care provider after a final transition visit (58) ○ Transition clinics were incorporated within the RCC and were operated by a nurse practitioner, 	<ul style="list-style-type: none"> ● Overall, there was substantial variation in cancer-survivorship care models, with the optimal nature, timing, intensity, format and outcomes of models being uncertain; the evidence from survivorship care models was also limited, particularly regarding potential advantages of different models, effects on survivors' health outcomes, costs/benefits, and potential structural and/or process barriers to offering survivorship care (57) ● For the post-primary treatment follow-up of cancer survivors, models of care included survivorship clinics, shared care between oncologists and primary-care physicians, nurse-led survivorship care and multidisciplinary models of care (40; 50) <ul style="list-style-type: none"> ○ Some studies compared these models of care; randomized controlled trials (RCTs) that compared oncologist-led follow-up with primary-care physician or nurse-led follow-up

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		<p>advanced-practice nurse, or a general-practice oncologist; cancer survivors typically visit the transition clinic between one to three times before fully transitioning to their primary-care provider, and nurses from the transition clinic connect with primary-care providers to establish a seamless transition of care and direct survivors who developed a recurrence (58)</p> <ul style="list-style-type: none"> ○ Shared-care models targeted high-risk survivors (e.g., persistent side effects, receiving hormonal treatment) and provided follow-up care with both the primary-care provider and the specialist oncologist (58) 	<p>reported no differences in quality of life or disease recurrence outcomes (40); however, patient satisfaction was higher for nurse-led care in one trial, higher scores for emotional functioning at 12 months were reported with nurse-led care in one trial, and less psychological distress was reported with nurse-led care in one trial</p> <ul style="list-style-type: none"> ● There was evidence of an association between the implementation of a chronic care model (CCM) in the primary-healthcare setting and improvements to healthcare practice or health outcomes for people living with chronic disease (not specific to cancer); the most used elements of CCMs were self-management support and delivery-system design (43) <ul style="list-style-type: none"> ○ Regarding the implementation of CCM elements, the Plan-Do-Study-Act cycle and learning collaboratives may be associated with the development of contextually relevant interventions ○ Several papers also determined that there is a key role for leaders (within healthcare organizations) to play in guiding the CCM development and implementation process(43; 52) ○ Other proven facilitators of CCM implementation and uptake in primary care include an organizational culture that promotes multidisciplinary or patient-centred care, and support from clinical providers and recognition of their role in care-change efforts (52) ○ Barriers to the implementation and uptake of CCMs in primary care include creating additional responsibilities for staff, characteristics of an organization (e.g., size, whether it had adopted a team-based approach, flexibility in rearranging care) and leadership turnover (52)
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Question 2 - What cancer-survivorship educational content and resources are available in Canadian provincial and territorial health systems?

We identified cancer-survivorship educational content and resources that are available in Canadian provincial and territorial health systems. This included documenting key features of programs that are designed to meet a variety of needs for patients and their caregivers/families (in general and for specific patient populations), as well as for primary-care providers. We provide detailed findings in Table 2. Experiences from these provinces and territories are presented below.

General educational content and resources

With the exception of Nunavut, all of the provinces and territories had distinct cancer-care coordinating bodies, health authorities or networks that were responsible for cancer programs and services (including through to survivorship and palliative care). Among these, team-based approaches to cancer care were common, which often included teams of oncologists, general practitioners, nurses, care coordinators/navigators and supportive-care specialists (e.g., physiotherapists, dietitians, speech pathologists, social workers). These coordinating bodies had websites that contained information and resources for patients and their families/caregivers, and sometimes for healthcare professionals (links to provincial and territorial resources are provided in Table 2).

Provincial government reports and frameworks were identified in seven provinces (British Columbia, Alberta, Manitoba, Ontario, New Brunswick, Newfoundland and Labrador, Prince Edward Island) and one territory (Northwest Territories), which detailed strategies for cancer control, chronic-disease prevention and management and primary-care integration. These strategies included relevant initiatives for survivorship care, as well as for transitions to survivorship care, including: 1) supporting the integration of primary-care providers across the cancer-care continuum; 2) engaging various stakeholders to improve supportive care; 3) improving the flow of information between healthcare settings; and 4) supporting smoother transitions between each stage of the cancer journey.

Specific content for primary-care providers

Most provinces (except Prince Edward Island) and one of the territories (Nunavut) had information or resources available for primary-care providers related to cancer survivorship and/or transitions into follow-up care. In many cases, this information was delivered using portals for healthcare professionals on government websites, or on websites of provincially mandated cancer agencies (links to provincial and territorial resources are provided in Table 2). The majority of portals identified contained resources for all healthcare professionals generally, with a few portals that were targeted specifically to primary-care providers, such as the Primary Health Care Resource Centre in Alberta or the Primary Care Provider Portal in Manitoba.

The most frequent type of information offered was cancer care follow-up guidelines (clinical), which were often disease specific. Supportive-care guidelines and survivorship-care guidelines/models were also common. The Alberta guideline repository included examples of disease-specific transfer of care physician and patient letters (for primary care), and examples of end-of-care patient and physician letters (for shared care). These items were unique in that they targeted the transition period between cancer care and primary/community care. Cancer Care Ontario also offers a unique guideline focused on self-management education for patients with cancer, which is intended for healthcare providers who are involved in the development of programs to enhance patient education and self-management support (for patients in treatment or in recovery/survivorship).

Some provinces offered training programs, educational courses, or workshops for healthcare providers relating to cancer-care follow-up, survivorship, their role in cancer care, or to facilitate linkages between oncology and primary-care communities of practice. Though not specific to cancer survivorship or transition programs, British Columbia and Nunavut offered cultural-training programs for healthcare professionals who provide care to Indigenous (British Columbia) and Inuit (Nunavut) people. Two unique programs specifically

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targeted transitions in cancer care: 1) the Transitions in Care program by Cancer Care Ontario, which provides evidence-based tools and educational resources for healthcare providers to help their patients with follow-up care; and 2) the Changing Focus: Living with Advanced Cancer Initiative by CancerCare Manitoba, which supports advanced cancer patients and healthcare providers as patients transition into a palliative approach to care.

Specific content for patients, caregivers and their families

All provinces and most of the territories (except Nunavut) had information and/or programs and services available for patients and their caregivers/families related to cancer survivorship or transitions into follow-up care. Six provinces and one territory offered information and educational tools on survivorship or transitions that were accessible directly on government websites. This information was presented in various formats, for example on webpages, in factsheets, in downloadable PDF booklets, or in video series. Some of the information focused specifically on survivorship, which included information on nutrition, physical activity, mental health and wellness, managing long-term side effects (e.g., cancer related fatigue), psychosocial well-being (including managing emotions, fears, and relationships) and employment-related materials (such as returning to work). Some of the information focused on transitions in care, which mainly involved patient-navigation booklets that guide patients through their cancer-care journey, including through to survivorship. Alberta, Manitoba and Newfoundland and Labrador created specific versions of these booklets tailored to Indigenous patients.

Beyond educational content on websites, most provinces and territories (except Nunavut) provided cancer survivorship and/or transition programs or services, which were offered at hospital networks and/or community-based organizations in different formats (in-person, virtual, support groups) and frequency.

Some programs and services described a distinction between survivorship versus transitioning from cancer care to primary/community care after treatment. For survivorship, programs and supportive-care services often included education, nutrition, rehabilitation, self-management, exercise, counselling, social-work services, financial-support information, support groups, and different forms of art therapy. In Alberta, there are survivorship workshops, classes and programs that focused on sexuality. Saskatchewan used a unique delivery system (mobile health bus) to provide counselling and educational content to cancer survivors in rural communities. Clinics/centres dedicated to survivorship were identified in three places: the Late Effects, Assessment and Follow-Up (LEAF) clinic in British Columbia; the Long Term Survivor Clinic at Alberta Children's Hospital; and the ELLICSR, which is a health, wellness and cancer-survivorship centre in Ontario. In a few cases, cancer survivorship was incorporated in chronic-disease self-management programs, such as the Regional Chronic Diseases Program in B.C., the Improving Health: My Way program in Newfoundland and Labrador, and the Chronic Conditions Support Program in the Yukon.

Specific transitions programs for patients were identified in six provinces. These programs varied in their content and delivery format, but most focused on the time period directly after treatment completion. The most frequently cited content was information and support related to psychosocial needs, wellness, nutrition, physical activity and medical management. The After Cancer Treatment Transition Clinic (ACTT) in Ontario was unique in that it acts as a survivorship bridging program between cancer care and primary care (with patients meeting with ACTT before primary care), and patients have ongoing access to the ACTT team for any future referrals if cancer recurrence is detected. The Moving Forward After Cancer Treatment Program in Manitoba also specifically helps patients transition into follow-up care in the primary-care setting. Across the provinces and territories, patient-navigation programs were a common transition tool. These navigators were often part of a patient's cancer-care team and were available from diagnosis through to survivorship to assist in coordinating care, and to assist in accessing health services. Some places had information on navigator programs for specific populations, such as the Pediatric Cancer Patient Navigator program in New Brunswick, the Indigenous Cancer Patient Navigator program in Alberta, the Underserved Populations Program in Manitoba, and palliative-care nurse navigators and Indigenous-patient navigators in Newfoundland and Labrador.

While most of the educational resources and some of the programs/services were accessible to patients' families and caregivers, only a few places had dedicated information or programs/resources for caregivers. Though not specific to cancer care, British Columbia and Alberta had province-wide caregiver organizations that provided information, resources and some programs for caregivers. British Columbia also had information about a provincially funded caregiver respite/relief service (not specific to cancer caregivers). The Government of Yukon website had information about a caregiver's support group (not specific to cancer caregivers), which is co-facilitated by a mental health clinician, and is hosted at the Canadian Mental Health Association once a month. The Quebec Cancer Foundation provides information for caregivers on practical needs, as well as provides educational material on caring for different patient groups and self-care for caregivers. Cancer Care Ontario also recently published the Oncology Caregiver Support Framework, which describes providing caregiver-specific education to build capacity for self-advocacy and self-care, and regular check-ins throughout the cancer-care continuum.

Table 2: Cancer-survivorship educational content and resources available in Canadian provincial and territorial health systems

Province/Territory	General educational content and resources	Specific content for primary-care providers	Specific content for patients, caregivers and their families
British Columbia	<ul style="list-style-type: none"> • BC Cancer partners with the regional health authorities to provide a comprehensive cancer control program for B.C. residents, from screening/prevention through to supportive and palliative care <ul style="list-style-type: none"> ○ BC Cancer centres and clinics have highly specialized and collaborative cancer care teams, which include not only a patient’s general practitioner and oncology specialists, but also numerous supportive care specialists (e.g., physiotherapist, occupational therapist, speech pathologist, dietitian, social worker/counsellor) • In 2018, the Family Practice Oncology Network (FPON), in collaboration with the University of British Columbia, completed a provincewide primary-care oncology needs assessment <ul style="list-style-type: none"> ○ The purpose of the needs assessment was to support the expansion of the FPON, which is set to become the Provincial Primary Care Program (at BC Cancer) ○ The objectives were to understand the unmet needs of family physicians in providing care for patients across the continuum of cancer care, and to establish an effective communication mechanism between the program and family physicians ○ The top three priorities identified for the new Provincial Primary Care Program were 1) advocating for improved access to appropriate clinical resources/services for patients, 2) developing practice tools for supporting patients with cancer, and 3) 	<ul style="list-style-type: none"> • The Guidelines and Protocol Advisory Committee (GPAC) developed ‘BC Guidelines’, which is a repository of clinical practice guidelines and protocols (developed in-province) that provide recommendations for delivering high-quality care to patients with specific clinical conditions or diseases <ul style="list-style-type: none"> ○ B.C. physicians, nurse practitioners and medical students are the primary audiences for BC Guidelines ○ There are several published guidelines for the follow-up care of cancer patients, including Breast Cancer: Management and Follow-Up, Follow-up of Colorectal Polyps or Cancer and Prostate Cancer Part 2: Follow-up in Primary Care • The Provincial Health Services Authority website contains some resources for health professionals, including: <ul style="list-style-type: none"> ○ San’yas Indigenous Cultural Safety Training, which is an online training program designed to increase knowledge and strengthen the skills of those who work with Indigenous people 	<ul style="list-style-type: none"> • The health section of the Government of B.C. website contains information on home- and community-care services (not specific to cancer) and how to access them <ul style="list-style-type: none"> ○ A range of publicly subsidized healthcare and support services are available for people who have acute, chronic, palliative or rehabilitative healthcare needs ○ There is a caregiver respite/relief service available • The health section of the Government of B.C. website contains information (not specific to cancer) on health and drug coverage, including the Medical Services Plan and PharmaCare • The health section of the Government of B.C. website contains information for managing personal health (not specific to cancer), including: <ul style="list-style-type: none"> ○ Physical activity programs, including the Physical Activity Line (PAL), which is a free service that connects B.C. residents with exercise professionals who can provide them with a personalized physical activity plan based on their needs ○ Healthy eating information and programs, including the Email a HealthLinkBC Dietitian program, which allows B.C. residents to contact registered dietitians with non-emergency nutrition and food questions ○ Mental health and substance use information and programs • The HealthLinkBC website contains a variety of resources for cancer survivors, including: <ul style="list-style-type: none"> ○ Healthy eating guidelines for cancer survivors (available in eight languages)

	<p>providing education and training for physicians</p> <ul style="list-style-type: none"> ○ Specific initiative recommendations were listed for the following categories: information resources, educational programming, communication practices and relationship-building ● Cancer and Work, which is an initiative led by faculty at McGill University and the BC Cancer Agency in partnership with the de Souza Institute (and with funding support from the Canadian Partnership Against Cancer and Health Canada), aims to provide information and resources about returning to work for cancer survivors, healthcare providers and employers 	<ul style="list-style-type: none"> ○ Interpreting services for healthcare professionals, including spoken language and sign language ● BC Cancer collects patient information in an electronic health information system; patient information is provided to a patient's referring physician to support continuous and consistent care and service ● BC Cancer offers survivorship and primary-care resources for health professionals, including programs through the Family Practice Oncology Network and educational offerings through BC Primary Care Learning Sessions 	<ul style="list-style-type: none"> ○ Physical activity recommendations for cancer patients and survivors, including activity logs and relevant assessment forms ○ Mental health information and resources (general, not cancer patient/survivor-specific) ○ Searchable databases for finding specific information about medical tests and medications (general, not cancer patient/survivor-specific) ○ Various 'health topic' summaries in the area of cancer support, including being an active patient, dealing with emotions and fears, life after treatment, managing stress and family, friends and relationships ● HealthLink BC operates a free provincial health information and advice phone line (8-1-1), which is available to all B.C. residents (not specific to cancer) <ul style="list-style-type: none"> ○ Through 8-1-1 people can speak to a health service navigator, who can assist in finding health information and services, or can connect people directly with a registered nurse, dietitian, exercise professional or pharmacist ● The Provincial Health Services Authority website contains some health information on living well with chronic illness and healthy habits for life (not specific to cancer) ● BC Cancer offers various services to cancer patients and survivors through their centres and clinics, including: <ul style="list-style-type: none"> ○ Support information and resources for Indigenous cancer patients ○ Interpreters ○ The Late Effects, Assessment and Follow-Up (LEAF) clinic for adults who have survived childhood cancer
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			<ul style="list-style-type: none"> ○ Cancer support programs and numerous supportive care services (e.g., art therapy, nutrition, counselling, etc.) ○ Information on life after cancer ● The Family Caregivers of British Columbia website has information and resources for caregivers (not specific to cancer) ● The Regional Chronic Diseases Program (through Northern Health) helps Northerners with chronic diseases, with cancer care being one of the specific disease focuses <ul style="list-style-type: none"> ○ The program promotes partnership between primary care and specialty services for the care of those living with chronic diseases
Alberta	<ul style="list-style-type: none"> ● Changing Our Future: Alberta's Cancer Plan to 2030 (2013) provides a comprehensive planning framework for the ongoing development of cancer-care programs and services, and outlines a strategy that recognizes the role of the healthcare system in addressing the supportive care needs of patients, families and caregivers <ul style="list-style-type: none"> ○ There are 10 strategies for change, which will guide work and initiatives going forward ○ Strategy one involves stakeholders from across the wellness, healthcare and research spectrum in order to create a coordinated system of prevention/screening and care; CancerControl Alberta was created as a distinct division within Alberta Health Services (AHS) as a result of this strategy ○ Strategy two involves supporting, engaging and integrating primary healthcare providers in the delivery of cancer services ○ Strategy five involves better integrating care to deliver cancer diagnosis, treatment and support services 	<ul style="list-style-type: none"> ● CancerCare Alberta (division of Alberta Health Services) provides Cancer Guidelines for healthcare professionals that were developed by the Guideline Resource Unit (GURU) <ul style="list-style-type: none"> ○ There are guidelines for follow-up, palliative and supportive care as well as symptom management ○ There are sample disease-specific transfer-of-care physician and patient letters (for primary care), and sample end-of-care/treatment for patient and physician letters (for shared care) ○ The disease-specific letters (transfer of care and end of care) provide information on follow-up appointments and tests, managing side effects, signs of recurrence, support, 	<ul style="list-style-type: none"> ● CancerCare Alberta (division of Alberta Health Services) provides resources for patients who have finished treatment, including: <ul style="list-style-type: none"> ○ A book on how to manage healthcare, improve well-being and take action ○ An after-treatment worksheet ○ Resources for those returning to work after cancer treatment ○ Living Your Best Life With and Beyond Cancer: Video Series, which is part of the Cancer Transitions series and contains videos on physical activity, living well, and late and long-term effects ○ The Cancer Transition series also contains videos on brain fog, nutrition, sleep and cancer survivor stories ● CancerCare Alberta provides psychosocial and rehabilitation oncology services to patients/survivors and their families, from the point of diagnosis through to survivorship ● CancerCare Alberta created a Sources of Help book for people with cancer in Alberta, which contains information on Alberta Health Services programs and supports, community

	<ul style="list-style-type: none"> ○ Strategy six involves providing cancer patients/survivors and their families/caregivers with the best possible physical, psychosocial and supportive care throughout their cancer journey ● <u>The Supportive Care Framework Report (2016)</u> was created by CancerControl Alberta’s Supportive Care Council to serve as a foundational document for the provision of supportive care for cancer patients in Alberta <ul style="list-style-type: none"> ○ The framework identified gaps and outlined three priorities for action to address these gaps ○ Priority one is developing a model of provincial leadership and accountability to enable programmatic standards/practices within supportive care across CancerControl Alberta ○ Priority two is undertaking a current state analysis of CancerControl Alberta services ○ Priority three is intentionally integrating supportive care services into site and provincial tumour teams, clinical guidelines, care pathways, care teams, staff orientations, performance standards, and patient and family orientation ● There are <u>three main primary healthcare models in Alberta</u> (all three are team-based), including: <ul style="list-style-type: none"> ○ Primary Care Networks, which are groups of doctors that work together with teams of healthcare professionals (e.g., nurses, dietitians, pharmacists) ○ Community Health Centres, which are front-line healthcare and social support centres that address social barriers to health through integrating team-based care with health promotion, social services and community programs 	<p>and healthy lifestyle recommendations</p> <ul style="list-style-type: none"> ● Alberta Health Services (AHS) <u>Primary Health Care Resource Centre</u> provides <u>cancer care information and resources</u> for healthcare professionals, including: <ul style="list-style-type: none"> ○ Long-term follow-up guidelines for survivors of childhood, adolescent and young adult cancers ○ Supportive care guidelines ○ Cancer patient self-management resources ○ Information on the annual <u>Family Physicians and CancerControl: Strengthening Linkages Workshop</u>, which is put on by CancerControl Alberta in order to provide family physicians and health professionals with the opportunity to build linkages between the oncology and primary-care communities 	<p>supports and services, money and finances, and improving health and lifestyle</p> <ul style="list-style-type: none"> ● CancerCare Alberta created the <u>Guide to Cancer Care in Alberta for Newly Diagnosed Indigenous People</u>, which contains information on services and programs, including the <u>Indigenous Cancer Patient Navigator program</u> and the <u>Indigenous Health Program</u> ● The <u>Alberta Cancer Foundation Patient Navigator Program</u> exists in 15 regional and community cancer centres across Alberta; patient navigators ensure timely access to information, coordinate additional community supports and offer individualized care to meet specific needs ● CancerCare Alberta provides <u>classes, groups and events</u> for cancer patients/survivors and their families, including (items listed below have a focus on survivorship): <ul style="list-style-type: none"> ○ Classes: After Treatment, Cancer-Related Fatigue: “Energize”, Prostate Cancer Centre: Road to Recovery, Sex, Cancer & Couples, and Sexual Mechanics: A Workshop for Men ○ Programs: Mindfulness Based Cancer Recovery, ReCog Program ○ Support groups: Adolescent and Young Adult (AYA) Cancer Support Group, Family and Caregiver Support Group, Living with Chronic or Advanced Cancer, Mindfulness Relaxation, Spirituality Group ○ Workshops: The “Low Down” on “Down There” (LDDT) ● <u>Caregivers Alberta</u> provides information, resources and programs for caregivers (not specific to cancer) ● <u>Health Link 811</u> is a free, 24/7 telephone service which provides nurse advice and general health information, including
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	<ul style="list-style-type: none"> ○ Family Care Clinics, which provide individual and family-focused primary healthcare services ● The Primary Healthcare Integration Network works with several key partners (e.g., patient/family advisors, provincial programs, Primary Care Networks) to improve transitions of care at every level ● Path to care is an Alberta Health Services initiative that collaborates with programs and services to provide clear and timely communication between patients, primary care and specialty care ○ The program is designed to provide patients with detailed information about their care pathway, including what health services are provided by whom and where, and wait-time information for scheduled services 		<p>navigation services and online content support (not specific to cancer)</p> <ul style="list-style-type: none"> ● MyHealth.Alberta.ca was developed by the Government of Alberta and Alberta Health Services to provide Alberta residents with one place to go for health information; there is an extensive collection of cancer-related information and tools, including: <ul style="list-style-type: none"> ○ Video series on Indigenous cancer care experiences and on cancer and fatigue ○ Cancer and sexuality, including the Oncology and Sexuality, Intimacy and Survivorship Program (OASIS), which offers support, clinical services and education for people who have cancer in order to help them adjust to sexual changes ○ Cancer support information (including videos) and resources covering various topics, including dealing with emotions and fears, family, friends and relationships, life after treatment, managing stress and when your cancer comes back or gets worse ● There is a Long Term Survivor Clinic at Alberta Children’s Hospital that promotes the health and well-being of survivors, provides education to patients and families/caregivers on the late effects of childhood cancer treatment and provides access to dietary consultation, psychological therapy and neuropsychological assessment ● The health section of the Government of Alberta website contains information on (not specific to cancer): <ul style="list-style-type: none"> ○ The Alberta Health Advocate, who can help people find appropriate health services and health-related programs and resources to meet specific health needs ○ The Alberta Health Care Insurance Plan and drug coverage/health benefits ○ Addiction and mental health resources and services
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			<ul style="list-style-type: none"> ○ Healthy living resources ● Alberta Health Services provides numerous provincial health programs and services, as well as specific services and programs by zone (North, Edmonton, Central, Calgary, South) (not specific to cancer)
Saskatchewan	<ul style="list-style-type: none"> ● No information was identified 	<ul style="list-style-type: none"> ● The Saskatchewan Cancer Agency provides follow-up and discharge-pathway guidelines for community physicians that are specific to the type of cancer <ul style="list-style-type: none"> ○ Examples of related information include who should be continually monitored and for how long 	<ul style="list-style-type: none"> ● As part of rural community outreach, the Saskatchewan Cancer Agency delivers counselling and education content to cancer survivors using a mobile health bus ● The Saskatchewan Breast Cancer Connect helps cancer survivors in identifying appropriate support groups for their specific needs ● The Hope Cancer Centre offers financial support, workshops and information on support groups for cancer survivors within the Saskatoon area
Manitoba	<ul style="list-style-type: none"> ● To support Manitobans and primary-care practices, the province developed the initiatives Home Clinics and My Health Teams, which work together to help ensure reliable access, coordination and continuity of care for patients <ul style="list-style-type: none"> ○ Home Clinics are primary-care clinics, and within each Home Clinic is a patient's main primary-care provider; these clinics provide patients with timely access to care, manage their health records and coordinate their healthcare within the wider healthcare system ○ My Health Teams delivers primary care by teams of healthcare providers, including doctors, nurses, dietitians or any number of health professionals; one of the goals of My Health Teams is to connect providers within and across geographical boundaries to provide seamless transitions in care 	<ul style="list-style-type: none"> ● CancerCare Manitoba (CCMB) (provincially mandated cancer agency) provides a variety of resources and information for health professionals, including: <ul style="list-style-type: none"> ○ A referral guide for physicians ○ The Changing Focus: Living with Advanced Cancer Initiative, which supports advanced cancer patients and healthcare providers as patients transition into a palliative approach to care ○ Follow-up care resources and recommendations for family physicians and nurse practitioners ○ Health professionals can submit questions to CCMB about cancer follow-up or palliation through the website 	<ul style="list-style-type: none"> ● The health, seniors and active living section of the Government of Manitoba website contains information (not specific to cancer) for accessing home-care services, mental health services, healthcare coverage and the Manitoba Pharmacare Program ● CancerCare Manitoba (CCMB) (provincially mandated cancer agency) provides a variety of resources and information for patients and their families, including: <ul style="list-style-type: none"> ○ Patient pathway diagrams that show what a patient journey may look like for different types of cancer ○ The Underserved Populations Program, which helps people who experience barriers (geography, language, culture) in receiving cancer care, from diagnosis through to follow-up and palliative care ○ The First Nations Patient Guide, which navigates First Nations patients through the cancer journey

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	<ul style="list-style-type: none"> • The Manitoba Health, Seniors and Active Living 2019-2020 Annual Report describes some objectives and expected/actual results that are relevant to continuity of care, including: <ul style="list-style-type: none"> ○ The delivery of electronic data interchange and information sharing between the department, Shared Health, service-delivery organizations, health providers and other government departments ○ Building an integrated primary-care system, where service entities and organizations work toward a common set of measurable service standards to support improved health outcomes ○ Improving access to primary care and ensuring that care is comprehensive and continuous ○ Supporting smoother transitions between different health services along the continuum of care through enhanced coordination efforts within My Health Teams • The Manitoba Cancer Network consists of caring professionals and community volunteers who work together to improve access to information, services and support for all types of cancer across the care continuum 	<ul style="list-style-type: none"> • The primary-care provider portal on the Government of Manitoba website provides information for healthcare professionals on: <ul style="list-style-type: none"> ○ How to become a Home Clinic and the benefits of doing so ○ Service coordination resources ○ Primary care and cancer, including clinical tools and supports, tools for enhancing office practices, tools for enhancing communication (with patients and other healthcare providers) and education workshops or programs • The Government of Manitoba created the Primary Care Interprofessional Team Toolkit, which provides instructions and resources to help clinics in the Physician Integrated Networks to identify which providers to integrate, and how to do so effectively 	<ul style="list-style-type: none"> ○ Support services including cancer navigation, interpreter services, nutrition services, patient representatives and support groups and counselling ○ Two programs to support patients after treatment is over; the Moving Forward After Cancer Treatment Program helps patients transition into follow-up care in the primary-care setting, and the After Care Program helps patients who had a childhood or adolescent cancer ○ Information on managing both short and long-term symptoms and side effects • The Breast Health Centre through Shared Health Manitoba provides a variety of services and resources for breast cancer patients and survivors, including <ul style="list-style-type: none"> ○ Counselling related to coping with breast cancer and other life stressors ○ Nutrition services and education relating to survivorship, including group sessions for breast cancer survivors led by a dietitian
Ontario	<ul style="list-style-type: none"> • The Ontario Cancer Plan 2019-2023 by Cancer Care Ontario (and which eventually will be led by Ontario Health) describes the intended road map of cancer-care continuum which will include related resources on survivorship • A 2017 report by Cancer Care Ontario on models of care for cancer survivorship describes and provides specific 	<ul style="list-style-type: none"> • The Transitions in Care Program by Cancer Care Ontario provides evidence-based tools and educational resources for healthcare providers to help their patients with follow-up care • Cancer Care Ontario released recommendations for healthcare 	<ul style="list-style-type: none"> • As part of the First Nations, Inuit, Métis, and Urban Indigenous Cancer Strategy 2019-2023, there is an emphasis on improving general education about cancer and navigation of the healthcare system with culturally relevant information for Indigenous people • The Oncology Caregiver Support Framework published in 2019 by Cancer Care Ontario describes providing caregiver-specific

	<p>recommendations on care pathways for survivors of breast cancer, colorectal cancer, prostate cancer, and other types of cancers</p> <ul style="list-style-type: none"> ○ As an example, survivors of breast cancer can be referred to a community-based family physician-led care team ○ The report found a positive impact of nursing models within institutional settings, but further research is needed on nursing models within community settings ○ No recommendations about shared-care models were made given the lack of published literature 	<p>providers in the follow-up model of care for cancer survivors in 2019</p> <ul style="list-style-type: none"> ○ Detailed recommendations include follow-up care planning, surveillance, management of consequences of cancer, and prevention and health promotion ○ Implementation considerations involve developing or integrating information systems, accessing diagnostic/surveillance tests and psychosocial oncology providers, creating training and education materials on follow-up care for survivors through online modules and existing continuing professional development programs, and developing standard templates for treatment summaries and individualized plans of care ● Cancer Care Ontario released a report in 2016 on self-management education for patients in the treatment or recovery/survivorship phases of the cancer pathway which is intended for healthcare providers who are involved in the development of programs to enhance patient education <ul style="list-style-type: none"> ○ Eight core elements of self-management education interventions include: tailored information based on patient 	<p>education to build capacity for self-advocacy and self-care (e.g., financial/legal support, respite care, employment rights, physical/emotional support, spiritual support, bereavement support), regular check-ins throughout the cancer-care continuum, and monitoring and evaluating caregiver supports</p> <ul style="list-style-type: none"> ● Princess Margaret Cancer Centre offers a cancer rehab and survivorship program where individuals can access services and educational materials related to the exercise program, specialized rehab, and community and wellness programs <ul style="list-style-type: none"> ○ The care team typically involves physiatrists, occupational therapists, physiotherapists, kinesiologists, massage therapists, social worker, psychologist, neuropsychologist, dietitian, wellness chef and coordinators ● The ELLICSR: Health, Wellness and Cancer Survivorship Centre provides services and programs for survivors, family, friends, and caregivers such as psychosocial and wellness programs, community-based programs, exercise services, and education-based services ● The After Cancer Treatment Transition Clinic (ACTT) is a comprehensive cancer survivorship program based at the Women's College Hospital, which involves access to educational resources and services on specific types of cancers <ul style="list-style-type: none"> ○ As part of each 35-to-45-minute visit, individuals are provided a care plan that includes a review of a patient's health history and current medications, any additional surveillance tests, and referrals to other health services at the hospital or within the community ○ Patients are eventually shifted to their primary-care physician, but have access to the ACTT team for any future referrals if cancer recurrence is detected
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		<p>characteristics, facilitating patient self-efficacy, developing effective communication skills, understanding of health- and support-service systems navigation, coaching from trained instructor, collaboration and guidance from healthcare team, goal setting, and developing problem-solving skills to address barriers</p> <ul style="list-style-type: none"> ○ The report found that self-management education interventions may relieve symptoms of depression, anxiety, and emotional distress; however, it is difficult to conclude which combinations of which elements work best 	
Quebec	<ul style="list-style-type: none"> • Cancer and Work, which is an initiative led by faculty at McGill University and the BC Cancer Agency in partnership with the de Souza Institute (and with funding support from the Canadian Partnership Against Cancer and Health Canada), aims to provide information and resources about returning to work for cancer survivors, healthcare providers and employers 	<ul style="list-style-type: none"> • The McGill University Health Centre is a resource for healthcare providers related to current evidence-based recommendations and information on cancer survivor referrals • The Rossy Cancer Network based at McGill University conducted a needs-based survey on healthcare providers <ul style="list-style-type: none"> ○ As a result of the study, a Survivorship Care Plan was developed, which is a document to help summarize treatment plans for cancer survivors and provide guidance on surveillance 	<ul style="list-style-type: none"> • The cancer control program in Quebec <u>involves access to services and resources for patients across the cancer continuum</u> <ul style="list-style-type: none"> ○ Patients have access to an extensive oncology health team (hemato-oncologist, surgical oncologist, radiation oncologist, nurses, pharmacists, dietitians, social worker, psychologists, rehabilitation specialists, spiritual-care professionals, and other community professionals) ○ An <i>Oncology Passport</i> is given to patients with cancer as a self-management tool during their cancer-care journey, which includes the follow-up period (end of treatment and transition to survivorship) ○ Existing educational resources and information are available on corporate support program and services <u>for individuals returning to work</u>

			<ul style="list-style-type: none"> ○ Available resources from the Quebec Cancer Foundation for caregivers include information on practical needs and services, and educational material on self-care and caring for someone with cancer
<p>New Brunswick</p>	<ul style="list-style-type: none"> ● A Chronic Disease Prevention and Management Framework for New Brunswick was developed by the Government of New Brunswick (N.B.) Department of Health in 2010; the framework is based on the Expanded Chronic Care Model, and outlines several goals including: <ul style="list-style-type: none"> ○ Changing the role of information, which includes building strong information networks and increasing data-use ○ Changing the role of the patient, which includes moving toward patient self-management through education and support ○ Changing the role of the community, which includes involving communities as partners in health and wellness ○ Changing the focus from illness to wellness, which includes a shift towards the prevention of chronic conditions ● A Primary Health Care Framework for New Brunswick is a long-term strategic plan for improving primary healthcare in N.B.; it was developed by the Primary Health Care Steering Committee, and it contains numerous recommendations for government, including: <ul style="list-style-type: none"> ○ Integrating primary healthcare services ○ Assembling team-based models of care that are community-specific, including establishing electronic medical records for team-based settings ○ Implementing an accountability framework ○ Engaging with patients and stakeholders 	<ul style="list-style-type: none"> ● The New Brunswick Cancer Network (NBNC) offers educational sessions to healthcare providers across the province; sessions aim to foster professional development, as well as facilitate interaction among healthcare providers 	<ul style="list-style-type: none"> ● The Government of N.B. Health Department offers a service called Tele-Care (not specific to cancer), which is a free, confidential telephone service that employs registered nurses to provide telephone triage and information for non-urgent health concerns ● The Extra-Mural Program (EMP) is a provincial home healthcare program (not specific to cancer) that provides healthcare services to N.B. residents of all ages <ul style="list-style-type: none"> ○ Services include acute, palliative, maintenance, supportive care and coordination of support services ○ Healthcare services are delivered by an interdisciplinary team, and services range from health education (e.g., chronic-disease management) to more complex medical needs (e.g., post-surgery, medication management) ● The Government of N.B. Health Department website contains some information for patients (not specific to cancer) on chronic-disease prevention and management, the New Brunswick Drug Plan, addictions and mental health (including how to access services) and healthy eating ● The Horizon Health Network (regional health authority) website offers some information on the Horizon Health Network Oncology Program, including information on the Pediatric Cancer Patient Navigator, who can help coordinate with the healthcare team to transition children with cancer back into their home healthcare community after treatment

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	<ul style="list-style-type: none"> • The New Brunswick Cancer Network (NBNC) is a branch of the Government of N.B. Department of Health; the NBNC is responsible for ensuring a provincial, evidence-based approach in delivering cancer programs and services across the cancer-care continuum, including prevention, treatment, follow-up, palliative care and education 		<ul style="list-style-type: none"> • The Horizon Health Network offers various support and therapy services, including clinical nutrition, occupational therapy, physiotherapy, addictions and mental health, recreational therapy, social work and chronic-disease prevention and management • Vitalité Health Network (regional health authority) also offers the Pediatric Oncology Navigation program, and the Dr. Léon-Richard Oncology Centre has nurse navigator programs at the Breast Health Centre and for brachytherapy for prostate cancer <ul style="list-style-type: none"> ○ Vitalité Health Network also offers a variety of supportive services (e.g., mental health and addictions, physiotherapy, social work) • The New Brunswick Breast and Women’s Cancer Partnership is a non-profit organization that provides information, support and resources to women living with cancer, including underserved women (e.g., those living in rural communities, French-speaking, Indigenous, and multicultural communities)
Nova Scotia	<ul style="list-style-type: none"> • The Cancer Outcomes Research Program, which is based at Dalhousie University’s Department of Surgery, focuses on researching the cancer-care continuum with a special interest on issues related to cancer treatment and cancer survivorship, as well as the interface between specialist and primary care • The Nova Scotia Health Authority website on cancer care provides specific resources for cancer survivors, family members or caregivers, and health professionals 	<ul style="list-style-type: none"> • Healthcare providers have access to educational content on oncology programs and services in Nova Scotia, including general information on survivorship care of their patients 	<ul style="list-style-type: none"> • The Nova Scotia Health Authority created an educational resource for cancer survivors (general content and specific content for survivors of breast cancer, colon cancer, rectal cancer, and thyroid cancer) that describes information on follow-up care plans and schedules, expectations after cancer treatment, and support and learning programs <ul style="list-style-type: none"> ○ Follow-up care may involve visits to a family physician or nurse practitioner with frequency dependent on the advice of a healthcare provider and number of months or years after remission • Cancer survivors and their family members can join the Cancer Patient Family Network, which connects individuals to help improve the cancer system through participation in focus

			<p>groups, committees, completion of surveys, and reviewing education resources</p> <ul style="list-style-type: none"> • A 2.5- hour session called Living Beyond Cancer is available to cancer survivors at participating hospitals, where they are provided information on follow-up care, side effects of cancer treatment, physical activity, nutrition, psychosocial services, and access to other health services • Cancer Transitions in collaboration with the Cape Breton Cancer Centre and YMCA is a free six-week program specifically designed for cancer survivors that is focused on psychosocial support and wellness, and dietary and physical activity concerns • Emotional and practical support from a psychosocial team (involving psychologists, psychiatrists, social workers, nurses, and spiritual-care providers) are available at specific hospitals for eligible Nova Scotians • Support groups focus on social support and/or provide education about different areas of cancer
<p>Newfoundland & Labrador</p>	<ul style="list-style-type: none"> • Improving Health Together: A Policy Framework for Chronic Disease Prevention and Management in Newfoundland and Labrador was released by the Provincial Government in 2011; it is based on the Expanded Chronic Care Model, and includes cancer as a priority area of focus <ul style="list-style-type: none"> ○ The framework outlines examples of initiatives to improve health outcomes for individuals at risk for or living with chronic disease according to the six guiding policy statements of self-management, prevention and awareness, healthcare delivery (organizing and coordinating services), practice guidelines, 	<ul style="list-style-type: none"> • The Chronic Disease Action Plan identified two initiatives that the Government of N.L. was committed to implementing (in 2017 and 2018) to support healthcare providers in helping their patients manage chronic disease <ul style="list-style-type: none"> ○ The first initiative was offering professional development opportunities on self-management and recovery approaches to care to staff in the regional health authorities, as well as to local providers like family 	<ul style="list-style-type: none"> • Improving Health: My Way is a free (provincially sponsored) chronic-disease self-management program, which is open to any N.L. resident living with a chronic condition (including cancer) <ul style="list-style-type: none"> ○ The workshop contains six sessions, which are held once a week over a six-week period ○ Workshops are co-led by trained leaders who live with or care for someone with a chronic condition ○ Workshops are held in each of the four regional health authorities across the province • There is a cancer navigation program available to all N.L. residents through the Cancer Care Program (of Eastern Health)

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	<p>information systems and research, and community action (partnerships)</p> <ul style="list-style-type: none"> ○ The framework provided a foundation for actions to be developed and implemented over several years, with some outcomes achievable in the short-term (one-to-two years) and others in the long-term (five-to-10 years) ● The Chronic Disease Action Plan identified actions that the Government of Newfoundland and Labrador (N.L.) was committed to implementing in 2018 and 2019 to enhance to the effective prevention and management of chronic disease (including cancer) <ul style="list-style-type: none"> ○ The action plan outlines various initiatives under the categories of prevention, self-management and treatment and care ● Gaining Ground: A Provincial Cancer Control Policy Framework for Newfoundland and Labrador was released by the provincial government in 2010; the framework encompasses all aspects of cancer care along the cancer-care continuum <ul style="list-style-type: none"> ○ The framework provides a foundation upon which government, regional health authorities and community-based organizations can build specific action plans ○ There are nine policy directions which form the basis for the specific goals that were to be advanced ○ Policy direction three is coordinating care, under which the goal was to improve the coordination of services along the cancer-care continuum ○ Policy direction four is supportive and palliative care, under which the goal was to develop social policies and initiatives that increase access to supportive care and palliative services 	<p>physicians and community-based pharmacists</p> <ul style="list-style-type: none"> ○ The second initiative was a partnership between the provincial government and the Family Practice Renewal Program, which aimed to establish new supports for physicians who manage complex and chronic conditions ● The Health and Community Services Department website contains resources for healthcare providers to assist in finding mental health or addiction services for their patients ● The provincial Cancer Care website (Eastern Health) provides some resources for healthcare professionals, including: <ul style="list-style-type: none"> ○ Supportive cancer-care guidelines ○ Referral forms and distress screening resource pathways 	<ul style="list-style-type: none"> ○ Navigators are trained oncology nurses, who can support patients from diagnosis through to follow-up and survivorship ○ There are also palliative care nurse navigators and Indigenous patient navigators ● The provincial Cancer Care website (Eastern Health) provides a variety of resources and information for patients and their families, including: <ul style="list-style-type: none"> ○ The Cancer Care Journey booklet, which assists N.L. residents along the cancer journey and contains information on survivorship, palliative care and pain management - this booklet is also offered in First Nations versions ○ A guide on managing cancer-related fatigue ○ Information for accessing nutrition services ○ Information on oncology social workers and how to access them ○ Links to relevant community resources for patients, survivors and their families ○ Information on telehealth/tele-oncology ● The social work team at the Dr. H. Bliss Murphy Cancer Centre offers a seven-week program called Cancer Transitions, Moving Beyond Treatment, which supports patients as they move from active treatment to post-treatment <ul style="list-style-type: none"> ○ Meetings are once a week for seven weeks, followed by a ‘booster session’ which occurs one month after the program ○ The program provides emotional support as well as education about emotional health, well-being, medical management, nutrition and exercise ● Each of the four Regional Health Authorities websites feature cancer-care information (their own, or linked to Eastern Health) as well as information on the specific programs and services they offer
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	<ul style="list-style-type: none"> ○ Policy direction six is access and advocacy, under which the goal was to develop social policies and initiatives that increase cancer patients’ access to care services along the care continuum ○ Policy direction eight is education and training, under which the goal was to develop awareness and continuing education programs for both the public and healthcare professionals within the cancer-control continuum ● The Provincial Cancer Care Program (of Eastern Health) is responsible for providing services to cancer patients in N.L. <ul style="list-style-type: none"> ○ The program is responsible for the operations of the Dr. H. Bliss Murphy Cancer Centre and other regional cancer centres, and the program also works with all regional health authorities to provide treatment, follow-up and supportive care services in various other sites across the province ○ Cancer centers have interdisciplinary cancer-care teams, which send updates to a patient’s family doctor after every visit 		<ul style="list-style-type: none"> ○ Eastern Health: cancer care, programs/services ○ Western Health: cancer care, programs/services ○ Central Health: cancer care, programs/services ○ Labrador-Grenfell Health: cancer care, programs/services ● The Health and Community Services Department website contains information (not specific to cancer) on provincially funded health-service programs for those with disabilities, as well as information on mental health promotion and healthy living, the Medical Care Plan, the Prescription Drug Program and mental health and addictions resources, including provincially funded counselling options, online supports and help lines/navigators
<p>Prince Edward Island</p>	<ul style="list-style-type: none"> ● The PEI Cancer Strategy (most recent 2016-2019) describes recommended actions from the Provincial Cancer Coordination Steering Committee, which includes ensuring standardized follow-up care plans and electronic health records through the cancer-care continuum, collaborating with partners to identify community-based programs and services, expanding psychosocial and wellness programs, and recognizing caregiver burden 	<ul style="list-style-type: none"> ● No information was identified 	<ul style="list-style-type: none"> ● Moving Forward is a free cancer transition program offered by the PEI Cancer Treatment Centre and the Canadian Cancer Society (PEI Division) which provides assistance on follow-up care, nutrition and physical activity, psychosocial and well-being services, and survivorship and community resources (typically three-hour in-person sessions with a limit of 10 people per session) ● As part of the cancer-care continuum, Health PEI developed a cancer patient navigation program that guides cancer patients and their families/caregivers through the continuum of care, including survivorship support programs

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<p>Yukon</p>	<ul style="list-style-type: none"> • Whitehorse General Hospital coordinates the care of people living with cancer in Yukon, and the hospital has a highly specialized and collaborative cancer-care team <ul style="list-style-type: none"> ○ The cancer-care team consists of registered nurses specializing in chemotherapy, general practitioners in oncology, pharmacists and cancer-care coordinators ○ The cancer-care team works closely together with a patient’s oncologist specialist and family physician, including during follow-up ○ Cancer-care coordinators are hospital staff members who provide a free service to patients with cancer and their families, including answering questions/concerns, navigating next steps, locating educational resources, explaining the roles of the healthcare professionals involved in their care, connecting patients to key experts and accessing support services • Walk a Mile in My Moccasins – Advancing the First Nations and Métis Cancer Journey in the Yukon was a joint project (2014-2017) by the Canadian Partnership Against Cancer (CPAC) and the Council of Yukon First Nations (CYFN) that aimed to advance education and training for First Nations patients and healthcare providers <ul style="list-style-type: none"> ○ The priorities and concerns of First Nations cancer patients and survivors were identified ○ Local cancer-control priorities were identified ○ The CYFN created a cancer workbook, <i>Following My Path with Cancer</i>, to provide information about navigating the cancer system in the Yukon, which is available to First Nations patients across the Yukon 	<ul style="list-style-type: none"> • No information was identified 	<ul style="list-style-type: none"> • The care services section of the Government of Yukon website contains resources for caregivers (not specific to cancer) as well as information on the Chronic Conditions Support Program (CCSP) and available exercise programs for people with chronic conditions that are provided through CCSP <ul style="list-style-type: none"> ○ CCSP works with residents of Yukon who live with a chronic condition to provide collaborative chronic care and self-management support ○ While CCSP services focus on chronic obstructive pulmonary disease (COPD), diabetes and hypertension/high blood pressure, the website states that Yukoners of all ages are eligible for the program if they have a chronic condition • The mental wellness section of the Government of Yukon website contains information (not specific to cancer) for accessing adult counselling services, and has information about a caregiver’s support group <ul style="list-style-type: none"> ○ The caregiver’s support group is co-facilitated by a mental health clinician and is hosted at the Canadian Mental Health Association once a month • Whitehorse General Hospital (cancer care centre) has support services for First Nations patients, which include assisting with in-patient care and complex care discharge plans, as well as providing access to mental health services • The Canadian Mental Health Association Yukon Division offers counselling services as well as specific programs for youth, adults and families (not specific to cancer)
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<p>Northwest Territories</p>	<ul style="list-style-type: none"> • Charting Our Course: Northwest Territories Cancer Strategy 2015-2025 is the first cancer strategy in the Northwest Territories (N.W.T.); the strategy was developed by the Department of Health and Social Services <ul style="list-style-type: none"> ○ Goal three in this strategy is improving patient transitions between each stage of the cancer journey, under which a strategic priority is enhancing navigation support systems throughout the cancer journey ○ Goal four is supporting healthcare professionals to communicate within the circle of cancer care, under which there are two strategic priorities: 1) identifying opportunities to improve data flow by accessing information systems and technology, and 2) strengthening cancer prevention and care in primary healthcare service delivery through creating information and tools ○ There are five-year plans included for both of these goals with action items 	<ul style="list-style-type: none"> • No information was identified 	<ul style="list-style-type: none"> • There is a Cancer Navigation Program available to all residents (free service) across the N.W.T. from cancer diagnosis through to palliation and survivorship <ul style="list-style-type: none"> ○ Within the program there are two registered Nurse Navigators and one Oncology Medical Social Worker, who work closely with the patient and their family as well as their healthcare team ○ The navigators improve continuity of care and coordinate care between all members of a patient's healthcare team, facilitate access to healthcare and community services, and provide informational, practical and psychosocial supports ○ There is a program poster and brochure to summarize the program and relevant contacts ○ The navigation program developed a brochure for caregivers • The N.W.T. Health and Social Services Authority created a navigation resource for cancer patients in the N.W.T., which includes sample questions for patients to use in discussing survivorship with their healthcare provider, as well as providing cancer support contacts • The Northern Health Services Network (NHSN) helps N.W.T. residents to coordinate their care and support while receiving medical care in Edmonton; the NHSN also provides discharge coordination • The Government of N.W.T. created the website Let's Talk About Cancer, which contains information on the N.W.T. cancer pathway, a Community Action Toolkit for those interested in organizing a group/activity to address cancer needs in their community, and reports from cancer sharing circles
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			<ul style="list-style-type: none"> • The health and wellness section of the Government of N.W.T. website contains information on patient/client relations (not specific to cancer), which includes information about the Health and Social Services (HSS) System Navigator <ul style="list-style-type: none"> ○ The HSS System Navigator can help residents of N.W.T. by providing information on all the health and social services available in the N.W.T., as well as how to access them • The health and wellness section of the Government of N.W.T. website contains information on the N.W.T. Community Counselling Program (CCP), which is a free service available for all N.W.T. residents (not specific to cancer) <ul style="list-style-type: none"> ○ The CCP provides access to mental health services in all of the regions, with trained counsellors living in 20 communities ○ There is contact information for community counsellors by region • The Inuvik Cancer Support Group holds workshops and group activities in the Inuvik community in N.W.T. in order to break down stigma and open up conversations about cancer for participants (including patients, survivors and caregivers)
Nunavut	<ul style="list-style-type: none"> • According to Canadian Cancer Survivor Network, there is no cancer specialist care available in Nunavut, with most residents traveling to Ottawa Regional Cancer Care Centre through the Ottawa-Baffin Island Program • In an effort to streamline cancer care (generally, and not specific to cancer transition programs or cancer survivorship), the Government of Nunavut aims to coordinate patient care with specially-trained physicians by region 	<ul style="list-style-type: none"> • Children’s Hospital of Eastern Ontario (CHEO) in collaboration with the Government of Nunavut developed cultural competency modules for healthcare providers who are providing care to Inuit people (not specific to cancer survivorship or transition programs) 	<ul style="list-style-type: none"> • No information was identified

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APPENDICES

The following tables provide detailed information about the systematic reviews and primary studies identified in the rapid synthesis. The ensuing information was extracted from the following sources:

- systematic reviews - the focus of the review, key findings, last year the literature was searched, and the proportion of studies conducted in Canada; and
- primary studies - the focus of the study, methods used, study sample, jurisdiction studied, key features of the intervention and the study findings (based on the outcomes reported in the study).

For the appendix table providing details about the systematic reviews, the fourth column presents a rating of the overall quality of each review. The quality of each review has been assessed using AMSTAR (A MeaSurement Tool to Assess Reviews), which rates overall quality on a scale of 0 to 11, where 11/11 represents a review of the highest quality. It is important to note that the AMSTAR tool was developed to assess reviews focused on clinical interventions, so not all criteria apply to systematic reviews pertaining to delivery, financial or governance arrangements within health systems. Where the denominator is not 11, an aspect of the tool was considered not relevant by the raters. In comparing ratings, it is therefore important to keep both parts of the score (i.e., the numerator and denominator) in mind. For example, a review that scores 8/8 is generally of comparable quality to a review scoring 11/11; both ratings are considered “high scores.” A high score signals that readers of the review can have a high level of confidence in its findings. A low score, on the other hand, does not mean that the review should be discarded, merely that less confidence can be placed in its findings and that the review needs to be examined closely to identify its limitations. (Lewin S, Oxman AD, Lavis JN, Fretheim A. SUPPORT Tools for evidence-informed health Policymaking (STP): 8. Deciding how much confidence to place in a systematic review. *Health Research Policy and Systems* 2009; 7 (Suppl1):S8).

All of the information provided in the appendix tables was taken into account by the authors in describing the findings in the rapid synthesis.

Appendix 1: Summary of findings from systematic reviews about educational content and resources to support seamless transitions between cancer programs and primary care

Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
Cancer-survivorship care models (26)	<p>This review included nine studies describing various cancer-survivorship care models.</p> <p>Overall, the results found that there is substantial variation in survivorship care models, with the optimal nature, timing, intensity, format and outcomes of models being uncertain and requiring further research. These models were found to be highly individualized to the institution or setting where they are provided. In addition, it is anticipated that future shortages in the oncology workforce may require the expanded use of nurse practitioners, physician assistants, and shared-care models to deliver survivorship care to a growing number of survivors. Concerns associated with survivorship-care models include payment considerations, adequacy of training, and the potential for lack of coordination and fragmented care.</p> <p>Of all the survivorship interventions described, only three models involving survivorship-care plans explicitly incorporated transition of care into the intervention.</p> <p>Examining the context of survivorship care, it was found that patient characteristics may affect needs for survivorship care. For example, age, race, number of comorbidities, income, and stage of disease may predict unmet survivor need.</p> <p>The type of care preferred by patients may also vary depending on the context. A survey of adult cancer survivors in the United Kingdom suggested that cancer survivors prefer consultant-led (i.e., oncologist or other specialist) care to nurse-led, telephone-based, or family physician-led care. A study of breast cancer survivors in the United States similarly found that visits with oncologists significantly decreased the odds of worrying among survivors compared with visits to primary-care providers. This may reflect survivors' preference for continuity of care and the value they place on relationships with specialists who treat their cancer.</p> <p>Evidence from survivorship-care models was limited, particularly regarding potential advantages of different models, effects on survivors' health outcomes, structural or process barriers to offering survivorship care, evaluation of existing survivorship programs, and costs and benefits of survivorship care. Among the included studies that did provide comparative information on survivors' health outcomes, no significant differences were observed.</p> <p>The authors of the review cite the heterogeneity in program setting, components, timing, healthcare providers involved, and even the very definition of "cancer survivor" as a limitation of the study. The review was also based on a technical brief, which the authors recognize did not capture the entirety of every aspect of survivorship-care models.</p>	2013	7/9 (AMSTAR rating from McMaster Health Forum)	Not reported in detail

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Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
Strategies, personal characteristics, and attitudes associated with culturally competent patient-provider communication in cancer management (27)	<p>This review included 35 studies examining the strategies, personal characteristics, and attitudes associated with culturally competent patient-provider communication in the management of cancer.</p> <p>In this review, various strategies and personal characteristics and attitudes for culturally competent communication were identified and grouped into various themes: healthcare-provider skills, awareness and knowledge, culturally competent healthcare, healthcare providers' personal characteristics and attitudes, and models of effective cross-cultural communication.</p> <p>The theme of healthcare-provider skills primarily encompasses the skills required for culturally competent communication. The literature underscored that healthcare providers should avoid stereotyping and generalizations when managing patient care. The building of critical skills in manoeuvring of the initial medical encounter, building physician-patient rapport, gaining patient trust, engaging with the patient's extended family, addressing patients appropriately according to their cultural preference, and engaging in culturally sensitive communication, were also found to be crucial. The importance of assessment skills was also underscored in the literature, particularly with regards to patient assessment beyond the biomedical aspect.</p> <p>Cultural awareness has also proven to be an essential aspect of delivering culturally competent patient-provider communication. Self-awareness with regard to the provider's own culture, cultural beliefs, health belief systems, spirituality and cultural assumptions, personal biases, and stereotypes is critical to effective delivery of care. The importance of developing interpersonal awareness with regards to the inherent patient-provider power differences, and communication regarding potential differences in cultures, is also underscored in the literature.</p> <p>The importance of acquiring sound factual knowledge and an understanding of various cultural aspects is highlighted in the theme of healthcare-provider knowledge. Factual understanding of the family physician's and patient's respective cultures, health belief systems, decision-making processes, and standards of etiquette critically underlies successful patient-provider communication.</p> <p>It must be noted that culturally competent communication extends beyond the individual provider to the healthcare system as a whole. Culturally competent healthcare systems are agents for the provision of appropriate patient care for diverse population groups that extend beyond addressing individual patient needs, to policy and community level. Specific organizational strategies for culturally competent communication are well represented in the literature, the most common of which are the use of patient navigators and professional translators to facilitate communication.</p> <p>The personal characteristics and attitudes of healthcare providers also contribute to successful patient-provider communication, with the most prominent being the demonstration of respect for cultural diversity and patients' cultural values.</p>	2015	5/9 (AMSTAR rating from McMaster Health Forum)	2/35

McMaster Health Forum

Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
	<p>Models of effective cross-cultural communication have also been cited in some of the documents included in this review. Kleinman’s questions, the LEARN Model, the BELIEF Model, and the Four Habits Model of Highly Effective Clinicians emerged as key findings relating to this theme.</p> <p>The findings of the review provide some insight into various methods of delivering culturally competent patient-provider communication to adult patients diagnosed with cancer. However, the results should be treated with caution as they are largely drawn from low-level evidence, highlighting a lack of high-level research in this study area.</p>			
<p>Efficacy of interventions aiming to improve continuity of cancer care on patient, healthcare-provider, and process outcomes (28)</p>	<p>This review included 51 studies aiming to classify, describe and evaluate the effectiveness of interventions aiming to improve continuity of cancer care on patient, healthcare-provider, and process outcomes.</p> <p>Three intervention models were analyzed in the review: case management, shared care, and interdisciplinary teams. Six additional intervention strategies were used in addition to these models: patient-held records; telephone follow-up; communication and case discussion between distant healthcare professionals; change in medical-record system; care protocols, directives and guidelines; and coordination of assessments and treatment. No significant difference in patient health-related outcomes was found between patients assigned to interventions and those assigned to usual care. A limited number of studies reported psychological health, satisfaction of providers, or process-of-care measures. The main limitations of this review were the various differences between the included studies, especially in their study designs, interventions, participants, patients' phase of care, measured outcomes, healthcare settings, and length of follow-up.</p>	<p>2009</p>	<p>9/11 (AMSTAR rating from McMaster Health Forum)</p>	<p>4/51</p>
<p>Experiences and support services for Indigenous cancer survivors following the completion of cancer treatment (29)</p>	<p>This review analyzed 17 studies in order to assess the experiences and support services for Indigenous cancer survivors following the completion of cancer treatment.</p> <p>Cancer care for members of Indigenous communities must take into consideration cultural needs and social factors, in order to ensure equitable access to care. This review aimed to understand the current state of cancer support for Indigenous cancer survivors, by reviewing experiences from either the survivor’s, family’s or clinician’s perspective. Secondary to this analysis, this review aimed to understand the barriers or enablers to care that may be faced by Indigenous cancer survivors.</p> <p>A number of important factors were reported when exploring the experience of Indigenous cancer survivors. The importance of family was paramount, as these connections serve as a source of emotional support. Fear was a common emotion underpinning the Indigenous cancer survivor experience, as there is sometimes a belief among family that this diagnosis arose as a result of sin and that consequences would continue. Stigma from the community was reported by some as an experience, but many survivors also reported feeling the support of their communities through their recovery. Spirituality was of significant importance to many people through the recovery journey. Quality of life was lower among Indigenous survivors, who reported feelings of isolation, distress and financial burden.</p>	<p>2014</p>	<p>5/10 (AMSTAR rating from McMaster Health Forum)</p>	<p>0/17</p>

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Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
	<p>In light of these experiences, interventions must focus on re-integrating survivors back into families and communities, in order to enhance quality of life and create a network of support. Spirituality may be considered as a key component of the recovery journey of many Indigenous survivors, and thus should be considered as part of the survivorship program.</p> <p>As it stands, current cancer-recovery programs may not cater to the needs of Indigenous survivors. Services should listen to the needs of these survivors and should develop programs that assist in re-integration. Patient-navigator programs may be a potential avenue for additional support and access to care, as they have proven successful among Indigenous populations in the past. Tailoring survivor-care programs to the needs of this community will enhance quality of life and contribute to recovery.</p>			
<p>Efficacy of telephone, print and web-based interventions for physical activity, diet, and weight control among cancer survivors (30)</p>	<p>This review included 27 studies evaluating the efficacy of physical activity, dietary, and weight-control interventions for cancer survivors in which telephone, short-message service, print, and web are the primary methods of delivery.</p> <p>Of the 27 studies in the review, 16 targeted physical activity, two targeted diet, and nine targeted multiple behaviours. Most studies targeted a single survivor group, namely breast cancer. Nineteen of 27 studies found evidence for initiation of behaviour change, with only eight reporting on maintenance and one on cost-effectiveness.</p> <p>Most studies targeted physical activity only, although a notable proportion targeted both physical activity and diet, with five also targeting weight control. Based on a lenient definition to categorize studies as successful (i.e., at least one significant end-of-intervention effect for one behavioural or weight outcome), nearly three-quarters were efficacious. However, when examining studies targeting multiple behaviours, few achieved improvements across all targets.</p> <p>With almost three-quarters of studies using the telephone as the primary means of intervention delivery, the majority of support is for telephone-delivered interventions among cancer survivors. An evident lack of studies using other modalities, particularly newer technologies, was noted. This is in contrast to evidence from the general adult population in which there has been a dramatic increase in trials of interventions using newer communication methods. In particular, there is growing evidence demonstrating short-term, modest effectiveness of SMS-delivered interventions for behaviour change. However, SMS-delivered services offer an as yet unexplored means for both primary delivery of lifestyle interventions for cancer survivors, as well as a potentially cost-effective adjunct to address long-term maintenance following telephone-delivered interventions.</p> <p>Overall, evidence from this review supporting the maintenance of behaviour change and weight loss is somewhat limited, with only one-third of studies evaluating outcomes after the end of intervention. However, similar to adults without cancer, it is likely that cancer survivors will face challenges to maintaining regular physical activity, a healthy diet, and weight. Broad-reach intervention modalities</p>	<p>2013</p>	<p>7/9 (AMSTAR rating from McMaster Health Forum)</p>	<p>3/27</p>

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	<p>appear ideal as they have the potential to offer a cost-effective and more easily accessible means of delivering the repeated contacts necessary to sustain behavioural change.</p> <p>Overall, broad-reach intervention delivery modalities for healthy-lifestyle programs provide a means to meet the needs of a growing and disparate group of cancer survivors, and have strong potential to improve health behaviours and in turn, treatment-related side effects, quality of life and health outcomes.</p> <p>The authors note that this review is limited by the inclusion of studies which were underpowered, some of which were pilot studies. The heterogeneity of outcomes reported across physical activity and diet limited their ability to draw conclusions about the magnitude of intervention effects.</p>			
<p>Exploring the role of family physicians in the provision of follow-up cancer care (12)</p>	<p>This review examined 48 studies to explore the role of family physicians in the provision of follow-up cancer care.</p> <p>There are many benefits to including primary-care providers (family physicians) in cancer treatment, including for reasons of cost-effectiveness, management of side effects and symptoms, and continuity of care. However, the existing role of family physicians in cancer care must be explored, from the perspective of both patients and primary-care providers.</p> <p>From the perspective of the patient, thoughts on the family-physician role were largely influenced by the existing relationship between patients and providers. Patients were more likely to report the expectation of primary healthcare not related to cancer from their family physician. Patients broadly recognized the benefits of family-physician involvement in follow-up care, citing factors such as greater trust, convenience and continuity of care. However, patients also broadly cited the barriers to engaging family physicians for follow-up care. This engagement was reported to be influenced by a lack of solid relationship, poor communication and coordination, issues with diagnosis/treatment, and poor access to facilities. Building on these barriers, patients still reported a desire to engage their family physician in care. Patients suggested that family physicians be involved in the management, coordination and reporting aspects of care, as well as providing emotional and social support.</p> <p>From the perspective of the family physician, significant differences in involvement were noted between urban, rural and remote family physicians – level of involvement varied depending on the needs of a family physician’s population. Family physicians generally viewed themselves as advocates, a role which was more likely for rural and remote family physicians. The types of care reported by family physicians as being of focus included general medical care, comorbid management, psychosocial care, and management of pain and other side effects. Family physicians pointed to a number of factors that could facilitate their involvement in follow-up cancer care, including enhanced communication between primary- and tertiary-care providers and the use of electronic records. Barriers to care provision were identified as miscommunication, loss of contact with patients, uncertainty of role, and lack of training and information. Family physicians suggested that their role could be improved by addressing these barriers and enhancing the provision of emotional support and symptom relief. Further, a study of</p>	<p>2015</p>	<p>7/9 (AMSTAR rating from McMaster Health Forum)</p>	<p>8/58</p>

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	<p>Canadian family physicians indicated that specialist follow-up was crucial in order to keep patients in the system.</p> <p>Taken together, this evidence indicates that some of the responsibility for follow-up cancer care should be redirected from the tertiary sector to the primary sector. In order for this transfer to be successful, guidelines must be provided and roles must be outlined.</p>			
<p>Examining the impact of multidimensional rehabilitation programs on physical and psychosocial health outcomes in adult cancer survivors (9)</p>	<p>Increases in the number of people surviving cancer has necessitated the development of ongoing treatment programs. Survivors of cancer may experience adverse physical and psychosocial effects, and access to support becomes difficult after the completion of treatment. Multidimensional rehabilitation programs include physical and psychosocial interventions aimed at enhancing the knowledge, coping behaviour, self-efficacy, and quality of life among persons who have survived cancer. The review examined the effect of multidimensional rehabilitation programs on a range of physical and psychosocial outcomes.</p> <p>The selected studies examined models of care that were categorized as having either a multidimensional or unidimensional focus.</p> <p>Interventions with a multidimensional focus aimed to improve functioning across both physical and psychosocial domains. The evidence of efficacy among these programs was limited in the current review. Three studies demonstrated physical and psychosocial benefits of programs. The first study combined cognitive behavioural therapy with exercise therapy to enhance the quality of life among nasopharyngeal cancer patients. This intervention indicated positive outcomes among physical, cognitive, emotional, fatigue, and quality-of-life measures. Similarly, the second study combined a stress-management program with physical activity to improve energy levels, quality of life, fitness and distress among breast cancer survivors. Improvement was seen on outcomes of fatigue, energy levels and emotional distress. The third study implemented a social cognitive model, including group discussions, supervised exercise, home-based exercise, and counselling sessions with an exercise specialist. Improvements were seen across measures of physical fitness and psychosocial measures among breast cancer survivors. However, bias among all three of these studies was assessed as moderate or high. None of the remaining multidimensional programs indicated success among physical and psychosocial measures.</p> <p>Four of five unidimensional programs indicated significant outcomes for the stated aim of the given program. It should be noted, however, that the majority of the studies indicating significance had the goal of improving physical outcomes. Improvements in physical outcomes across these studies included an increase in physical activity and lifestyle behaviours such as diet quality. Only one unidimensional study aimed to improve psychosocial outcomes; this study indicated that participants who had received information on “cancer, diet and exercise” demonstrated improved mental health, fewer interpersonal conflicts, improved self-efficacy, and reduced distress. However, similar to other unidimensional studies in this review, this study had a high risk of bias.</p>	<p>2012</p>	<p>11/11 (AMSTAR rating from McMaster Health Forum)</p>	<p>1/11</p>

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	<p>Given the diversity of the studies included in this review, it was not possible to assess the effectiveness of multidimensional rehabilitation programs in improving physical and psychosocial outcomes. The majority of participants had received a diagnosis of either prostate or breast cancer. There was an under-representation of older participants, people with lower education or people of lower socio-economic status, limiting the generalizability of findings. However, the results suggest that multidimensional rehabilitation programs had a positive impact on physical outcomes among adult cancer survivors. Unidimensional programs yielded greater success among targeted outcomes, and programs that targeted cancer site-specific diagnoses did not demonstrate advantages over programs for people with mixed diagnoses. The evidence suggests that patients may benefit from choosing a program that matches their specific needs.</p>			
<p>Models of care that aim to improve the coordination of cancer treatment between primary-care and oncology-care providers (13)</p>	<p>This review examined 22 studies in order to evaluate models of care that aim to improve the coordination of cancer treatment, specifically for adults with breast and/or colorectal cancer, between primary-care and oncology-care providers.</p> <p>For people diagnosed with cancer, primary care is often the first and most frequent point of contact with the health system. However, in order to enhance continuity and quality of care, the coordination of treatment between primary- and oncology-care providers is essential. The eligibility of articles for this review did not depend on any specific set of outcomes; however, patient outcomes such as survival, quality of life, and side effects of treatment were prioritized. This review included five systematic reviews, six randomized controlled trials (RCTs), and 11 non-randomized studies.</p> <p>The systematic reviews chosen for analysis did not support any one model, largely due to the heterogeneity of outcomes and overall low quality of the studies. The most notable result from this literature was the finding that primary care and nurse-led care are equivalent models in the post-surgical period for patients with colorectal cancer, and following treatment in patients with breast cancer. All studies indicated that better quality research must be pursued in this area.</p> <p>Of the six RCTs chosen for review, many demonstrated risk of bias. These studies did not indicate any significant changes in the measured outcomes resulting from a specific model of care.</p> <p>Of the 11 non-randomized studies included in this review, eight were of serious risk of bias and three were at moderate risk of bias. While these studies examined a range of care models, interventions and outcomes, all results were inconclusive.</p> <p>The lack of findings presented in this review indicated two conceptual issues with the existing research. First, the studies included in this review did not provide sufficient systematic rationale for the model or intervention being examined. Second, the evaluation of the model at hand was often a secondary objective of the study, which led to inconsistent monitoring and analysis. Methodological concerns such as small sample sizes, bias and lack of clarity were prevalent across studies.</p>	<p>2015</p>	<p>11/11 (AMSTAR rating from McMaster Health Forum)</p>	<p>5/22</p>

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	<p>Taken together, the inconsistencies and lack of definitiveness demonstrated by these studies indicates that little progress has been made in this field of research. In order to develop policies that strengthen continuity of cancer care across primary and oncological providers, high-quality research must be conducted.</p>			
<p>Methods of follow-up care for survivors of childhood cancer (31)</p>	<p>This paper reviewed 4,010 articles to identify studies that evaluated methods of follow-up care for survivors of childhood cancer. This search yielded no comparative studies, indicating a need for this focus on future research efforts. However, this paper retained eight papers from this search in order to reflect current evidence.</p> <p>While the review of these eight studies did not lead to any overall conclusions as to clinical benefits or perceived patient needs, this review did yield a number of important outcomes. A number of different clinical models were examined in these studies.</p> <p>A number of these clinical models explored provision of care that extended past hospital-based clinics. For instance, one study found that targeting high-risk patients to encourage attendance in follow-up clinics led to increased knowledge among patients, and helped to identify areas of further intervention. A shared-care model in the Netherlands, combining hospital clinics with primary care, was found to be feasible and acceptable to patients and primary-care providers. A multidisciplinary clinic was found to enhance clinical efficiency, while providing greater satisfaction to families.</p> <p>A number of the studies in this review focused on hospital-based clinics. A long-term follow-up hospital-based clinic that focused on transferring care from parents to young adults contributed to patient satisfaction, while pointing to patients who preferred seeing a family physician rather than being seen in a hospital-based clinic. A study on the perspectives of survivors and families who had attended a survivorship clinic illustrated that there were a number of perceived health benefits of follow-up care. These included late-effects care, personal relationship with the nurse, and health maintenance. One hospital-based clinic offered support to young adults from a pediatric oncologist, endocrinologist and late-effects special nurse. Clinical care, such as checking for symptoms and developments, was generally rated as more important in this scenario, although supportive care was rated highly among patients with more symptoms and poorer mental health. Finally, a study examining predictors of patient satisfaction in a traditional pediatric late-effects clinic and a multidisciplinary adult clinic found that survivors were satisfied with care regardless of group. Patients who understood the clinical nature of these follow-ups were more satisfied than those who expected psychological support.</p> <p>Taken together, the outcomes of these eight studies were based largely on patient- or parent-reported data. Clinical care was highly valued among survivors, and supportive care was seen as more important by survivors who had greater clinical needs. Ultimately, however, this systematic review did not identify any studies that presented comparative data that evaluated methods of follow-up care for survivors of childhood cancer. The results of this review suggest that further research is crucial in exploring models of care that best support survivors of childhood cancer.</p>	<p>2010</p>	<p>6/10 (AMSTAR rating from McMaster Health Forum)</p>	<p>1/8</p>

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<p>Impact of health information technology that supports patient-centred care on a number of health outcomes (14)</p>	<p>This paper reviewed 327 studies to assess the impact of health information technology that supports patient-centred care on a number of outcomes. Health information-technology applications included tools such as decision support, telemedicine, and tools for patient self-management. Components of patient-centred care included the coordination and integration of care and clinician-patient relationships. These outcomes included healthcare processes, clinical outcomes, intermediate outcomes such as satisfaction and knowledge, decision-making and communication, and access to information. Further, this review aimed to explore barriers and facilitators in health information-technology use, and gaps in evidence that may inform future research.</p> <p>First, this study reviewed articles addressing the impact of information-technology applications that address patient-centred care on a range of outcomes. This review found that health information-technology applications had a positive effect on process outcomes such as compliance with standards of care and use of healthcare resources. Clinical outcomes were also improved by health information-technology applications that enhanced patient-centred care, with telehealth applications and care-management tools being most frequently cited as positive tools. The studies under review did not consistently measure intermediate outcomes, such as satisfaction and knowledge. While it is difficult to summarize the impact of information technology on intermediate outcomes, the impact was found to be positive. This review found that studies reported that health information technology had a positive outcome on the responsiveness to individual patient needs and preferences. Telehealth was most frequently cited as the application that supported this outcome. Finally, health information technology was found to have a positive impact on improving shared decision-making in the patient-clinician context. Decision-making applications were most often cited as having positive effects on this outcome.</p> <p>Following the study of health information technology on various outcomes, this review examined the barriers and facilitators that affect the use and implementation of health information-technology applications. Barriers to utilizations included poor usability and issues with access due to factors such as age, socio-economic status and education. Logically, poor computer literacy skills negatively affected health information-technology use. Physicians cited concerns of added work and issues with implementation, and all users expressed concern over confidentiality. High satisfaction, usefulness and efficiency are factors that enable use of health information technology.</p> <p>The knowledge and evidence deficits that inhibit the implementation of health information technology were examined in this review. While most evidence focused on outcomes, greater attention must be devoted to the effects of health information technology on responsiveness to needs of unique individuals, and the cost and sustainability of these interventions. Further, there is a lack of evidence examining how health information technology may promote patient-centred care based on racial background, education, socio-economic status and age.</p> <p>This review concluded that all stakeholders must have information about the usefulness and applicability of health information-technology applications. While health information technology that supports</p>	<p>2010</p>	<p>9/10 (AMSTAR rating from McMaster Health Forum)</p>	<p>15/327</p>

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	patient-centred care was found to have a positive impact across a number of outcomes, more studies are needed to diversify and develop these findings.			
Use of technology in cancer care follow-up (32)	<p>This review examined 17 studies exploring the use of technology in cancer care follow-up. This review posited that current models of cancer follow-up care, which are generally in-person visits focused on monitoring disease and effects of treatment, are likely to become unsustainable. While this care is valued by patients, the number of cancer diagnoses is growing and certain groups of patients, such as those who live in rural areas, may be unable to access cancer-centre care. Taken together, these factors merit study into modern models of cancer follow-up care.</p> <p>The impact of technology in follow-up care was evaluated across a number of factors, including patient acceptability/satisfaction, clinical safety, health-related quality of life, and health economic outcomes. Patients reported satisfaction with technological support, such as telephone calls, across studies. In some cases, this type of intervention was preferred. No significant differences were found in the study that examined clinical safety across technological intervention and control groups. Studies on health quality of life suggest that quality of life may improve in patients who are given technological support in the follow-up period. Some studies indicated that monitoring symptoms via a telephone system yielded the reporting of more severe symptoms when compared to a nurse-assisted program. Taken together, the studies examining health quality of life indicated that there were no significant differences in psychological distress or quality of life between groups. Lastly, studies of health economic outcomes indicated that telephone follow-up services were costlier, however, these costs were anticipated to decrease after staff training, and were overall less costly for patients.</p> <p>This review indicates the potential for the use of technology in cancer care follow-up. However, further research is required to deduce the cost-effectiveness of this model of care.</p>	2014	6/10	2/16
Patient views on patient-held records to examine the effectiveness, benefits and drawbacks of these records (51)	<p>This review examined 10 papers in order to synthesize patient views on patient-held records and to examine the effectiveness, benefits and drawbacks of this form of record. Patient-held records are used across healthcare systems and are designed to facilitate communication between patients and health professionals. Three major themes emerged from this work pertaining to patient-held records: practical benefits, psychological benefits and drawbacks.</p> <p>The practical benefits of the patient-held records examined the usefulness of this type of record to the patient. Patients widely reported value in having personal records, to track health, remember events and share information. The sharing of information using patient-held records was seen as valuable across patients and healthcare providers.</p> <p>Psychological benefits arising from the use of patient-held records included empowerment through the ability to ask questions and challenge assumptions, to be actively involved in care, and the sense of having more control as a patient.</p>	2013	3/9 (AMSTAR rating from McMaster Health Forum)	0/10

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	<p>While practical and psychological benefits arise from the use of patient-held records, negative impacts were also seen across some studies in this review. Some patients saw the use of patient-held records as the allocation of unwanted responsibility. The ineffectiveness of this type of record was touched upon, with the lack of awareness across staff being a barrier to use.</p> <p>Given the potential benefits of patient-held records use, this review concluded that in order to yield these benefits the use of patient-held records must be embedded across health systems. Further, more robust qualitative studies examining patient experience are required to gain insight into patient perspectives.</p>			
<p>Telehealth interventions focused on family-caregiver outcomes (33)</p>	<p>This review examined 65 studies in order to explore telehealth interventions that focused on family-caregiver outcomes.</p> <p>Family caregivers are informal persons who take care of loved ones, a role that has been found to adversely affect physical and psychological health, among other factors. Technology such as telehealth has been used to support coping and healing, but few studies have examined the effect of telehealth interventions on family caregivers. The review examined studies in which there were six main categories of telehealth interventions: education, consultation, psychosocial/cognitive behavioural therapy, social support, data collection and monitoring systems, and clinical-care delivery.</p> <p>The majority of the studies under review indicated an improvement in caregiver outcomes following technological interventions. These outcomes included improved psychological health, satisfaction with telehealth, social support, coping, communication, cost saving, physical health, and productivity. While a minority (5%) of studies indicated that caregivers using telehealth interventions did not experience significant improvement in comparison to face-to-face care, the effects of both types of care were similar.</p> <p>This review examined studies that found a positive effect of technological interventions on caregiver outcomes.</p>	<p>2014</p>	<p>4/9 (AMSTAR rating from McMaster Health Forum)</p>	<p>8/65</p>
<p>Evidence for use of survivorship-care plans for cancer survivors (34)</p>	<p>This paper reviewed 10 studies to examine the evidence for the use of survivorship-care plans for cancer survivors.</p> <p>Survivorship-care plans were recommended by the Institute of Medicine in 2006 to address the many issues that cancer survivors face, including the late effects of treatments, long-term emotional effects, and tumor recurrence. The review examined the effect of survivorship-care plans on outcomes of health-related quality of life, distress, survivor satisfaction with care plan, understanding of information in the survivorship-care plan, satisfaction with care, uptake of recommended screening, and feasibility.</p> <p>No major differences were found in health-related quality of life – however, one study found that the use of a survivorship-care plan in a follow-up care package resulted in fewer unmet needs among patients. There was some evidence that survivorship-care plans may reduce distress in cancer survivors;</p>	<p>2013</p>	<p>5/10 (AMSTAR rating from McMaster Health Forum)</p>	<p>2/10</p>

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	<p>however, other evidence has suggested that distress may be higher due to increased worry about one's health and negative memories that may be triggered by reading the survivorship-care plan. Survivor satisfaction with care plans was very high across studies, accompanied by positive feelings towards the survivorship-care plans. Studies demonstrate good understanding of survivorship-care plan content among survivors. Evidence suggests that patient satisfaction with medical care does not vary greatly based on the use of survivorship-care plans. The use of survivorship-care plans may promote the uptake of recommended screening. While survivorship-care plans are feasible, they are resource intensive, taking hours to develop and coming at a cost to health resources.</p> <p>The unclear benefits of survivorship-care plans drawn from this review may be due to other factors that prevented the detection of these benefits. Patient feedback about survivorship-care plans was extremely positive, with survivors reporting value to the information provided. The fact that some studies point to the potential distress that may arise due to survivorship-care plans points to the fact that some patients may be better suited to this content than others.</p> <p>Going forward, there is a need for more long-term data examining the impacts of survivorship-care plans, in order to examine the potential benefits of use among survivors.</p>			
Effectiveness of patient navigation on healthcare-utilization outcomes (15)	<p>This review examined 25 studies to assess the effectiveness of patient navigation on healthcare-utilization outcomes.</p> <p>Patient-navigation programs can decrease barriers to care and improve survival among patients, however, evidence remains mixed on the effectiveness of patient navigation. This review sought to evaluate the effectiveness of patient navigation on measures of health-utilization outcomes such as health screening rates, attendance to care events, adherence to cancer care follow-up treatment, and completion of an appointment for a diagnostic resolution.</p> <p>Patient navigation was found to significantly increase the likelihood of a patient attending health screening. The majority of the studies in this review examined cancer screening, indicating that patient navigation was effective for screenings such as Pap tests, mammograms, colonoscopies and endoscopies.</p> <p>Patient navigation was also effective in promoting attendance to care events, such as cardiac rehabilitation after a cardiac event. Participants were almost three times more likely to attend these events if they were part of a patient-navigation intervention.</p> <p>The impact of patient navigation on outcomes of adherence to follow-up treatment and completion of an appointment for a diagnostic resolution indicated promising potential for this intervention.</p> <p>The majority of participants in these studies were ethnic minorities – patient navigation was initiated as an intervention for marginalized minority populations and continues to be an effective mechanism for</p>	2015	9/11 (AMSTAR rating from McMaster Health Forum)	1/25

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	reducing barriers to care. The majority of participants in these studies were women; future research should consider the effects of patient navigation for men.			
Role of navigators in supporting chronically ill older adults through healthcare transitions (35)	<p>This review examined 15 articles in order to assess the role of navigators in supporting chronically ill older adults through healthcare transitions. Transitions are exceptionally difficult for older persons, and any medical episodes often result in many interactions with the health system due to the multiple morbidities that these patients often have.</p> <p>Outcome measures of navigator programs fell into three general categories: economic benefits, psychosocial benefits, and quality-of-life benefits. Of the nine navigator programs identified by this review, five reported positive economic outcomes. This may have been due to reduced readmissions and hospital days in intervention groups. Two studies reported higher patient satisfaction after involvement with the intervention. Finally, five of the included studies reported increased patient quality of life and functionality. The emphasis on the post-acute care period for older patients may have eased the transition back into daily living, hence contributing to an improved overall quality of life.</p> <p>The results of this review indicate that special care must be provided to older adults in the healthcare system in order to preserve their desires while health declines. This review indicated mixed results in terms of navigation-program effectiveness; while greater patient satisfaction and quality of life was reported, some studies revealed no effects and one study reported higher use of emergency health services by these patients. However, the promising positive results indicate that navigator roles may help divert older patients from higher levels of care, and in doing so improve patient lives. Future research must further explore the role of the navigator, considering economic and systems impacts.</p>	2011	5/10 (AMSTAR rating from McMaster Health Forum)	2/9
How nurse-led follow-up breast cancer interventions have been evaluated, with a specific focus on patient outcomes and cost-effectiveness (36)	<p>This review examined 13 articles in order to explore how nurse-led follow-up interventions in breast cancer have been evaluated, with a specific focus on patient outcomes and cost-effectiveness.</p> <p>Breast care nurses are key figures in the care pathway for women with breast cancer. Breast care nurses provide supportive care that improves quality of life for patients with cancer, including supporting the physical, psychological and social needs of patients. As survival rates increase, nurse-led breast cancer follow-up has become an increasingly common route of care as opposed to traditional hospital outpatient clinics. This review explored how nurse-led interventions have been evaluated, focusing on patient outcomes such as quality of life, psychosocial support and cost-effectiveness.</p> <p>The studies included in this review indicated that nurse-led interventions in the follow-up stage of breast cancer contributed positively to quality of life among patients. Significant improvements in symptoms such as constipation, nausea and pain were also seen among patients involved in this intervention. Patients involved in nurse-led care experienced similar levels of anxiety to patients not involved in this form of intervention, but nurse-led programs led to higher levels of satisfaction than hospital clinics.</p> <p>In terms of outcomes of psychosocial support, no significant differences were found along measures of mood disturbance, cancer-related worry, or symptom distress when nurse-led groups were compared to</p>	2013	6/10 (AMSTAR rating from McMaster Health Forum)	1/13

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Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
	<p>control groups. However, patients enrolled in nurse-led follow-up studies reported more perceived benefits, and experienced less worry about their disease-related problems.</p> <p>Patients enrolled in nurse-led interventions reported fewer financial problems, and telephone follow-up visits yielded lower cost. However, telephone-led interventions should be paired with educational group programs in order to benefit patient quality of life while balancing cost-effectiveness.</p> <p>This review found promising results for the effectiveness of nurse-led follow-up breast cancer care. These interventions contributed to continuity of care and psychosocial support, however, future research should focus on survival, recurrence, patient well-being and cost-effectiveness, as no concrete conclusions on these outcomes could be drawn from this review.</p>			
Effectiveness of psycho-educational interventions on the management of symptom clusters in patients with cancer (16)	<p>This review included four studies evaluating the effectiveness of psycho-educational interventions on managing symptom clusters in patients with cancer.</p> <p>The review found that symptom clusters seemed to improve with the provision of psycho-educational interventions. A meta-analysis showed significant improvement in functional performance. The evidence that psycho-educational interventions could alleviate cancer symptom clusters is encouraging but inconclusive in this review. The review also suggests a promising role of psycho-educational interventions in managing cancer symptom clusters.</p> <p>Of the four included studies, three showed statistically significant improvement in symptom clusters for the intervention groups. One study had a significant reduction in symptom severity for four of five symptom clusters, except the affective symptom clusters (nervousness, anxiety and stress). Significantly improved symptom clusters in these three studies included breathlessness, fatigue, and anxiety; pain, fatigue, and sleep disturbance; and gastrointestinal cluster (nausea, vomiting, stomach pain, loss of appetite, and diarrhea); cognitive cluster (diminished concentration, memory problems, and fatigue); functional cluster (muscle aches and joint aches); and mucositis cluster (mouth pain, throat pain, and difficulty swallowing). All three studies adopted progressive muscle relaxation as one of the intervention components, with one adding patient education. Furthermore, interventions of the three studies were all provided by nurses, in an individual format and during the active treatment period; one study continued the intervention after the completion of treatment. Duration of the interventions lasted for two to 12 weeks.</p> <p>Symptom clusters in the studies were found to be improved, however, the results did not reach statistical significance. These symptom clusters included gastrointestinal cluster (nausea, vomiting, lack of appetite, shortness of breath, dry mouth and numbness), cognitive/psychological cluster (distress, sadness, pain and remembering), and fatigue cluster (fatigue, disturbed sleep and drowsiness). This study combined meditation with social support as its intervention, which was delivered by a clinical psychologist and in a group format. The intervention was conducted after the completion of cancer treatment and lasted for six weeks.</p>	2014	8/10 (AMSTAR rating from McMaster Health Forum)	0/4

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Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
	<p>With regard to functional performance, the pooled results of two studies revealed a statistically significant improvement in symptom interference with daily living for the intervention group. Functional ability was also found to be enhanced over time in the intervention group. None of the included studies measured the outcome of quality of life; thus, the effect of psycho-educational interventions on quality of life in patients with cancer is unknown in the situation of studying symptom clusters.</p> <p>Unfortunately, the small sample size of included studies in this review prevented any definitive conclusions from being made.</p>			
<p>Electronic symptom reporting between patient and provider for improved healthcare service delivery (17)</p>	<p>This review included 32 studies exploring electronic symptom reporting between patients and providers to improve healthcare service quality.</p> <p>Findings of the review were divided into four categories based on effects: in terms of consultation support, monitoring with clinical support, self-management, and therapy.</p> <p>Effects in consultation support were categorized by the Institute of Medicine’s quality domains. In the consultation support category, all studies provided patient-centred care, ensuring that patient-reported symptoms guided the clinical decisions. Except for the study where nurses coached patients, symptom reporting was generally conducted while the patient was present at the clinic, and a summary of the reported symptoms was made available to the physician. These summaries were found effective in identifying and prompting discussion of troublesome symptoms, which made it possible to focus the conversation on issues relevant to the patient’s problems. The electronic symptom-reporting systems also showed positive outcomes for patient symptom distress, symptom management, and health-related quality of life.</p> <p>In terms of effects in monitoring with clinical support, only two monitoring studies reported benefits for patients, while nearly no benefits for the health system and none for the health professionals were reported. The two studies identifying health benefits for the patient focused on asthma outcomes. Both studies included a strong self-management element. In one of the studies, some side effects for the healthcare system and patient need to be resolved. No healthcare costs or healthcare-system benefits were identified in any of the monitoring studies: there was no improvement in total number of home-care services or informal social support, number of consultations, occurrence of emergency-room visits, hospital or specialist team use, number of hospital admissions, or mean costs per patient.</p> <p>In terms of self-management, all self-management interventions were found equally effective to or better than the control option, with one exception. Substantial benefits for patients, and partly also for health professionals and healthcare systems, have been documented in this area. For health professionals, a decrease in resource utilization was reported. At the healthcare-system level, healthcare cost benefits were analyzed and reported for internet treatment of panic disorder, which was nearly four times cheaper than group treatment.</p>	<p>2011</p>	<p>8/10 (AMSTAR rating from McMaster Health Forum)</p>	<p>0/32</p>

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Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
	<p>With regards to therapy, patients receiving email therapy for complicated grief improved significantly relative to participants in the waiting list condition, and were quite satisfied with the treatment. Only 20% missed face-to-face contact with a therapist, and 85% had positive attitudes toward being treated via the internet instead of face-to-face.</p> <p>The authors note that some of the articles included in the review had sources of bias, which may have had an impact on its findings. As well, the presence of unclear statistical analyses may have hindered the credibility of the results.</p>			
Self-management and self-management support as an approach for long-term condition management (37)	<p>This review included 41 studies exploring self-management and self-management support as an approach for long-term condition management.</p> <p>The majority of evidence included in the review related to diabetes. Few studies directly focused on stakeholders' views concerning desired self-management outcomes; the majority of evidence was derived from studies focusing upon the experience of self-management. The views of healthcare commissioners were absent from the literature. Authors identified that self-management outcomes embrace a range of indicators, from knowledge, skills, and bio-psychosocial markers of health through to positive social networks.</p> <p>One of the key limitations of the review lies in the fact that no included study explicitly focused on the outcomes of self-management. Further research is therefore required to build on these early findings from the existing literature to identify which outcomes of self-management are important from the perspectives of differing stakeholders.</p>	2014	6/10 (AMSTAR rating from McMaster Health Forum)	2/41
Impact of telehealth interventions to support self-management on disease control and healthcare utilization (38)	<p>This review included 53 systematic reviews examining the impact of telehealth interventions to support self-management on disease control and healthcare utilization.</p> <p>Of the 53 systematic reviews, six related to diabetes, nine related to heart failure, eight related to asthma, eight related to COPD, and three related to cancer. Findings varied between and within disease areas. The highest-weighted reviews showed that blood glucose telemonitoring with feedback and some educational and lifestyle interventions improved glycemic control in Type 2, but not Type 1, diabetes, and that telemonitoring and telephone interventions reduced mortality and hospital admissions in heart failure, but these findings were not consistent in all reviews. Results for the other conditions were mixed, although no reviews showed evidence of harm. Of the three reviews that contained cancer randomized controlled trials (RCTs), two analyzed physical outcomes. One (RCT of moderated internet-based self-help for breast cancer patients) reported no evidence of improved quality of life or physical/emotional well-being. The other review, which analyzed internet-based education programs that link patients with clinicians, found no improvement in quality of life in two RCTs, but found an improvement in symptom scores in one RCT.</p> <p>Analysis of the mediating role of self-management, and of components of successful interventions, was limited and inconclusive. More intensive and multifaceted interventions were associated with greater improvements in diabetes, heart failure and asthma.</p>	2016	5/9 (AMSTAR rating from McMaster Health Forum)	6/53

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Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
	<p>As this meta-review considered only six long-term conditions, the authors conceded that different conclusions may have been reached had a different set of conditions been selected. In addition, not all the included systematic reviews explicitly focused on self-management.</p>			
<p>Efficacy of group-based self-management programs to improve physical and psychological outcomes in patients with cancer (39)</p>	<p>This review included six studies examining the efficacy of group-based self-management programs for patients with cancer.</p> <p>Group-based self-management programs were found to improve physical function. No significant results were found between groups for quality-of-life and physical-activity-level outcomes. Group-based self-management programs for individuals with cancer resulted in improvements in physical outcomes.</p> <p>Unfortunately, considerable heterogeneity was found between the included studies and the quality of evidence was very low for all main outcomes. Another limitation of this review is the small number of included studies, all of which had a high risk of bias and a very low quality of evidence. Blinding of participants and assessors was also poorly executed in the included studies.</p>	2014	7/11 (AMSTAR rating from McMaster Health Forum)	0/6
<p>Efficacy of self-management education interventions to support patients with cancer (40)</p>	<p>This review included 42 studies examining the effectiveness and essential components of self-management education interventions to support patients with cancer.</p> <p>Narrative qualitative synthesis suggested that self-management education interventions improve symptoms of fatigue, pain, depression, anxiety, emotional distress and quality of life. Results for specific combinations of core elements were inconclusive. Very few studies used the same combinations of core elements, and among those that did, results were conflicting. Thus, conclusions as to the components or elements of self-management education interventions associated with the strength of the effects could not be assessed by this review.</p> <p>Variations in outcome measures, study design, and execution of interventions precluded a meta-analysis of effects and presented as one of the key limitations of the review. In addition, scarce details were provided in many studies regarding the various interventions carried out. The inclusion of only English studies is another limitation of this review.</p>	2015	7/10 (AMSTAR rating from McMaster Health Forum)	0/42
<p>Assessing the effects of home-based, multidimensional survivorship (HBMS) programs on maintaining or improving quality of life for breast cancer survivors (18)</p>	<p>This review included 22 randomized controlled trials (RCTs) and four quasi-RCTs that assessed the effects of HBMS programs relating to quality of life in breast cancer survivors. Intervention components were categorized into four groups: educational and psychological; educational and physical; physical and psychological; and educational, physical and psychological. Most studies used usual care (i.e., routine medical follow-up) as the comparator, while a few used a lower level or different type of intervention or attention control. The following questionnaires were used to assess quality of life: Functional Assessment of Cancer Therapy-Breast (FACT B), European Organisation for Research and Treatment of Cancer Quality of Life C30 (EORTC C30), Quality of Life (QoL) Breast Cancer and SF36.</p> <p>Results as measured by the FACT-B and EORTC 30 indicated that HBMS may increase breast cancer-specific quality of life and global quality of life immediately after the intervention. However, there was</p>	2016	11/11 (AMSTAR rating from McMaster Health Forum)	1/26

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Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
	<p>no evidence of difference in quality of life when measured by QoL Breast Cancer or SF36. Results as measured by the FACT-B, the EORTC 30 and the QoL Breast Cancer indicated that HBMS may increase breast cancer-specific quality of life and global quality of life at one to three months after the intervention. There was little to no difference in quality of life between groups at six and 12 months. Findings also reveal that compared to the control, HBMS programs may decrease anxiety immediately after the intervention. However, the effect of the intervention did not persist at four to six months. There was no improvement in depression immediately after intervention or at follow-up. Lastly, it was reported that HBMS programs may decrease insomnia and fatigue immediately after intervention.</p> <p>A possibility limitation of this study is potential for the robustness of the findings of included studies being compromised due to detection and performance bias, as well as by the subjective nature of quality-of-life reporting.</p>			
Assessing the role hospitals can play in the downstream collaboration for chronic-disease management (19)	<p>This review included 32 articles and synthesized the documented advantages and disadvantages of hospital interference in the chronic discourse for chronically ill patients. In synthesizing the evidence about the roles of hospitals in chronic-disease management, this study outlines different clinical field types, diverse methodologies, and multiple outcome measures. The results are structured following four large domains, including: the impact of transitional-care (TC) interventions, the role of specialized care settings, the comparison of inpatient and outpatient care, and the effect of chronic-care coordination on patient experience.</p> <p>Fifteen papers evaluated the effectiveness of TC interventions initiated within the hospital, and all but one compared the intervention with usual care. Several papers demonstrated lower readmission rates and lower hospital costs for the intervention patients compared to the control subjects, while some other studies found no difference in hospital readmission rates. Some other positive outcomes cited to be associated with TC interventions include high patient confidence in managing their condition and understanding their medical regimen, improvements in quality of life after discharge, and patient satisfaction. One study found a positive change in hospital culture since TC intervention implementation; however, another study highlighted major issues that have an impact on the effectiveness and sustainability of the TC model (e.g., patient factors, local system issues).</p> <p>Relating to results about specialized care settings, three studies examined the effect of interventions at a heart failure clinic (component of hospital) compared to usual care. The results for such clinics showed lower hospitalization duration, fewer hospital readmissions, lower mortality rates, and clinical outcome improvements. It was also found that among the intervention group, cost of care was reduced, and quality of life was improved. Relating to results comparing inpatient versus outpatient care, three articles that compared effectiveness of long-term institutional care versus home-based care had mixed results. One study reported that home-care for patients was more expensive and less effective; however, another study found that home-based care was more affordable. Some studies examined the effectiveness of follow-ups for chronically ill patients in secondary versus primary care. Relating to cancer, one study</p>	2016	8/10 (AMSTAR rating from McMaster Health Forum)	2/32

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Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
	<p>showed that patient satisfaction was higher for patients who had cancer-care follow-ups with their general practitioner rather than in hospital outpatient clinics.</p> <p>One study relating to patient experiences and expectations in continuity of care for diabetes showed that most problems occurred at transition points. For example, a lack of cross-boundary continuity between healthcare sites or providers, or lack of flexibility in coordination when there are major changes in patients' needs. One study showed there was positive association between relational continuity and long-term specialist led-care. This study also showed that access to care and flexibility issues were barriers and facilitators of continuity.</p> <p>Continuity of care was determined to be very important, which supports the need for more research on hand-overs in healthcare processes. Some studies showed the importance of case managers and patient care teams in transitional interventions. General practitioners were identified as playing coordinating roles; however, there were some negative patient perceptions about primary care versus secondary care. Namely, that primary care is less efficient and of lower quality. Despite these views, it was observed in other studies that primary care can be important in integrated-care programs. Therefore, increasing integrated-care arrangements might introduce a shift of certain hospital-guided tasks to primary-care (or more specialized) services.</p> <p>Limits to this study include the small sample size of articles, the omission of studies focused on the elderly or pediatric patients, the absence of grey literature, and the heterogenous nature of the studies included.</p>			
Clinical effectiveness and cost-effectiveness of clinical nurse specialist (CNS)-led transitional care (55)	<p>This review evaluated 13 randomized controlled trials (RCTs) for clinical and cost-effectiveness of CNS transitional care. Overall, there was low-quality evidence that CNS transitional care delays re-hospitalization and reduces hospital length of stay, rates of re-hospitalization and associated costs.</p> <p>Results indicate that CNS care was superior in reducing patient mortality following cancer surgery. Relating to elderly patients and caregivers, CNS care improved caregiver depression and reduced re-hospitalization rates, length of stay and costs. CNS care for patients with heart failure improved treatment adherence and satisfaction, as well as reduced death or re-hospitalization and the length of re-hospitalization stay (including associated costs). CNS care improved infant immunization rates and maternal satisfaction with care for high-risk pregnant women and very low birthweight infants.</p> <p>Regarding limitations, the studies in this review had low (n=2), moderate (n=8) and high (n=2) risk of bias. Additionally, there was weak economic analyses, and further research that incorporates robust economic evaluation is needed.</p>	2013	(No rating tool available for this type of document)	Not reported in detail
Effectiveness of interventions targeting transitions from hospital to the primary-care setting for	This review evaluated the effectiveness of transitional-care (TC) interventions that focus on the transition from hospitals to primary-care settings for chronically ill older patients. Ninety-two studies (randomized controlled trials) were included. This review used a random-effects model to calculate risk differences (RD) and number needed to treat (NNT) or mean differences (MD).	2015	8/11 (AMSTAR rating from McMaster)	5/92

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Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
chronically ill older patients (20)	Results revealed that compared to usual care, significantly better outcomes were observed with TC interventions. For example, a lower mortality rate at three, six, 12 and 18 months after hospital discharge. There was also a lower rate of emergency-department visits and a lower rate of readmissions observed at three, six, 12 and 18 months. Further, there was a lower mean of readmission days at three, six, 12 and 18 months. There were no significant differences noted relating to quality of life. The conclusion of this review suggests that TC interventions do improve transitions for older patients and should be included in the reorganization of healthcare services.		Health Forum)	
Effects of different follow-up strategies following completion of primary cancer treatment in adult cancer survivors (21)	<p>This review included 53 randomized controlled trials (RCTs) that compared the effect of different follow-up strategies (following the completion of primary cancer treatment) in adult cancer survivors on the primary outcomes of time to detection of recurrence and overall survival. The secondary outcomes considered were health-related quality of life, anxiety, depression and cost.</p> <p>This review compared the effectiveness of the following: 1) non-specialist-led follow-up (i.e., general practitioner (GP)-led, nurse-led, patient-initiated or shared care) versus specialist-led follow-up; 2) less intensive versus more intensive follow-up (based on clinical visits, examinations and diagnostic procedures); and 3) follow-up integrating additional care components relevant for detection of recurrence (e.g., patient symptom education or monitoring, or survivorship-care plans) versus usual care. Evidence relating to the effectiveness of the different follow-up strategies varied significantly.</p> <p>Seventeen studies compared non-specialist-led follow-up with specialist-led follow-up. Because the certainty of the evidence was very low, it was uncertain how this strategy affected overall survival, time to detection of recurrence or cost. Additionally, results revealed that non-specialist versus specialist-led follow-up may make little to no difference to anxiety at 12 months, and it is more certain that it has little or no effect on depression at 12 months. Twenty-four studies compared intensity of follow-up. Results revealed that less intensive versus more intensive follow-up may make little to no difference to overall survival, but likely increases time to detection of recurrence. No studies reported on depression, and because the certainty of the evidence was very low, it was uncertain how this strategy affected health-related quality of life, cost or anxiety. Twelve studies compared patient symptom education/monitoring or survivorship plans with usual care; however, none of these studies reported on overall survival time or time to detection of recurrence. Because the certainty of evidence was very low, it was not certain if this strategy made a difference to health-related quality of life, anxiety, depression or cost.</p> <p>A limit to this review is the low certainty of much of the evidence. Among the studies included, the risk of bias was generally low, with a higher risk of bias in the smaller trials.</p>	2018	10/11 (AMSTAR rating from McMaster Health Forum)	2/53
Effects of interactive communication between collaborating primary-care physicians and specialists on outcomes for patients	This review included 23 studies that evaluated the effects of interactive communication (timely, two-way exchange of pertinent clinical information) between collaborating primary-care physicians and specialists on outcomes for patients with diabetes, psychiatric conditions and cancer. A meta-analysis was conducted, which indicated consistent and clinically important effects across 11 randomized and seven non-randomized mental health studies, and five non-randomized diabetes studies.	2008	7/11 (AMSTAR rating from McMaster)	2/23

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Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
receiving ambulatory care (41)	Meta-regression indicated that compared to studies that did not include interventions to enhance the quality of information exchange, studies that did include these interventions had larger effects on patient outcomes. Because the collaborative interventions included were multifaceted, this review was limited as the efficacy of interactive communication by itself could not be established.		Health Forum)	
Effectiveness of communication skills training (CST) for healthcare professionals (HCPs) working with people who have cancer (22)	<p>This review included 17 randomized controlled trials (RCTs) that evaluated the impact of CST for healthcare professionals (HCPs) (doctors, nurses and other allied health workers) who work with people with cancer. The review aimed to determine if CST is effective in changing HCP behaviours and in improving HCP well-being, patient status and satisfaction. The following reported outcomes were considered: use of open questions, elicited concerns, delivery of appropriate information, demonstration of empathy, use of fact contents, HCP burnout, and patient anxiety.</p> <p>Eleven trials compared CST with no CST intervention, three trials compared the effect of a follow-up CST intervention after initial CST training, two trials compared CST with patient coaching, and one trial compared two different types of CST. Study participants included oncologists, residents, other physicians, nurses and a mixed team of HCPs.</p> <p>The objective of most trials was training the professionals in general communication skills; two trials trained the professionals specifically to detect and respond to patients' emotions, four trained the professionals in giving bad news, and two trials trained the professionals in addressing palliative care and/or the transition to palliative care. The types of communication-skills-training courses evaluated in these trials were diverse. Most trials used learner-centred, experiential adult education methods delivered by experienced facilitators. Nine trials used co-teaching methods, and 12 trials taught communication-skills training in small groups. All of the small-group studies used role-play. Nine trials used written material, 10 trials used short didactic lectures, eight used role-modelling and 13 used audio or video material. Two trials used b-learning and two trials used only e-learning.</p> <p>A meta-analysis was conducted using 10 of the trials. Results indicated that compared to the control groups, HCPs in the intervention groups were more likely to use open questions in the post-intervention interviews, however the certainty of evidence was very low. They were also more likely to demonstrate empathy towards their patients (moderate certainty evidence) and were less likely to give only the facts without individualizing their responses to the patient's emotions (low certainty evidence).</p> <p>There was evidence of moderate certainty to suggest that there was no difference between CST and no CST on eliciting patient concerns and providing appropriate information. There was no evidence to support differences in other HCP communication skills, such as negotiation or clarifying and/or summarizing information. Evidence did not indicate differences between the groups regarding HCP burnout, patient satisfaction or patient perception of the HCP communication skills. Regarding the patient anxiety outcome, three studies contributed data and there were no differences observed between the intervention and control groups.</p>	2018	10/11 (AMS TAR rating from McMaster Health Forum)	1/17

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Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
	<p>This review was unable to ascertain whether CST-related effects are sustained over time or if consolidation sessions are necessary. This review was also unable to determine which CST programs are most likely to work; because the types of CST as well as the length of training and time spread varied across studies, it was not possible to determine the relative efficacy of different programs. Therefore, there is a limit to the generalizability of the findings of this review, as they are not necessarily applicable to all types of CST.</p>			
<p>Communication-skills-training (CST) interventions for patients that aim to increase their participation in healthcare interactions (42)</p>	<p>This review presented an overview of 32 CST intervention studies, most of which targeted primary care or cancer patients. The majority of studies used a randomized control design, and the interventions used various CST formats and modes of delivering educational material. Training programs were classified using three categories: 1) materials only; 2) materials plus individual coaching; and 3) group-based. The aim was to examine the content and structure of existing training programs, the design of intervention studies, and the evidence relating to the impact of CST on patient behaviour, communication processes and other outcomes.</p> <p>Relating to CST program characteristics, most interventions were delivered immediately pre-visit and were one hour or less. Four interventions used written materials to deliver content and six interventions used face-to-face delivery. Nine interventions used some form of multimedia, and 13 used a mixed-mode of presentation. Twelve interventions gave participants the opportunity to practise the skills they were being taught. The majority of interventions (n=31) targeted skills across multiple behavioural categories. Eight interventions included a training component for providers.</p> <p>Relating to communication behaviour outcomes, the strongest evidence was observed for the relationship between CST and patients' overall level of participation within interactions. Of the 10 studies that measured total active participation, eight reported a significant difference between intervention and control groups or in pre-post intervention. Expressing concerns was the communication behaviour that had the most significant difference in favour of CST. Relating to communication process outcomes, an important finding was that CST was not associated with longer patient visits (reported in seven studies). Additionally, seven of the 10 studies that evaluated the amount of information exchanged between providers and patients observed that trained patients received significantly more information within visits.</p> <p>The findings suggested that CST is an effective approach in increasing patients' total level of active participation in healthcare interactions. Findings also revealed that training may be more effective on some communication behaviours than others. Additionally, the majority of studies that targeted and assessed the expression of emotions and concerns by patients reported a significant difference in favour of training. Most studies included in this review found no relationship between CST and improved treatment outcomes, health or psychosocial well-being.</p> <p>Limits to this review include the fact that over three quarters of the studies included were conducted in either primary-care or cancer settings. Therefore, there are limits to the generalizability of findings across</p>	<p>2016</p>	<p>7/10 (AMSTAR rating from McMaster Health Forum)</p>	<p>0/32</p>

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Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
	different settings. Additionally, only four interventions were conducted outside of the United States, so they may not be contextual in other countries.			
Effectiveness of chronic-care models for improving healthcare practices and health outcomes within primary-healthcare settings (43)	<p>This review synthesized relevant international evidence (from 77 included papers) on the effectiveness of different elements that have been included in a chronic-care model (CCM) for improving healthcare practices and health outcomes within primary-healthcare settings.</p> <p>Studies in this review focused on people with or healthcare providers who cared for people with a non-specific chronic disease, or alternatively with at least one of the specified chronic diseases (cardiovascular, chronic kidney disease, chronic respiratory disease, Type 2 diabetes or depression) in a primary-healthcare setting. A scoping exercise of published CCMs was conducted to identify which elements of CCMs should be included in this review. Eight relevant elements were identified: 1) facilitated community support (CS) to meet needs of patients; 2) facilitated unpaid/informal family support (FS) to meet needs of patients; 3) self-management support (SMS) to meet needs of patients; 4) health system (HS) improvement to meet needs of healthcare providers; 5) delivery-system design (DSD) to meet needs of healthcare providers; 6) enhanced healthcare professional case management (CM) support to meet needs of patients; 7) decision support to meet needs of healthcare providers; and 8) clinical information systems (CIS) to meet needs of healthcare providers. Outcome measures for effectiveness included any reported changes (improvements or declines) to healthcare practice or to the health outcomes of patients as a result of the implementation of a CCM.</p> <p>Results indicated that of the papers which included effectiveness measures, the majority reported an association between CCM implementation and improvements to healthcare practice or health outcomes for people living with chronic disease. Only two studies reported a decline in any health outcome measures due to CCM implementation. The most commonly used elements of CCMs were self-management support and delivery-system design; however, there was considerable variation between studies in terms of which combinations of elements were included, as well as the implementation method of the CCM. As such, the review could not identify any optimal combination of the eight CCM elements that could lead to improvements in either healthcare practice or health outcomes.</p> <p>A finding relating to how CCM elements were implemented is that the Plan-Do-Study-Act cycle and learning collaboratives may be associated with the development of contextually relevant interventions. Additionally, important to the implementation of CCM elements is reflective practice, which encourages healthcare providers to highlight anomalies between current practice and future organizational priorities. A number of papers included in this review also determined that there is a key role for leaders to play in guiding the CCM development and implementation process. Leaders within organizations need to be committed to the implementation and sustainability of a new CCM. Finally, contextual relevance was identified as important to successful CCM development and implementation, especially given that disadvantaged populations often experience a higher burden of chronic disease.</p> <p>Limits to this review include a high risk of bias in some of the studies included (randomized and nonrandomized control trials, retrospective cohort and cross-sectional studies). Additionally, the case</p>	2013	6/10 (AMSTAR rating from Program in Policy Decision-making)	5/77

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Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
	studies included were of poor quality. Lastly, given that all the interventions differed, generalizations were impossible to make.			
Facilitators and barriers to implementing the Chronic Care Model (CCM) in primary care (52)	<p>This review synthesized the findings of 22 studies that implemented CCM in primary care to identify facilitators and barriers encountered during the implementation process. The Consolidated Framework for Implementation Research was used to interpret facilitators and barriers. Results revealed that the major emerging themes were related to the inner setting of the organization, the process of implementation, and the characteristics of the individual healthcare providers. These included the culture of the organization, as well as its structural characteristics, networks and communication, implementation climate/readiness, supportive leadership, and provider attitudes/beliefs.</p> <p>Relating to facilitators, an organizational culture that promotes multidisciplinary or patient-centred care was identified as important to CCM implementation. Support from clinical providers and recognition of their role in care change efforts was found to increase the uptake of CCM in primary care. Studies also found that an organization's commitment and recognition of the need for change influenced the implementation climate. It was also noted that healthcare providers, including specialists and non-physician staff, have a key role to play in facilitating the operationalization of CCM components. Strong and engaging leadership, in the form of supportive administration and supervisors, was also cited as a facilitator.</p> <p>Relating to barriers, many studies identified barriers in executing the intervention process. For example, implementing multiple CCM elements created additional responsibilities for staff who were already limited by time constraints. Additionally, characteristics of an organization (size, whether it had adopted a team-based approach, flexibility in rearranging care) were found to influence the success of CCM implementation and adoption. Leadership turnover was cited as a barrier towards implementing care change processes; studies found that executing the intervention process was challenging without support and accountability from senior leadership. Additionally, organizational readiness for implementation of CCM was found to be affected by lack of interest and commitment from leadership, and unavailability of implementation resources.</p> <p>This reviewed cited several limitations, the first being that the literature review excluded grey literature, studies that were not published in peer review journals, and studies that were not published in English. The search may have also missed certain CCM-based interventions if the study did not refer to the intervention as such. Also, it is difficult to be certain that implementation issues are reflective of issues that are relevant to the CCM.</p>	2015 (publication date)	2/9 (AMSTAR rating from Program in Policy Decision-making)	2/22
Effects of self-management interventions (SMIs) for cancer survivors who completed primary treatment (23)	This review evaluated the effects of 12 self-management intervention (SMI) studies (randomized controlled trials) for cancer survivors who completed primary treatment. The 12 studies were systematically reviewed for the following components: self-management content, session composition, mode of delivery and type of self-management skills used. Following this component review, a meta-analysis (using nine of the interventions) was conducted to compare SMIs with usual care, attention control, and a waitlist group.	2016	8/10 (AMSTAR rating from McMaster Health Forum)	0/12

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Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
	<p>Results of the qualitative synthesis indicated that breast cancer survivors made up most of the study population. Results also indicated that SMIs focused on medical/behavioural and emotional management, and the most common SMI delivery method was web-based. The most frequently evaluated outcomes of SMIs were self-efficacy, depression and health-related quality of life. Quantitative results revealed that there were no statistically significant effects of SMIs on anxiety, depression and self-efficacy. However, SMIs had a significant medium effect on health-related quality of life, and a large effect on fatigue (borderline significance).</p> <p>The findings of this review should be cautiously interpreted because of substantial heterogeneity.</p>			
<p>Ability of health-coaching interventions to grow capacity in cancer survivors (44)</p>	<p>This review included 12 health coaching intervention studies (six randomized trials and six pre-post) that explored the ability of health coaching to grow capacity among cancer survivors. These studies compared health coaching to alternative interventions. These studies included 1,038 cancer survivors with various types of cancer, including lung, breast, colorectal and prostate.</p> <p>The Theory of Patient Capacity was used to analyze data. This theory is represented by the acronym BREWS, where capacity is affected by factors that influence ability to reframe biology (B), recruit or mobilize resources (R), interact with the care environment (E), accomplish work (W) and function socially (S).</p> <p>Results revealed that health coaching was not associated with self-efficacy, but was associated with improved mood, physical activity and quality of life. Results according to BREWS indicated that 67% of the studies included had statistically significant B outcomes relating to quality of life, acceptance and spirituality. Further, 75% of studies included had statistically significant R outcomes (e.g., decreased fatigue, pain), 67% had statistically significant W outcomes (e.g., increased physical activity) and 33% had statistically significant S outcomes according to the social deprivation index. None of the studies addressed elements of E.</p> <p>Overall, results suggested that health coaching improved quality of life and supported patient capacity in cancer survivors.</p>	<p>2018 (publication date)</p>	<p>5/9 (AMSTAR rating from McMaster Health Forum)</p>	<p>Not reported in detail</p>
<p>Impact of practice facilitation on chronic-disease outcomes in the primary-care setting (45)</p>	<p>This review includes 25 studies (12 randomized controlled trials and 13 prospective cohort studies) and evaluated the impact of practice facilitation on chronic-disease outcomes in the primary-care setting. The studies included had implemented practice facilitation and reported quantifiable care processes and patient outcomes for chronic disease. Practices and their clinicians were aware of the implementation of practice facilitation in all the studies included.</p> <p>Chronic disease measures related to asthma, cancer, cardiovascular disease, chronic kidney disease and Type 2 diabetes were categorized into two groups: process or outcome. Process measures included screening, diagnosis and clinical process. Outcome measures included laboratory results, blood pressure, hospitalization and patient-reported outcome for chronic-illness care. Changes related to chronic-disease measures were categorized as having improved, decreased or no change.</p>	<p>2017</p>	<p>7/10 (AMSTAR rating from McMaster Health Forum)</p>	<p>3/25</p>

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Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
	<p>Results indicated that across the 25 studies that implemented practice facilitation, process measures improved on average by 8.8%, and outcome measures improved on average by 5.4%. Screening and diagnosis improved the most among process measures. Laboratory results and blood pressure improved the most among outcome measures. Improvements in measures and outcomes were observed for most studies that involved patients with asthma, cancer, cardiovascular disease and Type 2 diabetes. However, there were mixed results for studies that involved patients with chronic kidney disease.</p> <p>Overall, the studies included in this review showed a beneficial effect of practice facilitation on chronic-disease outcomes in the primary-care setting. In these interventions, the implementation of practice facilitation led clinicians and their primary-care practices to adopt changes in chronic-disease management, which resulted in improved disease process and outcome measures.</p> <p>This review cited several limitations, the first being that studies with potential biases were included. Additionally, the studies included were conducted in the United States and Canada, which reduces the generalizability beyond North America. Results may also be influenced by the inclusion of patients who were already receiving ongoing treatment for chronic disease. Further, reporting of results is limited because there was no meta-analysis conducted. Some studies had small sample populations, and there were different baseline population characteristics in each study. The study durations also ranged from three months to one year, which could have influenced the impact of the intervention.</p>			
Evidence for patient-navigator programs for people with chronic diseases compared to usual care (46)	<p>This review summarized the evidence from 67 reports of randomized controlled trials (RCTs) that compared patient-navigator programs to usual care for adult patients with any one of a defined set of chronic diseases. The topic of 44 reports was cancer, eight reports focused on diabetes, seven on HIV/AIDS, four on cardiovascular disease, two on chronic kidney disease, one on dementia, and one on patients with more than one chronic condition. Of the studies that focused on patient navigation for cancer care, the majority were in cancer screening, where the patient navigator was helping the patient to complete the screening test.</p> <p>Because the patient-navigator programs and their outcome measures were largely heterogeneous, a narrative approach was used for data synthesis. For each study, the primary outcome was tabulated as well as a summary of the result and whether the observed changes were statistically significant. Three major outcome categories were defined (patient-oriented, surrogate outcomes, process measures), and this review determined the proportion of studies with positive outcome results (primary or secondary) in each outcome category, stratified by chronic disease.</p> <p>In discussing intervention characteristics, over half of the patient-navigator programs were based in primary care or in the community. Telephone was the primary mode of communication, and most programs employed lay persons who were trained for the role. Care facilitation (e.g., referrals, communication with providers, coordinating care) and appointment scheduling were the most common strategies used to address health-system barriers. Providing appointment reminders, addressing patients'</p>	2017	7/10 (AMSTAR rating from McMaster Health Forum)	3/67

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	<p>attitudes and beliefs, and providing health literacy and practical support were the most common activities for mitigating health-system barriers. Many patient navigators provided some form of psychosocial support to patients, and many studies reported employing patient navigators who were culturally aligned with the patient population.</p> <p>In discussing outcomes, 45 of the 67 studies (67%) reported a statistically significant improvement in one or more primary outcomes. Compared to other chronic diseases, a higher proportion of studies in cancer prevention or management reported a statistically significant positive effect for one or more primary outcomes. However, this review was unable to identify the most important program elements or characteristics that were associated with improvements in primary outcomes. Relating to the outcome categories, studies were more likely to report positive results for process measures, and less likely to report positive results for surrogate outcomes and patient-oriented outcomes. This review could not determine the effect of patient-navigator programs on clinical outcomes.</p> <p>Some limitations of this review include the heterogeneity in both the design of the patient-navigator programs and the outcomes reported. Because of this, definitive statements could not be made about the effectiveness of specific intervention activities. Other potential limitations include incomplete reporting (in the RCT reports), variation in the implementation of patient-navigator programs and their elements, and publication bias.</p>			
<p>Experience of cancer and comorbid illness from the perspective of patients, carers and healthcare professionals to identify psycho-social support needs (47)</p>	<p>This review synthesized qualitative evidence from 31 articles (based on 28 studies) on the experience of living with and beyond cancer with one or more additional long-term illnesses (diagnosed before or after cancer diagnosis, but not caused by cancer) from the perspective of patients, carers and healthcare providers. The review aimed to identify the psychosocial support needs of patients who live with (or beyond) cancer and comorbid illness, as well as determine this patient populations' experience of service provision from diagnosis to end of life. This review focused on the physical, social, emotional, psychological and spiritual elements of the experience of patients living with (or beyond) cancer and comorbid illness.</p> <p>The final studies included in this review were heterogenous and included different cancer and comorbidity types. Nine studies focused on breast cancer, and other common cancers included were prostate, lung, colorectal and lymphoma. The majority of studies reported comorbid conditions in general, but three studies focused on specific conditions including diabetes, dementia and depression. Most studies did not focus on the experience of cancer and comorbidity. It was more common for comorbid conditions to be mentioned briefly in relation to other issues. The majority of studies were set in secondary care hospitals, specialist clinics and cancer clinics; however, some studies were set in primary- and community-care settings.</p> <p>The synthesis identified five key themes: the interaction between cancer and comorbid conditions; symptom experience; illness identities and aging; self-management; and the role of primary and secondary care. Having cancer and comorbid illness was seen to produce a complex and increased burden of ill health, which affected quality of life, recovery and treatment decisions. Relating to</p>	<p>2017</p>	<p>7/9 (AMSTAR rating from McMaster Health Forum)</p>	<p>3/28</p>

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	<p>symptom experience, the complexity of experiencing multiple diseases sometimes led to a blurring of symptoms, which hindered patients' ability to attribute a symptom to a particular condition. This became a source of fear of cancer relapse for some patients. The experience of illness was observed to be connected to one's previous experience of illness, illness expectations and the severity of the burden of illness. In order to reduce the pressure on primary care in providing follow-up and support to this patient group (cancer and comorbid illness), studies suggested the need for shared care or supported self-management, as well as the need for resources to support this. In terms of the role of primary and secondary care, this review suggested that oncologists often do not consider the management of comorbid conditions as part of their role. It was more likely for general practitioners to view the holistic management of conditions as part of their role; however, primary-care practitioners did not always feel comfortable managing advanced symptoms of cancer. This could lead to a fragmented experience of care.</p> <p>This review suggested that to improve patient care for this patient group, further research is needed to better understand the symptom and treatment experiences, support needs, and experiences of and efficacy of self-management. It also highlighted that optimal models of survivorship care and support can be developed by addressing challenges for primary, secondary and social care.</p> <p>This review states a possible limitation being the fact that it was difficult to design a search strategy that was sensitive and specific. Small pieces of qualitative data relating to the experience of cancer and comorbid illness were often nested within studies, rather than being the focus of studies. Therefore, there may be additional articles that were not identified.</p>			
<p>Application of electronic and mobile health technologies in the management of chronic diseases including cancer (48)</p>	<p>This review examined evidence from 29 peer-reviewed articles in order to gain an understanding of research developments in the application of electronic and mobile health technologies for managing chronic diseases, with a focus on cancer. In this review, three components of electronic health technologies (as defined by the World Health Organization) were focused on. The first was mobile health, which delivers health services and information using mobile and wireless technologies. The second was Health Information Systems (HIS), which includes electronic patient records and administrative systems. The third was telemedicine, which delivers healthcare services at a distance and can be used for interprofessional communication, communication with patients and remote consultations. This review examined the context and mechanisms of electronic health technology applications, as well as their impacts and outcomes. Outcomes included measurable health and efficiency outcomes, and acceptance and uptake of electronic health technology (based on reported findings in the included articles).</p> <p>The findings of this review were divided into four broad themes. The first was technological advances, where it was suggested that the widespread adoption of electronic health technologies are enabling earlier diagnosis and risk detection, as well as more targeted treatment and rehabilitation. The second theme was differences between developed and developing countries. It is explained that in developed countries, electronic health technology is focused on applying information technology to improve the</p>	<p>2015</p>	<p>4/9 (AMSTAR rating from McMaster Health Forum)</p>	<p>0/29</p>

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	<p>effectiveness and efficiency of healthcare delivery. Whereas in developing countries, electronic health technology is focused on using lower-cost technology (e.g., mobile phones) to provide access to basic healthcare for those who experience poverty or disadvantage. The third theme was implications for management and self-management, where it was suggested that internet-based applications can support self-care through enabling new forms of healthcare. These internet-based applications can also facilitate the connection of doctors with other doctors, patients and doctors, and patients and other patients, regardless of geography. The final theme was socio-technical factors that affect the usability and uptake of electronic health technology. Much of the literature included suggested that electronic health technology applications must be accessible and easy to use, taking into account issues that can arise in human-computer interaction and other socio-technical factors. For people with chronic diseases, including cancer, electronic health technology technologies can have significant effects on health behaviours, perceived social support, knowledge and clinical outcomes. However, it is suggested that the implementation of electronic health technology can be a disruptive change in the healthcare workplace, and that implementation may require changes to individual job design and clinical pathways in order for the integration of new technologies to be successful.</p> <p>In order for electronic health technology policy and regulation to keep pace with the rapid research developments in this area, much still needs to be done. This review cites privacy, liability and payment models as priorities in this regard. Some other barriers in the adoption of electronic health technologies include governance and regulatory issues, information management and integration.</p>			
<p>Appropriateness and effectiveness of physical activity during and post cancer treatment (53)</p>	<p>This review included 82 studies involving 6,838 cancer survivors in order to evaluate the effectiveness of physical activity interventions conducted during and post cancer treatment. Cancer survivor was defined as “any individual that has been diagnosed with cancer, from the time of discovery and for the balance of life”. Breast cancer was the most common diagnosis included in all studies (83%). The physical activity interventions included in this review were restricted to those delivered outside of the physical therapy setting with a concurrent comparison group. Weighted mean effect sizes (WMES) were calculated from 66 high-quality studies, and 60 outcomes were evaluated through applying a systematic level of evidence criteria.</p> <p>In terms of the characteristics of the interventions included, the majority of interventions exceeded five weeks in length, with 40% being more than three months in length. The most common intervention types were aerobic exercise or combined activity, which were typically of moderate to vigorous intensity, three to five times per week and for 30-45 minutes per session. These characteristics were consistent for both during and posttreatment physical-activity interventions. 51% of the post-treatment interventions focused on behavioural change, where the primary aim was to increase physical-activity behaviour.</p> <p>Significant WMES from post-treatment physical-activity intervention studies were observed for physical-activity level, aerobic fitness, upper body strength, lower body strength, body weight, body fat percentage, body mass index (BMI), overall quality of life, breast cancer-specific concerns, perception of physical condition, mood disturbance, confusion, body image, fatigue and general symptoms and side effects. The majority of studies reported a significant positive impact of physical-activity interventions</p>	<p>2009</p>	<p>3/11 (AMSTAR rating from McMaster Health Forum)</p>	<p>21/82</p>

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	<p>post treatment for aerobic fitness, upper and lower body strength, lower body flexibility, lean body mass, overall quality of life, trial outcome index, breast cancer subscale, vigor/vitality, fatigue, IGF-I, IFG-BP-II, immune parameters (neutrophil count, NK cell activity, C-reactive protein, cytokines), pain and general symptoms and side effects.</p> <p>Numerous studies (n=25) discussed issues relating to the potential harms of physical activity in cancer survivors. A theme across these discussions was fearing harm from exercise during or close to the end of treatment, specifically related to anemia, lymphedema and weight loss. However, one intervention study did not exclude anemia and did not report any adverse effects of a six-week, vigorous aerobic-exercise intervention immediately after hospital discharge following treatment completion (high-dose chemotherapy and autologous stem cell transplant). With the exception of a small number of patients in two studies, aerobic, lifestyle and upper body resistive exercise was well-tolerated by breast cancer survivors, with no adverse effect on the development or exacerbation of lymphedema. Regarding weight loss, a three-month (thrice weekly) aerobic and resistance exercise intervention study reported an increase in the recovery of fat-free mass after stem cell transplantation (compared to stretching control group), with no difference in body weight changes over the same time period.</p> <p>A limit to generalizability is the fact that the dominant population represented across all intervention studies was breast cancer survivors. Breast cancer is the most widely studied cancer for physical activity interventions, and until more literature is generated in this regard for other cancers, it is not possible to summarize findings by cancer diagnosis, treatment type or time points. Because of this, the positive effects of physical activity observed for specific outcomes must be interpreted cautiously. Publication bias was also not assessed for the studies included; however, the inclusion of I-squared values for WMES results intended to mitigate this.</p>			
Effectiveness of interventions that aim to enhance the return-to-work process for cancer patients (24)	<p>This review included 15 randomized controlled trials (RCTs) that represented 1,835 cancer patients in order to evaluate the effectiveness of interventions in facilitating the return-to-work (RTW) process for cancer patients. Of the 15 studies, three had multiple study arms, therefore this review included 19 evaluations of interventions.</p> <p>All of the studies included were conducted in high income countries. Seven studies described interventions that were aimed at breast cancer patients, two studies involved prostate cancer patients and one study each reported results for patients with thyroid cancer, head and neck cancer, laryngeal cancer, leukemia, mixed cancer diagnoses, and gynecological patients. This review included any type of intervention that aimed to enhance RTW. The primary outcome measure was RTW, which included return to either full or part-time employment, to the same or a reduced role, and to either the previous job or any new employment. Quality of life (QoL) was the secondary outcome, which included overall QoL, physical QoL and emotional QoL measured with validated or unvalidated questionnaires.</p> <p>Four main types of RTW intervention were identified. Psycho-educational interventions (two studies), where participants learned about physical side effects, stress/coping and took part in group discussions:</p>	2014	10/11 (AMSTAR rating from McMaster Health Forum)	0/15

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	<p>physical interventions (one study), where participants completed physical training or exercises such as walking; medical interventions (seven studies), where patients received interventions ranging from cancer drugs to surgery; and multidisciplinary interventions (five studies), which combined vocational counselling, patient education/counselling, behavioural training and/or physical exercises.</p> <p>The studies assessing psycho-educational interventions (two) included a total of 260 patients (n=148 in intervention groups, n=112 in control groups). Two arms of one RCT compared the effect of a psycho-educational intervention, or a psychosocial intervention plus group discussion, to usual care. Two arms of another RCT compared the effect of radiotherapy fatigue education (delivered either pre- or post-radiotherapy) to usual care. The combined results of these assessments indicated that there is low-quality evidence of no considerable difference in the effect of psycho-educational interventions compared to usual care on RTW, or on QoL. The study assessing a physical intervention (breast cancer patients were offered a physical training program) indicated that there is low-quality evidence that the intervention was not more effective than usual care in improving RTW or QoL.</p> <p>The studies assessing medical interventions (seven) included a total of 1,097 patients; in all studies, a less radical medical intervention was compared with a more radical medical intervention. Pooled results (using a meta-analysis) of all these studies indicated that less radical (function-conserving) approaches produced similar RTW rates as more radical treatment. Two studies reported moderate-quality evidence of no differences in the effect of less radical medical interventions compared to more radical treatment on QoL. The studies assessing multidisciplinary interventions (five) included a total of 450 patients. Pooled results (using a meta-analysis) of all of these studies indicated moderate-quality evidence that multidisciplinary interventions, in which vocational counselling, patient education/counselling, biofeedback-assisted behavioural training and/or physical exercises were combined, led to higher RTW rates than usual care. Two studies reported low-quality evidence of no differences in the effect of multidisciplinary interventions compared to usual care on QoL.</p> <p>This reviewed considered patients from the United States and Europe. Therefore, for the generalization of patients outside of the United States or Europe, cultural differences regarding cancer disclosure and employment should be taken into account. Additionally, breast cancer patients were the most studied diagnosis group, which should be considered in the generalizability of the findings.</p>			
<p>Adult patient perceptions of the acceptability of telephone-based interventions during or post cancer treatment (25)</p>	<p>This review included 48 papers (which described 50 studies) in order to assess patients' perceptions of satisfaction and acceptability of cancer support delivered by telephone (by a healthcare professional) during or post-treatment. Acceptability and satisfaction were defined as perceptions, experiences, impressions, attitudes, views, beliefs or opinions.</p> <p>The majority of studies (n=43) focused on a single cancer type, specifically breast cancer (n=16), colorectal cancer (n=11) or prostate cancer (n=7). Mixed samples that included patients with varying cancer diagnoses were reported in seven studies. Patients included in the studies had either finished receiving or were still receiving treatment for their cancer (e.g., surgery, chemotherapy, targeted agents,</p>	<p>2014</p>	<p>8/10 (AMSTAR rating from McMaster Health Forum)</p>	<p>3/50</p>

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	<p>hormone therapy). All studies were conducted in developed countries, mainly in the United States, Canada, the United Kingdom and Australia.</p> <p>The characteristics of the interventions varied greatly (e.g., content, timing, duration, format, delivery); however, three main categories of intervention were identified. The first category was telephone follow-up in lieu of routine hospital follow-up (six studies), which involved the monitoring of general/cancer symptoms, as well as the provision of information and support post-diagnosis and/or treatment. These interventions were nurse-led. The second category was telephone interventions for treatment side-effect monitoring and toxicity management (23 studies), which were delivered during and after cancer treatment supplementary to usual care, and sometimes included side-effect management/coping strategies and/or education and information provision. These interventions were often nurse-led. The third category was supplementary psycho-educational telephone interventions (21 studies), which were provided by nurses (most common), psychologists, physiotherapists, social workers, counsellors and health educators. Many of these interventions (n=13) reported involving an element of counselling, coping strategies and skills trainings, problem solving, self-management, cognitive behavioural skills training or intimacy enhancement programs.</p> <p>Regarding acceptability outcome data, high-quality evidence across all three intervention categories frequently indicated that cancer patients valued telephone-based interventions for their convenience. Convenience was reported in terms of facilitating personal organization, time and travel savings, and overcoming participant restrictions. Positive personal experiences were also reported across the intervention categories, which were supported by both high- and low-quality evidence. Positive personal experiences included patient acceptance and appreciation of calls, as well as perceptions of intervention helpfulness or usefulness, and ease of participation. Regarding satisfaction data, high overall satisfaction was reported from low-quality evidence across the three intervention categories. Three studies included a control group and reported statistically significant greater satisfaction with telephone-based intervention support compared to standard hospital care. Across the three intervention categories, there were conflicting patient perceptions regarding the quality of the support received, the impact of telecare on the patient-healthcare professional relationship and the need for telecare interventions.</p> <p>This review acknowledged several limitations, the first being that only interventions delivered by healthcare professionals were included. Additionally, the review only considered data presented within original research papers, which may have been restricted by word limits/space, which could lead to selective rather than complete reporting of findings. Lastly, the review explains that the instruments that are chosen to assess patient satisfaction quantitatively do not always reflect the patient-centred priorities that emerge from qualitative data. As such, the interpretation of findings is limited by the methodological limitations in the primary research.</p>			
Use of computer-mediated communication by a variety	This review included 31 publications and aimed to explore how computer-mediated communication has been used as a tool by various healthcare professionals in providing support to their patients. In this	2016	5/9 (AMSTAR rating from	3/31

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<p>of healthcare professionals to support their patients (49)</p>	<p>review, computer-mediated communication was defined as, “the use of computers, phones or mobile devices to interact and share information, thoughts and ideas with users.”</p> <p>Across the 31 publications, there were four main computer-mediated communication types identified: computer-mediated social support groups (e.g., linking numerous people with common conditions/illnesses via computer platforms such as Facebook) (n=9); email (n=8); videoconferencing (n=7); and multifaceted interventions (e.g., email intervention that incorporates package of tools such as online social support and/or email or written information) (n=7). The interventions were conducted over a range of healthcare fields including diabetes (n=7), primary care (n=5), post-partum care and cancer (n=4 each), pediatrics and mental health (n=3 each), dermatology (n=2) and epilepsy and smoking cessation (n=1 each).</p> <p>There were positive and negative outcomes associated with interventions across all categories; however, 25/31 studies (81%) reported that computer-mediated communication strategies could produce positive effects when used for providing patient support.</p> <p>A thematic analysis was conducted to reveal common aims across interventions, and three main aims were identified: 1) providing or improving access to healthcare professionals; 2) providing more valuable services; and 3) supporting improved patient support. Outcomes of these themes were analyzed for each of the four main computer-mediated communication types. Email interventions were seen to increase access to healthcare. Additionally, the nature of email allows time for formulating questions/responses, which can sometimes better meet informational needs. Videoconferencing could provide healthcare services to a wider community and link the outside world to the hospital-based patient. Patients who used videoconferencing were satisfied when it saved travel time. Patients who were of a younger generation also reported being more satisfied with videoconferencing. Videoconferencing was seen to have some negative consequences, for example, technology can cause technical difficulty for some patients and providers, therefore increasing workload. Videoconferencing can also cause some patients to feel uncomfortable; though patients reported positive experiences, many still preferred face-to-face interactions. Computer-mediated social support groups were seen to be easily accessible and easy to use. Reading through posts of others can provide a perceived sense of support for some patients; however, it was observed that the perception of support increased as patients increased their own level of engagement and posts. The sense of anonymity also provided comfort to some patients. Regarding patient outcomes, there was no evidence for the ability of computer-mediated social support groups to enhance or supplement learning. While multifaceted interventions varied in format and content, some common themes emerged. Patients reported enjoying the asynchronous aspects that allowed them to write their story, and they liked sharing pictures and messages. Despite proving ineffective in achieving primary outcomes (e.g., smoking cessation, post-partum care), many of the multifaceted interventions provided patients with a sense of security/reassurance. There were no increases observed in self-efficacy, and engagement was seen as difficult.</p> <p>A limitation cited for this review was the heterogeneity of the interventions (e.g., structure, practice area, participants), which made the comparisons difficult.</p>		<p>McMaster Health Forum)</p>	

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Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
<p>Necessary services and models of care for post-treatment follow-up of adult cancer survivors (50)</p>	<p>This review included 10 practice guidelines and nine studies (randomized controlled trials, RCTs) to assess the effectiveness of models of care that can enhance health and quality of life in the post-treatment cancer survivor population. The aim of the review was to determine the optimum organization and care-delivery structure for cancer survivorship services. Evidence was summarized according to four categories: 1) models of care and provider type; 2) site of care; 3) structure of care: care transition process; and 4) structure of care: preparation of providers.</p> <p>In terms of models of care, five clinical practice guidelines contained recommendations for some aspects of models of survivorship care. For the post-primary treatment follow-up of cancer survivors, models of care included survivorship clinics, shared-care between oncologists and primary-care physicians, nurse-led survivorship care and multidisciplinary models of care. Two guidelines recommended that a survivorship-care team should be interdisciplinary, including oncology nurses, urology nurses, radiotherapy nurses, dietitians, physiotherapists, psychologists and sexologists. One guideline recommended that rehabilitation services should be available to patients throughout the continuum of cancer care. One guideline highlighted the importance of collecting data on health-related outcomes and the costs associated with the delivery of cancer survivorship care by different healthcare providers. Evidence to support any of the recommendations relating to models of care across the guidelines was weak and was based primarily on consensus.</p> <p>Nine RCTs also examined models of care. In these RCTs, standard follow-up provided by the oncologist was compared to care provided by either primary-care physicians (three trials) or by nurses (four trials). The three trials that compared primary-care physician- and oncologist-led follow-up reported no differences in quality of life or disease recurrence outcomes. The four trials that compared nurse- and oncologist-led follow-up reported no differences in quality of life or disease-recurrence outcomes. However, patient satisfaction was higher for nurse-led care in one trial, higher scores for emotional functioning at 12 months were reported with nurse-led care in one trial, and less psychological distress was reported with nurse-led care in one trial. Additionally, higher patient satisfaction was reported in one nurse-led follow-up care model that included patient-initiated care.</p> <p>In terms of site of care, none of the guidelines contained specific recommendations that addressed the site of survivorship care. Additionally, none of the RCTs described any advantages or disadvantages associated with the site of care. In terms of the structure of care related to transition-care processes, most of the guidelines contained recommendations for the structure of follow-up care processes, including the provision of survivorship-care plans. Two guidelines suggested the need for written survivorship-care plans that prepare patients for the transition from active treatment into follow-up. It was also recommended that patients be educated on late adverse effects that can occur in survivorship, and symptoms to report without waiting for their next scheduled appointment. Additionally, it was recommended that patients be educated on which care provider to contact for different emerging problems. In terms of the structure of care related to the preparation of providers, four guidelines recommended that survivorship-care teams be provided with ongoing education opportunities. It was also recommended that organizations that provide research funding should support the assessment of</p>	<p>2009</p>	<p>7/10 (AMSTAR rating from McMaster Health Forum)</p>	<p>Not reported in detail</p>

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Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
	<p>the implementation of education, training and clinical practice outcomes of the workforce competencies necessary to provide psychosocial care.</p> <p>The RCTs reviewed suggest that nurse-led and primary-care physician follow-up care is equivalent in detecting disease recurrence when compared to oncologist follow-up care, and that patients are satisfied with this approach. However, the evidence base is limited, and further research is needed on how to best structure care for post-treatment cancer survivors (including cost-effectiveness).</p>			
<p>Categorizations of models of aftercare for survivors of childhood cancer (54)</p>	<p>This review evaluated nine previous categorizations of models of care for survivors of childhood cancer to identify the key program features of these classifications. The purpose was to develop a revised taxonomy that allows for more consistency in the classification and description of these models.</p> <p>Six fundamental program features were identified in previous classifications: 1) the provider primarily responsible for managing aftercare; 2) other providers who are frequently involved in providing aftercare; 3) location of care; 4) method of engaging survivors (including aftercare delivery method and how the population is tracked); 5) aftercare services provided; and 6) who receives care through the aftercare program (e.g., risk-stratified, focused on select survivor groups).</p> <p>Based on the review, the newly proposed model begins with the primary provider (who it is) as the basis of the classification of the models of aftercare. Aftercare is initially provided by the pediatric team; however, following adolescence, cancer programs vary in terms of who is responsible for providing care.</p> <p>Following identifying the lead provider, the proposed model then collects data on five other relevant features: 1) which providers are regularly involved in providing aftercare; 2) location of care; 3) how survivors are engaged; 4) services provided; and 5) who receives services. These features are useful to include in identifying models of aftercare; however, in practice, attempts to develop specific categories for each of the features can force artificial distinctions, and cause relevant information to be missed. Therefore, instead of categorizing each of the five key features, the intent is to capture the detail information around each. The goal of the newly proposed model is to allow for grouping of relevant programs, while also allowing for a level of detail to be collected to be able to distinguish key program features.</p> <p>A limitation cited was that some models of aftercare for survivors of childhood cancer may have been missed in conducting the systematic review. Further, the Distant Follow-Up Model (under provider type) may be seen as a communication type rather than a provider type.</p>	<p>2019 (publication date)</p>	<p>2/9 (AMSTAR rating from McMaster Health Forum)</p>	<p>Not reported in detail</p>

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Appendix 2: Summary of findings from primary studies about educational content and resources to support seamless transitions between cancer programs and primary care

Focus of study	Study characteristics	Sample description	Key features of the intervention(s)	Key findings
Supporting models to transition breast cancer survivors to primary care (58)	<p><i>Publication date:</i> 2015</p> <p><i>Jurisdiction studied:</i> Ontario, Canada</p> <p><i>Methods used:</i> Qualitative formative evaluation</p>	Data collection consisted of submissions of budget plans, annual reports, and a seven-item questionnaire to assess patient experience over the course of an 18-month period from 14 Regional Cancer Centres (RCCs) in Ontario	The model involved engagement from primary-care providers, specialist oncologists, and breast cancer survivors, with supporting guidelines “Follow-up after treatment for breast cancer” by the Clinical Practice Guidelines for the Care and Treatment of Breast Cancer Steering Committee	<p>Breast cancer survivors were defined as individuals identified by primary-care providers who completed their planned radiation and/or chemotherapy with no reoccurrence. Of the allocated \$1.4 million to 14 RCCs in 2012, the majority of the funding was used for personnel support, followed by project management, coordination support, and information-technology support and software development. The RCCs reported three main models of follow-up care – direct to primary care, transition clinics, and shared care. Direct to primary care transitions breast cancer survivors directly to their primary-care provider after a final transition visit. Transition clinics were incorporated within the RCCs that were operated by a nurse practitioner, advanced-practice nurse, or a general-practice oncologist. In the transition clinics, the nurse would complete an updated history, identify any healthcare needs, and provide resources or health education on follow-up care, disease prevention, and health promotion. Additionally, the nurses connect with primary-care providers to establish seamless transition of care and direct survivors who developed a recurrence. Among the RCCs that provide this model of care, cancer survivors typically visited the transition clinic between one to three times before fully transitioning to their primary-care provider. Five regions developed a shared-care model, where survivors considered high risk (e.g., persistent side effects, receiving hormonal treatment) were provided follow-up care with their primary-care provider and their specialist oncologist.</p> <p>A majority of the RCCs implemented one model, while five implemented a combination of two or three models.</p> <p>Related to patient resources, all RCCs developed survivorship-care plans, transition letters, and patient education material. Most survivorship-care plans were completed by a nurse at the cancer centre and sent to the primary-care provider by fax or email. Most of the care plans consisted of information on treatment history, long-term effects, screening recommendations, and up-to-date lists of community-based resources. Cancer survivors and the primary-care providers had access to transition-clinic nurses or RCCs for any additional follow-up, facilitated repatriation, or to triage other related questions (including suspected recurrence). Of the 752 cancer survivors surveyed, 85% felt prepared for their transition given their satisfaction of the received information. Overall, the</p>

Focus of study	Study characteristics	Sample description	Key features of the intervention(s)	Key findings
				authors reported that investments are needed in the delivery of transitional care.
Examining health-system resources and costs associated with transitioning cancer survivors to primary care (60)	<p><i>Publication date:</i> 2018</p> <p><i>Jurisdiction studied:</i> Ontario, Canada</p> <p><i>Methods used:</i> Propensity-score-matched quasi-experimental study</p>	2,324 low-risk breast cancer survivors in the Well Follow-Up Care Initiative (WFCI) who were transitioned from oncologist-led clinics to primary-care providers	WFCI involved survivorship-care plans, patient education materials, direct transition to primary care and stepped-approach for transition clinics, with an average 25 months of follow-up	Compared to the control group, breast cancer survivors in the WFCI intervention reported lower hospitalization rates, cancer-clinic visits and appointments with specialist oncologists, with similar frequency of primary-care visits. The intervention group averaged \$4,257 lower costs to the health system, with main cost drivers attributed to hospitalization, physician visits, medications, and home care. Additionally, the intervention group had significantly lower mean annual costs for other health services such as surveillance tests, cancer-clinic and physicians' visits, medications, long-term care, and home care. The authors concluded that transitional care did not compromise health outcomes in the intervention group. Effective communication and resources such as survivorship-care plans and discharge visits are integral to cancer survivorship transitions. Based on these findings, the authors reported that transitional care for low-risk breast cancer survivors from oncologist-led care to primary-care providers were associated with fewer costs, and estimated that a population-wide implementation of the program could result in savings between \$9.6 million and \$64.3 million in Ontario.
Optimizing childhood oncology care transition from pediatric to adult settings (70)	<p><i>Publication date:</i> 2020</p> <p><i>Jurisdiction studied:</i> Quebec, Canada</p> <p><i>Methods used:</i> Qualitative survey</p>	Primary-care providers and family medicine residents identified through Fédération des médecins omnipraticiens du Québec (FMOQ) and the Fédération des médecins résidents du Québec (FMRQ)	The survey consisted of knowledge assessment, role of primary-care provider, patient barriers, and selection or tailoring of interventions related to cancer-survivor care	According to a survey of 238 participants, a significant proportion did not have knowledge on long-term health complications related to adults who survived childhood cancer and information resources available to them. Based on the survey results, it appears that primary-care providers and residents are unaware of screening guidelines for cancer survivors. Knowledge-related barriers such as lack of exposure to the population group and lack of awareness on existing guidelines were identified by primary-care providers and residents. Primary-care providers preferred receiving patient information directly from specialist oncologists in one-to-one settings. Additional resources and integration of training in primary-care provider residency curriculum were identified as potential facilitators to improve the general awareness of oncology-care transition of adults.
Experiences of adult cancer survivors in transitions (71)	<p><i>Publication date:</i> 2019</p> <p><i>Jurisdiction studied:</i> Canada</p> <p><i>Methods used:</i> Qualitative survey</p>	12,929 surveys were completed by adult cancer survivors aged 30 years and older between one to three years following cancer treatment for breast, prostate, colorectal and	Survivorship care was identified as care to a patient after cancer treatment completion and before the identification of cancer recurrence	Of the proportion of individuals with unmet needs, emotional and practical domains were highest. Cancer survivors reported changes in sexual intimacy, neuropathy, anxiety and depression. The authors recommended strategies to identify individuals with unmet needs and those at risk of facing difficulties with transitional care.

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Focus of study	Study characteristics	Sample description	Key features of the intervention(s)	Key findings
		melanoma diseases with no metastatic spread and certain hematological cancers		
Examining a breast cancer survivorship planning tool (64)	<p><i>Publication date:</i> 2020</p> <p><i>Jurisdiction studied:</i> Canada</p> <p><i>Methods used:</i> Literature review</p>	Breast cancer survivors seeking survivorship care in the primary-care setting	The tool was based on a systematic literature review and reviewed by medical oncologists and the Cancer Care Program Committee in Canada.	The Breast Cancer Survivorship Tool (BCST) was developed for breast cancer survivors and their primary-care providers to provide guidance on patient history, cancer surveillance, management of long-term effects, and health promotion. The tool includes gathering information on a patient's medical history and cancer therapy. The tool recommends breast cancer survivors complete follow-up visits with their primary-care provider every six months for the first five years after treatment completion, with completion of a thorough history, screening for symptoms, and treating any side effects. Additional screening is recommended such as psychosocial and behavioural changes, and other common long-term side effects of treatment. Additionally, the tool recommends primary-care providers to provide health education and preventive care to patients.
Implementing colorectal cancer patient-centred transitions program (59)	<p><i>Publication date:</i> 2020</p> <p><i>Jurisdiction studied:</i> Manitoba, Canada</p> <p><i>Methods used:</i> Qualitative post-implementation survey</p>	Curatively treated stage II and III colorectal cancer survivors participating in the Moving Forward after Cancer provincewide transition program	Patients were identified by their treating oncology team at the first post-treatment CT scan. The transitional clinic visit involves the oncologic clinic nurse and the oncologist where patients can ask questions about their future care and to develop a survivorship-care plan. The plan involves three parts: 1) summary of the patient's treatment, tabulated schedule of follow-up tests and appointments, list of potential ongoing symptoms; 2) printed resource manual on specific information on colorectal cancer such as diet and nutrition, follow-up care and side effects, exercise and activity, and emotional and psychological impacts due to treatment; and 3) general survivorship resources related	The survivorship-care plans were well received by patients and primary-care providers, which the authors attribute to the success of implementation due to the involvement of patients and community providers in the development of the survivorship care plan. A standardized template integrated into the EMR improved its acceptance into primary-care workflow. The transition program may work best in jurisdictions with a strong primary-care foundation. Overall, patients reported improved coordination, continuity in their care, and self-management due to the transition program.

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			to returning to work, navigating primary care, sleep wellness, and decision-making. The survivorship-care plan is faxed to the patient's primary-care provider.	
Examining discharge to primary care for survivorship follow-up (57)	<p><i>Publication date:</i> 2015</p> <p><i>Jurisdiction studied:</i> Alberta, Canada</p> <p><i>Methods used:</i> Mixed methods</p>	240 structured telephone interviews with women aged 18 or older who had stage I, II, or III invasive breast cancer diagnosed from June 2006 to September 2009 and were treated at cancer centres	Structured interviews included gathering information on current symptoms, type of treatment and surgeries, adherence to treatment and health promotion, and follow-up care assistance	Of the completed telephone interviews, 68.8% of participants were transferred from cancer centres to primary-care providers for transitional care. Adherence to guideline recommendations were high for surveillance, but examinations were slightly lower than cancer-centre care. Adherence to follow-up was higher among women who had a clear transfer of survivorship care to primary-care providers. The authors concluded that individuals with high ongoing needs could benefit from a telephone-based clinic for transition care.
Optimizing registered nurse roles in the delivery of cancer survivorship care with primary-care settings (67)	<p><i>Publication date:</i> 2016</p> <p><i>Jurisdiction studied:</i> Ontario, Canada</p> <p><i>Methods used:</i> Qualitative</p>	18 registered nurses in a primary-care setting such as family health groups, family health networks, family health organizations, community health centres, family health teams, and solo family practices	Semi-structured interviews consisted of questions on demography and practice setting	Nurses expressed their strongest involvement in cancer survivorship care to include care coordination and system navigation, emotional support, and facilitating access to community resources. In terms of accessing community resources, nurses utilized a combination of formal referrals, brochures, and professional connections for their patients. The level of involvement from nurses varied among the primary-care settings, with some actively connecting patients to community resources and subsequent follow-ups, whereas as some nurses only informed patients about existing resources. Promoting health and self-management skills to cancer survivor patients was less frequently mentioned by the participating nurses. Examples of those who did provide health education include coordinating and conducting cancer screening, goal setting, and supports related to home and education on lifestyle choices. Most of the participating nurses described the lack of knowledge support or awareness on resources related to cancer survivorship care on delivering effective care. At the practice-setting level, lack of care structure, demanding workload, clinic workflow, and competing priorities limited their activities with providing effective cancer survivorship care. In contrast, nurses described that the use of clinical information systems such as EMRs played a major role in nurse-delivered interventions related to survivorship care. The nurses highlighted possible solutions such as developing protected time for cancer survivorship care, and education materials and resources for support in practice settings. The authors indicate that there are existing gaps that need to be addressed such as identifying priority needs, strengthening communication between oncology

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				interprofessional teams, and providing community resource information to nurses.
Evaluating a survivorship-care plan for breast cancer survivors (61)	<i>Publication date:</i> 2014 <i>Jurisdiction studied:</i> Ontario, Canada <i>Methods used:</i> Randomized clinical trial	408 patients with early-stage breast cancer randomized into intervention (survivorship-care plan) or control group	Patient self-completed questionnaires with telephone interviews during a 24-month study period with cancer-specific distress as the primary outcome	The intervention involved a 30-minute educational session with a nurse and a comprehensive care plan that involves personalized treatment summary, guidelines tailored to patients, and a resource kit. The care plan in addition information on follow-up care and follow-up visit reminder table were forwarded to their primary care provider. The authors reported no negative effect in health service and patient-reported outcomes. Additionally, there was improved adherence to guidelines among women in Quebec (compared to women in Western Canada), women within two years of treatment completion, and had a higher SF-36 mental component score. The authors concluded that additional investigation is required before spreading the implementation of survivorship-care plans in clinical practice.
Evaluating the impact of post-treatment self-management guidelines for prostate cancer survivors (69)	<i>Publication date:</i> 2019 <i>Jurisdiction studied:</i> Alberta, Canada <i>Methods used:</i> Prospective qualitative study	18 English-speaking cancer survivors aged 18 years and older who completed curative prostate external beam radiation therapy between October and November 2017	Cancer survivors were provided self-management guidelines after their final treatment with a follow-up after four weeks, where they answered questions related to guideline timeliness, patient-centeredness, safety, effectiveness, and comprehensiveness	The self-management guidelines included sections on basic follow-up care information, side effects, genetics, fertility, sexuality, psychosocial issues, resources for support, lifestyle recommendations, and additional health resources such as workshops on post-treatment recovery. The authors reported that participants were satisfied with the self-management guidelines, but majority of the participants preferred receiving the information before their last appointment and to receive information in multiple formats (e.g., internet-based, paper-based) and in combination of an in-person educational visit with their healthcare provider. Additional tailored information to the needs of the patient population may be warranted.
Examining the continuity of care of colorectal cancer survivors at the end of treatment: The oncology-primary care interface (72)	<i>Publication date:</i> 2012 <i>Jurisdiction studied:</i> Manitoba, Canada <i>Methods used:</i> Qualitative survey	246 cancer survivors that had stage II or III colorectal cancer between 2008 to 2009	The survey included questions from the patient continuity of care questionnaire that assessed care before and after the end of cancer treatment, functional assessment of cancer therapy (colorectal) and the colorectal cancer subscale to assess quality of life	Over 60% of the participants reported receiving a care plan, and health information and other resources about support services. Overall, participants had positive views of receiving care from their primary care providers after transitioning from cancer treatment. However, there is a need for additional support to clarify roles and coordination of care.
Evaluating a multifaceted survivorship-care plan (62)	<i>Publication date:</i> 2013 <i>Jurisdiction studied:</i> Ontario, Canada <i>Methods used:</i>	Breast cancer survivors and family physicians recruited from one tertiary-care academic teaching hospital	The multi-phased approach involved conducting 35 interviews with family physicians, patients with breast cancer, and oncologist specialists to inform the survivorship-care plan package	The survivorship cancer plans were tailored for both patients and family physicians and included a summary of treatments and individualized follow-up plans. The plans were considered helpful by both the patients and their family physicians as they felt more engaged with transition care. For patients, they were additionally provided with a patient information booklet called a passport that included appointment bookings and key contact numbers and

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	Qualitative pilot study		(web-based, paper-based tailored resources), which was then developed and evaluated with focus groups and interviews with 26 participants	program information, in addition to an online resource with information available on community resources, side effects from treatments. While for family physicians, they were provided with digital information on clinical practice guidelines, symptom management and community resources for their patients. All the patients indicated that they would prefer to receive these resources before the transition phase. Additionally, the support services section on the online resource was considered helpful by patients but wanted more information on breast reconstruction and support groups in their community. An emphasis on health and wellness instead of clinical terms was also identified by the patients. For providers, they expressed the need for succinct instructions, printable checklists, and validated patient-scored instruments to improve clinic visits. Further research is needed to understand how this intervention can be integrated to existing infrastructure of care.
Describing patient experience with early-stage testicular cancer during the transition from active treatment to follow-up surveillance (63)	<i>Publication date:</i> 2016 <i>Jurisdiction studied:</i> Ontario, Canada <i>Methods used:</i> Cross-sectional qualitative study	90 patients aged 18 years and older who are within two years of completing primary treatment of early-stage testicular cancer (stages I to III) with no persistent recurrence	90 patients completed an adapted version of the breast cancer survivors knowledge of disease and treatment questionnaire and 13 completed either a focus group or phone interview	Of those that completed the questionnaire, 39% of the participants received information on their treatment plan, which were corroborated where the two main key messages from the qualitative interviews were the lack of preparation and difficulty to access health information and resources. Participants expressed a need for information on monitoring symptoms and recurrence and maintaining their health and wellness.
Describing the experiences of care delivery for endometrial cancer survivors at end of treatment (66)	<i>Publication date:</i> 2011 <i>Jurisdiction studied:</i> Ontario, Canada <i>Methods used:</i> Cross-sectional mixed-methods	English-speaking women aged 18 years and older who are within two years of completing their final cancer treatment from early stage endometrial cancer and have no persistent recurrence of disease	169 patients completed the survey, and 14 patients were part of a focus group	Most of the participants indicated that they did not receive information after treatment ended or who to contact if they had questions or concerns, which led the participants to seek information on the internet or at community programs. Participants expressed that they needed a health provider to discuss any long-term effects of treatment and how to access resources. All of the participants requested additional information such as follow-up appointment schedules and a tailored document such as a survivorship-care plan. The authors recommend developing a survivorship-care plan with information on long-term physical and psychosocial effects of cancer, monitoring for symptoms, and promoting lifestyle changes, in addition to primary-care providers playing a central role in providing education. They also recommend that oncology programs need to develop a comprehensive list of evidence-based resources and community programs for patients.
Evaluating the cost-effectiveness of a	<i>Publication date:</i> 2013	Patients (n=408) with early-stage breast cancer who had successfully	The survivorship care-plan (SCP) package included a treatment summary, a patient-	This study used data from a recent RCT to assess the cost-effectiveness of an SCP intervention compared with standard care. Cost-effectiveness of the SCP was assessed from the healthcare

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<p>survivorship care plan for breast cancer survivors (68)</p>	<p><i>Jurisdiction studied:</i> Canada</p> <p><i>Methods used:</i> Randomized controlled trial (RCT)</p>	<p>completed primary treatment at least three months previously, and were to have their care transferred to their own primary-care physician (PCP)</p>	<p>friendly version of follow-up guidelines and information about local supportive care resources; patients received this package and had an educational session with a nurse, and PCPs were given a copy of all of the documents (including full follow-up guidelines)</p>	<p>system perspective as well as from the societal perspective through measuring incremental costs and incremental quality-adjusted life years (QALYs).</p> <p>The time of the analysis was restricted to 24 months, and all costs were measured in 2011 Canadian dollars. Four defined cost groups were measured: 1) physician visits; 2) diagnostic and laboratory tests; 3) patient travel costs/lost productivity; and 4) additional SCP-associated costs.</p> <p>The analysis identified little difference between SCP and standard care regarding the costs of physician visits, diagnostic and laboratory tests, and patient travel costs/lost productivity. The analysis revealed that the total costs of the four cost categories were almost the same over the 24-month time period; however, the SCP was associated with \$10.41 greater total societal costs and with \$40.12 greater healthcare costs per patient. When including the costs of the SCP, the SCP was confirmed to be more expensive (per patient) than standard care (\$765.07 versus \$694.70, respectively). Additionally, over the 24-month time period, the average QALYs were lower for patients who received the SCP compared to standard care (1.41 versus 1.42, respectively). However, the difference may be considered negligible.</p> <p>Probabilistic analysis determined that the probability that the SCP was cost effective was only 0.26 at a threshold value of a QALY of \$50,000. A variety of sensitivity analyses were conducted, which did not change the conclusions of the analysis. Overall, the study concluded that the SCP would be costly to introduce and would not be an effective use of healthcare resources.</p> <p>The study cited that a limitation to the results may be the restricted time period of the RCT, which could limit the ability of the economic evaluation to identify significant differences in quality of life or resource use.</p>
<p>Examining healthcare-system barriers to long-term follow-up for adult survivors of childhood cancer in British</p>	<p><i>Publication date:</i> 2018</p> <p><i>Jurisdiction studied:</i> British Columbia (B.C.), Canada</p> <p><i>Methods used:</i></p>	<p>Adult childhood cancer survivors (CCS) (n=30) and healthcare professionals (HCPs) (n=13) in B.C.; the CCS ranged from 19 to 43 years of age at the time of the interview, HCPs</p>	<p>In-depth interviews with CCS and HCPs that were conducted either in-person or via telephone, lasted between 45 and 120 minutes, and consisted of open-ended questions that explored the personal factors, interpersonal relationships and</p>	<p>Using 43 in-depth interviews, this study examined the perspectives of CCS and HCPs relating to health-system factors that act as barriers to long-term follow-up (LTFU) in B.C.</p> <p>Inductive, thematic analysis of the interview transcripts revealed five main themes that highlighted CCS and HCP perspectives of health-system factors acting as barriers to the accessibility of LTFU.</p>

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Columbia, Canada (65)	Qualitative thematic analysis (of in-depth interviews) and constant comparative methods	included six physicians, two registered nurses, two healthcare administrators and one (each) social worker, counsellor and patient/parent advocate	social contexts that shaped the participants' experiences	<p>The first theme was the difficult and abrupt transition from pediatric to adult healthcare. From the perspective of CCS, participants reported feeling 'kicked out' of pediatric healthcare and reported being unprepared to navigate adult healthcare services, which led to worry about whether they were receiving adequate healthcare. From the HCP perspective, the transition is problematic because there is no professional ownership in this period and the timing is compounded by developmental transitions.</p> <p>The second theme was inconvenient and under-resourced healthcare services, which involved the location of multiple services, lack of HCP time and limited designated LTFU funding. From the perspective of CCS, there is burden associated with travel and time off work, and participants reported feeling like doctors are unable to address numerous health challenges. HCPs reported experiencing financial burdens due to missed appointments and loss to follow-up, as well as compromised quality of care due to lack of time and resources.</p> <p>The third theme was shifting patient-HCP relationships, wherein CCS were reluctant to seek care and discuss late effects with their HCP when a foundation of trust was not previously built. HCPs reported a lack of time to build positive patient-HCP relations in this transition period.</p> <p>The fourth theme was family doctors having inadequate experience with late effects. CCS feelings that their HCP had inadequate knowledge of cancer treatment details and health risks often led to CCS seeking out an oncology HCP for care. HCPs reported this to be a consequence of evolving evidence about late effects, as well as the small number of CCS followed by family doctors.</p> <p>The fifth theme was overdue and insufficient late effects communication with CCS. Lacking knowledge about late effects prevented CCS from engaging in late effects prevention and early detection, and prevented CCS from incorporating late effects information into life decisions. HCPs reported this as a failure of communication and information provision along the healthcare continuum.</p> <p>Overall, the results suggested that the relationship between CCS and LTFU HCPs influences patient-provider communication and ongoing health-seeking and engagement behaviours. A cited limitation to the study was that CCS who were already receiving</p>

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Between Cancer Programs and Primary Care*

Focus of study	Study characteristics	Sample description	Key features of the intervention(s)	Key findings
<p>Examining patient perceptions of communications on the threshold of cancer survivorship (56)</p>	<p><i>Publication date:</i> 2012</p> <p><i>Jurisdiction studied:</i> Canada</p> <p><i>Methods used:</i> Ongoing longitudinal cohort study, applied qualitative methodology (interpretive description)</p>	<p>A subset of Canadian cancer patients (n=14) from a larger cohort study who are at various stages of their cancer journey; this subset includes 12 women and two men ranging in age from 34 to 73, and their disease sites include breast (n=7), hematological (n=2), gynecological (n=2), and one each of prostate, gastrointestinal and lung</p>	<p>Face-to-face initial interviews by interviewers (with both health professional and qualitative inquiry training), followed by ongoing interviews according to patient preference (face-to-face or telephone, or both) as frequently as bi-monthly; interviews discuss changing communication needs/preferences across the cancer trajectory</p>	<p>cancer-related LTFU were over-represented. Further, there was limited input from CCS whose LTFU was primarily managed by their family doctor (i.e., pre-existing trusting relationship).</p> <p>This study analyzed data extracted from interviews with cancer patients relating specifically to participant accounts that addressed examples and/or recommendations relating to communication at the end of primary-treatment phase.</p> <p>Results from the thematic analysis revealed that the transition from treatment into aftercare can be a painfully difficult time for patients; there is often a major disjuncture between the relief/normalcy they expect to feel when treatment is over, compared to their actual experience. The disconnect between expectation and reality was reported to be profoundly influenced by the communications that patients had with their oncology-care providers during the transition period.</p> <p>The communicative environment of patient experience was characterized by several emotions, including confusion (closure is very blurry), insecurity (due to it being a transition phase), vulnerability (fear of cancer recurrence), loss (abrupt end to frequent contact with care teams), and abandonment (navigating the transition/new healthcare systems on their own). Contributing to these emotions were communication gaps and misinterpretations by clinicians, where they failed to respond accurately and sensitively to individual conditions and needs.</p> <p>There were seven thematic patterns identified relating to communication challenges for clinicians, and recommendations were made for mitigating each of these challenges.</p> <p>The first challenge identified was attending to patient cues, where it was recommended that clinicians anticipate heightened emotions and increase responsiveness to context, as well as respect the temporal context of cancer care. The second challenge was giving prior warning, where it was recommended that transitions be anticipated and informational needs be recognized. The third challenge was avoiding avoidance, where it was recommended that clinicians be sensitive to subjective experience and improve pattern recognition. The fourth challenge was sensitivity to context, where it was recommended to contextualize a new normal, initiate consideration of future possibilities, and create opportunities to process transitional information. The fifth challenge was managing</p>

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<p>Exploring main challenges in survivorship transitions for older adults with cancer (10)</p>	<p><i>Publication date:</i> 2020</p> <p><i>Jurisdiction studied:</i> Pan-Canadian, 10 provinces (those residing in the three territories not included)</p> <p><i>Methods used:</i> Cross-sectional survey study</p>	<p>Older adult (75+) cancer survivors (n=3,274); 55% of survivors were male (n=1,788), 37% reported their treatment had occurred between one and three years previously (n=1,214), and prostate cancer (26.5%) and colorectal cancer (26%) represented the largest respondent groups</p>	<p>National survey that was conducted across the 10 Canadian provinces to assess the experiences of cancer survivors relating to follow-up (one-to-three years post-treatment); the survey was designed to identify the needs of cancer survivors who are being followed in the community, and to explore their experiences in transitioning to follow-up care</p>	<p>This paper focused on the survey responses to the open-ended question: “What was the main challenge you experienced after you completed cancer treatment?” Of the total sample population (n=3,274), 2,057 wrote responses to this question, and of these, 23.6% (n=486) reported they had not experienced a main challenge or wrote a positive response. This left 1,571 respondents who identified at least one main challenge.</p> <p>Regarding the frequency of major challenges, the 1,571 respondents reported experiencing 2,426 main challenges. Less than half of respondents in each age group (75-84 and 85+) identified a main challenge, and of these, the majority (61.9%) identified a single main challenge, while 26.2% identified two, 9.2% identified three, and 2.8% listed more than three. The challenges were categorized into physical, emotional, practical, lifestyle adjustments, healthcare delivery and relationships/support. Physical challenges (e.g., physical capacity, symptoms/side effects, changes in body function/appearance) accounted for 68.2% of the main challenges identified, and the second most frequently identified challenges were emotional (10.2%) (e.g., psychological effects, coping with changes).</p> <p>Three major themes emerged across the major challenges. The first theme was ‘getting back on my feet’, which reflected participants’ strong desire to recover, including overcoming the resulting physical limitations from cancer treatment and restoring their previous level of functioning. The second theme was ‘adjusting to changes’, which involved a wide range of emotional and practical adjustments that participants faced after treatment. The third was ‘finding the support I needed’, which addressed the ways in which respondents desired support. Under this theme, many respondents</p>

*Identifying Educational Approaches and Resources to Support Seamless Transitions
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				<p>acknowledged their need for help or expressed appreciation for help they received after their primary cancer treatment. Respondents also believed that healthcare providers should provide survivorship care, specifically, they expected to receive a care plan and have a clear idea about who to contact if issues arose.</p> <p>The paper concludes that the patterns in the challenges point to structural ageism, which may be situated within an individual healthcare provider and/or the wider organizational structure through which people access care. The paper suggests that highlighting structural ageism as a common element to be identified and examined creates the opportunity to address patterns in survivorship care.</p> <p>Limitations cited include that the issues reported may not be reflective of all the issues that respondents experienced. Further, written comments from respondents reflect how they interpreted the question. Lastly, though the survey focused on a specific time period (one-to-three years after cancer treatment), it cannot be verified that responses focused only on this time period.</p>
<p>Evaluating the factors associated with unmet needs in adult cancer survivors in Canada (11)</p>	<p><i>Publication date:</i> 2020</p> <p><i>Jurisdiction studied:</i> Pan-Canadian, 10 provinces (those residing in the three territories not included)</p> <p><i>Methods used:</i> Cross-sectional survey study</p>	<p>Adult (30+) cancer survivors (n=10,717) who underwent chemotherapy, radiation therapy, surgical treatment (or a combination of these) within the past one-to-three years for breast, prostate, colorectal, melanoma or hematological cancer; 53% (n=5,660) of respondents were female, 60% (n=6,367) were 65 years or older, and breast cancer was the most represented cancer type (34%)</p>	<p>National survey that was conducted across the 10 Canadian provinces (disseminated via mail or completed online); the survey was designed to assess the physical, emotional and practical needs of cancer survivors, identify the specific needs of most survivors, identify the most vulnerable survivors, and to determine the factors/resources associated with needs being unmet</p>	<p>This study obtained data from the Experiences of Cancer Patients in Transitions Study of the Canadian Partnership Against Cancer.</p> <p>The outcomes of the study were: 1) quantification of the proportion and median of the physical, emotional and practical concerns reported; 2) examining the magnitude of associated unmet needs; and 3) identification of specific factors (related to patients, treatment, clinicians or cancer) associated with reporting unmet needs. An unmet need was defined as the percentage of respondents who reported not receiving help for their concern, regardless of whether they sought help.</p> <p>The median number [interquartile range (IQR)] of concerns reported per respondent was six (3-10). Those who reported concerns reported seeking help for a median (IQR) of two (0-4) concerns. Unmet needs were reported for a median (IQR) of four (2-7) concerns.</p> <p>Physical concerns were reported by the greatest number of respondents (n=9,236, 86%), followed by emotional concerns (n=8,330, 78%) and practical concerns (n=4,668, 44%). Among those with emotional concerns, 84% reported at least one unmet</p>

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				<p>need. The same was true for 81% of those with physical concerns, and 74% of those with practical concerns.</p> <p>The top reported physical concerns with the highest proportion of associated unmet needs were fatigue (68%), change in sexual activity (45%), change in concentration and memory (39%), and nervous system problems (37%). The top reported emotional concerns were anxiety (69%), depression (47%), change in sexual intimacy (43%), and change in body image (40%). Of those who reported emotional concerns, more than 70% reported unmet needs, regardless of the type of emotional concern. Less than 25% of respondents reported any type of practical concern; however, the extent of unmet needs for practical concerns ranged from transport to appointments (55%) to difficulty getting insurance (73%).</p> <p>Significant factors found to be associated with unmet needs included age, sex, annual income, marital status, geographic location, language and treatment type. Specific to the different cancer types represented, melanoma survivors were significantly more likely to report unmet emotional needs. Compared to breast cancer survivors, prostate and hematological cancer survivors were significantly less likely to report unmet needs for physical concerns. Additionally, involving the general practitioner and the oncologist in providing care was associated with a significantly lower likelihood of reporting unmet emotional or practical needs.</p> <p>This paper suggests that the findings of the study should be used to develop tools for risk-stratification (according to factors associated with unmet needs) of patients with cancer before they transition into survivorship. Other actionable recommendations included: 1) better patient education; 2) early involvement of primary-care physicians in cancer care; 3) improved coordination between primary-care physicians and oncologists; and 4) access to alternative care practitioners (e.g., nurses, social workers).</p> <p>This paper cited a few limitations, including that the survey tool was not validated. The response rate and inability to apply weightings may also limit the generalizability of the findings to all cancer survivors in Canada. Lastly, the sample may include a large proportion of older adults with other comorbidities, which may make the symptoms associated with cancer hard to distinguish from those of the comorbidities.</p>



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