Survivorship services for adult cancer populations: a pan-Canadian guideline

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ABSTRACT

Objective

Our goal was to develop evidence-based recommendations for the organization and structure of cancer survivorship services, and best-care practices to optimize the health and well-being of post–primary treatment survivors. This review sought to determine the optimal organization and care delivery structure for cancer survivorship services, and the specific clinical practices and interventions that would improve or maximize the psychosocial health and overall well-being of adult cancer survivors.

Data Sources

We conducted a systematic search of the Inventory of Cancer Guidelines at the Canadian Partnership Against Cancer, the U.S. National Guideline Clearinghouse, the Canadian Medical Association InfoBase, MEDLINE (OVID: 1999 through November 2009), EMBASE (OVID: 1999 through November 2009), PsychINFO (OVID: 1999 through November 2009), the Cochrane Library (OVID; Issue 1, 2009), and CINAHL (EBSCO: 1999 through December 2009). Reference lists of related papers and recent review articles were scanned for additional citations.

Methods

Articles were selected for inclusion as evidence in the systematic review if they reported on organizational system components for survivors of cancer, or on psychosocial or supportive care interventions designed for survivors of cancer. Articles were excluded from the systematic review if they focused only on pediatric cancer survivor populations or on populations that transitioned from pediatric cancer to adult services; if they addressed only pharmacologic interventions or diagnostic testing and follow-up of cancer survivors; if they were systematic reviews with inadequately described methods; if they were qualitative or descriptive studies; and if they were opinion papers, letters, or editorials.

Data Extraction and Synthesis

Evidence was selected and reviewed by three members of the Cancer Journey Survivorship Expert Panel (SM, TC, TKO). The resulting summary of the evidence was guided further and reviewed by the members of Cancer Journey Survivorship Expert Panel. Fourteen practice guidelines, eight systematic reviews, and sixty-thee randomized controlled trials form the evidence base for this guidance document. These publications demonstrate that survivors benefit from coordinated post-treatment care, including interventions to address specific psychosocial, supportive care, and rehabilitative concerns.

Conclusions

Ongoing high-quality research is essential to optimize services for cancer survivors. Interventions that promote healthy lifestyle behaviours or that address psychosocial concerns and distress appear to improve physical functioning, psychosocial well-being, and quality of life for survivors.

KEY WORDS

Psychosocial, supportive care, cancer survivor, survivorship, organization of care, care plan

1. INTRODUCTION

Despite the mortality associated with cancer, survivors are a growing population in Canada. According to 2009 statistics, more than 260,000 people were expected to be alive within 10 years of a primary diagnosis of cancer, a number that equates to more than twice the number of people surviving cancer in the early 1990s [1]. Several definitions of cancer survivorship exist, but the U.S. National Cancer Institute considers an individual a survivor from the time of a diagnosis through the balance of his or her life. Family members, friends, and caregivers are also affected by the survivorship experience and are therefore included in that definition [2].

Along the cancer continuum, much attention is paid to the diagnostic and treatment phases of care; however, the post–primary treatment phase is a distinct part of the cancer trajectory that needs to be specifically addressed because it has been largely neglected in advocacy, education, clinical practice, and research [3]. Cancer and cancer treatment have a substantial impact on long-term health and quality of life, leading to questions about the most appropriate configuration of health care services for survivors. People who survive their cancer are at risk of late or protracted effects that depend on the type and stage of cancer and on all the various therapies used to treat the cancer or to reduce side effects. As a result of their experience with cancer and its treatment, post-treatment survivors have supportive care needs in the physical, informational, emotional, psychological, social, spiritual, and practical domains, just as they do during active treatment [4].

The purpose of the present paper is to describe the development of a pan-Canadian guideline with evidence-based recommendations for the organization and structure of survivorship services and for best-care practices to optimize health and well-being. We also report on the results of a national survey that obtained external feedback on the appropriateness and relevance of these recommendations to cancer care organizations. To our knowledge, this is the only national or international evidence-based guideline regarding the structure and composition of survivorship care services.

2. REVIEW QUESTIONS

These questions were used to guide the systematic review of the literature:

- What is the optimum organization and care-delivery structure for cancer survivorship services?

  Examples of organization and care-delivery structures are follow-up care delivery models, care plan components, and interventions related to transition planning or to transition preparation for survivorship.
- What are the clinical practices and specific interventions that improve or maximize the psychosocial[a] health and overall well-being of adult cancer survivors?

  Examples of clinical practices and interventions include psychoeducation, cognitive behavioural therapy, counselling, exercise, nutrition, and rehabilitation programs.

Outcomes of interest included survival, recurrence, survivor satisfaction, psychosocial and supportive care needs, and health-related quality of life.

2.1 Target Population

Evidence was included for review if it addressed adult cancer survivors in the periods of survivorship described as "extended survival" (recovery from initial treatment, watchful waiting, surveillance with medical testing, fear of recurrence, and uncertainty) and "permanent survival" (coping with late and long-term physical, emotional, and other effects; adjusting to the "new normal" life beyond cancer). Evidence pertaining to adult cancer survivors receiving ongoing hormonal therapies in the post-treatment phase of survivorship and to those with advanced disease was included. Although we recognize that cancer survivorship begins at diagnosis (that is, during acute survival), that specific phase of survivorship was considered outside the scope of the present review.

2.2 Target Users

This guideline document is intended to inform Canadian health authorities, key administrative and policy decision-makers, advocacy groups, and health and supportive care practitioners about the optimal structure for survivorship services and about clinical practices for adult cancer survivors in the post–primary treatment survivorship period. It is also intended for use by survivors and their caregivers to assist in making informed decisions about survivorship services and health practices.

3. METHODS

3.1 Guideline Development

This guideline was developed as part of on-going cooperation between the Canadian Partnership Against

[a] In this work, "psychosocial" encompasses the physical, psychological, social, and spiritual health domains.

Cancer and the Canadian Association of Psychosocial Oncology. The Cancer Journey Survivorship Expert Panel, whose members have expertise in cancer survivorship, conducted a systematic review of the literature, current to November 2009. A draft version of the guideline was distributed to content experts and key stakeholders across Canada, who had the opportunity to provide feedback about the collection and interpretation of the evidence, and the development and content of the recommendations. The final guideline document was approved through a formal and unanimous consensus vote of the Cancer Journey Survivorship Expert Panel. The literature will be periodically reviewed, and the guideline will be updated as new or compelling evidence is identified.

3.2 Expert Panel

The membership of the Cancer Journey Survivorship Expert Panel included psychologists, nurses, spiritual care professionals, researchers, social workers, family physicians, health services researchers, cancer survivors, and clinical practice guideline developers. To ensure that the views and preferences of the target population were addressed, the draft document was circulated to cancer survivors for external feedback. As part of that process, several members of the Cancer Journey Survivorship Expert Panel and 7 members of the external review committee disclosed that they were also cancer survivors.

3.3 Literature Search Strategy

The systematic search of the literature included the Inventory of Cancer Guidelines maintained by the Canadian Partnership Against Cancer, the U.S. National Guideline Clearinghouse, the Canadian Medical Association InfoBase, MEDLINE (OVID: 1999 through November 2009), EMBASE (OVID: 1999 through November 2009), PsychINFO (OVID: 1999 through November 2009), the Cochrane Library (OVID; Issue 1, 2009), and CINAHL (EBSCO: 1999 through December 2009). Reference lists of related papers and recent review articles were scanned for additional citations.

Evidence was selected and reviewed by 4 members of the Cancer Journey Survivorship Expert Panel (DH, SM, TC, TKO). The resulting summary of the evidence was guided further and reviewed by the members of Cancer Journey Survivorship Expert Panel.

3.4 Study Selection Criteria

3.4.1 Inclusion Criteria

Articles were selected for inclusion as evidence in the systematic review if they reported on organizational system components for survivors of cancer or on psychosocial or supportive care interventions designed for survivors of cancer. Studies also had to

- be an organizational standard, practice guideline, systematic review (with or without meta-analysis), or randomized controlled trial published during or after 1999.
- report on adult cancer survivors in the post–primary treatment phase of their cancer journey.
- include data on outcomes, including survival, recurrence, survivor satisfaction, psychosocial and supportive care needs, and health-related quality of life.

3.4.2 Exclusion Criteria

Articles were excluded from the systematic review if they

- focused only on pediatric cancer survivor populations or patients who transitioned from pediatric cancer to adult services.
- described pharmacologic interventions or diagnostic testing and follow-up of cancer survivors.
- were systematic reviews with inadequately described methods.
- were qualitative or descriptive studies.
- were opinion papers, letters, or editorials.

4. RESULTS

The literature search identified 3275 relevant articles. Of those articles, fourteen practice guidelines [5–19], eight systematic reviews [20–27], and sixty-three randomized trials [28–89] were considered eligible for inclusion.

Regarding the organization and care-delivery structure of survivorship services, the reviewed literature provided recommendations for models of care, type of provider, and structural approaches such as survivorship care plans. In terms of psychosocial and supportive care interventions for cancer survivors, the literature predominantly included recommendations for physical outcomes; emotional, psychological, informational, social, spiritual, and practical outcomes were occasionally addressed. The AGREE II [90] tool was used to critically appraise the quality of the clinical practice guidelines, which were assessed to be poor to moderate in overall reporting quality.

The psychosocial and supportive care interventions that were reviewed included cognitive behavioural and psychoeducational interventions and lifestyle management interventions such as exercise and nutrition programs. Using the Scottish Intercollegiate Guidelines Network critical appraisal tool [91], the systematic reviews were rated as being of poor to moderate overall methodologic quality. Limitations of the systematic reviews included substantial heterogeneity in mode, frequency, intensity, and duration of the interventions. Breast cancer survivors were the focus of most of the studies reviewed. Low sample sizes and weak methodologic quality characterized many of the studies.

Of the sixty-three randomized trials, nine reported interventions related to follow-up care, twenty-one reported on psychoeducational or cognitive behavioural interventions, and thirty-three reported interventions related to lifestyle management. Using the Scottish Intercollegiate Guidelines Network methodology [91], the quality of the sixty-three trials ranged from non-assessable to poor or modest quality. Because of the nature of the interventions, most trials did not blind participants or an assessor, which is a common challenge within psychosocial research. The reporting of procedures and outcomes was deemed inadequate, and most trials had insufficient statistical power to detect significant differences between treatment groups for the primary outcomes of interest. Because most of the trials were conducted with breast cancer survivors, generalizability of the results may be limited. Furthermore, few studies reported rates of adherence rates to interventions, particularly for unsupervised exercise programs.

As seen in Tables I and II, assessment using the GRADE (Grading of Recommendations Assessment, Development and Evaluation) approach for summarizing and assessing the quality of the body of evidence [92] found that the evidence informing the outcomes of interest was of low quality, that the results were generally inconsistent, and that the data were too heterogeneous to pool across studies. High-quality evidence that directly answered the questions of interest for all cancer survivor populations was scarce, and an informal assessment of precision indicated that wide confidence intervals would accompany any estimates of effect if data were to be pooled across studies by outcome of interest.

5. EXTERNAL REVIEW

The final guideline and recommendations were reviewed by 36 health care professionals from across Canada, purposively selected for their expertise in psychosocial and supportive care of cancer survivors. Respondents were asked to complete a survey on the relevance and quality of the guideline and were invited to comment on the draft. The Cancer Journey Survivorship Expert Panel reviewed the results of the external review, addressed each comment, and modified the guideline accordingly. Table III summarizes the findings of the external review.

As seen in Table III, most respondents agreed that the guideline was both needed and appropriate; 83% indicated they would likely or very likely make use of the recommendations to inform the development of survivorship services in their own organization, practice, or community program.

6. DISCUSSION

A systematic search of the literature yielded clinical practice guidelines, systematic reviews, and randomized controlled trials that help to inform the organization of cancer survivorship services and clinical practices to optimize the health and well-being of adult cancer survivors. Although generally weak, the evidence identifies important themes in the cancer

TABLE I Evidence summary: organization and care delivery of survivorship services

Studies (n)	*Quality assessment*						*Summary of findings*	
	Design	*Limitations*	*Inconsistency*	*Indirectness*	*Imprecision*	*Other*	*Quality*	*Importance*
Models of care								
15	CPG, RCT	Serious	Serious	Serious	Serious	None	●●oo Low	Low
Site of care								
3	RCT	Serious	Serious	Serious	Serious	None	●●oo Low	Low
Type of provider								
13	CPG, RCT	Serious	Serious	Serious	Serious	None	●●oo Low	Low
Support services								
4	CPG	Serious	No serious inconsistency	No serious indirectness	No serious imprecision	None	●●oo Low	Low
Structural approaches								
8	CPG	Serious	No serious inconsistency	No serious indirectness	No serious imprecision	None	●●oo Low	Low
Other								
4	CPG	Serious	Serious	Serious	Serious	None	●●oo Low	Low

CPG = clinical practice guideline; RCT = randomized controlled trial.

TABLE II Evidence summary: psychosocial and supportive care interventions

Studies (n)	*Quality assessment*						*Summary of findings*	
	Design	*Limitations*	*Inconsistency*	*Indirectness*	*Imprecision*	*Other*	*Quality*	*Importance*
Survival/recurrence								
3	SR, RCT	Serious	Serious	Serious	Serious	None	●●oo Low	Critical
Physical function—								
Overall physical health								
38	RCT	Serious	Serious	No serious indirectness[a]	Serious	None	●●oo Low	Important
Fatigue								
11	CPG, SR, RCT	Serious	No serious inconsistency	No serious indirectness	Serious	None	●●oo Low	Important
Vasomotor symptoms								
2	RCT	Serious	No serious inconsistency	Serious	No serious imprecision	None	●●oo Low	Moderate
Sleep function								
3	RCT	Serious	No serious inconsistency	Serious	No serious imprecision	None	●●oo Low	Moderate
Sexual function								
3	CPG, RCT	Serious	Serious	No serious indirectness[a]	Serious	None	●●oo Low	Moderate
Psychosocial function								
14	CPG, RCT	Serious	Serious	Serious	Serious	None	●●oo Low	Important
Quality of life—								
Psychoeducational or cognitive behavioural therapy								
12	RCT	Serious	Serious	Serious	Serious	None	●●oo Low	Moderate
Lifestyle management								
18	RCT	Serious	Serious	Serious	Serious	None	●●oo Low	Moderate

[a] While much of the evidence pertains to breast cancer patients, a sufficient number of studies pertain to multiple cancer survivors.
CPG = clinical practice guideline; SR = systematic review; RCT = randomized controlled trial.

survivorship journey. Further, the evidence is consistent if viewed not by specific intervention, but rather by thematic approach, such as overall improvement in physical or psychosocial outcomes.

Evidence related to models of care—including the site of care, type of provider, and supportive services—is modest. Even so, the evidence supports the importance of interdisciplinary survivorship care, in which members of the cancer treatment team are knowledgeable about issues facing cancer survivors and skilled at detecting and responding to distress in individuals. The evidence also supports survivorship services that meet a range of survivor needs, including informational, psychological, emotional, spiritual, physical, and social needs. Satisfaction was generally higher and other outcomes, such as distress, were generally improved when those needs were met. Several randomized trials investigated the value of follow-up care according to provider type (primary care physicians, nurses, oncology specialists) or trigger-context (routine appointments or survivor-initiated care). Overall, satisfaction with care was greater with alternative follow-up approaches than with standard approaches, but the evidence is not robust, and no compelling differences were observed in other outcomes to adequately inform the topic of a preferred model of care.

In terms of outcomes related to survival or disease recurrence, it appears that dietary behavioural modification interventions were effective at improving intake of fruits, vegetables, and fibre, and at reducing intake of dietary fat, which corresponds with improved body weight and body composition outcomes. If the goal is to improve survival, the results of such interventions

TABLE III Summary of external review survey results

Survey items 7–18	*Responses [n (%)]* *Strongly agree*	*Agree*	*Somewhat agree*	*Undecided /NA*
The rationale for developing a guideline, as stated in the "Introduction" and "Scope and Purpose" sections of the draft report, is clear.	14 (38.9)	21 (58.3)	0 (0.0)	1 (2.8)
There is a need for a pan-Canadian guideline on organization and care delivery structure for adult cancer survivors.	23 (63.8)	11 (30.6)	1 (2.8)	1 (2.8)
There is a need for a pan-Canadian guideline on clinical practices for psychosocial and supportive care interventions for adult cancer survivors.	21 (58.3)	13 (6.1)	2 (5.6)	0 (0.0)
The literature search described in the draft report is complete (no key studies or guidelines were missed).	9 (25.0)	23 (63.9)	2 (5.6)	2 (5.6)
The evidence described in the draft guideline on organization and care delivery structure for cancer survivorship services is relevant.	11 (30.6)	24 (66.7)	1 (2.8)	0 (0.0)
The evidence described in the draft guideline on clinical practices for psychosocial and supportive care interventions for adult cancer survivors is relevant.	12 (33.3)	22 (61.1)	2 (5.6)	0 (0.0)
I agree with the methods used to summarize the evidence included in the draft guideline.	7 (19.4)	25 (69.4)	2 (5.6)	2 (5.6)
The results of the studies described in the draft guideline are interpreted according to my understanding of the data.	7 (19.4)	26 (72.7)	1 (2.8)	2 (5.6)
The draft recommendations are clear.	16 (44.4)	18 (50.0)	2 (5.6)	0 (0.0)
I agree with the draft recommendations on organization and care delivery structure for cancer survivorship services as stated.	14 (38.9)	18 (50.0)	2 (5.6)	2 (5.6)
I agree with the draft recommendations on clinical practices for psychosocial and supportive care interventions for adult cancer survivors as stated.	13 (36.1)	22 (61.1)	0 (0.0)	1 (2.8)
I would feel comfortable having these recommendations applied in my hospital/cancer centre/community programs.	17 (47.2)	13 (36.1)	4 (11.0)	2 (5.6)[a]

Survey items 19, 20	*Responses [n (%)]* *Very likely*	*Likely*	*Somewhat likely*	*unlikely*
How likely would you be to make use of the recommendations on organization and care delivery structure for cancer survivorship services to inform the development survivorship services in your own organization/practice/community program(s)?	15 (41.7)	15 (41.7)	4 (11.1)	1 (2.8)
How likely would you be to make use of the recommendations on clinical practices for psychosocial and supportive care interventions for adult cancer survivors to inform the development of survivorship services in your own organization/practice/community program(s)?	16 (44.4)	14 (38.9)	3 (8.3)	3 (8.3)

[a] One respondent strongly disagreed with the item.
NA = not applicable.

are inconclusive. Although two large trials in patients with breast cancer helped to inform the discussion, results were inconsistent. One trial detected a survival difference; the other did not. Study quality was poor, and results are generalizable only for patients with breast cancer.

Not surprisingly, interventions that promoted exercise, diet, or both, with or without counselling, were generally effective at improving outcomes in overall physical health. Most interventions were effective in improving health, but the multi-component interventions were consistently effective at improving short-term physical health. Whether such change was sustained over time is unknown; however, it is reasonable to offer exercise, dietary, or smoking cessation programs to survivors on the basis of improved outcomes. Programs should be tailored to meet the individual survivor's goals, ability level, and available community resources. The appropriateness and safety of any program should be considered in consultation with the survivor and their interdisciplinary health care team.

Interventions designed to reduce fatigue through psychosocial or exercise interventions were generally successful, but the results pertain primarily to breast cancer survivors. Effect sizes were small to moderate, and long-term data on the sustainability of the improved outcomes were inconclusive. Two small randomized controlled trials indicated that breast cancer survivors should have access to multi-component cognitive behavioural therapy and lifestyle management programs to help with postmenopausal vasomotor symptoms.

Evidence is limited, but it is reasonable to conclude that, compared with standard care, sleep-oriented interventions based on cognitive behavioural therapy are more effective in improving sleep outcomes. The effects of such interventions may be sustainable for at least 1 year post treatment.

Sexual function was assessed in one practice guideline and two randomized trials. With improvements in function detected in the two trials, it is reasonable to conclude that survivors should have access to psychoeducational interventions addressing changes in sexual health during and after treatment and should be offered access to programs that include both the cancer survivor and the survivor's partner—that is, couples therapy.

Psychosocial functioning is an amorphous outcome and was generally defined as any improvement in psychological, social, or spiritual health. A, series of psychoeducational or cognitive behavioural therapy interventions were used to address this important outcome. Most interventions resulted in meaningful improvements in some aspect of psychosocial functioning, thereby improving aspects of quality of life, but the trials were not designed to detect significant improvements in overall distress. However, based on these data, it seems reasonable to reduce psychosocial distress by recommending that survivors with psychosocial concerns or distress be offered referral to psychosocial services or individualized or group-based cognitive behavioural or psychoeducational programs provided by trained professionals.

Quality of life is a multi-dimensional concept that includes physical, social, emotional, and spiritual well-being. As an outcome, quality of life is hard to define despite the use of numerous surrogate measures. Regardless of the measures used, most interventions improved quality of life more than standard care did. Any improvements in a cancer survivor's journey might result in improved quality of life, and because the evidence supports that association, a survivorship care plan should consider interventions that both indirectly and directly improve quality of life.

Overall, the evidence supports a benefit for cancer survivors from ongoing post-treatment survivorship care (a variety of services and interventions designed to improve survivor outcomes). Survivors should have access to coordinated, interdisciplinary, multi-component psychosocial and supportive care services during the transition from active treatment to extended survival. Ongoing high-quality research is needed to optimize services for cancer survivors, but interventions that promote healthy lifestyle behaviours (daily physical activity, balanced nutrition, and access to smoking cessation programs, among others) and those that address psychosocial concerns or distress appear to improve physical functioning, well-being, and quality of life for survivors. Furthermore, the research reviewed for this guideline suggests that the provision of psychosocial and supportive care services need not be limited to specialist cancer care settings. Indeed, individually or in combination, primary care or nurse-led follow-up models may be viable options for delivering psychosocial and supportive care services, particularly during extended survival.

The provision of optimal survivorship services depends on a rigorous evaluation of care delivery structures and interventions developed to meet the specific needs of survivors in the post-treatment phase. The evidence base will be strengthened by study designs that strive to overcome the limitations of existing research: for example, ensuring adequate statistical power, and blinding participants where possible. To facilitate the application of empirical findings to clinical settings, future research should consider the respective roles of system indicators (for example, cost-efficiency, continuity of care) and individual outcomes (for example, specific late effects, distress, social costs) in determining the effectiveness of various approaches to care delivery and the specific psychosocial and supportive care interventions.

This guideline document does not address the underserved cancer survivor populations (that is, those having literacy issues or living in poor

socio-economic conditions). Further research is needed to understand the specific needs and support requirements of vulnerable populations.

It is also recognized that cancer centres across Canada vary substantially with respect to community resources, capacity for implementation, education, and knowledgeable professionals. Those variations could make it difficult to implement standardized cancer survivorship services. For effective implementation, organizations will need to tailor the recommendations based on local organizational structures and abilities to deliver care.

Some resources and greater research must focus on approaches to implementation: Which approach is most effective in facilitating adoption and uptake of the guideline recommendations? The knowledge translation approaches and strategies recommended by the Knowledge Translation Institute of the Canadian Institutes of Health Research will be helpful to organizations developing a systematic approach to health care and change in practice (http://www.cihr-irsc.gc.ca/e/39152.html). Recommendations and tactics for implementation are offered by the Cancer Journey Survivorship Expert Panel (Appendix A).

7. EDITORIAL INDEPENDENCE

The Cancer Journey Survivorship Expert Panel is editorially independent of any funding sources. The views and interests of the funding sources have not influenced the recommendations in the guideline document.

8. ACKNOWLEDGMENTS

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9. CONFLICT OF INTEREST DISCLOSURES

Members of the Cancer Journey Survivorship Expert Panel were asked to declare any conflicts of interest that may potentially have influenced or biased the recommendations presented in the guideline document. Conflict of interest forms were completed by each Panel member and forms were centrally collected and filed. None of the members of the Cancer Journey Survivorship Expert Panel declared any real or perceived conflicts of interest associated with the guideline document.

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APPENDIX A

RECOMMENDATIONS

The recommendations that follow are based on the consensus of the Cancer Journey Survivorship Expert Panel, informed by a systematic review of the evidence current to December 2009. The body of evidence includes clinical practice guidelines, systematic reviews, and randomized controlled trials. Each recommendation was developed with consideration for the balance between the expected health benefits and the potential harms, side effects, or risks associated with the guidance offered. Tactics for guideline implementation across various health care jurisdictions or health models are offered and can be used in auditing or monitoring survivorship services. Final and formal approval of the document was obtained through an online vote by the members of the Cancer Journey Survivorship Expert Panel. Where recommendations were taken directly or adapted from any of the identified practice guidelines, the source document is listed after the recommendation. While there is a great volume of data on the topic, recommendations should be considered consensus-based and informed by the evidence unless otherwise stated.

Please visit http://www.cancerview.ca or http://www.capo.ca for more extensive information on the systematic review results, the external review process, and the methods used to inform the guideline document. The Canadian Association of Psychosocial Oncology has assumed stewardship of this guideline, and the recommendations are published here with their permission.

ORGANIZATION AND CARE DELIVERY STRUCTURE FOR SURVIVORSHIP SERVICES

Recommendation 1

Access to Survivorship Services to Meet a Broad Range of Needs: It is recommended that survivorship services be recognized as a distinct component and standard of cancer care, with access by survivors to services to meet a broad range of their physical, psychosocial, supportive, informational, and rehabilitative needs. [Adapted from U.S. Institute of Medicine (IOM) consensus recommendation 2]

Tactics

- Develop specific programs to establish survivorship services as a distinct component of cancer care and to ensure equitable access to these services, taking into consideration needs of survivors from diverse backgrounds and living in remote or rural settings.
- Establish outreach programs working in partnership with community groups and assist community providers in offering care that meets a broad range of survivor needs.
- Use technology-based or alternative forms of care such as the Internet, health portals, or mobile clinics to provide survivors with rapid access to necessary survivorship support services.
- Develop and maintain an up-to-date database of local resources available to support cancer survivors, their families, and caregivers.
- Provide information about access to a comprehensive range of rehabilitation services including, but not limited to, psychosocial services; nutrition support; spiritual care services; vocational rehabilitation; and physical, occupational, and other therapy services including speech pathology, lymphedema services, and enterostomal services.

Recommendation 2

Support During the Transition to Extended Survival: It is recommended that individuals completing cancer treatment and their families receive individualized information and support in consultation with a designated and skilled member of the health care team to prepare them for the life-long monitoring and follow-up care required post cancer treatment and to minimize distress in the transition from active treatment to the follow-up phase of the cancer journey.

Tactics

- All cancer treatment team providers should be knowledgeable about the issues facing cancer survivors and skilled in detecting and responding to distress in the weeks leading up to and at the time of discharge from the treatment phase of the cancer journey.
- Cancer care organizations should designate at least one specific member of the interdisciplinary team who will provide an end-of-treatment consultation to individuals and family members to counsel and prepare them for the transition to the follow-up phase of the cancer journey.
- The end-of-treatment consultation should link individuals to psychosocial, rehabilitative, or supportive care services, and to employment counselling, in coordination with the primary care provider, depending on the issues or concerns identified.

Recommendation 3

Treatment Summary and Follow-Up Care Plan: It is recommended that all individuals completing primary treatment for cancer receive a written treatment summary and follow-up care plan ("survivorship care plan") from a designated member of the care team. The plan should include a standard set of core multidimensional elements tailored to

the individual's cancer and treatment experience. (Adapted from IOM consensus recommendation 2)

Tactics

- The multidimensional components of the survivorship care plan should include the core elements listed here and should clearly designate the person or persons accountable for completing the care plan or parts of the care plan:
  - Cancer type, treatment received, and the potential adverse late and long-term effects of cancer treatment that must be routinely screened for, monitored, and managed on an ongoing basis
  - Goals, frequency, and timing of follow-up visits, and designation of a specific coordinator or provider for follow-up care tests and procedures
  - Specific procedures or tests for ongoing surveillance and detection of recurrence tailored to cancer type and treatment modalities
  - The need to report new, persistent symptoms promptly, without waiting for the next scheduled appointment, and the specific provider to notify
  - Psychosocial, rehabilitative, supportive care, and other health care services that are available on site, in the local community, or through the Internet; education on selecting peer support programs and resources that meet best-practice standards
  - Guidance on strategies to reduce the risk of recurrence and to maximize health and well-being (such as lifestyle changes related to nutrition, physical activity, and smoking cessation, among others)
  - Information about employment, financial, and legal issues, and about counselling services available in the local community
- Cancer care programs or organizations should designate at least one specific member of the interdisciplinary team to ensure completion of the treatment summary, of the recommendations about specific tests for monitoring for disease recurrence, and of the late and long-term consequences (based on current guidelines, where available, or on best practices based on consensus where specific guidelines are lacking)
- To support the survivor's use of the plan, and to ensure coordination of care, the survivorship care plan should be given to primary care providers and other providers designated for follow-up care.

Recommendation 4

Care Models and Coordination of Survivorship Services: It is recommended that one or more health care providers be designated to be responsible for providing survivorship follow-up services, with integration of primary care physicians in monitoring for late and long-term treatment consequences, coordinated access to interdisciplinary specialists as required, and an emphasis on actively engaging and empowering survivors.

Tactics

- Primary care physicians should be integrated into the oncology follow-up plan for monitoring early detection of cancer recurrence and for managing late and long-term consequences of treatment as part of survivorship care.
- Primary care physicians and other designated providers of follow-up care should have a copy of the survivorship care plan and specific recommendations for required follow-up tests and procedures to monitor for late and long-term complications.
- Service configurations should ensure access to services that can meet a broad range of the cancer survivor's physical, psychosocial, practical, and rehabilitation care needs.
- A coordinated referral system should be established to ensure quick referral when a specific need for specialist services or interdisciplinary specialists has been identified.
- To ensure rapid referral back to the specialty centre, a tiered follow-up care approach or shared-care model between primary care physicians and oncology specialists is advisable for cancer survivors with complex issues and problems (high-risk model).
- As appropriate, cancer survivors and their families should be educated on the accessibility and benefits of follow-up care delivered either by their primary care physicians or by oncology nurse specialists.
- Nurse-led care delivery models have been shown to be acceptable in delivering survivorship follow-up care services.

Recommendation 5

Screening for Distress and Evidence-Based Practice: It is recommended that valid tools be used to routinely screen survivors for distress across a broad range of late and long-term treatment effects: persistent symptoms and functional problems, symptoms of mood disorders (anxiety and depression), and other common problems such as cognitive changes or alterations in sexual health. Screening should be followed by focused assessment and interventions based on recommendations found in evidence-based clinical practice guidelines. (Adapted from IOM consensus recommendation 3 and the Psychosocial Health Care Needs Assessment Guideline for Adults, 2009)

Tactics

- Develop a team to lead implementation of evidence-based practice change, including

representatives from all key stakeholder groups that would be affected by the proposed practice change (for example, the inter-professional team, survivors, administrators). This group may prioritize recommendations within the guideline to be implemented, can identify the barriers and facilitators to change in the local environment, and should plan the approaches to be used.
- Seek formal commitments from stakeholder organizations, including resources for support strategies (for example, education sessions, staff involvement), that would further the success and sustainability of implementing the practice change.
- Ensure that implementation plans reflect a multifocal approach, targeting change at both the individual level (for example, education, audit, and feedback) and the organizational level (for example, policy and structural changes).
- Promote the development and evaluation of clinical tools specific to the care of survivors in the post-treatment phase.
- To achieve and sustain the long-term care effects, the practice change must be effectively managed using a programmatic approach based on the most effective and multifaceted implementation strategies.

Recommendation 6

Support Active Engagement of Survivors in Self-Management: It is recommended that approaches which support effective self-management be used. Designated providers of survivorship follow-up care should focus on enabling and empowering individuals and their families by giving them the skills and knowledge they need to be active participants in optimizing their own health and well-being.

Tactics

- Organizations providing care for cancer survivors should offer access to tailored education, training, and support for the development of self-management skills and strategies, based on personalized assessment and care planning. The assessment should take into consideration the resources available to the survivor, including individual strengths (for example, resilience) and family support.
- Self-management support may be provided through a variety of methods including, but not limited to, peer counselling, psychoeducation, and telephone- or Internet-based support.
- Cancer care programs or organizations should encourage cancer survivors to be proactive in their own care by promoting skill development, access to community agencies, and positive decision-making skills for healthy lifestyles.
- Self-management programs should be developed that focus on goal-setting and problem-solving strategies, health coaching based on motivational interviewing skills, and health behaviour-change theories.

Recommendation 7

Survivorship Education for Health Care Providers: It is recommended that all clinical staff receive education to increase awareness of the needs of cancer survivors. Specific education programs should be targeted to designated follow-up care providers to ensure effective monitoring for disease recurrence and prevention and management of late and long-term effects of cancer treatment, and to encourage specific strategies that empower survivors to be actively engaged in self-management and to adopt healthy lifestyle behaviours.

Tactics

- The curriculum should include the need for cancer surveillance, the personal impact of cancer, the roles of nutrition and of rehabilitation, and the management of distress, pain, and other symptoms.
- At a minimum, health care provider education to support self-management should include assessment skills, motivational interviewing, information sharing, problem solving and goal setting, shared decision-making, self-efficacy assessment, and follow-up interventions.
- Designated follow-up care providers and family physicians should be knowledgeable and trained in screening for distress and in conducting physical assessments, including body weight, waist-to-hip ratio, and body mass index; physiologic assessments; and brief dietary intake assessments.
- Partnerships should be formed with survivorship organizations to provide ongoing professional development and skill acquisition for assessing and managing specific survivorship issues.
- Technology-based resources (for example, the Internet) should be used to distribute survivorship information to health care professionals in readily accessible and user-friendly formats.

Recommendation 8

Promoting Awareness of Survivorship Issues: It is recommended that cancer care organizations, advocacy groups, and governments, as part of cancer control initiatives, work in partnership to increase awareness in the broader community (members of the public, decision-makers, policymakers, and employers) of the physical, emotional, spiritual, social, return-to-work, and rehabilitative needs of survivors post cancer treatment, and take into account variations depending on cancer type, treatment, individual, and support systems (economic support, family, rehabilitation).

Tactics

- Engage organizations to develop public service announcements to inform the public of the gains being made in survivor rates.
- Assist survivor organizations in funding public platforms to share survivor stories.
- Keep survivor-driven organizations aware and informed of the latest evidence on effective survivorship care.

Recommendation 9

Leadership in Research: It is recommended that cancer care providers, provincial and federal health research organizations, and advocacy groups support the development of new research initiatives focused on post-treatment follow-up care and recovery. In particular, research is needed to examine the late and long-term effects of cancer and its treatments, the effectiveness of survivorship care plans and transition care, interventions to improve quality of life, and alternative models of care for cancer survivors.

Tactics

- Create interdisciplinary teams of clinicians and researchers, which would include primary care, oncology, nursing, allied health, and health services researchers.
- Use and expand existing research mechanisms and groups (such as the Clinical Trials Group at the National Cancer Institute of Canada, and cancer and population-based registries), and develop new focused research consortiums.
- Develop comprehensive electronic databases to collect, summarize, analyze, and store clinical data and to support survivorship research.

Recommendation 10

Evaluation of Services: It is recommended that organizations use, and report on, performance measures and indicators that capture self-reported physical or psychosocial domains to monitor the quality of survivorship services, and demonstrate improvement for a comprehensive range of survivor outcomes. Quality improvement practices and programs should be accelerated based on those data.

Tactics

- Cancer control or provincial organizations, or both, should establish an effective and feasible performance measurement plan to evaluate the efficacy of psychosocial and supportive care services in improving the well-being of cancer survivors.
- Organizations providing survivorship services should develop or adopt quality-improvement practices to accelerate the process of evaluating and improving psychosocial and supportive care interventions for cancer survivors.
- Survivorship care organizations should encourage the engagement of cancer survivors, their families, local community partners, advocacy groups, and health agencies in developing performance measurement plans.

Recommendation 11

Inclusive Health Public Policy: It is recommended that health policy and legislation (employment law, insurance, human rights) be enacted to meet the diverse needs of cancer survivors and to allow for full survivor access to and participation in employment, education, and health and community services. (Adapted from IOM Recommendation 8)

Tactics

- Advocacy groups, health care providers, and stakeholders should
  - raise public awareness of survivorship issues and be active in establishing cancer survivorship as a distinct phase of the cancer journey.
  - educate stakeholder organizations, including employers and insurance companies, on the specific issues faced by cancer survivors, the late and long-term effects of the disease and its treatments, and the importance of delivering and coordinating survivorship care programs.
  - work with employers and other community organizations to establish vocational rehabilitation programs and other programs to facilitate return to work.
  - communicate with provincial and federal stakeholders and decision-makers.

PSYCHOSOCIAL AND SUPPORTIVE CARE INTERVENTIONS

Recommendation 1

Supporting Healthy Lifestyle Behaviours: It is recommended that survivors have access to self-management-focused education and support to facilitate tailored adoption of healthy lifestyle behaviours (inclusive of daily physical activity, balanced nutrition, and smoking cessation programs) designed to improve health-related quality-of-life and physiologic outcomes and to reduce distress and risk of recurrence.

Tactics

- Exercise, dietary, and smoking-cessation programs should be tailored to meet the individual survivor's goals, ability level, and available resources. The

appropriateness and safety of the program should be considered in consultation with the survivor and the interdisciplinary health care team.
- Advise cancer survivors to gradually increase physical activity intensity, as tolerated, for a minimum goal of 30 minutes of exercise daily, 5 days per week, if possible.
- Advise cancer survivors to integrate a combination of aerobic exercises (for example, leisure sports, jogging, exercise classes, bike riding), strength training (for example, resistance training with weights, bands, or body weight), flexibility training (for example, stretching, yoga, Pilates), as appropriate.
- Refer cancer survivors to the Canada Food Guide for healthy diet recommendations and consider special needs related to cancer diagnosis and treatment (for example, ostomy management, swallowing difficulties, drug interactions).
- Consider referring cancer survivors to a registered exercise professional and a registered dietician to facilitate adoption of healthy lifestyle management behaviours, especially for issues such as weight maintenance, body composition, and management of persistent fatigue.

Recommendation 2

Use of Theory-Based Approaches: It is recommended that psychosocial and supportive care programs and interventions be designed based on health behaviour–change theories that are known to be influential and necessary for sustaining the adoption of healthy lifestyle behaviours.

Tactics

- Developers and providers of cancer survivorship services should consider using well-tested theories of behaviour change such as the trans-theoretical model, theory of reasoned action, or social cognitive theory to support the development of effective psychosocial and supportive care behavioural change interventions for post-treatment cancer survivors.

Recommendation 3

Management of Psychosocial Concerns and Distress: It is recommended that survivors at risk of, or with identified and significant, psychosocial concerns or distress be offered referral to psychosocial services, individualized or group-based cognitive behavioural or psychoeducational programs provided by trained professionals.

Tactics

- Psychoeducational and cognitive behavioural therapy interventions should be adopted or developed to address the unique needs of cancer survivors in the post-treatment phase and should
  - address a specific and explicit need of the cancer survivor population (that is, cancer-related fatigue or psychosocial distress).
  - incorporate multiple components such as education, problem-solving, stress management, coping skill training, and psychological support.
  - use individualized therapy and potentially incorporate group counselling.
  - integrate a variety of interventions such as face-to-face, group, video, and telephone counselling.
  - empower individuals and their families with the skills and knowledge necessary to be active participants in their life-long care.

Recommendation 4

Monitoring for Symptoms and Late and Long-Term Effects: It is recommended that protocols for routine follow-up include monitoring for and managing physiologic and psychosocial symptoms, including pain and fatigue and late and long-term effects, including pulmonary or cardiac effects, osteoporosis, and other endocrine or body-system abnormalities. A coordinated shared-care approach should be used, including referrals to appropriate interdisciplinary team members as appropriate.

Tactics

- Standardized screening and assessment protocols for early identification of late and long-term effects should be adopted for use in all cancer programs.
- Protocols for management of late and long-term effects adopted from evidence-based guidelines should be implemented in cancer follow-up programs and family physician practices.
- Early interventions in anticipation of late effects such as osteoporosis, implemented early in the treatment trajectory, may be important in reducing persistent problems.

Recommendation 5

Managing Concerns About Sexual Health: It is recommended that survivors receive specific psychoeducational-based care regarding changes in sexual health and function. They should have access to programs that include couples therapy for both the cancer survivor and the survivor's partner and sexual rehabilitation programs to promote healthy post-treatment sexual health and maximal function.

Tactics

- All health care providers should be trained in the use of structured assessment processes supported

by models—for example, BETTER or PLISSIT (consult the full guideline document for further information)—to assess sexual health concerns with the goal of ensuring systematic assessment and appropriate referrals to specialists.
- All health care providers should be trained to provide education and support with regard to changes in sexual health and to offer appropriate referrals to specialists when necessary.
- Management of survivor concerns about sexual health and sexual function should also include an assessment of possible causal factors to determine whether other targeted interventions (for example, counselling, medical management) are also required.
- Early intervention is critical, particularly in populations with prostate or gynecologic cancers, in whom the management of interruptions in sexual functioning throughout the course of treatment may influence long-term recovery.

Recommendation 6

Managing Post-Treatment Fatigue: It is recommended that survivors be screened for cancer-related fatigue and have access to exercise programs combined with psychoeducational interventions and multi-component cognitive behavioural therapy to manage post-treatment fatigue.

Tactics

- Psychoeducational interventions and multi-component cognitive behavioural therapy approaches targeted to alleviating fatigue should include a variety of elements, including sleep education, problem-solving skills, stress management, and psychological counselling.
- Exercise programs targeted to alleviating fatigue should promote a range of physical activity options, including cardiovascular, flexibility, and strength training, as appropriate.
- Management of post-treatment fatigue should also include an assessment of possible causal factors to determine whether other targeted interventions (for example, medical management) such as specific interventions for sleep disturbances or depression are additionally required.

Recommendation 7

Managing Vasomotor Symptoms: It is recommended that all female cancer survivors have access to multi-component cognitive behavioural therapy and lifestyle management programs to effectively manage vasomotor symptoms. This type of management is also important for other cancer survivors, such as those with prostate cancer, in whom hormonal deprivation therapies may lead to significant physical and emotional effects.

Tactics

- Psychosocial and supportive care programs to manage postmenopausal vasomotor symptoms should consider using any or all of education, counselling, or hypnosis-based approaches to alleviate symptoms.
- Management of vasomotor symptoms should include an assessment of possible causal factors to determine whether other targeted interventions (for example, medical management) are also required.
- A trial of pharmacologic therapies could be helpful, but the evidence for these approaches is weak.

Recommendation 8

Managing Disruptions in Sleep–Wake Patterns: It is recommended that survivors have access to multi-component cognitive behavioural therapy programs to manage disruptions in sleep–wake patterns.

Tactics

- Multi-component cognitive behavioural therapy programs should include stimulus control instructions, sleep education, sleep restriction, and proper sleep hygiene to promote improved sleep-onset latency, wake after sleep onset, total sleep time, and time in bed.
- Management of disruptions in sleep–wake patterns should include an assessment of possible causal factors to determine whether other targeted interventions (for example, counselling, medical management) or specialist medical interventions for insomnia disorders are also required.

DISCLAIMER

Care has been taken in the preparation of the information contained in this practice guideline. Nonetheless, any person seeking to apply or consult the practice guideline is expected to use independent clinical judgment and skills in the context of individual clinical circumstances or to seek out the supervision of a qualified clinician. The Cancer Journey Advisory Group of the Canadian Partnership Against Cancer and their guideline copyright partner, the Canadian Psychosocial Oncology Association, make no representation or warranties of any kind whatsoever regarding guideline content or use or application, and disclaims any responsibility for guideline application or use in any way.