Pan-Canadian Guidance on Organization and Structure of Survivorship Services and Psychosocial-Supportive Care Best Practices for Adult Cancer Survivors

Disponsible en français:
http://www.capo.ca/pdf/FRENCH_Survivorship_Guideline_Sept2011.pdf

April 2011

Production of this guideline has been made possible through a financial contribution from Health Canada, through the Canadian Partnership Against Cancer.

This guideline was developed through a collaborative partnership between the Canadian Partnership Against Cancer and the Canadian Association of Psychosocial Oncology (CAPO). CAPO is the steward of this guideline.

This practice guideline is editorially independent of the funding sources. The views and interests of the funding sources have not influenced the recommendations in this document.

The views expressed herein represent the views of the National Advisory Group (acting as the Expert Panel), a sub-group of the Standards, Guidelines and Indicators Working Group of the Cancer Journey Advisory Group, Canadian Partnership Against Cancer (the Partnership).

All reviewers are acknowledged for their participation and valuable contribution to the development of this guideline.

Canadian Association of Psychosocial Oncology
Association Canadienne d'Oncologie Psychosociale

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Referencing of the guideline should be as follows:

Howell D , Hack TF, Oliver TK, Chulak T , Mayo S, Aubin M , Chasen M, Earle CC, Friedman AJ, Green E , Jones GW, Jones JM , Parkinson M, Payeur N, Sabiston CM, Sinclair S, Tompson M.

A Pan-Canadian Practice Guideline Pan-Canadian Guidance on Organization and Structure of Survivorship Services and Psychosocial-Supportive Care Best Practices for Adult Cancer Survivors, Toronto: Canadian Partnership Against Cancer (Cancer Journey Action Group) and the Canadian Association of Psychosocial Oncology, April 2011.

Access to the Guideline is available on cancerview.ca and the Canadian Association of Psychosocial Oncology website (www.capo.ca).

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Scheduled for update: April 2014

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Conflict of Interest Disclosures
Each member of the National Advisory Group acting in the role of the guideline expert panel completed a Conflict of Interest Document. No conflicts of interest were identified by members of the practice guideline writing team that could have compromised the recommendations contained within this document.

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Executive Summary

Questions

1. What is the optimum organization and care delivery structure for cancer survivorship services?
2. What clinical practices and specific interventions improve and/or maximize the psychosocial health and overall well-being of adult cancer survivors?

Target Population

Adult cancer survivors who have had treatment for their cancer and who require survivorship services to optimize their overall health and well-being.

Methods

Cancer Journey Survivorship Expert Panel

The Cancer Journey Survivorship Expert Panel has the expertise necessary to provide guidance on cancer survivorship. Specifically, panel members include psychologists, nurses, spiritual care professionals, researchers, social workers,, family physicians, health services researchers, rehabilitation specialists, cancer survivors and clinical practice guideline developers. Panel members have extensive experience in their respective fields in cancer survivorship, in palliative care needs, or in the development of clinical practice guidelines.

Guideline Development

A search of the literature was conducted according to systematic review methodology where the best available evidence was sought using a targeted search of medical databases, including the Canadian Partnership Against Cancer's Inventory of Cancer Guidelines, the National Guideline Clearinghouse, the Canadian Medical Association's Infobase, MEDLINE (Ovid: 1999 to November 2009), Embase (Ovid: 1999 to November 2009), PsycINFO (Ovid: 1999 to November 2009), the Cochrane Library (Ovid: Issue 1, 2009), and CINAHL (EBSCO: 1999 to December 2009). Reference lists of related papers and recent review articles were also scanned for additional citations.

Evidence was selected and reviewed by three members of the Cancer Journey Survivorship Expert Panel. Prior to completion, the guideline was distributed to content experts and key stakeholders across Canada, who were given the opportunity to provide feedback concerning the collection and interpretation of the evidence, as well as the development and content of the recommendations. The external review was conducted using an online questionnaire, and comments were addressed by the Expert Panel through a teleconference meeting. Final and formal approval of the document was obtained through consensus of the Expert Panel. As part of an updating strategy, the literature will be periodically reviewed (annually), and the guideline will be updated as new or compelling evidence is identified. This guideline was developed in a partnership between the Cancer Journey Advisory Group of the Canadian Partnership Against Cancer and the Canadian Association of Psychosocial Oncology.

Key Evidence

- A total of 14 practice guidelines, eight systematic reviews and 63 randomized controlled trials were considered eligible for inclusion in the systematic review of the evidence (Table 1).
- The practice guidelines addressed aspects of survivorship care delivery structure or psychosocial or supportive care needs in the post-cancer treatment survivorship phase (Table 2). In terms of organizational system factors, the guidelines provided recommendations for models of care, type of provider, and structural approaches or interventions such as survivorship care plans. In terms of psychosocial and supportive care needs of cancer survivors, the guidelines mainly included recommendations for physical outcomes, while emotional, psychological, informational, social, spiritual and practical outcomes were briefly addressed. Using the AGREE II to critically appraise the recommendations, the overall reporting quality of the guidelines was assessed as poor to moderate (Table 3).
- The systematic reviews evaluated psychosocial and supportive care interventions implemented among cancer survivors with focus on the post-treatment phase (Table 4), including cognitive behavioural or psychoeducational interventions, or lifestyle management interventions such as exercise or nutrition programs. Using the SIGN critical appraisal tool, the overall methodological quality of the systematic reviews was rated as being of poor to moderate. Limitations of the systematic reviews included substantial heterogeneity in mode, frequency, intensity, and duration of the interventions; breast cancer survivors were either the focus of or were the largest group in the majority of reviewed studies; and authors noted low sample sizes and weak methodological quality among many of the included studies.
- Of the 63 randomized trials, nine reported interventions related to follow-up, 21 reported on psychoeducational or cognitive behavioural interventions and 33 reported interventions related to lifestyle management. Overall, the quality of the trials ranged from non-assessable to poor or modest quality. Due to the nature of the interventions, the majority of the trials did not blind the participants or the assessors. The reporting of procedures and outcomes was deemed inadequate, with the majority of the trials not powered to detect statistically significant differences between treatment groups for the primary outcomes of interest. In addition, since the majority of the trials were conducted in breast cancer survivors, the generalizability of the results is limited. Furthermore, few studies reported adherence to the interventions, particularly related to unsupervised exercise programs.
- Overall, following the GRADE approach for summarizing and assessing the quality of the body of evidence, the majority of the evidence informing the outcomes of interest was assessed as being of low quality. The data were too heterogeneous to pool across studies, there was little evidence that directly answered the questions of interest for all cancer survivor populations, and an informal assessment of precision indicates that wide confidence intervals would accompany any estimates of effect if data were pooled across studies by outcomes of interest (Tables 12 and 13).

Recommendations

The following recommendations are based on the expert 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 the consideration of the expected health benefits balanced with the potential harms, side effects or risks associated with the guidance offered. Tactics for guideline implementation across various healthcare jurisdictions or health models are offered and can be used as part of auditing or monitoring of 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, unless otherwise stated, recommendations should be considered consensus-based and informed by the evidence.

Organization and Care Delivery Structure of Survivorship Services AGREE II Items 15,16,17

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 to services to meet a broad range of survivors' physical, psychosocial, supportive, informational, and rehabilitative needs. (Recommendation adapted from the Institute of Medicine's (IOM) consensus recommendation #2).

Tactics

a) 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.

b) Establish outreach programs working in partnership with community groups and assist community providers in providing care that meets a broad range of survivor needs.

c) 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.

d) Develop and maintain an up-to-date database of local resources available to support cancer survivors, their families and caregivers.

e) Provide information about accessing 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

a) All cancer treatment team providers should be knowledgeable in 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.

b) 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.

c) The end-of-treatment consultation should include linking individuals to psychosocial, rehabilitative, or supportive care services, and 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 that includes a standard set of core multidimensional elements tailored to the individual's cancer and treatment experience. (Recommendation adapted from IOM consensus recommendation #2)

Tactics

a) The multidimensional components of the survivorship care plan should include the following core elements and should clearly designate who is accountable for completing the care plan and/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.
- Goal, frequency and timing of follow-up visits as well as designating 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 standards for best practice.

- Guidance on strategies to reduce the risk of recurrence and maximize health and well-being (such as lifestyle changes related to nutrition, physical activity, smoking-cessation, etc.).
- Information about employment, financial and legal issues, and counselling services available in the local community.

b) Cancer care programs or organizations should designate at least one specific member of the interdisciplinary team to ensure completion of the treatment summary and recommendations regarding specific tests for monitoring for disease recurrence; late and long-term consequences based on current guidelines, where available, or best practices based on consensus where specific guidelines are lacking.

c) 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 as 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, with an emphasis on actively engaging and empowering survivors.

Tactics

a) Primary care physicians should be integrated into the oncology follow-up plan for monitoring early detection of cancer recurrence and managing late and long-term consequences of treatment as part of survivorship care.

b) 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.

c) 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,

d) A coordinated referral system should be established to ensure quick referral when a specific need for specialist services or interdisciplinary specialists has been identified.

e) A tiered follow-up care approach or shared-care model between primary care physicians and oncology specialists are advisable for cancer survivors with complex issues and problems to ensure rapid referral back to the specialty centre (high-risk model).

f) As appropriate, cancer survivors and families should be educated on the accessibility and benefits of follow-up care delivered by either their primary care physicians or oncology nurse specialists.

g) 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 survivors be routinely screened for distress using valid tools 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. (Recommendation adapted from IOM consensus recommendation #3, and Psychosocial Health Care Needs Assessment Guideline for Adults, 2009).

Tactics

a) Develop a team to lead the implementation of evidence-based practice change, including representatives from all key stakeholder groups that would be affected by the proposed practice change (e.g., 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.

b) Seek formal commitments from stakeholder organizations, including resources for support strategies (e.g., education sessions, staff involvement), that would further the success and sustainability of implementing the practice change.

c) Ensure that implementation plans reflect a multifocal approach, targeting change at both the individual (e.g., education, audit and feedback) and organizational (e.g., policy and structural changes) levels.

d) Promote the development and evaluation of clinical tools specific to the care of survivors in the post-treatment phase.

e) 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 using approaches recommended for supporting effective self-management, 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 health and wellbeing.

Tactics

a) Organizations providing care for cancer survivors should provide 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 (e.g., resilience) and family support.

b) 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.

c) 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.

d) 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, preventing and managing late and long-term effects of cancer treatment, and to encourage specific strategies that empower survivors to be actively engaged in self-management and adopt healthy lifestyle behaviours.

Tactics

a) The curriculum should include the need for cancer surveillance, personal impact of cancer, role of nutrition, role of rehabilitation, management of distress, pain and other symptoms.

b) 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.

c) Designated follow-up care providers and family physicians should be knowledgeable and trained in screening for distress and conducting physical assessments, including body weight, waist-to-hip ratio and BMI; physiological assessments; and brief dietary intake assessments.

d) Partnerships should be formed with survivorship organizations to provide ongoing professional development and skill acquisition for assessing and managing specific survivorship issues.

e) Technology-based resources (e.g., 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, policy-makers, and employers) of the physical, emotional, spiritual, social, return-to-work, and rehabilitative needs post-cancer treatment, and any variations depending on cancer type, treatment, individual and support systems (economic support, family, and rehabilitation).

Tactics

a) Engage organizations to develop public service announcements to inform the public of the gains being made in survivor rates.

b) Assist survivor organizations in funding public platforms to share survivor stories.

c) Keep survivor-driven organizations aware and informed of the latest evidence of 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

a) Create interdisciplinary teams of clinicians and researchers, which would include primary care, oncology, nursing, allied health, and health services researchers.

b) Use and expand existing research mechanisms and groups (such as the National Cancer Institute's clinical trials groups, and cancer and population-based registries), and develop new focused research consortiums.

c) Develop comprehensive electronic databases to collect, summarize, analyze and store clinical data and 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, emotional, and social domains to monitor the quality of survivorship services, and demonstrate improvement for a comprehensive range of survivor outcomes, and accelerate quality improvement practices and programs based on these data.

Tactics

a) Cancer control and/or provincial organizations 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.

b) 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.

c) 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 and human rights) be enacted to meet the diverse needs of cancer survivors and allow for full survivor access to, and participation in, employment, education and health and community services. (Recommendation adapted from IOM Recommendation #8)

Tactics

a) 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 AGREE II Items 15,16,17

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 physiological outcomes, reduce distress and risk of recurrence.

Tactics

a) Exercise, dietary, or 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.

b) Advise cancer survivors to gradually increase physical activity intensity, as tolerated, for a minimum goal of 30 minutes of exercise a day for five days a week if possible.

c) Advise cancer survivors to integrate a combination of aerobic exercises (e.g., leisure sports, jogging, exercise classes, bike riding), strength training (e.g., resistance training with weights, bands or body weight), flexibility training (e.g., stretching, yoga, Pilates), as appropriate.

d) Refer cancer survivors to the Canada Food Guide for recommendations for a healthy diet, considering special needs related to cancer diagnosis and treatment (e.g., ostomy management, swallowing difficulties, drug interactions).

e) Consider referring cancer survivors to a registered exercise professional and registered dietitians to facilitate the 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

a) 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 health services, individualized or group-based cognitive behavioural or psychoeducational programs provided by trained professionals.

Tactics

a) 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 (i.e., cancer- related fatigue or psychosocial distress).
- Incorporate multiple components such as education, problem solving, stress management, coping skill training and psychosocial 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 physiological and psychosocial symptoms, including pain and fatigue, and late and long-term effects, such as 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

a) Standardized screening and assessment protocols for early identification of late and long term effects should be adopted for use in all cancer programs.

b) 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.

c) 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 Regarding 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 couple's therapy for both the cancer survivor and his or her partner, and sexual rehabilitation programs to promote healthy post-treatment sexual health and maximize function.

Tactics

a) All health care providers should be trained to assess sexual health concerns using structured assessment processes supported by models (e.g., BETTER or PLISSIT [Reference 153,154]) to ensure systematic assessment and appropriate referrals to specialists.

b) All health care providers should be trained to provide education and support regarding changes in sexual health and offer appropriate referrals to specialists when necessary.

c) Management of survivors' concerns regarding sexual health and sexual function should also include an assessment of possible causal factors to determine whether other targeted interventions (e.g., counselling, medical management) are also required.

d) Early intervention is critical, particularly in populations with prostate or gynaecological cancers, where 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/or multi-component cognitive behavioural therapy to manage post-treatment fatigue.

Tactics

a) Psychoeducational interventions and/or 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 psychosocial counselling.

b) Exercise programs targeted to alleviating fatigue should promote a range of physical activity options, including cardiovascular, flexibility and/or strength training, as appropriate.

c) Management of post-treatment fatigue should also include an assessment of possible causal factors to determine whether other targeted interventions (e.g., medical management) are additionally required such as specific interventions for sleep disturbances or depression.

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 is also important for other cancer survivors, such as those with prostate cancer, where hormonal deprivation therapies may lead to significant physical and emotional effects.

Tactics

a) Psychosocial and supportive care programs to manage post-menopausal vasomotor symptoms should consider using education, counselling and/or hypnosis-based approaches to alleviate symptoms.

b) Management of vasomotor symptoms should include an assessment of possible causal factors to determine whether other targeted interventions (e.g., medical management) are also required.

c) A trial of pharmacological 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

a) 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.

b) Management of disruptions in sleep-wake patterns should include an assessment of possible causal factors to determine whether other targeted interventions (e.g., counselling, medical management) or specialist medical interventions for insomnia disorders are also required.

Full Guideline Document

Scope and Purpose[AGREE II Item 1]

The purpose of this guidance document is to inform Canadian health authorities, key administrative and policy decision-makers, and health practitioners on the optimum organization of survivorship services and best care practices and interventions to maximize the psychosocial health and well-being of adult cancer survivors. A guideline on this topic is needed to inform best practices, to provide a basis for identifying gaps in care, and to set priorities and directions for future research. The scope of this guidance document is to establish the optimum organization and care delivery structure for cancer survivors post-primary treatment, and to identify the best care practices and interventions to maximize the psychosocial health and overall well-being of adult cancer survivors. This document pertains to individuals in the post-primary treatment (surgery, chemotherapy, radiotherapy, etc.) phase of cancer therapy, as well as those who receive adjuvant treatment or live with advanced disease. Although cancer survivorship and the need for early intervention begin at diagnosis (termed acute survivorship), this guidance document focuses on evidence in the post-treatment phase. The acute survivorship phase was considered outside the scope of this document.

Questions[AGREE II Item 2]

For post-primary treatment cancer survivors:

- What is the optimum organization and care delivery structure for cancer survivorship services?
  - Examples of organization and care delivery structures include: follow-up care delivery models, care plan components, and interventions related to transition planning or transition preparation for survivorship.
  - Outcomes of interest include survival/recurrence, survivor satisfaction, psychosocial and supportive care needs, and health-related quality of life.
- What clinical practices and specific interventions improve and/or maximize the psychosocial health and overall well-being of adult cancer survivors?
  - Examples of clinical practices and interventions include psychoeducation, cognitive behavioural therapy, counselling, exercise, nutrition, or rehabilitation programs compared with standard or similar care.
  - Outcomes of interest include survival/recurrence, psychosocial and supportive care needs, and health-related quality of life.

Target Population[AGREE II Item 3]

This organizational and clinical practice guideline pertains primarily to adult cancer survivors who are post-primary treatment and who require survivorship services to optimize their overall health and well-being. The recommendations pertain to the periods of survivorship described as extended survival (recovery from initial treatment, watchful waiting, surveillance with medical testing, and fear of recurrence and uncertainty), as well as *permanent survival* (coping with late and long-term physical, emotional and other effects, and adjustment to the “new normal” of life

beyond cancer). This guidance document also pertains to cancer survivors who receive adjuvant therapy in the post-primary treatment phase of survivorship and individuals living with advanced disease. Although cancer survivorship begins at diagnosis (termed acute survival), guidance on that phase of survivorship is outside the scope of this document. This document also recognizes that being clinically disease-free may not mean being free of cancer from a survivor's perspective.

Target Users AGREE II Item 6

This guidance document is intended to inform Canadian health authorities, key administrative and policy decision-makers, advocacy groups, and health and supportive care practitioners on the optimum survivorship services and best care practices for adult cancer survivors in the post-primary treatment survivorship period. Health and supportive care practitioners, such as interdisciplinary oncology teams, primary care physicians, nurses, occupational therapists, physiotherapists, psychosocial or supportive care specialists, spiritual care providers, or other health or supportive care professionals, can use this document to help shape survivorship services and best practices to optimize the health and well-being of adult cancer survivors. This document is also intended for use by survivors and their caregivers to help them make informed decisions on survivorship services.

Background

In 2009, an estimated 171,000 Canadians were expected to be diagnosed with cancer and 75,300 were expected to die from their disease (1). Despite the mortality associated with a cancer diagnosis, cancer survivors are a growing population in Canada. This is because of improved prevention and detection, more precise and effective treatment methods, population-based disease prevention and management, and overall positive changes in lifestyle behaviours. According to Cancer Care Ontario 2004 statistics, more than 260,000 cancer survivors were expected to be alive within 10 years of a primary diagnosis of cancer; more than twice the number of survivors surviving cancer 20 years ago (2).

Several definitions of cancer survivorship exist; however, according to the National Cancer Institute, an individual may be considered a cancer survivor from the time of 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 (3). Along the cancer continuum, the most attention is paid to the diagnostic and treatment stage of care (4). However, cancer survivorship in the post-treatment phase is a distinct phase of the cancer trajectory that needs to be addressed since it has been largely neglected in advocacy, education, clinical practice, and research.

Cancer and cancer treatment have a substantial impact on the long-term health and quality of life of survivors, leading to questions about the most appropriate configuration of health care services for this population. People who survive their cancer are at risk of late or long-term effects that are dependent on the type of the cancer, the stage of the cancer, and the therapies used to treat the cancer. Similar to survivors during active treatment, survivors will have supportive care needs - physical, informational, emotional, psychological, social, spiritual, and practical - as a result of their experience of the cancer and its treatment (5). The late and long-term effects

experienced by survivors of cancer are diverse. Late or long-term effects can affect survivors with any type of cancer, and depending on the type of treatment used, the effects may include increased incidence of second cancers, cardiac dysfunction, cognitive dysfunction, pain, fatigue, sleep disturbances, sexual dysfunction, or issues with body image or sexual health (6-21). Looking at the most common cancer types, disease-specific consequences associated with prostate cancer may include erectile, bladder, or bowel dysfunction, whereas lung cancer survivors may face difficulty with shortness of breath, fatigue, stamina, or maintaining pulmonary hygiene (22-24). Female breast cancer survivors may experience lymphedema, premature menopause, fatigue, or sexual dysfunction (25). Colorectal cancer survivors report bowel dysfunction, decreased sexual functioning, or issues around body image or colostomy management (26).

A multitude of psychosocial issues may also be common across survivor populations, as psychosocial distress is a prevailing problem for many survivors, depending on the nature of the disease, treatment type, and other socio-demographic, psychological, and environmental factors. Psychological distress may manifest as depression, anxiety, uncertainty, fear, or anger, and it may affect many aspects of quality of life, sexual health, body image, or coping (2,25-31). Social issues affected by cancer survivorship may include changes in relationships, functional status, communication, or community involvement (26,27,32). Existential and spiritual transformations are also commonly reported among cancer survivors (29,33). In addition, cancer survivors may have practical concerns about insurance coverage (35) and system navigation, and may need information about resources and post-treatment symptom management (37-41). With various treatment methods many survivors have employment and financial concerns in the post-treatment phase (10,34-36). According to a recent meta-analysis of 26 articles from the United States, Europe, and other regions, cancer survivors were more likely to be unemployed than healthy controls and the unemployment rate was higher among breast, gastrointestinal, and gynaecological cancer survivors (34). Factors such as cancer site, clinical prognosis, treatment method, socio-economic status, and attributes of the work itself influenced the re-employment of cancer survivors (42). The financial burden, including direct and indirect costs, experienced by cancer survivors and their families has a substantial impact on individuals. In Canada, out-of-pocket costs, such as drugs, home care, homemaking, complementary and alternative medicines, vitamins and supplements, family care, travel, parking, accommodations, and devices, were problematic for 20% of survivors, and more than one-third of survivors required family members or caregivers to take time off work (43).

To ensure the supportive care and health care needs of survivors are appropriately addressed, a number of essential components of survivorship care have been identified (4). These essential components include screening for recurrence of the primary cancer and for new cancers, assessment of medical and psychosocial late effects, intervention for consequences of cancer and treatments, health promotion, and coordination of care between oncology specialists and primary care practitioners (4,44,45). Moreover, oncology experts specifically recommend follow-up survivorship care plans to prepare survivors for the transition from the active treatment phase to the post-treatment survivorship phase (4,44-46). These follow-up care plans are essential for empowering survivors and primary care practitioners and informing them of the follow-up care and monitoring required.

Follow-up care plans for cancer survivors allow health professionals to promote healthy lifestyle changes, check for disease recurrence or the development of new malignancies, and manage the lasting effects of the cancer experience. Care plans, written by the primary provider of the oncology treatments, must include a summary of the critical information needed for the survivor's long-term care, (44-46). This written summary must include critical information such as cancer type, treatment received, and the potential late effects; specific information about the follow-up timing and content; information on preventive practices to maintain health and well-being; information regarding employment, financial, and legal issues; and the availability of psychosocial services in the community. The goal is to generate a plan that is personalized to the survivor's specific disease, treatments, and identified needs. With more focus on this growing population in the last decade, survivorship follow-up services have become a growing trend in clinics and communities. However, follow-up plans often fail to address the physical expectations and psychosocial needs of survivors and their families, and many survivors report that their needs are not met in this regard (38-41).

Therefore, survivorship care plans that address survivor's physical and psychosocial needs require an organizational structure to support the plan and the use of best practices (i.e., the practices that have shown the greatest promise in meeting the physical and psychosocial needs of survivors in the post-treatment period). To date, limited formal evaluation has been done on these plans and their implementation among post-treatment cancer survivors. The challenge then is to develop, implement, and evaluate coordinated models of care that are effective at identifying and reducing late and long-term effects experienced by cancer survivors. A review by Jacobsen reports that the impact of survivorship care plans on reducing cancer-related morbidity and mortality is one of the major issues still to be addressed (46). Jacobsen also reports that studies are needed to address whether survivorship care planning is effective at promoting the adoption of healthy lifestyle behaviours, to identify optimal ways of conducting assessments at the end of treatment, to link survivors to resources within their communities, and to identify which models of survivorship care are cost-effective (46). Moreover, survivorship services should address the need for a coordinated and well-organized system and allow for the expressed allocation of responsibilities for different functions and processes of various entities or units, such as hospitals, oncology health care departments, health and supportive care teams, and survivors. Organizational considerations include staffing and staff mix, personnel training, and constant communication between health professionals (47,48).

In terms of best care practices, the effectiveness of interventions to address the psychosocial and supportive care needs of cancer survivors has been studied extensively. Such trials have included lifestyle management interventions (exercise, nutrition, smoking cessation, etc.); psychoeducational, cognitive behavioural, and psychosocial interventions; peer support and counselling groups; and complementary alternative medicine trials (meditation, massage, acupuncture, etc.). These specific interventions, and how they could be incorporated into follow-up services for cancer survivors, have not yet been clearly addressed in the literature.

Cancer survivors in Canada represent a diverse population who are at risk of a number of potentially debilitating late and long-term health effects. Presently, there is wide variation in the care and organization of services to address survivor's needs.

Developing organizational standards of care and evidence-based practice guidelines for the care of cancer survivors is essential to coordinate the care of this growing population. Without such guidelines, health and supportive care may vary widely, which could affect the delivery or quality of care and subsequently affect survivors' quality of life. This guidance report is based on a systematic review of the health care literature and the consensus of an expert panel based on an interpretation of the evidence and best care practices. It is intended to inform the optimum organization of cancer survivorship services and care practices to best maximize the health and well-being of adult cancer survivors in Canada.

Guiding Principles

In the development of this clinical practice guideline, a number of guiding principles were viewed as overarching fundamentals for survivorship care. These guiding principles set the context for interpreting the evidence and developing recommendations for the care of adult cancer survivors. The guiding principles were as follows:

- Care should be tailored to the needs of survivors, and be sensitive to issues of religious and spiritual values, culture, language, gender, age, disability, and literacy.
- Family, as defined by the survivor, is an essential consideration in survivorship services. As such, survivors and their families should be active participants and collaborators in planning care throughout the survivorship period.
- Psychosocial and supportive care services involve a range of disciplines, which may differ based on geographic location and resources available. These disciplines include, but are not limited to, nurses, oncologists, psychiatrists, psychologists, social workers, dietitians, rehabilitation providers, spiritual care providers, and primary care providers.
- The essential components of survivorship services are not limited to psychosocial and supportive care, but include the prevention of and surveillance for recurrent and new cancers, as well as other late effects that are generally not amenable to psychosocial and supportive care intervention (i.e., they are more appropriately addressed through medical management). Assessing and managing such issues was considered outside the scope of this guideline and was not addressed.
- Survivorship services and interventions should focus on empowering survivors, with the support of their caregivers, to adopt self-management and other behaviours necessary to optimize health and well-being.

Appendix I contains operational definitions for a number of key terms used in this guideline.

Methodology

Cancer Journey Survivorship Expert Panel[AGREE II Item 4]

The Cancer Journey Survivorship Expert Panel comprises the relevant expertise necessary to provide guidance on cancer survivorship. Specifically, panel members include psychologists, nurses, spiritual care professionals, researchers, psychosocial oncologists, family physicians, health services researchers, rehabilitation specialists, cancer survivors, and clinical practice guideline developers. Panel members have

extensive experience in their respective fields in cancer survivorship, palliative care needs, or the development of clinical practice guidelines.

Guideline Development[AGREE II Items 13,14]

This clinical practice guideline was developed according to the convention of the 23-item AGREE II instrument, the current gold standard in appraising the reporting of clinical practice guidelines (49). Where guideline components align with the AGREE II convention, the specific AGREE II item is listed as part of the subject heading. The Cancer Journey Survivorship Expert Panel, with expertise in cancer survivorship, conducted a systematic review of the literature, which is current to December 31, 2009. Prior to completion, the guideline was distributed to content experts and key stakeholders across Canada for the opportunity to provide feedback about the collection and interpretation of the evidence, as well as the development and content of the recommendations. To ensure that the views and preferences of the target population were addressed, the draft document was circulated to cancer survivors for feedback. In addition, several members of the Cancer Journey Survivorship Expert Panel and seven additional members of the external review committee disclosed that they were also cancer survivors. Final consensus on the recommendations was reached through a formal voting process. The literature will be periodically reviewed (annually) and the guideline will be updated as new or compelling evidence is identified.

Systematic Review[AGREE II Item 7]

The search of the literature was conducted according to systematic review methodology, in which the best available evidence was sought using a targeted search of a variety of medical databases. A focused environmental scan of the grey literature was also conducted for evidence produced by other credible cancer guideline development groups. This involved scanning the websites of known cancer guideline developers, as identified by the Canadian Partnership Against Cancer's Inventory of Cancer Guidelines, and searching the website of the Institute of Medicine for their pivotal work on cancer survivorship issues.

Literature Search Strategy

The following electronic medical databases were searched for relevant evidence: The Canadian Partnership Against Cancer's Inventory of Cancer Guidelines (ICG), the National Guideline Clearinghouse, the Canadian Medical Association's Infobase, MEDLINE (Ovid: 1999 to November 2009), EMBASE (Ovid: 1999 to November 2009), PsycINFO (1999 to November 2009), the Cochrane Library (Ovid; Issue 1, 2009), and CINAHL (EBSCO: 1999 to December 2009). Reference lists of related papers and recent review articles were also scanned for additional citations.

The literature search included the use of MeSH headings and related text and keyword searches. As seen in Appendices II and III, the search for evidence combined cancer-related terms with survivorship terms and terms related to post-treatment interventions or the organizational delivery of survivorship services and study design.

Study Selection Criteria[AGREE II Item 8]

Inclusion Criteria

Articles were included in the systematic review of the evidence if they a) reported on organizational system components for survivors or b) reported on a psychosocial or supportive care intervention designed for survivors. Studies were to report on adult cancer survivors in the post-primary treatment phase of their cancer journey and were to include data on psychosocial and supportive care outcomes, including psychosocial distress, late effects, long term symptoms, health-related quality of life, or risk reduction. Studies were to:

- Be an organizational standard, practice guideline, systematic review (with or without meta-analyses), or randomized controlled trial,
- Be published between the years of 1999 and 2009, and
- Include adult cancer survivors during the post-treatment phase of their cancer journey.

Exclusion Criteria

Articles were excluded from the systematic review of the evidence if:

- They focused on pediatric cancer survivor populations or those who transitioned from pediatric cancer to adult services,
- They addressed pharmacological interventions or diagnostic testing/follow-up of cancer survivors,
- The methodology used to systematically review the literature was not adequately described,
- They were qualitative or descriptive studies, or
- They were opinion papers, letters, or editorials.

Literature Search Results

A total of 3275 citations were identified in the search of the literature, and of these, 14 practice guidelines (50-63), eight systematic reviews (64-71), and 63 randomized controlled trials (72-134) were considered eligible for inclusion in the systematic review of the evidence (Table 1).

Table 1. Literature Search Results

Report Type	References	Number of Reports	Relevant Tables	
			Trial Characteristics	Critical Appraisal
Practice Guidelines	50-63	14	Table 2	Table 3
Systematic Reviews	64-71	8	Table 4	Table 5
Randomized Controlled Trials	72-134	63	Tables 6,8,10	Tables 7,9,11
(Follow-up)	(72-80)	(9)	(Table 6)	(Table 7)
(PSE/CBT)	(81-101)	(21)	(Table 8)	(Table 9)
(Lifestyle Management)	(102-134)	(33)	(Table 10)	(Table 11)

Notes: PSE = psychoeducational; CBT = cognitive behavioural therapy.

The practice guidelines addressed some aspect of organizational care or care relating to psychosocial or supportive care needs in the post-cancer treatment survivorship phase (Table 2), while the systematic reviews evaluated psychosocial and supportive care interventions implemented among cancer survivors with focus on the post-treatment phase (Table 4). Of the 63 randomized trials, nine reported interventions on follow-up strategies (72-80), 21 reported psychoeducational or cognitive behavioural interventions (81-101) and 33 reported interventions related to lifestyle management (102-134). A number of the randomized trials were reported in multiple publications (80,91,92,99,111,112,116,119,120,124,129,132), and while considered eligible and referenced accordingly (135-150), for the purposes of reporting, only the original reports are referenced throughout this document.

Practice Guidelines

As shown in Table 2, the practice guidelines addressed aspects of survivorship care delivery structure or psychosocial or supportive care needs in the post-cancer treatment survivorship phase (50-63). Eight guidelines included recommendations across multiple disease sites, while the remaining six guidelines were disease-site specific (two breast, one colon, one rectal, one prostate, and one renal cell). In terms of organizational system factors, five guidelines provided recommendations for models of care (52,53,55,57,61); four provided recommendations for type of provider (52,53,55,58); two provided a recommendation for support services (54,61); and seven provided recommendations for structural approaches such as survivorship care plans (50-54,56,61). None of the guidelines addressed the site of the post-treatment survivorship care. In terms of psychosocial and supportive care recommendations, nine guidelines addressed support for physical function outcomes (50,51,55,56,59-63); three addressed psychosocial outcomes (56,58,59), none specifically addressed quality of life, and two guidelines addressed informational or practical needs (56,61).

Table 2. Practice Guidelines Identified in the Search of the Literature

Author Year (Reference)	Disease Site	Organizational Care Outcomes					Psychosocial and Supportive Care Outcomes				
		Model of Care	Site of Care (e.g., specialized or integrated)	Type of Provider	Support Services	Structural approaches (e.g., survivorship transition care plans)	Survival/ Recurrence	Physical Function [a]	Psychosocial unction	Quality of Life	Other
NCCN 2010 (50)	Colon	-	-	-	-	√	-	√	-	-	-
NCCN 2010 (51)	Rectal	-	-	-	-	√	-	√	-	-	-
ASPO 2009 (52)	Multiple	√	-	√	-	√	-	-	-	-	-
ACCC 2009 (53)	Multiple	√	-	√	-	√	-	-	-	-	-
IOM 2008 (54)	Multiple	-	-	-	√	√	-	-	-	-	-
DACCC 2007 (55)	Prostate	√	-	√	-	-	-	√	-	-	-
IOM 2006 (56)	Multiple	-	-	-	-	√	-	√	√	-	√ [b,c]
ASCO 2006 (57)	Breast	√	-	-	-	-	-	-	-	-	-
DACCC 2006 (58)	Renal cell	-	-	√	-	-	-	-	√	-	-
Rizzo 2006 (59)	Multiple	-	-	-	√	-	-	√	√	-	-
ACS 2006 (60)	Multiple	-	-	-	√	-	-	√ [c]	-	-	-
CBCI 2005 (61)	Breast	√	-	-	√	√	-	√	-	-	√ [b]
ACS 2003 (62)	Multiple	-	-	-	-	-	-	√	-	-	-
ACS 2001 (63)	Multiple	-	-	-	-	-	-	√	-	-	-

Note: √ = outcome reported; - = outcome not reported; NCCN = National Comprehensive Cancer Network; ASPO = American Society of Preventive Oncology; ACCC = Association of Community Cancer Centers; IOM = Institute of Medicine; ASCO = American Society of Clinical Oncology; DACCC = Dutch Association of Comprehensive Cancer Centres; ACS = American Cancer Society; CBCI = Canadian Breast Cancer Initiative.
[a] Physical function included overall physical health, sleep function, sexual function, symptom management, and fatigue.
[b] Spiritual.
[c] Informational or practical needs.

Critical Appraisal of Practice Guidelines

Table 3 provides a description of the reporting quality of the identified practice guidelines with the AGREE II instrument (49) by a minimum of two reviewers. The AGREE II instrument consists of 23 items that evaluate guidelines over six domains: scope and purpose, stakeholder involvement, rigour of development, clarity and presentation, applicability, and editorial independence (49). Overall, the reporting quality was moderate to poor, especially in the domain of rigor of development, where only one guideline scored highly (60).

Table 3. AGREE Scores for Reporting Quality of the Identified Guidelines

Author Year (Reference)	Number of Reviewers/ AGREE Instrument Used:	Scope and Purpose	Stakeholder Involvement	Rigor of Development	Clarity and Presentation	Applicability	Editorial Independence	Overall Assessment (1-7)
NCCN 2010 (50)	4 / AGREE II	44.4%	50.0%	49.5%	73.6%	22.9%	47.9%	4.3
NCCN 2010 (51)	3 / AGREE II	53.7%	40.7%	47.2%	83.3%	31.9%	77.8%	5.3
ASPO 2009 (52)	2 / AGREE II	43.0%	15.0%	3.0%	25.0%	0.0%	50.0%	2.5
ACCC 2009 (53)	2 / AGREE II	22.0%	33.0%	0.0%	47.0%	17.0%	4.0%	3.5
IOM 2008 (54)	2 / AGREE II	75.0%	43.0%	65.0%	75.0%	58.0%	50.0%	5.5
DACCC 2007 (55)	3 / AGREE II	75.9%	68.5%	54.9%	81.5%	40.3%	30.6%	5.3
IOM 2006 (56)	2 / AGREE II	67.0%	43.0%	46.0%	75.0%	45.0%	46.0%	5.0
ASCO 2006 (57)	4 / AGREE II [a]	68.1%	33.3%	57.1%	69.8%	45.8%	77.1%	5.3
DACCC 2006 (58)	3 / AGREE II	75.9%	68.5%	54.9%	81.5%	40.3%	30.6%	5.6
Rizzo 2006 (59)	2 / AGREE II	47.0%	11.0%	15.0%	69.0%	10.0%	21.0%	4.0
ACS 2006 (60)	4 / AGREE II [a]	69.4%	61.5%	73.8%	88.5%	48.6%	33.3%	5.8
CBCI 2005 (61)	2 / AGREE II	39.0%	53.0%	17.0%	25.0%	2.0%	4.0%	2.5
ACS 2003 (62)	4 / AGREE II	81.9%	58.3%	30.2%	66.7%	10.4%	0.0%	3.5
ACS 2001 (63)	2 / AGREE II	50.0%	25.0%	20.0%	28.0%	2.0%	8.0%	2.5

Note: NCCN = National Comprehensive Cancer Network; ASPO = American Society of Preventive Oncology; ACCC = Association of Community Cancer Centers; IOM = Institute of Medicine; ASCO = American Society of Clinical Oncology; DACCC = Dutch Association of Comprehensive Cancer Centres;, ACS = American Cancer Society; CBCI = Canadian Breast Cancer Initiative.
[a] Beta version of the AGREE II.

Systematic Reviews

Overall, 19 systematic reviews were identified in the search of the literature; however, since the majority of these reviews included studies with participants in the treatment and post-treatment phases of the cancer trajectory, only reviews that focused on the post-treatment phase and were of high methodological quality were included as evidence informing the recommendations (64-71). Nonetheless, the reference lists of excluded reviews were included in the subsequent hand search for randomized controlled trials. The Cancer Journey Survivorship Expert Panel recognized that the results of the excluded systematic reviews may be of interest to other groups planning survivorship services across the cancer continuum; therefore, a summary of included and excluded systematic reviews can be found in Appendices V and VI.

As seen in Table 4, eight systematic reviews focused on the post-treatment phase of the cancer trajectory or provided separate analyses for the post-treatment phase (64-71). Three reviews included cognitive behavioural or psychoeducational interventions, including two reviews with trials of various cancer populations (66,71) and one review of breast cancer survivors (64). The outcomes of interest were survival time (71), cancer-related fatigue (66), and return to work (64). Five reviews included lifestyle management interventions, such as exercise or nutrition programs, including three reviews with trials of participants with various cancers (67,68,70) and two reviews of breast cancer survivors (65,69). The outcomes of interest included physiological outcomes such as physical fitness, muscular strength, body composition, or body weight (65,69); psychological health (65); cancer-related fatigue (68,70); and effective theoretical components of interventions (67).

Table 4. Systematic Reviews Identified in the Search of the Literature

Author Year (Reference)	Disease Site	Evidence base		Outcomes of Interest				
		Number of RCTs	Number of non-RCTs	Survival/ Recurrence	Physical Function	Psychosocial Function	Quality of Life	Other
Hoving 2009 (64)	Breast	-	4	-	-	-	-	√ [a]
Cheema 2008 (65)	Breast	5	5	-	√	√	-	-
Kangas 2008 (66)	Multiple	57	62	-	√	-	-	-
Pinto 2008 (67)	Multiple	21	-	-	-	-	-	√
Cramp 2008 (68)	Multiple	28	-	-	√	-	-	-
Ingram 2006 (69)	Breast	8	6	-	√	-	-	-
Schmitz 2005 (70)	Multiple	27	5	-	√	√	-	-
Smedslund 2004 (71)	Multiple	8	5	√	-	-	-	-

Note: √ = outcome reported; - = outcome not reported; RCTs = randomized controlled trials.
[a] Informational or practical needs.

Critical Appraisal of Systematic Reviews

The quality of the systematic reviews was appraised using criteria specified in the Scottish Intercollegiate Guidelines Network (SIGN) guideline development handbook (151). Table 5 shows the quality appraisal of the systematic reviews included in this guidance document. Overall, the systematic reviews were poor (64,67) to moderate quality (65,70,71). Three systematic reviews were considered higher methodological quality (66,68,69) because of an adequately described methodology, including the rigor of literature search, assessment of study quality, and adequate descriptions of study homogeneity and heterogeneity.

Table 5. Quality Appraisal of the Systematic Reviews Identified in the Search of the Literature

Author Year (Reference)	Appropriate and Focused Question	Methodology Described	Rigor of Literature Review	Study Quality Assessed	Studies Sufficiently Similar	Study Types Included
Hoving 2009 (64)	-	-	+	-	+	RCT, other
Cheema 2008 (65)	-	-	+	+	+	RCT, other
Kangas 2008 (66)	+	+	+	++	+	RCT, other
Pinto 2008 (67)	-	-	+	-	-	RCT
Cramp 2008 (68)	++	++	++	++	+	RCT
Ingram 2006 (69)	+	++	++	++	+	RCT, other
Schmitz 2005 (70)	+	+	-	+	+	RCT, other
Smedslund 2004 (71)	+	+	+	-	+	RCT, other

Note: RCT = randomized controlled trial; ++ = well addressed; + = adequately addressed; - = poorly or not addressed.

Overall, the reviews of exercise interventions had limitations including variations in the mode of exercise (e.g., aerobic and/or strength training, home-based or gym-based, supervised or unsupervised), intensity, frequency, and duration. Similarly, the reviews of psychosocial interventions included a variety of approaches, such as cognitive behavioural therapy, psychoeducation, individualized or group counselling, and stress reduction. Moreover, breast cancer survivors were either the focus of or were the largest group in the majority of reviewed studies. As a result, it is difficult to generalize the findings to other cancer populations. The authors also noted low sample sizes and weak methodological quality among many of the included studies. Furthermore, few studies reported adherence to the interventions, particularly related to unsupervised exercise programs.

Randomized Control Trials

Sixty-three randomized controlled trials were identified in the search of the literature (72-134). Of the 63 trials, nine reported interventions on follow-up strategies (72-80), 21 reported on psychoeducational or cognitive behavioural interventions (81-101), and 33 reported interventions related to lifestyle (102-134).

Randomized Controlled Trials of Interventions on Follow-up Care

Trials on follow-up interventions were conducted in the following survivor populations: breast cancer (72,74,76,77,79,80), prostate cancer (78), lung cancer (75), and colon cancer (73) (Table 6). The majority of the trials compared the effectiveness of follow-up by an oncology specialist (clinic or hospital setting) with that of a primary care physician (72,73,77) or a nurse trained in oncology (74-76,78). Three trials compared conventional follow-up with on-demand or survivor-initiated follow-up (76-78). One trial compared a conventional schedule of visits to the clinic with visits only after mammography (79). Primary outcomes of interest included quality of life (73,75,77); psychological morbidity such as anxiety, depression, and well-being (73,74,76,77); detection of serious clinical events (72); and satisfaction with care (73,74,76,78-80). Secondary outcomes included diagnosis of recurrence or survival rates (72-76,80); length of follow-up (73,76,80); cost (75,80); and access to medical care and use of resources (74,75,78).

Table 6. Randomized Control Trials of Follow-up Strategies

Author Year (Reference)	# of Pts.	Type of Intervention(s) (versus usual care)	Disease Site	Outcomes of Interest				
				Survival / Recurrence	Patient Satisfaction	Psychosocial Function	Quality of Life	Other
Grunfeld 2006 (72)	968	Primary care	Breast	√	-	-	√	-
Wattchow 2006 (73)	203	Primary care	Colon	√	√	√	√	-
Koinberg 2004 (74)	264	Nurse-led	Breast	√	√	√	-	√
Moore 2002 (75)	202	Nurse led	Lung	√	√	√	√	√
Baildam 2002 (76) [b]	525	Nurses-led [a]	Breast	√	√	√	-	√
Brown 2002 (77)	61	Patient-initiated	Breast	-	√	√	√	-
Helgeson 2000 (78)	400	Nurse-led [a]	Prostate	√	√	√	-	√
Gulliford 1997 (79)	193	Less follow-up [c]	Breast	-	-	-	-	√
Grunfeld 1996 (80)	296	Primary care	Breast	√	√	√	√	√

Note: # of Pts = number of patients; √ = outcome reported; - = outcome not reported.
[a] On demand.
[b] Abstract.
[c] Follow-up after regularly scheduled mammography only.

Critical Appraisal of Randomized Controlled Trials on Models for Follow-up Care

The quality of the randomized trials was appraised using the criteria identified in the SIGN guideline development handbook (151). Table 7 shows the quality appraisal of the randomized controlled trials included in this review. The quality of the trials ranged from non-assessable (76) to poor (74,75,77-79) or modest quality (72,73,80). The trials by Grunfeld et al. (80,135,136) were combined in the discussion since only one trial was conducted but three publications were identified in the search. Blinding was not possible in most trials due to the nature of the interventions and the reliance on self-reports; however, in one trial the block size was unknown to study coordinators at the centres (74). Self-reported outcomes, including quality of life and psychological morbidity, were assessed with validated tools such as the EORTC-QLQ-C30 (72,75,77,80), the Medical Outcomes Study Short Form 12 (MOS-SF-12) (73), the Hospital Anxiety and Depression Scale (72-74,76,77), and the Spielberg State-Trait Anxiety Inventory (76). Five of the trials evaluating patient satisfaction as a primary outcome did not use validated measures (74-76,78,79); however, three studies pilot-tested the items with focus groups (75,78) or provided reliability statistics (74). Two trials used validated tools to collect patient satisfaction information (73,80).

Table 7. Critical Appraisal of Nine Randomized Trials of Follow-up Strategies

Author Year (Reference)	Appropriate and Focused Question	Randomization Method Described	Blinding	Balanced Arms (groups similar at start of trial)	Treatment Only Difference Between Groups	Outcomes Assessed with Validated and Reliable Measures	Drop-out Rate Reported	Intention-to-Treat Analysis	Sponsorship	Power Calculation
Grunfeld 2006 (72)	-	+	-	++	++	++	-	+	-	++
Wattchow 2006 (73)	+	++	+	+ [b]	+	+	>20%	+	+	+
Koinberg 2004 (74)	+	++	- [a]	-	+	+	-	+	+	+
Moore 2002 (75)	-	+	-	+	+	+	-	-	+	+
Baildam 2002 (76) [c]	-	-	-	-	-	-	-	-	-	-
Brown 2002 (77)	+	+	-	+	+	+	<20%	-	-	-
Helgesen 2000 (78)	+	+	-	+	+	-	>20%	-	+	-
Gulliford 1997 (79)	-	+	-	+	-	-	-	-	+	-
Grunfeld 1996 (80)	+	+	-	++	++	+	<20%	+	+	+

Note: ++ = well addressed; + = adequately addressed; - = poorly or not addressed.
[a] Block size unknown to study coordinators at centers.
[b] Trend toward higher education in surgeon follow-up group.
[c] Abstract.

Randomized Controlled Trials of Interventions on Psychosocial and Supportive Care

As shown in Table 8, 21 randomized controlled trials evaluated a cognitive behavioural or a psychoeducational intervention (81-101). The majority of trials investigated interventions in breast cancer survivors (81,84,86,87,89,90,94-96,99,101). The primary outcomes of interest included quality of life (81-83,86,88,89,91,100,101); symptom management such as fatigue (94,98), vasomotor symptoms (101,110); sexual function (97); sleep function (85,90,94); physical functioning (92,94); psychological outcomes such as depression, anxiety, coping, and uncertainty (86,95,96,98); and other outcomes such as patient preferences, satisfaction, knowledge, and social support (87,93).

Table 8. Randomized Trials of Psychoeducational/Cognitive Behavioural Interventions

Author Year (Reference)	# of Pts.	Type of Intervention(s) (versus usual care)	Disease Site	Outcomes of Interest				
				Survival/ Recurrence	Physical Function [a]	Psychosocial Function	Quality of Life	Other
Heidrich 2009 (81)	82	PSE - symptoms	Breast	-	-	√	√	√
Otis Green 2008 (82)	33	PSE - quality of life	Ovarian	-	-	-	√	-
Nelson 2008 (83)	50	PSE - quality of life	Cervical	-	√	-	√	-
Fillion 2008 (84)	94	PSE/exercise - fatigue	Breast	-	√	√	√	-
Espie 2008 (85)	150	CBT - insomnia	Multiple	-	√	-	√	-
Dirksen 2008 (86)	81	CBT - insomnia	Breast	-	√	√	√	-
Bloom 2008 (87)	404	PSE - coping/knowledge	Breast	-	-	-	-	√
Ashing-Giwa 2008 (88)	23	CBT - coping/knowledge	Cervical	-	-	-	√	-
Meneses 2007 (89)	261	PSE - quality of life	Breast	-	-	-	√	-
Epstein 2007 (90)	72	CBT - insomnia	Breast	-	√	-	-	-
Campbell 2007 (91)	30	CBT - coping/knowledge	Prostate	-	-	-	√	√
Gielissen 2006 (92)	98	CBT - fatigue	Multiple	-	√	-	-	-
Bloom 2006 (93)	157	PSE - screening	Hodgkin's	-	-	-	-	√
Savard 2005 (94)	57	CBT - insomnia	Breast	-	√	√	√	√
Mishel 2005 (95)	509	CBT - coping/knowledge	Breast	-	-	√	-	-
Lane 2005 (96)	42	CBT - coping/knowledge	Breast	-	-	√	-	-
Canada 2005 (97)	84	PSE - sexual health	Prostate	-	√	√	-	√
Boesen 2005 (98)	262	PSE - distress	Melanoma	-	-	√	-	-
Stanton 2005 (99)	558	PSE - transition	Breast	-	√	√	-	√
Lepore 2003 (100)	250	PSE - quality of life	Prostate	-	√	√	√	√
Ganz 2000 (101)	76	CBT - symptoms	Breast	-	√	-	√	-

Note: # of Pts. = number of patients; √ = outcome reported; - = outcome not reported; PSE = psychoeducational; CBT = cognitive behavioural therapy.
[a] Physical function included overall physical health, sleep function, sexual function, symptom management, and fatigue.

Critical Appraisal of Randomized Controlled Trials on Psychosocial and Supportive Care

The quality of the randomized trials was appraised using the SIGN guideline development handbook (151). Table 9 shows the quality appraisal of the cognitive behavioural therapy and psychoeducational trials included in this review. Overall, the quality of the trials was poor to moderate. Due to the nature of the interventions, the majority of the trials did not blind the participants or the assessors. Overall reporting of procedures and outcomes was generally inadequate, and since the majority of the trials were conducted in breast cancer survivors, the generalizability of the results is limited to this population.

Table 9. Critical Appraisal of Randomized Trials of Psychoeducational/Cognitive Behavioural Interventions

Author Year (Reference)	Appropriate and Focused Question	Randomization Method Described	Blinding	Balanced Arms (groups similar at start of trial)	Treatment Only Difference Between Groups	Outcomes Assessed with Validated and Reliable Measures	Drop-out Rate Reported	Intention-to-Treat analysis	Sponsorship	Power Calculation
Heidrich 2009 (81)	+	-	-	-	-	+	<20%	-	+	-
Otis Green 2008 (82)	-	+	-	-	-	-	-	-	+	-
Nelson 2008 (83)	+	+	-	+	-	+	>20%	-	+	-
Fillion 2008 (84)	+	+	-	+	+	+	<20%	+	+	+
Espie 2008 (85)	+	++	-	-	+	++	>20%	+	+	+
Dirksen 2008 (86)	++	+	-	+	+	++	<20%	-	+	+
Bloom 2008 (87)	+	-	-	-	+	-	<20%	+	+	-
Ashing-Giwa 2008 (88)	-	-	-	+	+	+	-	-	+	-
Meneses 2007 (89)	+	+	-	+	-	+	20%	-	-	-
Epstein 2007 (90)	++	+	-	+	+	++	<20%	-	+	+
Campbell 2007 (91)	+	-	-	+	+	++	>20%	-	+	-
Gielissen 2006 (92)	+	+	-	-	-	+	>20%	+	+	+
Bloom 2006 (93)	+	+	-	-	-	-	<20%	-	+	-
Savard 2005 (94)	+	+	-	+	-	+	<20%	+	-	-
Mishel 2005 (95)	++	+	-	+	-	++	<20%	-	+	-
Lane 2005 (96)	+	-	-	+	-	-	-	-	-	-
Canada 2005 (97)	++	++	-	+	+	+	>20%	-	+	-
Boesen 2005 (98)	+	+	+	-	-	+	<20%	+	-	-
Stanton 2005 (99)	+	+	+	+[b]	+	+	> 20%	-	-	+
Lepore 2003 (100)	++	+	++	+	+	+	-	+	-	-
Ganz 2000 (101)	-	+	+	+[a]	-	+	<20%	+	+	-

Note: ++ = well addressed; + = adequately addressed; - = poorly or not addressed.
[a] Usual care group differed significantly at baseline on the following measures: SF-36 Vitality.
[b] Intervention arms differed significantly at baseline on the following measures: SF-36 Vitality, SF-36 MCS, and CES-D.

Randomized Controlled Trials of Interventions on Lifestyle Management

As shown in Table 10, 32 trials evaluated lifestyle management interventions, primarily physical activity and/or dietary restriction programs (102-109,111-134). Twenty-two trials included only breast cancer survivors (103,105-107,110-114,116,118-120,122-125,127-129,131-132), while nine trials included survivors of multiple cancers (104,108,109,115,117,121,126,133-134), and two trials included colon (130) or endometrial cancer survivors (102).

Outcomes of interest included quality of life (103,104,106,107,109,111,114,118,120-122,125,128-130,132-134); physiological outcomes, such as aerobic and muscular fitness, body composition, or body weight (102,106,108,112,113,116,119,120,122,124-126,129,132-134); symptom management of fatigue (121,124) or lymphedema (128); physical functioning (104,117); psychological outcomes of depression, anxiety, body image, or self-efficacy (102,106,118,123,124,127); disease recurrence or disease-free survival (119,131); and other outcomes such as physical activity participation or adherence (103,105,111,113,115,124), or vasomotor symptoms, such as hot flashes (101,110).

Table 10. Randomized Control Trials of Lifestyle Management Interventions

Author Year (Reference)	# of Pts.	Type of Intervention(s) (versus usual care)	Disease Site	Outcomes of Interest				
				Survival/ Recurrence	Physical Function	Psychosocial Function	Quality of Life	Other
von Gruenigen 2009 (102)	45	Exercise [a]	Endometrial	-	√	√	-	√
Rogers 2009 (103)	41	Exercise [b]	Breast	-	√	-	√	√
Morey 2009 (104)	641	Exercise [a]	Multiple	-	√	-	√	√
Courneya 2009 (105)	242	Exercise	Breast	-	√	-	-	-
Cadmus 2009 (106)	125	Exercise	Breast	-	-	√	√	-
Milne 2008 (107)	58	Exercise	Breast	-	√	-	√	√
May 2008 (108)	147	Exercise [b]	Multiple	-	√	-	-	-
Korstjens 2008 (109)	209	Exercise [b]	Multiple	-	-	-	√	-
Elkins 2008 (110)	48	Hypnosis	Breast	-	√	√	-	√
Vallance 2007 (111)	377	Exercise	Breast	-	√	-	√	√
Mefferd 2007 (112)	76	Exercise [a]	Breast	-	√	-	-	-
Matthews 2007 (113)	36	Exercise	Breast	-	√	-	-	√
Daley 2007 (114)	108	Exercise	Breast	-	√	√	√	-
Bennett 2007 (115)	56	Motivational	Multiple	-	√	-	-	-
Mustian 2006 (116)	21	Exercise	Breast	-	√	-	-	-
Demark-Wahnefried 2006 (117)	182	Exercise [a]	Multiple	-	√	-	-	√
Culos-Reed 2006 (118)	38	Exercise	Breast	-	√	√	√	-
Chlebowski 2006 (119)	2437	Diet [c]	Breast	√	√	-	-	√
Basen-Engquist 2006 (120)	60	Exercise	Breast	-	√	-	√	√
Thorsen 2005 (121)	111	Exercise	Multiple	-	√	√	√	-
Schmitz 2005 (122)	79	Exercise	Breast	-	√	√	√	-

Author Year (Reference)	# of Pts.	Type of Intervention(s) (versus usual care)	Disease Site	Outcomes of Interest				
				Survival/ Recurrence	Physical Function	Psychosocial Function	Quality of Life	Other
Sandel 2005 (123)	38 [e]	Exercise	Breast	-	√	√	-	-
Pinto 2005 (124)	86	Exercise	Breast	-	√	√	-	√
Herrero 2005 (125)	16	Exercise	Breast	-	√	-	√	-
Dimeo 2004 (126)	69	Exercise [d]	Multiple	-	√	-	-	-
Pinto 2003 (127)	24	Exercise	Breast	-	-	√	-	-
McKenzie 2003 (128)	14	Exercise	Breast	-	√	-	√	-
Courneya 2003a (129)	53	Exercise	Breast	-	√	√	√	-
Courneya 2003b (130)	102	Exercise	Colon	-	-	-	√	-
Pierce 2002 (131)	3088	Diet [c]	Breast	√	-	-	-	√
Djuric 2002 (132)	48	Diet [c]	Breast	-	√	-	√	√
Courneya 2002 (133)	108	Exercise [b]	Multiple	-	√	√	√	-
Burnham 2002 (134)	18	Exercise	Multiple	-	√	-	√	-

Note: √ = outcome reported; - = outcome not reported.
[a] Exercise and diet with cognitive behavioural therapy.
[b] Exercise and cognitive behavioural therapy.
[c] Diet and cognitive behavioural therapy.
[d] Relaxation therapy.
[e] Crossover trial.

Critical Appraisal of Randomized Controlled Trials

Table 11 shows the quality appraisal of the randomized controlled trials related to lifestyle management interventions included in this review. The quality of the randomized trials was appraised using the criteria identified in the SIGN guideline development handbook (151).

Table 11. Critical Appraisal of Randomized Trials of Lifestyle Management Interventions

Author Year (Reference)	Appropriate and Focused Question	Randomization Method Described	Blinding	Balanced Arms (groups similar at start of trial)	Treatment Only Difference Between Groups	Outcomes Assessed with Validated and Reliable Measures	Drop-out Rate Reported	Intention-to-Treat analysis	Sponsorship	Power Calculation
von Gruenigen 2009 (102)	+	+	-	-	+	+	-	+	+	-
Rogers 2009 (103)	+	+	-	+	-	+	<20%	+	+	-
Morey 2009 (104)	+	+	-	+	+	+	<20%	+	+	+
Courneya 2009 (105)	+	-	-	+	+	+	-	-	-	-
Cadmus 2009 (106)	+	+	-	+	+	+	<20%	+	+	+
Milne 2008 (107)	+	+	+	+	+	+	<5%	-	+	+
May 2008 (108)	+	+	+	+	-	+	<20%	+	+	+
Korstjens 2008 (109)	+	-	-	-	+	+	+	+	+	+
Elkins 2008 (110)	+	+	-	+	+	-	20%	-	+	+
Vallance 2007 (111)	+	+	-	+	+	+	<20%	+	+	-
Mefferd 2007 (112)	+	+	-	+	-	+	<20%	-	-	-
Matthews 2007 (113)	+	+	-	+	+	+	-	+	-	-
Daley 2007 (114)	+	+	-	-	-	+	-	-	-	-
Bennett 2007 (115)	+	+	-	-	+	+	>20%	-	+	+
Mustian 2006 (116)	+	+	-	+	-	+	>20%	+	+	-
Demark-Wahnefried 2006 (117)	+	+	-	+	++	+	<20%	+	+	+
Culos-Reed 2006 (118)	+	-	-	-	-	+	-	-	+	-
Chlebowski 2006 (119)	+	+	-	-	-	-	>20%	-	+	-
Basen-Engquist 2006 (120)	+	+	-	+	+	+	<20%	+	+	-
2005 Thorsen 2005 (121)	+	+	-	+	+	+	>20%	+	+	+
Schmitz 2005 (122)	+	-	+	+	-	+	<20%	+	-	-
Sandel 2005 (123) [a]	+	-	-	+	-	+	<10%	+	+	-
Pinto 2005 (124)	+	+	-	+	-	+	<20%	+	-	-
Herrero 2005 (125)	+	+	+	-	-	+	20%	-	+	-
Dimeo 2004 (126)	+	-	-	+	+	-	-	-	-	-
Pinto 2003 (127)	+	+	-	-	-	+	-	-	+	+
McKenzie 2003 (128)	+	+	-	+	-	+	-	-	-	-
Courneya 2003b (129)	-	+	+	+	+	+	<20%	-	+	-
Courneya 2003a (130)	-	+	+	+	+	+	<5%	+	+	+
Pierce 2002 (131)	+	+	-	+	+	+	<20%	+	+	-
Djuric 2002 (132)	-	-	-	-	-	+	<20%	-	+	-
Courneya 2002 (133)	+	+	+	+	-	+	<20%	+	+	+
Burnham 2002 (134)	+	-	-	+	+	-	+	-	-	-

Note: ++ = well addressed; + = adequately addressed; - = poorly or not addressed.
[a] Crossover trial

Overall, the quality of the trials was poor to moderate. Due to the nature of the interventions, the majority of the trials did not blind the participants or the assessors. The reporting of procedures and outcomes was deemed inadequate, with the majority of the trials not powered to detect statistically significant differences between treatment groups in the primary outcomes of interest. In addition, since the majority of the trials were conducted in breast cancer survivors, the generalizability of the results is limited to this population. Furthermore, few studies reported adherence to the interventions, particularly related to unsupervised exercise programs.

Results

Organization and Care Delivery Structure of Survivorship Services

Ten clinical practice guidelines (50-58,61) and nine randomized controlled trials (72-80) provided guidance on the organization and care delivery of survivorship services by examining models of care, sites of care (specialized or integrated), types of provider, support services, and structural approaches (e.g., survivorship transition plans) that may be considered when planning survivorship services. The recommendation matrix of clinical practice guidelines is available in Appendix IV, and Appendix VII provides a detailed description of the trials.

Models of Care

Six clinical practice guidelines provided recommendations on some aspect of models of survivorship care (52,53,55,57,61). Models for providing survivorship follow-up care included survivorship clinics (52), shared care between oncologists and primary care physicians (52), nurse-led survivorship care (52), or interdisciplinary care models (52,55). Other considerations included the need for service availability (53); continuity of care (53,57); involvement of appropriate health providers (53,55,57,61); identification of the goal, frequency, and duration of follow-up visits (55,57); and communication between team members to minimize redundancy (61).

Nine randomized trials (72-80) investigated models of follow-up care by comparing standard follow-up care with a specialist physician to less frequent follow-up contact (79), care provided by primary care physicians (72,73,80), care provided by nurses (74-76,78), and/or care that was patient-initiated (76-78). Patients in one study expressed a preference for less-frequent follow-up contact versus more; however, patients in both study arms expressed that preference (79). In that study, no increases in local practitioner services or telephone triage were reported as a consequence of less follow-up (79). For patients followed by primary care physicians in three trials, there appeared to be no differences in quality of life or disease recurrence outcomes (72,73,80); however, one study did report lower costs to patients and health services and higher patient satisfaction over baseline with primary care follow-up (80). In four trials with nurse-led follow-up, which was also patient-initiated in two trials (76,78), no significant differences in quality of life or disease recurrence outcomes were reported when compared with standard care (74-76,78). Patient satisfaction was significantly higher in most subscales with nurse-led care at three, six, and 12 months ($p<0.01$) in one study (75), and psychological functioning was significantly higher in two studies (75,76). One study also reported less severe dyspnoea at three months ($p=0.03$) and less peripheral neuropathy at 12 months ($p=0.05$) with nurse-led care. Patient-initiated care resulted in greater patient satisfaction in one trial (76), but no other significant differences reported across meaningful outcomes were reported (76-

78). One study of patient-initiated nurse-led care reported less detection of psychological distress (47% versus 92%) with the nurse-led intervention (76).

Site of Care

None of the guidelines provided recommendations specifically addressing the site of survivorship care, nor did the randomized controlled trials of follow-up interventions specifically explore advantages or disadvantages associated with the site of care (i.e., standard follow-up care at a cancer clinic, hospital, or specialist's office versus alternate settings such as the primary care office or specialized survivorship clinics). Of the randomized controlled trials where follow-up was conducted in the primary care office (72,73,80), two trials reported no overall differences in outcomes by study group (72,73), while one study reported increased patient satisfaction over baseline and more (3.4 versus 2.8 visits, $p<0.001$) and longer (10.5 versus 7.4 minutes, $p<0.001$) follow-up visits with primary care versus specialist care (80). That study also reported that costs to patients and health services were lower in primary care ($p<.001$), there was no difference in the total costs of diagnostic tests, and more tests were performed in the primary care setting ($p<0.001$).

Type of Provider

Four practice guidelines provided recommendations on type of provider to be included as part of the survivorship care team (52,53,55,58). The Dutch Association of Comprehensive Cancer Centers (DACCC) prostate and renal cancer guidelines recommended that the follow-up care team should consist of a interdisciplinary team including oncology nurses, urology nurses, radiotherapy nurses, dietitians, physiotherapists, psychologists, and sexologists (55,58). The interdisciplinary team should be established based on the specific problems, symptoms, and needs of the individual patient (55,58). The Association of Community Cancer Centers (ACCC) recommended that comprehensive rehabilitation services be available to cancer survivors and their families through the entire cancer care continuum from diagnosis to survivorship (53). The American Society of Preventive Oncology (ASPO) survivorship group expressed the importance of collecting data on health-related outcomes and cost associated with the delivery of cancer survivorship care by various healthcare providers, including advanced practice clinicians (e.g., nurse practitioners, physician assistants), primary care physicians with additional training in oncology, and oncologists who specialize in primary care (52).

Of the nine randomized controlled trials investigating the type of provider best suited to perform survivorship follow-up care (72-80), none of the five trials assessing quality of life by type of provider reported any significant differences between control versus intervention groups (72,73,75,77,80). Satisfaction with follow-up care was assessed in seven trials (73-78,80). Five trials reported no differences in satisfaction scores between intervention and standard care follow-up (73,74,77,78,80), while one trial (75) reported higher satisfaction in most subscales with nurse-led care at three, six and 12 months ($p<0.01$), and one trial (76) reported higher patient satisfaction with nurse-led care ($p<0.01$).

No significant differences between the intervention and control groups were reported in depression or anxiety scores in any of the trials assessing psychological functioning (73-78,80). One trial (75) reported higher scores for emotional functioning at 12 months with nurse-led care ($p=0.03$), while another trial (76) reported less detection

of psychological distress with nurse-led care versus standard follow-up care (47% versus 92%). Of the seven trials that assessed differences in diagnosis of recurrence, medical safety, or rate of recurrence-related serious clinical events by type of provider, no differences in any clinical outcomes were detected between primary care follow-up and the specialist follow-up groups (72-76,78,80). In one study, there was less dyspnoea at three months and less peripheral neuropathy at 12 months with nurse-led care (75), and in one study, arm-symptom subscale scores were higher with standard care compared with patient-initiated follow-up at Time 1 (p=0.003) and Time 2 (p= 0.028).

In terms of other outcomes informing the type of provider to perform follow-up services, the costs of care were comparable in one study (75), while two studies reported lower costs with nurse-led (78) or primary care physician-led follow-up (80). In the latter trial, costs to survivors were also reported as lower in the primary care arm (80).

Support Services

Four guidelines provided recommendations for some aspect of support services to be integrated into the follow-up care of cancer survivors (54,59-61). These guidelines advocated that psychosocial support should be encouraged and facilitated by all cancer providers (61). Discussions during follow-up consultation should not be limited to physical symptoms and test results, but rather it should also cover anxiety, worries, other topics related to quality of life (60), and sexual functioning (59). In addition, one guideline on the psychosocial care of cancer survivors urged the National Cancer Institute to help cancer care providers implement the standard of care by maintaining an up-to-date directory of psychosocial services available at no cost to individuals with cancer and their families (54).

Structural Approaches

Eight guidelines provided guidance on the structural approaches of follow-up care including providing survivorship transition care plans (50-56,61). The Institute of Medicine's (IOM) Lost in Transition report (56), as well as the Cancer Care for the Whole Patient report (54), specifically recommended the need for follow-up survivorship care plans to prepare survivors for the transition from the active treatment to the post-treatment survivorship phase. Lost in Transition made specific recommendations for essential elements of care plans to include a summary of the critical information needed for the survivor's long-term care, to be written by the primary provider of the oncology treatments (56). Some of the critical information to be integrated in this written summary included cancer type, treatment received, and potential late effects; specific information about the follow-up timing and content; information on preventive practices to maintain health and well-being; information about employment, financial, and legal issues; and information about local, regional, and national resources on survivorship and survivorship research via written materials and/or referrals on the Internet, from other experts, or from support organizations for any aspect of cancer, cancer care, research, advocacy, and survivorship (50,51,53,54,56). The patient must understand the adverse late effects that may occur in the survivorship phase (55); the frequency of visits to the healthcare provider should be adjusted to the individual patient needs (61); survivors should be encouraged to report new, persistent symptoms promptly, without waiting for the next scheduled appointment (61); and they should know which care provider to report

symptoms to (55). In addition, the U.S.-based Lost in Transition advocates that survivorship transition care planning should be reimbursed by third-party payers of the health care system (56). Overall, cancer survivorship follow-up care models and plans should be based on evidence of efficacy and effectiveness (52).

Other

Four guidelines advocated for ongoing educational opportunities to be provided to members of the survivorship care teams (52–54,56). The Association of Community Cancer Centers (53) and the Institute of Medicine (54,56) guidelines recommended that national cancer organizations, professional associations, and voluntary organizations expand and coordinate their efforts to provide educational opportunities to health care providers to equip them to address the health care and quality-of-life issues facing cancer survivors.

Moreover, the American Society of Preventive Oncology survivorship interest group advised that patient empowerment is important not only during active treatment but also during the extended period of follow-up care, and that research examining how to engage and activate survivors in their follow-up care is needed (52). The goal is to enable survivors to participate actively in their care by providing tools and training in how to obtain information, make decisions, solve problems, and communicate more effectively with their health care provider (54,56).

In addition, it was recommended that organizations providing research funding should support assessment of implementing education, training, and clinical practice outcomes of the workforce competencies necessary to provide psychosocial care and their impact on achieving the standard for such care set forth in recommendation (54). Based on the consensus of experts, the Association of Community Cancer Centers also recommended that resources be allocated to provide a robust survivorship program and that national standards for survivorship care be implemented into program planning, implementation, and evaluation (53).

Psychosocial and Supportive Care Interventions

As shown in tables 2, 4, 8, and 10, a number of clinical practice guidelines, systematic reviews, and randomized controlled trials provided evidence regarding the impact of psychosocial and supportive care interventions on a range of post-treatment outcomes. For the purposes of this review, interventions were grouped into two broad categories: outcomes related to psychosocial and supportive care interventions and outcomes related to lifestyle management. Psychosocial interventions included psychological and counselling components, including psychoeducational therapy, cognitive behavioural therapy, stress management, relaxation, skills training, social support, psychotherapy, and interventions that include a combination of psychological and behavioural/physical components (e.g., stress management and exercise). In contrast, lifestyle interventions were primarily based on physical activities, such as aerobic exercise or strength training.

For both psychosocial and supportive care interventions and lifestyle management interventions, outcomes of interest included the impact on survival or disease recurrence, physical function, psychosocial function, quality of life, or other outcomes

such as informational/practical needs. Across the identified guidelines, systematic reviews, and randomized controlled trials, the emotional and spiritual needs of cancer survivors were not explicitly addressed. Whether these needs were influenced in the context of other outcomes (e.g., distress, quality of life) is unclear.

The limitations of the reviews and trials were very similar. Psychosocial and supportive care interventions included a variety of approaches, such as cognitive behavioural therapy, individualized counselling, group counselling, or stress reduction. Exercise interventions included a variety of modes of exercise (e.g., aerobic and/or strength training, home-based or gym-based, supervised or unsupervised), intensity, frequency, and duration. Moreover, breast cancer survivors were either the focus of or were the largest group in the majority of studies. As a result, it is difficult to generalize the findings to other cancer populations. The authors also reported low sample sizes and weak methodological quality among many existing studies. Furthermore, few studies reported adherence to the interventions, particularly related to unsupervised exercise programs.

For greater detail on practice guideline recommendations, results of systematic reviews, or randomized trials, please refer to Appendices IV, V, VIII, and IX.

Survival/Recurrence

One systematic review (71) and two randomized controlled trials (119,131) inform the topic of psychosocial or lifestyle interventions designed to improve survival outcomes in the survivor population. Smedslund & Ringdal (2004) conducted a meta-analysis to investigate the effects of psychosocial interventions on cancer survival (71). Eight randomized trials and five controlled studies, consisting of 2626 participants, were included that involved any combination of psychosocial intervention and measured survival time. Interventions were conducted either pre- or post-treatment, primarily among women treated for breast cancer. Overall, no intervention effect on survival was detected; the total mean inverse-variance-weighted hazard ratio (HR) was 0.85 (95% confidence interval [CI] = 0.65 to 1.11). That finding remained after the randomized controlled trials and non-randomized trials were analyzed separately. Interventions using individual treatment (N=3) were found to be effective (HR = 0.55, 95% CI = 0.43 to 0.70) while interventions using group treatment were not effective (N=9) (HR = 0.97, 95% CI: 0.73 to 1.27), however the meaning of that finding is unclear.

Two large randomized controlled trials of lifestyle interventions evaluated disease-free survival and disease recurrence among breast cancer survivors (119,131). Both trials implemented a dietary modification program among breast cancer survivors. One trial compared a standard protocol program in 1,462 participants, which provided nutrient guidelines and education booklets to cancer survivors, with 975 intervention participants, which included a low-fat eating plan based on nutritional and behavioural science principles, incorporated social cognitive theory, and included self-monitoring (fat gram counting and recording), goal setting, modelling, social support, and relapse prevention and management (119). After a median 60 months of follow-up, dietary fat intake was lower in the intervention than in the control group ($p<0.001$). A total of 277 relapse events (local, regional, distant, or ipsilateral breast cancer recurrence or new contralateral breast cancer) were reported in 96 of 975 (9.8%) women in the intervention group and 181 of 1,462 (12.4%) women in the control group. The hazard ratio of relapse events in the intervention group compared with the control group was

0.76 (95% CI = 0.60 to 0.98, p=0.077 for stratified log rank and p=0.034 for adjusted Cox model analysis). Pierce et al. implemented a telephone counselling program among 1,537 breast cancer survivors, supplemented with cooking classes and newsletters that promoted daily intake of five vegetables per day plus 16 ounces of vegetable juice; three fruit servings per day and 30 grams of fibre intake, and decreased intake of fat to 15% to 20% (131). The 1,551 control group participants received print materials of dietary guidelines. Over a four-year period, the intervention group achieved and maintained statistically significant differences in servings of vegetables (+65%), fruit (+25%), fibre (+30%), and energy intake from fat (-13%) (131). Over the mean 7.3-year follow-up, 256 women in the intervention group (16.7%) versus 262 in the control group (16.9%) experienced an invasive breast cancer event (adjusted HR = 0.96; 95% CI = 0.80 to 1.14, p=0.63), and 155 intervention group women (10.1%) versus 160 control group women (10.3%) died (adjusted HR = 0.91, 95% CI, 0.72 to 1.15, p=0.43).

Physical Function

For the purposes of this guidance report, outcomes related to physical function are classified and reported according to the following categories: overall physical health, fatigue, symptom management, sleep function, and sexual function.

Overall Physical Health

The majority of the guidelines provided recommendations regarding nutrition and physical activity among cancer survivors (50,51,55,56,59-63). Many of the recommendations follow the American Cancer Society guidelines (60,62,63), which urge cancer survivors to eat healthy foods, with an emphasis on plant sources; eat five or more servings of vegetables and fruits per day; choose whole grains rather than processed grains and sugars; limit consumption of red meats, especially those high in fat and processed; and choose foods to help maintain a healthy weight. Those guidelines also advised cancer survivors to adopt a physically active lifestyle, including at least moderate activity for 30 minutes or more, five or more days a week. They also recommended that 45 minutes or more of moderate to vigorous activity on five or more days per week may further reduce the risk of breast or colon cancer recurrence. The overall message was to maintain healthy weight throughout life, balance caloric intake with physical activity, lose weight if currently overweight or obese, limit consumption of alcoholic beverages, and follow general guidelines on food safety (50,51,55,56,59-63). Counselling for tobacco use with emphasis on smoking cessation was also commonly recommended (51,52,55).

Three systematic reviews (65,69,70) reported benefits for survivors participating in post-treatment exercise programs. Cheema et al. reviewed 10 studies (five randomized controlled trials, one non-randomized, and four uncontrolled), most of which involved exercise interventions in the post-treatment phase (two weeks to five years) (65). Half of the trials prescribed eight weeks of exercise, and the remaining trials prescribed varying durations (16 weeks to six months), with progressive resistance training prescribed two to three times per week. Overall, the studies suggested a range of physical, psychological and functional benefits to women surgically treated for breast cancer who participated in progressive resistance training. However, most of the interventions included both aerobic and progressive resistance training components, making conclusions regarding the specific effect of progressive resistance training difficult. Yet, two large trials in that review which

tested progressive resistance training as the sole modality of exercise reported significant increases in upper and lower body strength compared with aerobic exercise alone. That finding was considered clinically significant based on the high incidence of lymphedema in that survivor population. The authors reported that no incidence or exacerbation of quantified or self-reported lymphedema was evident among patients in these studies.

Schmitz et al. conducted a systematic review of 32 controlled studies of physical activity in cancer survivors, most of which focused on survivors treated for breast cancer (70). The authors reported a significant effect on cardio-respiratory fitness with physical activity both during and after treatment (weighted mean effect size of 0.51 and 0.65, respectively, $p < 0.01$) when compared with standard care.

Ingram et al. conducted a systematic review to investigate the effects of exercise interventions on the body weight and composition of breast cancer survivors (69). Of the 14 randomized controlled trials and uncontrolled studies included in the review, eight examined exercise interventions provided in the post-treatment survivorship phase (three weeks to five years post-treatment). Body weight appeared to be less responsive to the effects of exercise than body composition (i.e., percentage of body fat); however, body weight and composition were generally secondary endpoints in relation to other outcomes, such as physical function and fatigue. As such, none of the studies were designed or sufficiently powered to examine the effect on body weight and composition.

Twenty-six randomized controlled trials examined interventions designed to improve physiological functioning in the survivor population (83,92,102-105,108,111,112,114-120,121-123,125-129,132,134). Of the 26 trials, two were psychoeducational or cognitive behavioural therapy interventions (83,92), while 24 trials were lifestyle management interventions (102-105,108,111,112,114-120,121-123,125-129,132,134). Physiological outcomes included physical function, aerobic fitness, muscular strength, extremity function, flexibility, levels of triglycerides, total cholesterol, immune system T-helper types 1 and 2, weight loss, and changes in body mass index.

Of the two psychosocial trials (83,92), one trial reported a significant difference in adaptive immunity with a telephone counselling intervention (83), while one trial reported a significant decrease in functional impairment with cognitive behavioural therapy (92).

Of the lifestyle management trials designed to improve physiological functioning, the majority of the trials included breast cancer survivors (103,105,111,112,114,116,118-120,122,123,125,127-129,132); seven included survivors of various cancers (104,108,115,117,121,126,134); and one included endometrial cancer survivors (102). Sample size ranged from 14 participants (128) to 2,437 participants (119). Intervention lengths varied from eight weeks to six months, and follow-up varied from eight weeks to 60 months. The majority of the randomized controlled trials included physical activity-based interventions (105,108,111,112,114-118,120-123,125-129,134), while two trials integrated dietary changes and physical activity participation (102,103), and two were specifically focused on changing dietary behaviours (119,132). Aerobic fitness was most often measured via objective peak oxygen consumption tests (VO2max, walking tests), and muscular strength was measured via strength-training tests (e.g., grip strength, sit and reach tests).

The majority of the trials reported improvements in physiologic outcomes related to aerobic fitness, physical fitness, muscular strength, or flexibility among those cancer survivors who received an exercise and/or diet intervention with or without additional cognitive behavioural counselling (102-104,108,109,111,112,114,116,118-125,128,132,134). Most of the multicomponent interventions were effective at improving patient outcomes (102-104,109,112,132), while three trials reported no differences in physiological outcomes between intervention and control groups (113,115,117).

Six trials of lifestyle interventions evaluated participation in and adherence to light to moderate physical activity, including walking, indoor bicycling, and strength training in supervised and home-based settings (103,105,111,113,115,124). All trials showed a significant increase in physical activity participation among intervention group participants as compared with control group participants. However, whether participation was sustained following the completion of the intervention is unclear: while one study reported adherence of 99% immediately at the end of a 12-week program (103), another study reported an adherence rate of 42.3% at six months post-intervention (105).

The effectiveness of an intervention to support sustainable behaviour change may depend on the theoretical approach used in its development (67). The systematic review by Pinto & Floyd examined 21 randomized controlled trials that tested various theory-based psychosocial interventions targeting such behaviours as smoking cessation, diet, and physical activity (67). Based on their qualitative review of these studies, interventions based on the transtheoretical model of change, social cognitive theory, and cognitive behavioural therapy showed benefits of changing lifestyle management behaviours in the context of smoking cessation, dietary changes, and exercise participation. These behaviour changes may lead to improvements in physical outcomes such as body weight, fitness, and fatigue.

Fatigue

One practice guideline (60), three systematic reviews (66,68,70), and seven randomized controlled trials (84,86,92,99,121,124,128) addressed interventions to manage post-treatment fatigue.

The Canadian Breast Cancer Initiative breast cancer guidelines (61) recommended that cancer survivors be screened for cancer-related fatigue and the potentially underlying physiological factors including pain and depression. Of the three systematic reviews, Kangas et al. reviewed 57 randomized controlled trials and 62 quasi-experimental studies of both psychosocial and exercise interventions on cancer-related fatigue (66). The most common psychosocial interventions were cognitive behavioural therapy, supportive-expressive therapy, education, and counselling. The most common exercise interventions were multimodal, walking, and cardiovascular/flexibility and/or strength. Based on their meta-analysis of randomized controlled trials of 41 psychosocial interventions and 16 exercise interventions (N=1001), both psychosocial and exercise interventions were effective in reducing cancer-related fatigue, especially when the interventions were designed specifically to address fatigue symptoms (i.e., had a cancer-related fatigue aim). Looking specifically at interventions provided in the post-treatment phase, both psychosocial and exercise interventions had small to moderate effect sizes (-0.16 to -0.57).

In the Cochrane review by Cramp & Daniel, the authors synthesized the results of 28 randomized controlled trials investigating the effect of physical activity on cancer-related fatigue (68). Based on a meta-analysis of 22 of the trials (N=1663), exercise either during or after treatment was statistically more effective than standard care at reducing fatigue (standard mean difference -0.23, 95% CI = -0.33 to -0.13). This finding remained in a separate analysis looking only at 11 studies carried out following cancer treatment. Exercise interventions provided during the post-treatment phase remained statistically more effective than the control care (standard mean difference -0.37, 95% CI = -0.55 to -0.18). However, the difference between the intervention and control groups did not appear to be sustained. In studies that included long-term outcomes of exercise interventions provided after cancer treatment, the differences in fatigue between the intervention and control groups were no longer statistically significant by 24 to 27 weeks post-treatment. Furthermore, while this review included several studies of other cancer populations (colorectal, prostate, and haematological cancers), statistically significant findings were specific to studies of breast cancer survivors.

The Schmitz et al. review synthesized a range of outcomes based on 32 controlled physical activity trials in primarily breast cancer survivors, with a total of 37% of the included studies involving interventions during the post-treatment phase (70). Consistent with the Cramp and Daniel review (68), their meta-analysis detected significant increases in vigour with post-treatment physical activity interventions (weighted mean effect size of 0.83, p=0.04).

Seven randomized controlled trials (84,86,92,99,121,124,128), four of psychoeducational or cognitive behavioural therapy (84,86,92,99) and three of lifestyle management (121,124,128), focused on fatigue management as an outcome of interest. Overall, the psychosocial interventions significantly decreased fatigue in post-treatment cancer survivors when compared with standard care. A brief group intervention including both psychoeducation and physical activity among breast cancer survivors showed a significant improvement in energy and fatigue (84), while Dirksen et al. reported that a cognitive behavioural therapy sleep education program significantly decreased fatigue among breast cancer survivors (86). Gielissen et al. reported that cognitive behavioural therapy was effective at significantly and clinically decreasing fatigue severity among survivors of multiple cancers (92). In the trial by Stanton et al., an educational video was found to be an effective method of reducing fatigue at six months when compared with no video, and the intervention was found to be more cost effective when a counselling arm was not included as part of the intervention (99).

Of the three randomized controlled trials of lifestyle interventions (121,124,128), Thorsen et al. reported that a 14-week home-based exercise program significantly decreased fatigue scores among cancer survivors when compared with survivors in the control group (121), while Pinto et al. reported that a 12-week home-based moderate intensity exercise program had a significant effect on vigour which was maintained at six months post-intervention (124). In their trial of 14 patients, Mackenzie et al. reported a trend toward increased vitality as a result of an upper-body exercise program (128).

Vasomotor Symptoms

Two randomized controlled trials reported data on interventions designed to improve vasomotor symptoms in breast cancer survivors (101,110). In one trial, menopausal symptoms (hot flashes, vaginal dryness, and stress urinary incontinence) among breast cancer survivors were significantly improved in the intervention group receiving a comprehensive menopausal symptom assessment intervention, including symptom assessment, education, and counselling (101). In the remaining trial, Elkins et al. reported that hypnosis was effective at improving hot flashes in breast cancer survivors, measured with the Hot Flash Related Daily Interference Scale (110). The authors reported that hypnosis appeared to reduce perceived hot flashes in breast cancer survivors and may have additional benefits, such as reduced anxiety, reduced depression, and improved sleep (110).

Sleep Function

Three trials (85,90,94) evaluated the effect of psychosocial interventions on sleep function among post-treatment breast (90,94) or multiple cancer survivors (85). The interventions were based on cognitive behavioural therapy components, including stimulus control, sleep restriction, sleep education, and sleep hygiene. The measures of sleep included subjective instruments, such as the Pittsburgh Sleep Quality Index, the Epworth sleepiness scale, sleep diaries, the Insomnia Severity Index, and the Insomnia Interview Schedule, as well as objective sleep measures, such an actigraphy or polysomnography. Overall, the trials detected that cognitive behavioural therapy strategies improved sleep function such as daily sleep, wake after sleep onset, total sleep time, sleep efficiency, and sleep qualities (85,90,94). The effects of the interventions were maintained six months (85) to 12 months (94) post-intervention. These improvements were also associated with increased quality of life and decreased fatigue (85,94).

Sexual Function

One clinical practice guideline (60) and two randomized controlled trials (97,100) addressed sexual function in cancer survivors. The Canadian Breast Cancer Initiative guideline recommended that primary care providers address sexual functioning during follow-up appointments (60). In one randomized controlled trial of prostate cancer survivors, compared with the control group of individual counselling sessions, 76 couples attended counselling designed to improve sexual satisfaction and increase use of medical treatments for erectile dysfunction (97). The intervention group showed significant improvements in male overall distress ($p<0.01$), and male and female global sexual function ($p<0.0001$ and $p<0.05$, respectively). Regression toward baseline scores was reported at six months follow-up; however, the use of erectile dysfunction treatments increased from 31% at baseline to 49% at six months of follow-up ($p=0.003$). In another randomized controlled trial, prostate cancer survivors received usual care, an education intervention, or education plus facilitated peer discussion (100). In that trial, men in the intervention groups were significantly less bothered by sexual problems after one year of follow-up (100). Differences between the two intervention groups were generally not significantly different.

Psychosocial Function

The psychosocial needs of cancer survivors were addressed by two guidelines (58,59) and reported as a primary outcome in 12 randomized controlled trials (81,84,86,95,96,98,102,106,118,123,124,127). Of the 12 trials, 6 involved psychoeducational or cognitive behavioural therapy interventions (81,84,86,95,96,98), while six involved lifestyle management interventions (102,106,118,123, 124,127).

The Dutch Association of Comprehensive Cancer Centers' clinical practice guideline recommended that during follow-up visits the primary care providers should not only focus on physical symptoms and tests, but also enquire about psychological concerns such as anxiety, worries, and other topics related to quality of life (58). Rizzo et al. recommended a high level of vigilance for psychological symptoms, with clinical assessments throughout the recovery period at six months, one year, and annually thereafter, and if psychological issues are identified, a mental health professional should be involved in survivor's care (59). Rizzo et al. also recommended that primary care providers enquire into the level of spousal/caregiver psychological adjustment and family functioning at regular intervals during follow-up visits (59).

Of the six randomized controlled trials of psychoeducational or cognitive behavioural therapy interventions that evaluated psychosocial outcomes as a primary outcome (81,84,86,95,96,98), five were among breast cancer survivors (81,84,86,95,96) and one was with melanoma survivors (98). In two trials, symptom distress decreased significantly over the control group with an individualized representational intervention (81) or with a brief group intervention combining stress-management psychoeducation and physical activity (84). Dirksen et al. reported that a cognitive behavioural therapy insomnia intervention significantly improved anxiety and depression among breast cancer survivors (86). An uncertainty-management intervention among older breast cancer survivors, including an audiotape of cognitive behavioural therapy techniques and a self-help manual for symptom management, significantly improved cognitive reframing skills, knowledge, and social support satisfaction at 10 weeks after the intervention (95). The trial by Lane et al. detected that among 42 breast cancer survivors, a construct group therapy intervention improved hope, threat, and dislocation scores at the three month follow-up (96). Boesen et al. reported that six weekly sessions of psychoeducation including health education, problem-solving skills, stress management, and psychological support significantly improved total mood disturbance compared with control at six months follow-up (98).

Of the six randomized controlled trials of lifestyle interventions where psychological function was a primary outcome of interest (102,106,118,123,124,127), study populations included breast cancer survivors in five trials (106,118,123,124,127) and endometrial cancer survivors in one trial (102). Psychological distress included outcomes such as anxiety, depression, coping, self-efficacy, and body image. The most commonly used measures of psychological distress were the Profile of Mood States and the Spielberg State-Trait Anxiety Inventory, while body image was assessed with the Body Image Scale (123) and the Body Esteem Scale (127).

Von Gruenigen et al reported greater self-efficacy outcomes for women with breast cancer after a six month exercise and counselling intervention when compared with standard care (102), while Cadmus et al. reported improved social functioning, in

those with low social functioning, with a home-based and supervised exercise program (106). Culos-Reed et al. reported significant differences in emotional functioning with a seven-week yoga program when compared with a control group of standard care (118), and Sandel et al. reported significant improvements in body image in a small crossover trial of a 12-week dance and movement program (123). Pinto et al. reported an improvement in body image among breast cancer survivors with a 12-week supervised moderate intensity aerobic exercise program (127).

Quality of Life

Quality of life is a multidimensional concept that includes physical, social, emotional, and spiritual well-being. As shown in tables 8 and 10, a large number of randomized controlled trials reported data on quality of life outcomes (81-86,88,89,91,94,100,101,103,104,106,107,109,111,114,118,120-122,125,128-130,132-134). Twelve trials reported on psychoeducational or cognitive behavioural therapy interventions (81-86,88,89,91,94,100,101), while 18 trials reported on lifestyle management interventions (103-107,109,111,114,118,120-123,125,128-130,132-134). The majority of the trials evaluated quality of life using validated and reliable measures such as the Medical Outcomes Study Short Form 36 (MOS-SF-36), Functional Assessment of Cancer Therapy, and EORTC-QLQ-C30.

Of the 12 randomized controlled trials that reported results on psychoeducational or cognitive behavioural therapy interventions, 10 reported significant improvements related to quality of life outcomes when compared with standard care (83-86,88,89,91,94,100,101), while two reported no significant differences in quality of life between groups of survivors (81,82).

Of the 18 randomized controlled trials on lifestyle management, both aerobic and resistance training in a home-based or supervised setting were generally effective at improving quality of life scores among intervention participants (103,104,107,111,118,120,122,125,129,130,132-134). Five trials reported no significant differences in quality of life between groups of survivors (106,109,114,121,128).

Other

Practical/Informational Needs

The practical and informational needs of cancer survivors were briefly addressed by the Institute of Medicine's Lost in Transition report (56), and the Canadian Breast Cancer Initiative's breast cancer guideline (61). Specifically targeting stakeholders and decision-makers, Lost in Transition made recommendations to encourage employers, legal advocates, health care providers, sponsors of support services, and government agencies to act to eliminate discrimination and minimize the effects of cancer on employment, while supporting cancer survivors with short- and long-term limitations in their ability to work (56). The Institute of Medicine guidelines urged federal and state policy-makers to act to ensure that all cancer survivors have access to adequate and affordable health insurance. Insurers and payers of health care should recognize survivorship care as an essential part of cancer care and design benefits, payment policies, and reimbursement mechanisms to facilitate coverage for evidence-based aspects of care (56). Lost in Transition (56) also recommended that health care providers use systematically developed evidence-based practice guidelines,

assessment tools, and screening tools to help identify and manage late effects of cancer and its treatment (56).

The Canadian Breast Cancer Initiative recommended that primary care providers teach breast cancer survivors the proper procedures to carry out breast self-examination (61). Also, women considering pregnancy following a diagnosis of breast cancer should be informed on the limited data on the effect of pregnancy on outcomes such as breast cancer recurrence and survival (61).

One systematic review by Hoving et al. looked at interventions around the return to work of breast cancer survivors (64). Four non-randomized controlled trials were identified that included 46 to 317 employed women who had had mastectomy, adjuvant therapy and rehabilitation and measured the outcome of return to work. The intervention programs included both individual and group counselling components, and focused on improving physical, psychological, and social recovery. While 75% to 85% of survivors returned to work after completing these programs, the specific effect of the psychosocial interventions is unclear, given the lack of comparison group in three of the four studies.

Bloom et al. evaluated a psychoeducational intervention among 404 long-term breast cancer survivors (longer than five years) to improve knowledge of breast cancer, its treatment, long-term health concerns, lifestyle habits, and communication with family and physicians (87). Women in the intervention group increased their knowledge and were more likely to be physically active than women in the control group (87).

Screening Uptake

Bloom et al. evaluated the effects of a psychoeducational program of mammography screening uptake among 157 Hodgkin's disease survivors (93). The theoretically based telephone education and counselling intervention showed a positive effect on mammography maintenance. The odds of being in maintenance were greater in the intervention group than the control group (OR = 3.6), and younger women (under 40 years old) were less likely to be in maintenance than older women (over 45 years old) (93).

Strengths and Weaknesses of the Identified Literature

AGREE II Item 9

While synthesizing the body of evidence is challenging given the diversity of studies reviewed, the GRADE (Grading of Recommendations, Assessment, Development, and Evaluation) approach has emerged as a promising system of grading the quality of evidence when developing clinical recommendations (152). As shown in tables 12 and 13, following the GRADE approach for summarizing and assessing the quality of the body of evidence, the majority of the evidence informing the outcomes of interest is of low quality, results are generally inconsistent with data too heterogeneous to pool across studies, there is little high-quality evidence that directly answers the questions of interest for all cancer survivor populations, and an informal assessment of precision indicates that wide confidence intervals would accompany any estimates of effect if data were pooled across studies by outcome of interest.

Table 12. Evidence Summary: Organization and Care Delivery of Survivorship Services

Quality Assessment							Summary of Findings	
Number of Studies	**Design**	**Limitations**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other**	**Quality**	**Importance**
Models of Care								
15	CPG, RCT	Serious	Serious	Serious	Serious	None	Low	Low
Site of Care								
3	RCT	Serious	Serious	Serious	Serious	None	Low	Low
Type of Provider								
13	CPG, RCT	Serious	Serious	Serious	Serious	None	Low	Low
Support Services								
4	CPG	Serious	No Serious Inconsistency	No Serious Indirectness	No Serious Imprecision	None	Low	Low
Structural Approaches								
8	CPG	Serious	No Serious Inconsistency	No Serious Indirectness	No Serious Imprecision	None	Low	Low
Other								
4	CPG	Serious	Serious	Serious	Serious	None	Low	Low

Note: CPG, clinical practice guideline; SR, systematic review; RCT, randomized controlled trial.

Table 13. Evidence Summary: Psychosocial and Supportive Care Interventions

Quality Assessment							Summary of Findings	
Number of Studies	Design	Limitations	Inconsistency	Indirectness	Imprecision	Other	Quality	Importance
Survival/Recurrence								
3	SR, RCT	Serious	Serious	Serious	Serious	None	Low	Critical
Physical Function - Overall Physical Health								
38	RCT	Serious	Serious	No Serious Indirectness [a]	Serious	None	Low	Important
Physical Function – Fatigue								
11	CPG, SR, RCT	Serious	No Serious Inconsistency	No Serious Indirectness	Serious	None	Low	Important
Physical Function - Vasomotor Symptoms								
2	RCT	Serious	No Serious Inconsistency	Serious	No Serious Imprecision	None	Low	Moderate
Physical Function - Sleep Function								
3	RCT	Serious	No Serious Inconsistency	Serious	No Serious Imprecision	None	Low	Moderate
Physical Function - Sexual Function								
3	CPG, RCT	Serious	Serious	No Serious Indirectness [a]	Serious	None	Low	Moderate
Psychosocial Function								
14	CPG, RCT	Serious	Serious	Serious	Serious	None	Low	Important
Quality of Life - Psychoeducational or cognitive behavioural therapy								
12	RCT	Serious	Serious	Serious	Serious	None	Low	Moderate
Quality of Life - Lifestyle Management								
18	RCT	Serious	Serious	Serious	Serious	None	Low	Moderate

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

External Review of the Evidence

Practitioner Feedback

A draft version of this report was reviewed by 36 health care professionals from across Canada who are involved in the psychosocial and supportive care of cancer survivors. Any changes made to the report as a result of feedback from this external review are summarized in the "Modifications" section below.

Methods

Feedback from health care professionals was obtained through an online survey of practitioners from across Canada. External reviewers were initially contacted by email on August 23, 2010; they also received three reminder emails, one on September 9, one on October 4, and one on October 21, 2010. The survey consisted of 20 items

evaluating the reviewer's current professional role and use of cancer survivorship guidelines, the relevance of the recommendations, the methods used to search and synthesize the literature, the results and summary of the recommendations, and how likely the reviewer would be to use the guidelines in his or her practice (Table 14). The Cancer Journey Survivorship Expert Panel reviewed the results of the external review, addressed each comment, and made modifications accordingly.

Results

Of the 45 practitioners approached, 36 responses were returned from health care professionals across Canada, specifically from Alberta (one), British Columbia (nine), Manitoba (two), New Brunswick (two), Nova Scotia (four), Ontario (12), PEI (one), Quebec (three), and Saskatchewan (two). The health care professionals' roles in psychosocial and supportive care of cancer survivors were varied and included administrator (eight), nurse (six), researcher (six), social worker (five), oncologist (four), psychologist (three), spiritual care professional (three), general practitioner (two), family practitioner (one), guideline methodology (one), occupational therapist (one), physiatrist (one), and other (four). In addition, seven of the external review members identified themselves as cancer survivors. Of the respondents, 83.4% and 83.3% (respectively) indicated that they would be likely or very likely to make use of the recommendations on the organization and care delivery structure for cancer survivorship services and on the best practices for psychosocial and supportive care interventions for adult cancer survivors to inform the development of survivorship services in their own organization, practice, or community program. The majority of the respondents (72.2%) indicated that they do not currently follow a guideline on survivorship services for adult cancer survivors. Of those that did, 17.4% reported that they followed a guideline with recommendations for organization and care delivery structure for cancer survivorship services or recommendations on best practices for psychosocial and supportive care interventions for adult cancer survivors. Key results are summarized in Table 14.

Summary of Written Comments

The majority of the health care professionals provided written comments. These are the main points contained in the comments:

- Overall the external review panel felt that the guidelines were well written, concise, and very dense, and that this was a much-needed document. There is great disparity between cancer centres in their ability to offer and deliver survivorship care. A guideline may help to raise awareness and guide organizations toward quality survivorship care.
- Overall, the reviewers were very likely to make use of the recommendations in the organization and structure of services. The recommendations would be very helpful in informing program development.
- The document lacked a section called "Scope and Purpose", as referred to in the AGREE II tool and in the external review questionnaire.
- The wording around "post-treatment" needs to be adjusted to include those survivors still on hormonal therapy and individuals with metastatic disease who may live for many years.

- Due to substantial variations with respect to knowledgeable professionals and resources, implementing a standardized care plan/guideline will be difficult. Identify the specific professionals and roles to enact the care delivery structure, as well as the link between the institutional and community-based system.
- More literature is needed on the issue of underserved populations, such as the poor and the illiterate, and how such guidelines would encompass their socio-economic situation and concerns about support.
- It is important to incorporate living with advanced disease into the survivorship framework, given that we know many may live for years with progressive disease but want to belong to the survivorship program.
- Recommendations around partners in sexual health interventions are based on evidence that is not strong enough to make evidence-based recommendations.
- The guideline could be enhanced with additional recommendations on the system structure needed for effective implementation.
- Reviewers were pleased to see this move forward. They would like to see more rigorous research in this area as there appears to be some weak methodology and low sample sizes. Survivorship support is critical and developing guidelines is very important, and beyond that is the need to get the cancer community and the public aware and supportive.
- Defining survivorship at the point of diagnosis purges the term of substantive meaning, and inhibits strategic use of the survivorship experience in advising necessary interventions. There is a gap between the institutional use of the term, and the experience of patients; in addition, there are significant inconsistencies in the use of the term just within the health care system.

Modifications and Actions

In response to the feedback provided by the 36 health care professionals acting as the external review committee, the following modifications were made.

- A “Scope and Purpose” section was added to the document. This section makes it clear that survivorship starts at the day of diagnosis; however, this was not the focus of the guideline.
- An “Executive Summary” section was also added to the document to summarize the work and the recommendations.
- The wording around “post-treatment” was revised to reflect that it includes survivors still on hormonal therapy and individuals living with advanced disease, since the recommendations were considered to apply to these populations. The wording was changed to “post-primary treatment” and a broader set of populations was identified.
- Cancer centres and cancer agencies differ in their organization and staff positions, and there are varying degrees of ability to implement. Implementing the guideline is critical; however, implementation issues must be addressed at the level of the local health care environment in order to address contextual issues such as availability of resources. Giving specific implementation strategies is beyond the scope of the guideline, but the discussion section states the need to use specific

knowledge translation and implementation approaches to facilitate successful uptake of the recommendations.

- Since the purpose of the guideline was not to identify gaps, the guidelines are now clear that underserved or vulnerable populations were not represented in the literature reviewed. A statement about underserved populations in the research was included in the discussion.
- Qualitative and descriptive studies are relevant sources of information about needs of cancer survivors, but a review of their findings was considered beyond the scope of the guideline. Opinion papers, letters, and editorials represent an individual's thoughts and were not considered valid sources of evidence.
- A statement was included to make it clearer that the recommendations are based on the expert consensus of the group informed by the evidence and clinical expertise.
- Guideline implementation dissemination to advocacy/survivorship groups was included. Two key groups recommended were the Canadian Cancer Action Network and the Canadian Cancer Society.

Table 14. Summary of External Review Survey Results

Survey items # 7-18	Number (%)			
	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]
	Number (%)			
Survey items # 19-20	**Very Likely**	**Likely**	**Somewhat Likely**	**Undecided/ 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)

Note: NA = Not applicable.
a One respondent strongly disagreed with the item.

Discussion

The systematic search of the literature yielded clinical practice guidelines, systematic reviews, and randomized controlled trials to help inform the organization of cancer survivorship services and best practices to optimize the health and well-being of adult cancer survivors. While generally weak, the evidence does identify important themes in the cancer survivorship journey. Furthermore, it is consistent in direction of effect if viewed by thematic approach, such as improving physical or psychosocial outcomes, rather than by specific intervention.

Evidence related to models of care, including the site of care, type of provider, and supportive services, is generally modest; however, it does support the importance of interdisciplinary survivorship care, where members of the cancer treatment team are knowledgeable in the issues facing cancer survivors and skilled in detecting and responding to the distress of individuals, and where survivorship services meet a range of survivor needs, including informational, psychological, emotional, spiritual, physical, and social. Satisfaction was generally higher and other outcomes, such as distress, were generally improved when these conditions were met. Several randomized controlled trials investigated the value of follow-up care through primary care physicians, nurse-led care, survivor-initiated care, or less frequent follow-up at the clinic versus standard specialist follow-up care. Overall, satisfaction with care appeared to be higher with alternate follow-up approaches than with standard care; however, the evidence is not robust and there were no compelling differences in other outcomes to adequately inform the topic of preferred model of care.

In terms of outcomes related to survival or disease recurrence, dietary behavioural modification interventions appear to be effective at improving intake of fruits, vegetables, fibre, and fat, which corresponds to improved body weight and body

composition outcomes. However, if the goal is to improve survival outcomes, the results of such interventions are inconclusive. Although two large breast cancer trials help to inform the discussion, results were inconsistent; a survival difference was detected in one study but not in the other, and the study quality was poor with the results only generalizable to breast cancer survivors.

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

While interventions designed to reduce fatigue through psychosocial or exercise interventions were generally successful at reducing fatigue among cancer survivors, the results pertain primarily to breast cancer survivors, the effect sizes were small to moderate, and the long-term data on the sustainability of the improved outcomes are inconclusive. Two small randomized controlled trials support access to multi-component cognitive behavioural therapy and lifestyle management programs for breast cancer survivors to manage post-menopausal vasomotor symptoms.

In terms of sleep functioning, while there is limited evidence, it is reasonable to conclude that interventions based on cognitive behavioural therapy are more effective than standard care in improving sleep outcomes, and that the effects of the interventions may be sustainable over time - at least up to one year post-treatment.

Sexual functioning was assessed in one practice guideline and in two randomized controlled trials. With improvements in sexual functioning detected in both 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 his or her partner in couple's therapy to promote healthy post-treatment sexual functioning.

While psychosocial functioning is an amorphous outcome that was generally defined as any improvement in psychological, social or spiritual functioning, a series of psychoeducational or cognitive behavioural therapy interventions were conducted to address this important outcome. Even though most of the interventions resulted in meaningful improvements in some aspect of psychosocial functioning, thereby improving aspects of quality of life, the studies did not detect, or were not designed to detect, significant improvements in overall distress. However, based on the data, it seems reasonable to conclude that survivors with identified psychosocial concerns or distress should be referred to psychosocial health services and/or individualized or group-based cognitive behavioural or psychoeducational programs provided by trained professionals to reduce psychosocial distress.

Quality of life is a multidimensional concept that includes physical, social, emotional, and spiritual well-being. It is an outcome that is hard to define despite the numerous surrogate measures used to assess quality of life. Of the measures used, the majority of interventions resulted in improvements in quality of life when compared with standard care, perhaps because any improvements in the cancer survivor's journey will result in improved quality of life. Thus, the evidence indicates that interventions improving important survivor outcomes also increase overall quality of life and must be incorporated into a survivorship care plan.

Overall, the evidence is clearly consistent that cancer survivors benefit from ongoing post-treatment survivorship care through the use of a variety of interventions designed to improve survivor outcomes. Survivors should have access to coordinated interdisciplinary, multicomponent psychosocial and supportive care services during the transition from active treatment to extended survival. While ongoing high-quality research is needed to optimize services for cancer survivors, interventions that promote healthy lifestyle behaviours (including daily physical activity, balanced nutrition, and access to smoking-cessation programs), or those that address psychosocial concerns or distress, appear to improve survivors' physical functioning, psychosocial well-being, and quality of life. Furthermore, research reviewed in this guideline suggests that providing psychosocial and supportive care services need not be limited to specialist cancer care settings. Primary care and/or nurse-led follow-up models may be viable options for delivering psychosocial and supportive care services, particularly in the period of extended survival.

The review of the evidence identified several research implications. Providing optimum survivorship services is dependent on the 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 current research, such as ensuring adequate statistical power is achieved and blinding participants wherever possible. To facilitate the application of empirical findings into real-world clinical settings, future research should also take into consideration the role of various system (e.g., cost-efficiency, continuity of care) and individual outcomes (e.g., specific late effects, distress, social costs) outcomes in the effectiveness of various care delivery approaches and/or psychosocial and supportive care interventions. In addition, this guidance document did not address the underserved cancer survivor populations (i.e., those with literacy issues or living in poor socio-economic conditions). These are vulnerable populations and further evidence is needed to understand their specific needs and support requirements. Furthermore, it is recognized that there are substantial variations in cancer centres across Canada with respect to community resources, capacity for implementation, education, and knowledgeable professionals, which could make it difficult implement standardized cancer survivorship services. Organizations will likely need to tailor the recommendations for effective implementation based on the local contextual health care organizational structure and availability of care delivery. Resources and research should focus on implementation approaches that are most effective in facilitating adoption and uptake of the recommendations in the guideline. The knowledge translation approaches and strategies recommended by the Knowledge Translation Institute of the Canadian Institutes of Health Research will be helpful to organizations in developing a systematic approach to health care and practice change to facilitate uptake of the recommendations (www.cihr-irsc.gc.ca/).

Recommendations AGREE II Items 10,11,12

Organization and Care Delivery Structure of Survivorship Services AGREE II Items 15,16,17

The following recommendations are based on the expert 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 the consideration of the expected health benefits balanced with the potential harms, side effects or risks associated with the guidance offered. Tactics for guideline implementation across various healthcare jurisdictions or health models are offered and can be used as part of auditing or monitoring of 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, unless otherwise stated, recommendations should be considered consensus-based and informed by the evidence.

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 to services to meet a broad range of survivors' physical, psychosocial, supportive, informational, and rehabilitative needs. (Recommendation adapted from the Institute of Medicine's (IOM) consensus recommendation #2).

Tactics

f) 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.

g) Establish outreach programs working in partnership with community groups and assist community providers in providing care that meets a broad range of survivor needs.

h) 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.

i) Develop and maintain an up-to-date database of local resources available to support cancer survivors, their families and caregivers.

j) Provide information about accessing 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

d) All cancer treatment team providers should be knowledgeable in 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.

e) 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.

f) The end-of-treatment consultation should include linking individuals to psychosocial, rehabilitative, or supportive care services, and 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 that includes a standard set of core multidimensional elements tailored to the individual's cancer and treatment experience. (Recommendation adapted from IOM consensus recommendation #2)

Tactics

a) The multidimensional components of the survivorship care plan should include the following core elements and should clearly designate who is accountable for completing the care plan and/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.
- Goal, frequency and timing of follow-up visits as well as designating 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 standards for best practice.

- Guidance on strategies to reduce the risk of recurrence and maximize health and well-being (such as lifestyle changes related to nutrition, physical activity, smoking-cessation, etc.).
- Information about employment, financial and legal issues, and counselling services available in the local community.

b) Cancer care programs or organizations should designate at least one specific member of the interdisciplinary team to ensure completion of the treatment summary and recommendations regarding specific tests for monitoring for disease recurrence; late and long-term consequences based on current guidelines, where available, or best practices based on consensus where specific guidelines are lacking.

c) 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 as 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, with an emphasis on actively engaging and empowering survivors.

Tactics

a) Primary care physicians should be integrated into the oncology follow-up plan for monitoring early detection of cancer recurrence and managing late and long-term consequences of treatment as part of survivorship care.

b) 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.

c) 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,

d) A coordinated referral system should be established to ensure quick referral when a specific need for specialist services or interdisciplinary specialists has been identified.

e) A tiered follow-up care approach or shared-care model between primary care physicians and oncology specialists are advisable for cancer survivors with complex issues and problems to ensure rapid referral back to the specialty centre (high-risk model).

f) As appropriate, cancer survivors and families should be educated on the accessibility and benefits of follow-up care delivered by either their primary care physicians or oncology nurse specialists.

g) 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 survivors be routinely screened for distress using valid tools 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. (Recommendation adapted from IOM consensus recommendation #3, and Psychosocial Health Care Needs Assessment Guideline for Adults, 2009).

Tactics

a) Develop a team to lead the implementation of evidence-based practice change, including representatives from all key stakeholder groups that would be affected by the proposed practice change (e.g., 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.

b) Seek formal commitments from stakeholder organizations, including resources for support strategies (e.g., education sessions, staff involvement), that would further the success and sustainability of implementing the practice change.

c) Ensure that implementation plans reflect a multifocal approach, targeting change at both the individual (e.g., education, audit and feedback) and organizational (e.g., policy and structural changes) levels.

d) Promote the development and evaluation of clinical tools specific to the care of survivors in the post-treatment phase.

e) 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 using approaches recommended for supporting effective self-management, 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 health and well-being.

Tactics

a) Organizations providing care for cancer survivors should provide 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 (e.g., resilience) and family support.

b) 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.

c) 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.

d) 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, preventing and managing late and long-term effects of cancer treatment, and to encourage specific strategies that empower survivors to be actively engaged in self-management and adopt healthy lifestyle behaviours.

Tactics

a) The curriculum should include the need for cancer surveillance, personal impact of cancer, role of nutrition, role of rehabilitation, management of distress, pain and other symptoms.

b) 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.

c) Designated follow-up care providers and family physicians should be knowledgeable and trained in screening for distress and conducting physical assessments, including body weight, waist-to-hip ratio and BMI; physiological assessments; and brief dietary intake assessments.

d) Partnerships should be formed with survivorship organizations to provide ongoing professional development and skill acquisition for assessing and managing specific survivorship issues.

e) Technology-based resources (e.g., 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, policy-makers, and employers) of the physical, emotional, spiritual, social, return-to-work, and rehabilitative needs post-cancer treatment, and any variations depending on cancer type, treatment, individual and support systems (economic support, family, and rehabilitation).

Tactics

a) Engage organizations to develop public service announcements to inform the public of the gains being made in survivor rates.

b) Assist survivor organizations in funding public platforms to share survivor stories.

c) Keep survivor-driven organizations aware and informed of the latest evidence of 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

a) Create interdisciplinary teams of clinicians and researchers, which would include primary care, oncology, nursing, allied health, and health services researchers.

b) Use and expand existing research mechanisms and groups (such as the National Cancer Institute's clinical trials groups, and cancer and population-based registries), and develop new focused research consortiums.

c) Develop comprehensive electronic databases to collect, summarize, analyze and store clinical data and 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, emotional, and social domains to monitor the quality of survivorship services, and demonstrate improvement for a comprehensive range of survivor outcomes, and accelerate quality improvement practices and programs based on these data.

Tactics

a) Cancer control and/or provincial organizations 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.

b) 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.

c) 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 and human rights) be enacted to meet the diverse needs of cancer survivors and allow for full survivor access to, and participation in, employment, education and health and community services. (Recommendation adapted from IOM Recommendation #8)

Tactics

a) 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[AGREE II Items 15,16,17]

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 physiological outcomes, reduce distress and risk of recurrence.

Tactics

a) Exercise, dietary, or 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.

b) Advise cancer survivors to gradually increase physical activity intensity, as tolerated, for a minimum goal of 30 minutes of exercise a day for five days a week if possible.

c) Advise cancer survivors to integrate a combination of aerobic exercises (e.g., leisure sports, jogging, exercise classes, bike riding), strength training (e.g., resistance training with weights, bands or body weight), flexibility training (e.g., stretching, yoga, Pilates), as appropriate.

d) Refer cancer survivors to the Canada Food Guide for recommendations for a healthy diet, considering special needs related to cancer diagnosis and treatment (e.g., ostomy management, swallowing difficulties, drug interactions).

e) Consider referring cancer survivors to a registered exercise professional and registered dietitians to facilitate the 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

a) 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 health services, individualized or group-based cognitive behavioural or psychoeducational programs provided by trained professionals.

Tactics

a) 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 (i.e., cancer- related fatigue or psychosocial distress).
- Incorporate multiple components such as education, problem solving, stress management, coping skill training and psychosocial 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 physiological and psychosocial symptoms, including pain and fatigue, and late and long-term effects, such as 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

a) Standardized screening and assessment protocols for early identification of late and long term effects should be adopted for use in all cancer programs.

b) 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.

c) 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 Regarding 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 couple's therapy for both the cancer survivor and his or her partner, and sexual rehabilitation programs to promote healthy post-treatment sexual health and maximize function.

Tactics

a) All health care providers should be trained to assess sexual health concerns using structured assessment processes supported by models (e.g., BETTER or PLISSIT [Reference 153,154]) to ensure systematic assessment and appropriate referrals to specialists.

b) All health care providers should be trained to provide education and support regarding changes in sexual health and offer appropriate referrals to specialists when necessary.

c) Management of survivors' concerns regarding sexual health and sexual function should also include an assessment of possible causal factors to determine whether other targeted interventions (e.g., counselling, medical management) are also required.

d) Early intervention is critical, particularly in populations with prostate or gynaecological cancers, where 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/or multi-component cognitive behavioural therapy to manage post-treatment fatigue.

Tactics

a) Psychoeducational interventions and/or 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 psychosocial counselling.

b) Exercise programs targeted to alleviating fatigue should promote a range of physical activity options, including cardiovascular, flexibility and/or strength training, as appropriate.

c) Management of post-treatment fatigue should also include an assessment of possible causal factors to determine whether other targeted interventions (e.g., medical management) are additionally required such as specific interventions for sleep disturbances or depression.

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 is also important for other cancer survivors, such as those with prostate cancer, where hormonal deprivation therapies may lead to significant physical and emotional effects.

Tactics

a) Psychosocial and supportive care programs to manage post-menopausal vasomotor symptoms should consider using education, counselling and/or hypnosis-based approaches to alleviate symptoms.

b) Management of vasomotor symptoms should include an assessment of possible causal factors to determine whether other targeted interventions (e.g., medical management) are also required.

c) A trial of pharmacological 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

a) 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.

b) Management of disruptions in sleep-wake patterns should include an assessment of possible causal factors to determine whether other targeted interventions (e.g., counselling, medical management) or specialist medical interventions for insomnia disorders are also required.

Guideline Implementation AGREE II Items 18,19,20,21

Cancer survivors are a growing population in Canada. The purpose of this pan-Canadian guidance document is to inform key Canadian health authorities, administrative and policy decision-makers, and health practitioners of the needs of this population and how to best organize survivorship services to meet these needs. Furthermore, this guidance document will help raise awareness of survivorship issues and the needs of this population in the post-treatment phase, which will guide organizations in evaluating their programs and services and improving the quality of survivorship care. In addition, cancer survivors need access to the best care practices to optimize their psychosocial health and well-being and to facilitate decision-making on the services that should be accessible to them.

This guidance report represents the first pan-Canadian effort in this area, and there will no doubt be challenges in applying the recommended guidance across Canada. Obvious barriers to application include increasing the awareness of survivorship issues and fostering understanding with the commitment and coordination of effort needed to change practice and policy in a variety of settings. Cancer survivors may not be aware of survivorship services and increasing their exposure to these services will be important. The first step, however, was to create the high-quality guideline, consistent with the survivorship literature, needed to inform the best practices related to survivorship care. By producing a pan-Canadian guideline using rigorous systematic review methodology with a credible guideline development panel, the “buy-in” required to implement change across a variety of jurisdictions should be less of a barrier. The guideline also provides tactics for implementing the guideline recommendations. As part of the next steps, practice protocols for professionals, patient versions, and workshops with key health providers across a variety of jurisdictions are being planned to promote the uptake of the guideline across Canada. The guideline will also be translated into French, and a formal communications plan will be developed to maximize dissemination of the guideline.

Another key consideration is the strategic composition of the inter-professional panel members enabling dissemination and implementation in their respective jurisdictions. Partnering with the Canadian Association of Psychosocial Oncology will also ensure greater exposure and guideline implementation. The guideline will be posted on the Internet on the websites of the Canadian Partnership Against Cancer (Cancer Journey Advisory Group) and the Canadian Association of Psychosocial Oncology, and will also be published in a peer-reviewed journal. Furthermore, this guidance document will be disseminated through cancer advocacy survivorship groups, including the Canadian Cancer Action Network and the Canadian Cancer Society. In addition, a summary of the guideline will act as an implementation tool, which will be distributed widely.

There was no evidence identified that provided insight on the potential resource implications of applying the recommendations, and it is well known that resources can vary widely across Canadian health jurisdictions. While the resources needed to implement the recommendations are unknown, the resources consumed to offer current survivorship services should also be to considered. It is intuitive that improving the health and well-being of cancer survivors is an investment worth making and may even lead to cost reductions and improve efficiencies in care (e.g., avoiding costly hospital admissions). The guideline recommendations were developed to be

implemented in a variety of health settings, and criteria to monitor or audit the organization of care or clinical practice are clearly defined throughout the document. In many cases, either the services are offered or they are not, and that will be the initial criteria to assess services. As the reorganization of survivorship care takes hold, program evaluation will be a very valuable component optimizing survivorship care for cancer survivors.

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Appendix I: Key Terms

Disease-free survival: This is the length of time after treatment for a specific disease during which a patient survives with no sign of the disease.[1] However, it is recognized that being clinically disease-free does not mean being free of the disease from a survivor's perspective.[2]

Distress: Distress is a multifactorial, unpleasant emotional experience of a psychological (cognitive, behavioural, or emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fear to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis.[3]

Psychosocial and supportive care services: Psychosocial services are psychological, social, and spiritual care services and interventions that enable patients, their families and health care providers to optimize biomedical health and manage the psychological, emotional, social, and spiritual, quality-of-life, and functional aspects of illness and its consequences in order to promote better health.[4,5] Supportive care is closely related to psychosocial oncology and involves preventing and managing the adverse physical and psychological effects of cancer and its treatment[6] with attention to informational, physical, psychological, emotional, spiritual, social, and practical needs.[7]

Survivor: According to the National Cancer Institute, an individual is considered a cancer survivor from the time of 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.[8]

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Survivorship: Survivorship, in the context of cancer, describes the period of time in which a person remains alive following a cancer diagnosis. The phase of survivorship beginning at diagnosis, called acute survival,[9] is not addressed in this document. This guideline focuses on the phases 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, and adjusting to the "new normal" of life beyond cancer).[9]

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Appendix II: Search Strategy of the Published Literature for Organization and Care Delivery Structure of Survivorship Services

Database	Search Strategy	Results
MEDLINE	1 exp neoplasms/ 2 oncologic nursing/ 3 oncology services, hospital/ 4 cancer care facilities/ 5 exp medical oncology/ 6 or/1-5 7 survivors/ 8 disease-free survival/ 9 survivor:.mp. 10 or/7-9 11 6 and 10 12 Program Development/ 13 Program Evaluation/ 14 Patient Care Planning/ 15 exp Patient Care Management/ 16 Aftercare/ 17 "Health Services Needs and Demand"/ 18 Health Planning Guidelines/ 19 exp Health Services Research/ 20 exp "Delivery of Health Care"/ 21 models, organizational/ 22 Benchmarking/ 23 Cooperative Behavior/ 24 exp Patient Care Team/ 25 "Continuity of Patient Care"/ 26 Case Management/ 27 Community Health Planning/og, st, td, mt [Organization & Administration, Standards, Trends, Methods] 28 exp Professional-Patient Relations/ 29 exp Interprofessional Relations/ 30 Patient-Centered Care/ 31 Patient Discharge/ 32 Professional-Family Relations/ 33 Population surveillance/ 34 (continuity adj2 care).ti,ab. 35 (continuum adj2 care).ti,ab. 36 (discharg: adj2 (plan: or patient or hospital)).ti,ab. 37 (shared adj (care or service: or notes)).ti,ab. 38 case management.ti,ab. 39 liaison nurse:.ti,ab. 40 (collaborative adj (practice or care)).ti,ab. 41 "nurse-led follow-up".ti,ab. 42 "telephone follow up".ti,ab. 43 (well: adj2 follow up).ti,ab. 44 (interdisciplinary adj (care or team:)).ti,ab. 45 "service integration".ti,ab. 46 "integrated care".ti,ab. 47 "multi agency working".ti,ab. 48 "seamless care".ti,ab. 49 "inter agency working".ti,ab.	850

Database	Search Strategy	Results
	50 "multi professional working".ti,ab. 51 "interprofessional working".ti,ab. 52 "care management".ti,ab. 53 "care plan:".ti,ab. 54 (model: adj care).ti,ab. 55 Patient Education as Topic/ 56 Family Practice/ 57 Health Status/ 58 models, nursing/ 59 Nurse's Role/ 60 Patient Satisfaction/ 61 exp Primary Health Care/ 62 Health Promotion/ 63 Community Health Services/ 64 "Outcome Assessment (Health Care)"/ 65 Quality Assurance, Health Care/ 66 exp "Patient Acceptance of Health Care"/ (67 Documentation/ 68 or/12-67 69 68 and 11 70 exp case-control studies/ or exp cohort studies/ 71 Cross-Sectional Studies/ 72 randomized controlled trial.pt. 73 Randomized controlled trial/ 74 Randomized Controlled Trials as Topic/ 75 clinical trial.pt. 76 Double-Blind Method/ 77 "double blind:".mp. 78 Placebos/ 79 placebo:.mp. 80 random:.mp. 81 Feasibility Studies/ 82 (systematic adj review:).mp. 83 or/70-82 84 69 and 83 85 limit 84 to "all child (0 to 18 years)" 86 84 not 85 (989) 87 limit 86 to (english language and yr="1999 -Current")	
Embase	1 exp neoplasm/ 2 oncology nursing/ or exp oncology/ or exp oncology ward/ 3 cancer center/ 4 or/1-3 5 program development/ 6 health care quality/ 7 patient care planning/ or patient care/ 8 health services research/ 9 health care delivery/ 10 health care organization/ 11 exp cooperation/ 12 human relation/ or doctor nurse relation/ or nurse patient relationship/ 13 patient education/ 14 nursing theory/ 15 nursing role/ 16 patient satisfaction/	208

Database	Search Strategy	Results
	17 quality control/ 18 or/5-17 19 4 and 18 20 cancer survivor/ or survivor/ 21 survivor:.ti,ab. 22 20 or 21 23 19 and 22 (542) 24 limit 23 to (english language and yr="1999 -Current") 25 19 and 20 26 limit 25 to (english language and yr="1999 -Current") 27 from 26 keep 1-208	
PsycINFO	1 exp neoplasms/ 2 (tumor: or tumour: or malignanc: or sarcoma: or carcinoma: or cancer:).mp. 3 oncology/ 4 oncolog:.mp. 5 or/1-4 6 survivors/ 7 surviv:.mp. 8 disease-free.mp. 9 or/6-8 10 5 and 9 11 program development/ or exp program evaluation/ 12 exp health care services/ 13 exp teams/ 14 exp Organizational Structure/ 15 (organizational adj model:).mp. 16 exp case management/ or exp health care administration/ or health service needs/ or exp treatment planning/ 17 exp health care delivery/ 18 exp Health Service Needs/ 19 "continuum of care"/ or aftercare/ or "quality of care"/ 20 (collaborative adj (practice: or team:)).mp. 21 (well: adj follow-up).mp. 22 telephone follow-up.mp. 23 nurse-led follow-up.mp. 24 (interdisciplinary adj (care: or team:)).mp. 25 multi-agency.mp. 26 multi-professional:.mp. 27 interprofessional:.mp. 28 inter-professional:.mp. 29 (model: adj2 care:).mp. 30 care plan:.mp. 31 client education/ 32 exp Family Physicians/ or exp Family Medicine/ or exp Primary Health Care/ 33 (nurs: adj model:).mp. 34 exp "quality of services"/ 35 client attitudes/ 36 or/11-35 37 10 and 36 38 limit 37 to (all journals and english language and yr="1999 -Current") 39 limit 38 to ("0400 empirical study" or "0430 followup study" or "0450 longitudinal study" or "0451 prospective study" or "0452 retrospective study" or "0830 systematic review" or 1200 meta analysis or 1800 quantitative study)	184

Database	Search Strategy	Results
	40 from 39 keep 1-184 (184)	
CINHAL	1. (MH "Neoplasms+") 2. (MH "Cancer Patients") 3. (MH "Oncology+") 4. (MH "Cancer Care Facilities") 5. (MH "Oncology Care Units") or (MH "Oncologic Care") or (MH "Oncologic Nursing+") or (MH "Radiation Oncology Nursing") 6. S1 or S2 or S3 or S4 or S5 7. (MH "Cancer Survivors") 8. MH "Survival") 9. TX survivor* 10. S7 or S8 or S9 11. S6 and S10 12. (MH "Program Development+") 13. (MH "Patient Care Plans") or (MH "Patient Centered Care") or (MH "Continuity of Patient Care") 14. (MH "After Care") 15. (MH "Health Services Needs and Demand+") 16. (MH "Health Services Research+") 17. (MH "Health Care Delivery+") 18. (MH "Organizational Theory") 19. (MH "Benchmarking") or (MH "Process Assessment (Health Care)+") 20. (MH "Cooperative Behavior") 21. (MH "Multidisciplinary Care Team+") 22. (MH "Case Management") 23. (MH "Professional-Patient Relations+") 24. (MH "Interprofessional Relations+") 25. (MH "Patient Discharge+") or (MH "Early Patient Discharge") or (MH "Patient Discharge Education") 26. (MH "Professional-Family Relations") 27. (MH "Disease Surveillance") 28. TX continuity N2 care 29. TX continuum N2 care 30. TX discharg* N2 plan* 31. TX discharg* N2 patient* 32. TX discharg* N2 hospital 33. TX shared N2 care* 34. TX shared N2 service* 35. TX shared N2 notes 36. TX case management 37. TX liaison nurse* 38. TX collaborative N1 practice 39. TX collaborative N1 care 40. TX "nurse-led follow up" 41. TX "telephone follow up 42. TX well* N2 follow up 43. TX interdisciplinary N1 care 44. TX interdisciplinary N1 team* 45. TX service integration 46. TX integrated care 47. TX seamless care 48. TX multi agency working 49. TX inter-agency working 50. TX multi professional working 51. TX interprofessional working 52. TX care management	264

Database	Search Strategy	Results
	53. TX model* N1 care 54. TX care plan 55. (MH "Patient Education+") 56. (MH "Family Practice") 57. (MH "Health Status+") 58. (MH "Nursing Models, Theoretical") 59. (MH "Nursing Role") 60. (MH "Patient Satisfaction") 61. (MH "Primary Health Care") 62. (MH "Health Promotion") 63. (MH "Community Health Services") 64. (MH "Outcome Assessment") 65. (MH "Quality Assurance+") 66. (MH "Documentation+") 67. or /S12-S66 68. S11 and S67 69. (MH "Case Control Studies+") 70. (MH "Cross Sectional Studies") 71. MH "Prospective Studies+") 72. (MH "Multicenter Studies") 73. (MH "Pilot Studies") 74. S69 or S70 or S71 or S72 or S73 75. S68 and S74(Limiters - Publication Year from: 1999-2010; Age Groups: All Adult)	
Cochrane Database of Systematic Reviews	1 (neoplasm: or tumor: or tumour: or malignanc: or sarcoma: or cancer: or carcinoma:).mp.) 2 (oncolog: adj nursing).mp. 3 (oncolog: adj service:).mp. 4 cancer care facilit:.mp. 5 ((medical or radiation) adj oncology).mp. 6 or/1-5 7 disease-free survival.mp. 8 survivor:.mp. 9 or/7-8 10 6 and 9 11 Program Development.mp. 12 Program Evaluation.mp. 13 Patient Care Plan:.mp. 14 Patient Care Management.mp. 15 Aftercare.mp 16 "Health Services Needs and Demand".mp. 17 Health Planning Guidelines.mp. 18 Health Services Research.mp. 19 "Delivery of Health Care".mp. 20 (organizational adj model:).mp. 21 Benchmarking.mp. 22 Cooperative Behavior.mp. 23 Patient Care Team:.mp. 24 "Continuity of Patient Care".mp. 25 Case Management.mp. 26 Community Health Plan:.mp. 27 (Professional adj Patient adj Relation:) .mp. 28 Interprofessional Relation:.mp. 29 Patient-Centered Care:.mp. 30 Patient Discharg:.mp.	79

Database	Search Strategy	Results
	31 (Professional adj Family adj Relation:).mp. 32 Population surveillance:.mp. 33 (continuity adj2 care).ti,ab. 34 (continuum adj2 care).ti,ab. 35 (discharg: adj2 (plan: or patient or hospital)).ti,ab. 36 (shared adj (care or service: or notes)).ti,ab 37 case management.ti,ab. 38 liaison nurse:.ti,ab. 39 (collaborative adj (practice or care)). ti,ab. 40 "nurse-led follow-up".ti,ab. 41 "telephone follow up".ti,ab. 42 (well: adj2 follow up).ti,ab. 43 interdisciplinary adj (care or team:)) .ti,ab. 44 "service integration".ti,ab. 45 "integrated care".ti,ab. 46 multi-agency.ti,ab. 47 "seamless care".ti,ab. 48 inter agency.mp. or interagency.ti,ab. 49 multi professional.ti,ab. 50 (interprofessional or inter-professional).ti,ab. 51 "care management".ti,ab. 52 "care plan:".ti,ab. 53 (model: adj care).ti,ab. 54 Patient Education.mp. 55 family practice:.mp. 56 health status:.mp. 57 (nursing adj model:).mp. 58 (nurs: adj role:).mp. 59 patient satisfaction:.mp. 60 primary health care.mp. 61 health promotion:.mp. 62 community health service:.mp. 63 outcome assessment:.mp. 64 quality assurance:.mp. 65 documentation:.mp. 66 or/11-65 67 10 and 66	
Cochrane Clinical Trials Register	1 exp Neoplasms/ 2 exp neoplasms/ 3 oncologic nursing/ 4 oncology services, hospital/ 5 cancer care facilities/ 6 exp medical oncology/ 7 or/2-6 8 survivors/ 9 disease-free survival/ 10 survivor:.mp. 11 or/8-10 12 7 and 11 13 Program Development/ 14 Program Evaluation/ 15 Patient Care Planning/ 16 exp Patient Care Management/ 17 Aftercare/ 18 "Health Services Needs and Demand"/	167

Database	Search Strategy	Results
	19 Health Planning Guidelines/ 20 exp Health Services Research/ 21 exp "Delivery of Health Care"/ 22 models, organizational/ 23 Benchmarking/ 24 Cooperative Behavior/ 25 exp Patient Care Team/ 26 "Continuity of Patient Care"/ 27 Case Management/ 28 Community Health Planning/og, st, td, mt [Organization & Administration, Standards, Trends, Methods] 29 exp Professional-Patient Relations/ 30 exp Interprofessional Relations/ 31 Patient-Centered Care/ 32 Patient Discharge/ 33 Professional-Family Relations/ 34 Population surveillance/ 35 (continuity adj2 care).ti,ab. 36 (continuum adj2 care).ti,ab. 37 (discharg: adj2 (plan: or patient or hospital)).ti,ab. 38 (shared adj (care or service: or notes)). i,ab. 39 case management.ti,ab. 40 liaison nurse:.ti,ab. 41 (collaborative adj (practice or care)). i,ab. 42 "nurse-led follow-up".ti,ab. 43 "telephone follow up".ti,ab. 44 (well: adj2 follow up).ti,ab. 45 (interdisciplinary adj (care or team:)).ti,ab. 46 "service integration".ti,ab. 47 "integrated care".ti,ab. 48 "seamless care".ti,ab. 49 "care management".ti,ab. 50 "care plan:".ti,ab. 51 (model: adj care).ti,ab. 52 Patient Education as Topic/ 53 Family Practice/ 54 Health Status/ 55 models, nursing/ 56 Nurse's Role/ 57 Patient Satisfaction/ 58 exp Primary Health Care/ 59 Health Promotion/ 60 Community Health Services/ 61 "Outcome Assessment (Health Care)"/ 62 Quality Assurance, Health Care/ 63 exp "Patient Acceptance of Health Care"/ 64 Documentation/ 65 multi-agenc:.ti,ab. 66 inter-agenc:.ti,ab. 67 interprofessional:.ti,ab. 68 inter-professional:.ti,ab. 69 or/13-68 70 12 and 69 71 limit 70 to yr="1999 -Current"	
	Total	1752

Appendix III: Search Strategy of the Published Literature of Psychosocial and Supportive Care Interventions for Cancer Survivors

Database	Search Strategy	Results
MEDLINE	1 exp neoplasms/ 2 oncologic nursing/ 3 oncology services, hospital/ 4 cancer care facilities/ 5 exp medical oncology/ 6 or/1-5 7 survivors/ 8 disease-free survival/ 9 survivor:.mp. 10 or/7-9 11 6 and 10 12 Rehabilitation/ or Rehab$ program$.mp. 13 Self care support program$.mp. or Self Care/ 14 Self management program$.mp. 15 Self management training.mp. 16 Self-help group$.mp. or self-help groups/ 17 Self help group$.mp. 18 Selfhelp group$.mp. 19 Social support/ or Social support intervention$.mp. 20 Support group$.mp. 21 group support.mp. 22 group therapy.mp. or psychotherapy, Group/ 23 group coping.mp. 24 exp Counseling/ 25 Counsel?ing.mp. 26 Psychotherapy.mp. or exp Psychotherapy/ 27 psychosocial therapy.mp. 28 psychological intervention$.mp. 29 psychosocial intervention$.mp. 30 psychological support.mp 31 psychosocial support.mp. 32 Relaxation techniques/ or relaxation training.mp 33 patient education.mp. or patient education as Topic/ 34 educational interventio$.mp. 35 educational therapy.mp. 36 Cognitive therapy.mp. or Cognitive Therapy/ 37 cognitive psychotherapy.mp. 38 cognitive behavio?r therapy.mp. 39 behavio?r therapy.mp. or behavior therapy/ 40 Social work.mp. or Social Work/ 41 Adaptation, Psychological/ 42 social support/ 43 Social Environment/ 44 Community Networks/ 45 Self-Help Groups/ 46 exp Psychotherapy, Group/ 47 "Quality of Life"/px [Psychology] 48 Counseling/ 49 Social Isolation/ 50 "cost of illness"/	243

Database	Search Strategy	Results
	51 self concept/ or "self assessment (psychology)"/ 52 ((best adj3 support$) or (optim$ adj3 support$) or (support$ adj3 care$) or (support$ adj3 caring) or (supportive adj3 treatment$)).mp. 53 or/12-52 54 11 and 53 55 randomized controlled trial.pt. 56 Randomized controlled trial/ 57 Randomized Controlled Trials as Topic/ 58 clinical trial.pt. 59 Double-Blind Method/ 60 "double blind:".mp. 61 Placebos/ 62 placebo:.mp. 63 random:.mp. 64 Meta-Analysis/ 65 meta-analysis.pt. 66 meta-anal:.mp. 67 metaanal:.mp. 68 quantitativ: review:.mp. 69 quantitativ: overview:.mp. 70 systematic: review:.mp. 71 systematic: overview:.mp. 72 methodolog: review:.mp. 73 methodolog: overview:.mp. 74 review.pt. and (medline or pubmed or grateful med).mp. 75 or/55-74 76 75 and 54 77 limit 76 to "all child (0 to 18 years)" 78 76 not 77 79 limit 78 to (english language and yr="1999 -Current")	
Embase	1 exp neoplasm/ 2 oncology nursing/ or exp oncology/ or exp oncology ward/ 3 cancer center/ 4 or/1-3 5 cancer survivor/ or survivor/ 6 survivor:.ti,ab. 7 5 or 6 8 4 and 7 9 self help/ 10 social support/ 11 group therapy/ 12 exp counseling/ 13 "psychological and psychosocial phenomena"/ 14 psychosocial adjustment to illness scale/ 15 psychosocial care/ 16 exp psychosocial disorder/ 17 psychosocial environment/ 18 psychosocial rehabilitation/ 19 psychosocial withdrawal/ 20 cognitive therapy/ 21 social work/ 22 ((best adj3 support$) or (optim$ adj3 support$) or (support$ adj3 care$) or (support$ adj3 caring) or (supportive adj3 treatment$)).mp. 23 or/10-22 24 8 and 23	43

Database	Search Strategy	Results
	25 limit 24 to (english language and yr="1999 -Current") 26 limit 25 to (embryo <first trimester> or infant <to one year> or child <unspecified age> or preschool child <1 to 6 years> or school child <7 to 12 years> or adolescent <13 to 17 years>) 27 25 not 26 28 from 27 keep 1-425 29 randomized controlled trial/ 30 meta analysis/ 31 (systematic adj review:).mp. 32 or/29-31 33 28 and 32	
PsycINFO	1 exp neoplasms/ 2 survivors/ 3 survivor:.mp. 4 or/2-3 5 1 and 4 6 Rehabilitation/ or Rehab$ program$.mp. 7 Self care support program$.mp. 8 self care/ 9 Self management program$.mp. 10 self management training.mp. 11 Self-help group$.mp. 12 Self help group$.mp. 13 selfhelp group$.mp. 14 Social support intervention$.mp. 15 Social support/ 16 Support group$.mp. 17 group support.mp. 18 group therapy.mp. 19 group coping.mp. 20 exp Counseling/ 21 Counsel?ing.mp. 22 Psychotherapy.mp. 23 psychosocial therapy.mp. 24 exp Psychotherapy/ 25 psychological intervention$.mp. 26 psychosocial intervention$.mp. 27 psychological support.mp. 28 psychosocial support.mp. 29 relaxation training.mp. 30 patient education.mp. 31 patient education/ 32 educational interventio$.mp. 33 educational therapy.mp. 34 Cognitive therapy.mp. 35 cognitive psychotherapy.mp. 36 Cognitive Therapy/ 37 cognitive behavio?r therapy.mp. 38 behavio?r therapy.mp. 39 behavior therapy/ 40 Social work.mp. 41 Social Work/ 42 social support/ 43 Social Environment/ 44 Social Isolation/	327

Database	Search Strategy	Results
	45 self concept/ 46 ((best adj3 support$) or (optim$ adj3 support$) or (support$ adj3 care$) or (support$ adj3 caring) or (supportive adj3 treatment$)).mp. 47 support groups/ 48 support groups/ or exp group psychotherapy/ 49 relaxation/ or exp relaxation therapy/ 50 exp "quality of life"/ or well being/ 51 or/6-50 52 5 and 51 53 limit 52 to (all journals and english language and yr="1999 -Current") 54 limit 53 to ("0200 clinical case study" or "0400 empirical study" or "0430 followup study" or "0450 longitudinal study" or "0451 prospective study" or "0452 retrospective study" or "0830 systematic review" or 1200 meta analysis or 1800 quantitative study or "2000 treatment outcome/randomized clinical trial") 55 limit 54 to (100 childhood <birth to age 12 yrs> or 120 neonatal <birth to age 1 mo> or 140 infancy <age 2 to 23 mo> or 160 preschool age <age 2 to 5 yrs> or 180 school age <age 6 to 12 yrs> or 200 adolescence <age 13 to 17 yrs>) 56 54 not 55	
CINAHL	1. (MH "Neoplasms+") 2. (MH "Oncology+") 3. (MH "Oncologic Nursing+") 4. (MH "Oncology Care Units") or (MH "Oncologic Care") 5. (MH "Cancer Care Facilities") 6. S1 or S2 or S3 or S4 or S5 7. (MH "Cancer Survivors") 8. TX survivor* 9. S7 or S8 10. S6 and S9 11. (MH "Support Groups") 12. (MH "Rehabilitation, Psychosocial+") 13. (MH "Psychotherapy+") 14. (MH "Spiritual Care") 15. (MH "Psychosocial Aspects of Illness+") 16. (MH "Social Networks") 17. (MH "Adaptation, Psychological+") 18. (MH "Social Adjustment") 19. (MH "Coping+") 20. (MH "Stress+") 21. (MH "Psychosocial Adjustment to Illness Scale") 22. (MH "Quality of Life+/PF") 23. (MH "Self Concept+") 24. TX best N3 support* 25. TX optimum* N3 support* 26. TX support* N3 care* 27. TX support* N3 caring 28. TX supportive N3 treatment 29. or/S11-S28 30. S10 and S29 (Limiters - Research Article; Peer Reviewed; Publication Year from: 1999-2010; English)	464
Cochrane Database of Systematic Reviews	1 survivor:.mp. (350) 2 (cancer: or tumor: or tumour: or sarcoma: or carcinoma: or malignanc: or neoplasm: or oncolog:).mp. (1646) 3 1 and 2 (92)	92
Cochrane	1 exp neoplasms/	133

Database	Search Strategy	Results
Central Register of Controlled Trials	2 oncologic nursing/ 3 oncology services, hospital/ 4 cancer care facilities/ 5 exp medical oncology/ 6 or/1-5 7 survivors/ 8 disease-free survival/ 9 survivor:.mp. 10 or/7-9 11 6 and 10 12 Rehabilitation/ or Rehab$ program$.mp. 13 Self care support program$.mp. or Self Care/ 14 Self management program$.mp. 15 self management training.mp. 16 Self-help group$.mp. or self-help groups/ 17 Self help group$.mp. 18 selfhelp group$.mp. 19 Social support/ or Social support intervention$.mp. 20 Support group$.mp. 21 group support.mp. 22 group therapy.mp. or psychotherapy, Group/ 23 group coping.mp. 24 exp Counseling/ 25 Counsel?ing.mp. 26 Psychotherapy.mp. or exp Psychotherapy/ 27 psychosocial therapy.mp. 28 psychological intervention$.mp. 29 psychosocial intervention$.mp. 30 psychological support.mp. 31 psychosocial support.mp. 32 Relaxation techniques/ or relaxation training.mp. 33 patient education.mp. or patient education as Topic/ 34 educational interventio$.mp. 35 educational therapy.mp. 36 Cognitive therapy.mp. or Cognitive Therapy/ 37 cognitive psychotherapy.mp. 38 cognitive behavio?r therapy.mp. 39 behavio?r therapy.mp. or behavior therapy/ 40 Social work.mp. or Social Work/ 41 Adaptation, Psychological/ 42 social support/ 43 Social Environment/ 44 Community Networks/ 45 Self-Help Groups/ 46 exp Psychotherapy, Group/ 47 "Quality of Life"/px [Psychology] 48 Social Isolation/ 49 "cost of illness"/ 50 self concept/ or "self assessment (psychology)"/ 51 ((best adj3 support$) or (optim$ adj3 support$) or (support$ adj3 care$) or (support$ adj3 caring) or (supportive adj3 treatment$)).mp. 52 or/12-51 53 11 and 52 54 limit 53 to yr="1999 -Current" (133)	
	Total	1302

Appendix IV: Matrix of Recommendations from Guidelines

Models of Care

Author Year (Reference)	Models of Care
ASPO 2009 (52)	The Institute of Medicine documented several models for providing survivor follow-up care; however the research base and empirical evidence are insufficient to draw broad conclusions on best practices or optimal models. Survivorship clinics and shared care models of follow-up care (i.e., both the oncologist and the primary care physician care for the patient) may make intuitive sense, but the relative effectiveness of each model has not been evaluated.
ACCC 2009 (53)	Each health-care discipline is available on staff or by consult to facilitate continuity of care for rehabilitation services. Outsourced services should be performed by properly credentialed individuals whose performance is reviewed annually.
DACCC 2007 (55)	At the beginning of the follow-up period, the goal, frequency, and duration of follow-up visits should be determined, as well as who will conduct the follow-up (e.g., urologist, radiation oncologist, others).
ASCO 2006 (57)	Continuity of care for breast cancer patients is encouraged and should be performed by a physician experienced in the surveillance of cancer patients and in breast examination, including the examination of irradiated breasts. If follow-up is transferred to a primary care physician, the physician and the patient should be informed of the long-term options regarding adjuvant hormonal therapy for the particular patient. This may necessitate referral for oncology assessment at an interval consistent with guidelines for adjuvant hormonal therapy.
CBCI 2005 (61)	The responsibility for follow-up should be formally allocated to a single physician. Communication between all members of the team must be ensured to avoid duplication of visits and tests.

Notes: ASPO = American Society of Preventive Oncology; ACCC = Association of Community Cancer Centers; DACCC = Dutch Association of Comprehensive Cancer Centres; ASCO = American Society of Clinical Oncology; CBCI = Canadian Breast Cancer Initiative.

Type of Provider

Author Year (Reference)	Type of Provider
ASPO 2009 (52)	It is important to collect data on health-related outcomes and costs associated with the delivery of cancer survivorship care by various healthcare providers, including 1) advanced practice clinicians (e.g., nurse practitioners, physician assistants), 2) primary care physicians with additional training in oncology, and 3) oncologists who specialize in primary care.
ACCC 2009 (53)	*Section 9: Rehabilitation Services* Comprehensive rehabilitation services are available to cancer patients and their families through the entire cancer care continuum from diagnosis to survivorship. A. Rehabilitation includes, but is not limited to: patient and family; attending physicians; oncology nursing services; psychosocial services; nutritional support services; pharmacy services; spiritual care services; physical, occupational, and recreational therapy services; speech pathology services; comprehensive, multidisciplinary lymphedema services; enterostomal therapy services; discharge planning services to address home care, community, and/or extended care facility services and needs; qualified volunteer services to provide support and advocacy for cancer patients and their families; other complementary services, such as music/art therapy, relaxation, massage, and others that may be used in conjunction with rehabilitation disciplines.

Author Year (Reference)	Type of Provider
DACCC 2007 (55)	Follow-up may involve various disciplines, such as oncology nurses, urology nurses, radiotherapy nurses, dietitians, physiotherapists, psychologists, and sexologists, depending on the specific problems, symptoms, and needs of the individual patient. If the prostate-specific antigen (PSA) level is stable (or increasing only very slightly), a general practitioner and/or specialized nurse may be asked to perform the annual PSA assessment after the PSA nadir has been reached.
DACCC 2006 (58)	Multidisciplinary coordination is desirable to systematically flag psychosocial problems for the purpose of providing appropriate support.

Notes: ASPO = American Society of Preventive Oncology; ACCC = Association of Community Cancer Centers DACCC = Dutch Association of Comprehensive Cancer Centres.

Support Services

Author Year (Reference)	Support services
IOM 2008 (54)	Health care providers: All cancer care providers should ensure that every cancer patient within their practice receives care that meets the standard for psychosocial health care. The National Cancer Institute should help cancer care providers implement the standard of care by maintaining an up-to-date directory of psychosocial services available at no cost to individuals/families with cancer.
Rizzo 2006 (59)	In adults, sexual function should be queried at a minimum of six and 12 months after hematopoietic cell transplantation.
ACS 2001 (60)	Discussions during consultation should not be limited to physical symptoms and test results. They should also cover anxiety, worries, and other topics related to quality of life.
CBCI 2005 (61)	Psychosocial support should be encouraged and facilitated.

Notes: IOM = Institute of Medicine; ACS = American Cancer Society; CBCI = Canadian Breast Cancer Initiative.

Structural Approaches

Author Year (Reference)	Structural Approaches (e.g., survivorship transition care plans)
NCCN 2010 (50)	NCCN offers a prescription for survivorship and transfer of care to a primary care physician that includes a summary of treatment, including all surgeries, radiation treatment, and chemotherapy received; describes a possible clinical course, including expected time to resolution of acute toxicities, long-term effects of treatment, and possible late sequelae of treatment; includes surveillance recommendations; and delineates appropriate timing of transfer of care with responsibilities identified.
NCCN 2010 (51)	NCCN offers a prescription for survivorship and transfer of care to a primary care physician that includes an overall summary of treatment, including all surgeries, radiation treatment, and chemotherapy; describes a possible clinical course, including expected time to resolution of acute toxicities, long-term effects of treatment, and possible late sequelae of treatment; includes surveillance recommendations; and delineates appropriate timing of transfer of care with responsibilities identified for primary care physician and oncologist.

Author Year (Reference)	Structural Approaches (e.g., survivorship transition care plans)
ASPO 2009 (52)	Survivorship follow-up care models and plans should be based on evidence of efficacy and effectiveness. The aim of survivorship care plans is to assist the patient in creating links between care providers for cancer-related follow-up care. ASPO members agreed that patient empowerment is important not only during active treatment but also during the extended period of follow-up care, and that research examining how to engage and activate patients around their follow-up care is needed.
ACCC 2009 (53)	Mechanisms exist, when necessary, to review the rehabilitation plan and coordinate communication among the various members of the rehabilitation team. Rehabilitation services are a part of the organizational structure of the program, follow proper policies and procedures, and are available to cancer patients and their families throughout their continuum of care. Information and programs specific to survivorship issues are available to cancer patients and their families. Programs and educational resources for survivors and their families should include: 1. A written cancer treatment summary and follow-up care plan that would include a summary of the cancer treatment, recommended follow-up for cancer surveillance, late and long-term effects of their disease and its treatment(s), symptom management, and psychosocial, spiritual, and financial concerns. Access to information about cancer prevention, early detection, genetics, disease treatment, symptom management, and psychosocial, spiritual, and financial concerns through written materials and/or referrals via the Internet, other experts, or support organizations. 2. Information about local, regional, and national resources on survivorship and survivorship research via written materials and/or referrals through the Internet, other experts, or support organizations for any aspect of their cancer, cancer care, research, advocacy, and survivorship. 3. Access to support groups either on-site or by referrals to local or Web-based support groups and other support mechanisms, such as telephone connection programs linking survivors together. 4. Information about specific survivorship issues, such as employment rights, insurance coverage, late and long-term effects of disease and treatment, advance directives, living will and durable power of attorney, estate planning, options for recurrent disease management, and end-of-life care planning. 5. Opportunity to participate with care team to develop community outreach education and support programs for quality cancer care and to educate professional staff about the cancer experience.
IOM 2008 (54)	Patient education and advocacy organizations should educate patients with cancer and their family caregivers to expect, and request when necessary, cancer care that meets the standard for psychosocial care. These organizations should also continue their work on strengthening the patient side of the patient–provider partnership. The goals should be to enable patients to participate actively in their care by providing tools and training in how to obtain information, make decisions, solve problems, and communicate more effectively with their health care providers. All parties establishing or using standards for the quality of cancer care should adopt the following: All cancer care should ensure the provision of appropriate psychosocial health services by facilitating effective communication between patients and care providers; identifying each patient's psychosocial health needs; and designing and implementing a plan that links the patient with needed psychosocial services, coordinates biomedical and psychosocial care, and engages and supports patients in managing their illness and health; and systematically following up, re-evaluating, and adjusting plans.
DACCC 2007 (55)	The patient must know the types of adverse events that may occur and to which care provider to report these events.
IOM 2006 (56)	Patients completing primary treatment should be provided with a comprehensive care summary and follow-up plan that is clearly and effectively explained. This "survivorship care

Author Year (Reference)	Structural Approaches (e.g., survivorship transition care plans)
	plan" should be written by the principal provider(s) that coordinated oncology treatment. This service should be reimbursed by third-party payers of health care.
CBCI 2005 (61)	Frequency of visits should be adjusted according to individual patient's needs. Patients should be encouraged to report new or persistent symptoms without waiting for the next scheduled appointment.

Notes: NCCN = National Comprehensive Cancer Network; ASPO = American Society of Preventive Oncology; ACCC = Association of Community Cancer Centers; IOM = Institute of Medicine; DACCC = Dutch Association of Comprehensive Cancer Centres; CBCI = Canadian Breast Cancer Initiative.

Other Recommendations

Author Year (Reference)	Other Recommendations
ASPO 2009 (52)	Patient empowerment is important not only during active treatment but also during the extended period of follow-up care, and research examining how to engage and activate survivors around their follow-up care is needed.
ACCC 2009 (53)	Ongoing educational opportunities are available to members of rehabilitation services. A mechanism is in place to inform patients and family members of the services available. Resources are allocated to provide a robust survivorship program. National standards for survivorship are incorporated into program planning, implementation, and evaluation.
IOM 2008 (54)	a. Educational accrediting organizations, licensing bodies, and professional societies should examine their standards and licensing and certification criteria with an eye to identifying competencies in delivering psychosocial health care and developing them as fully as possible in accordance with a model that integrates biomedical and psychosocial care. b. Congress and federal agencies should support and fund the establishment of a Workforce Development Collaborative on Psychosocial Care during Chronic Medical Illness. This cross-specialty, multidisciplinary group should comprise educators, consumer and family advocates, and providers of psychosocial and biomedical health services and should be charged with identifying, refining, and broadly disseminating to health care educators information about workforce competencies, models, and pre-service curricula relevant to providing psychosocial services to persons with chronic medical illnesses and their families; adapting curricula for continuing education of the existing workforce using efficient workplace-based learning approaches; drafting and implementing a plan for developing the skills of faculty and other trainers in teaching psychosocial health care using evidence-based teaching strategies; and strengthening the emphasis on psychosocial health care in educational accreditation standards and professional licensing and certification exams by recommending revisions to the relevant oversight organizations. c. Organizations providing research funding should support assessment of the implementation in education, training, and clinical practice of the workforce competencies necessary to provide psychosocial care and their impact on achieving the standard for such care set forth in recommendation 1.
IOM 2006 (56)	The National Cancer Institute, professional associations, and voluntary organizations should expand and coordinate their efforts to provide educational opportunities to health care providers to equip them to address the health care and quality-of-life issues facing cancer survivors.

Notes: ASPO = American Society of Preventive Oncology; ACCC = Association of Community Cancer Centers; IOM = Institute of Medicine.

Physical

Author Year (Reference)	Physical (prevention, healthy living and symptom management recommendations)
NCCN 2010 (50)	Counselling regarding healthy lifestyles and wellness (as per ACS recommendations) should include screening and counselling to maintain a healthy weight, screening for physical activity and counselling to adopt a physically active lifestyle (recommended activity of at least 30 minutes or more of moderate to vigorous physical activity at least five days a week), and screening and counselling for alcohol use or tobacco use with an emphasis on smoking cessation, and healthy diet adoption (with an emphasis on plant sources).
NCCN 2010 (51)	Counselling regarding healthy lifestyles and wellness (as per ACS recommendations) should include counselling to maintain a healthy weight, screening for physical activity and counselling to adopt a physically active lifestyle (recommended activity of at least 30 minutes or more of moderate to vigorous physical activity at least five days a week), and screening and counselling for alcohol use or tobacco use with an emphasis on smoking cessation and healthy diet adoption (with an emphasis on plant sources).
DACCC 2007 55)	Follow a healthy and varied diet, get sufficient physical activity, and do not smoke.
IOM 2006 (56)	Health care providers should use systematically developed evidence-based clinical practice guidelines, assessment tools, and screening instruments to help identify and manage late effects of cancer and its treatment. Existing guidelines should be refined and new evidence-based guidelines should be developed through public and private sector efforts.
CBCI 2005 (61)	Patients should be asked about symptoms of fatigue. Physiological causes of fatigue should be investigated and ruled out. Depression and pain are potentially treatable underlying factors. Weight management should be discussed with all breast cancer survivors. Overweight patients should be encouraged to participate in evidence-based weight management programs. Patients should be counselled on exercise and on adequate intake of calcium and vitamin D. Sexual functioning should be discussed with women at follow-up visits.
ACS 2003 (62)	Eat healthy foods, with an emphasis on plant sources. Eat five or more servings of vegetables and fruits per day. Choose whole grains rather than processed grains and sugars, Limit consumption of red meats, especially those high in fat and processed, Choose foods to help maintain a healthy weight, Adopt a physically active lifestyle. For adults, get at least moderate activity for 30 minutes or more, five or more days a week; 45 minutes or more of moderate to vigorous activity on five or more days per week may further reduce the risk for breast and colon cancer. Maintain healthy weight throughout life. Balance caloric intake with physical activity, Lose weight if currently overweight or obese. Limit consumption of alcoholic beverages. Follow general guidelines on food safety.

Note: NCCN = National Comprehensive Cancer Network; IOM = Institute of Medicine; DACCC = Dutch Association of Comprehensive Cancer Centres; ACS = American Cancer Society; CBCI = Canadian Breast Cancer Initiative.

Psychological

Author Year (Reference)	Psychological
IOM 2006 (56)	Same as physical.
Rizzo 2006 (59)	A high level of vigilance for psychological symptoms should be maintained. Clinical assessment is recommended throughout the recovery period, at six months, at one year, and annually thereafter, with mental health professional counselling recommended for those with recognized deficits. Asking two simple questions (“Over the past two weeks, have you felt down, depressed, or hopeless?” and “Over the past two weeks have you felt little interest or

	pleasure in doing things?") is probably as effective as longer screening tools. The frequency of screening is not stated, but it is reasonable to screen every six to 12 months post-transplantation or as clinically indicated. Affirmative answers to the questions above should trigger in-depth evaluation for depression to determine the need for pharmacological psychotherapeutic treatments.

Notes: IOM = Institute of Medicine.

Informational/Practical

Author Year (Reference)	Informational/ Practical
IOM 2006 (56)	Recommendation 8: Employers, legal advocates, health care providers, sponsors of support services, and government agencies should act to eliminate discrimination and minimize adverse effects of cancer on employment, while supporting cancer survivors with short-term and long-term limitations in ability to work. Recommendation 9: Federal and state policy-makers should act to ensure that all cancer survivors have access to adequate and affordable health insurance. Insurers and payers of health care should recognize survivorship care as an essential part of cancer care and design benefits, payment policies, and reimbursement mechanisms to facilitate coverage for evidence-based aspects of care.
CBCI 2005 (61)	If a woman wishes to carry out breast self-examination, it is reasonable to teach her the proper procedure. Women considering pregnancy following a diagnosis of breast cancer should be informed on the limited data on the effect of pregnancy on outcomes such as breast cancer recurrence and survival.

Notes: IOM = Institute of Medicine; ASCO = American Society of Clinical Oncology; CBCI = Canadian Breast Cancer Initiative.

Emotional

Author Year (Reference)	Emotional
IOM 2006 (56)	Same as physical

Note: IOM = Institute of Medicine.

Social

Author Year (Reference)	Social
IOM 2006	Same as physical
Rizzo 2006	Inquiry as to the level of spousal/caregiver psychological adjustment and family functioning should be performed at regular intervals.

Note: IOM = Institute of Medicine.

Spiritual

Author Year (Reference)	Spiritual
IOM 2006 (56)	Same as physical

Note: IOM = Institute of Medicine.

Appendix V: Matrix of Included Systematic Review Results

Author Year (Reference)	Included Reviews
Hoving 2009 (64)	**Data Sources:** Cochrane Controlled Trials Register, MEDLINE, Ovid, Embase and PsycINFO; 1970-2007. **Evidence Base**: 1 Controlled Trial, 3 Non-controlled. **Cancer Type:** Breast cancer . **Results/Conclusions:** 3 trials post-treatment, 1 trial across phases. ● All non-drug interventions. ● Outcome: Return to work post-treatment. ● 4 studies included in review. ● The intervention programs focused on improvement of physical, psychological and social recovery. ● A substantial percentage (75% to 85%) of patients returned to work after rehabilitation. ● It is not clear whether this proportion would have been lower for patients without counselling or exercise, or any other interventions, as three out of four studies did not include a comparison group
Cheema 2008 (65)	**Data Sources:** PubMed, MEDLINE, CINAHL, SportDiscus, Embase, and Web of Science; 1966-2007. **Evidence Base**: 5 RCTs, 4 uncontrolled trials; 1 non-randomized trial. **Cancer Type:** Breast cancer. **Results/Conclusions:** 2 studies during treatment, 8 studies post-treatment (2 weeks to 5 years). ● Progressive resistance training (PRT) in isolation or in combination with other exercise methods (e.g., aerobic training). ● Physiological, functional, and psychological outcomes. ● 10 studies included in systematic review; 5 RCTs, 1 non-randomized, and 4 uncontrolled; ● N = 538 female breast cancer survivors; age range 25-78. ● Half of the trials prescribed 8 weeks of exercise and the remaining varied in length (16 weeks-6 months); PRT was prescribed 2-3 times/week; long-term follow-up assessments only done in 1 trial. ● The studies reviewed suggest that women surgically treated for breast cancer can derive health-related physical, psychological, and functional benefits by performing PRT after breast cancer surgery. ● 2 large RCTs of PRT reported significant increases in upper and lower body strength compared with aerobic exercise alone. This is very important due to high incidence of lymphedema in this population. ● Compliance was high (75% to 97%); few adverse events were reported and there were no incidence or exacerbation of quantified or self-reported lymphedema. ● Overall trials reviewed were poor methodological quality with PRT interventions and subject characteristics not properly defined or described.

Author Year (Reference)	Included Reviews
Kangas 2008 (66)	**Data Sources:** Cancer, CINAHL, Embase, MEDLINE, PubMed, and PsycINFO; inception to December 2006. **Evidence Base**: 57 RCTs and 62 quasi-experimental (control group without randomization). **Cancer Type:** All cancers. **Results/Conclusions:** During and post-treatment. • Non-pharmacological interventions (psychological and exercise). • Outcome: Cancer-related fatigue (or related outcome – vigour, vitality). • 119 trials included in review. • Meta-analyses based on 57 RCTs: 41 psychosocial interventions and 16 exercise (N = 1001). • The individual effect sizes for the psychosocial interventions ranged from 0.43 to -1.10 (where negative indices indicated lower fatigue symptoms post-intervention), with a weighted pooled mean effect size of -0.31 (Z =-9.62, p<.001). • The overall effect sizes for exercise interventions ranged from 0.33 to -1.09, with a weighted pooled mean effect size of -0.42 (Z = -4.41, p<.001). • Physical exercise interventions were clearly found to have a stronger effect on improving vigour/vitality in cancer patients (0.69) compared with the small to moderate effect that emerged for psychosocial interventions (0.37). • Psychosocial interventions that included a cancer related fatigue (CRF) specific aim/ hypothesis had a somewhat stronger weighted (although moderate) effect size (-0.48) than the psychosocial interventions that did not include a CRF-specific aim/hypothesis (-0.23). • Both types of interventions showed clinically significant and small to moderate effect sizes for those in the post-treatment stage (-0.16 to -0.57).
Pinto 2008 (67)	**Data Sources:** MEDLINE, PsycINFO, CINAHL, CancerLit, and Cochrane Controlled Trials Register; up to 2007. **Evidence Base**: 21 RCTs. **Cancer Type:** All cancers (14 breast cancer trials; 3 head/neck/ lung cancer; 2 various cancers; 1 prostate and 1 childhood cancer). **Results/Conclusions:**12 during treatment, 8 post-treatment, 1 during and post treatment. • Theories as basis for the development of health promotion interventions among cancer patients and survivors (physical activity, dietary, smoking cessation). • 21 studies included in systematic review. • Theories tested included transtheoretical model (TTM) of change, motivational interviewing (MI), social cognitive theory (SCT), theory of planned behaviour (TPB), cognitive behavioural theory, and others. • Interventions based on the TTM, SCT, and cognitive behavioural therapy were most often evaluated and showed most benefit for lifestyle management behaviours including improving fitness, maintaining healthy diet and recommended body weight, reducing pain and improving general health, reducing fatigue, and increasing vigour. • MI has shown effectiveness in diet and exercise change, treatment adherence, and other health promoting behaviours. • TBP components of intervention have rarely been evaluated. • Limitations noted include poor quality of study methodology and limited research on the impact of the intervention on the theoretical constructs.

Author Year (Reference)	Included Reviews
Cramp 2008 (68)	**Data Sources:** The Cochrane Controlled Trials Register (CENTRAL/CCTR), MEDLINE, Embase, CINAHL, British Nursing Index, AMED, SIGLE, and Dissertation Abstracts International; to July 2007. **Evidence Base**: 28 RCTs. **Cancer Type:** Multiple (17 breast; 6 multiple; 2 prostate; 1 colon; 1 lymphoma; and 1 multiple myeloma). **Results/Conclusions:**14 during treatment, 13 post-treatment,1 during and post-treatment. • Aerobic and strength training exercise programs (home-based and supervised programs). • Outcome: Cancer-related fatigue. • N = 2083; majority breast cancer patients (N= 1172). • Meta-analysis performed for 22 studies (N = 1663). • Exercise was statistically more effective than the control intervention at reducing fatigue (standard mean difference [SMD] -0.23, 95% CI = -0.33 to -0.13); specifically in the post-treatment groups, exercise was also significantly more effective than the control group at reducing fatigue (SMD -0.37, 95% CI = -0.55 to -0.18). • In terms of other outcomes (quality of life, depression, anxiety, self-efficacy, physiological outcomes, etc.), the results across studies were inconsistent. • Limitations included poor study quality and low sample sizes (mean sample size = 75), few studies reported adherence to exercise (61% to 98%), long-term follow-up assessment was reported in 7 of the 28 studies, multiple outcome measures and assessment tools were used across studies, and most studies included breast cancer patients.
Ingram 2006 (69)	**Data Sources:** MEDLINE and Pre-MEDLINE, CancerLit, CINAHL, Cochrane CENTRAL, Embase, PsycINFO, PEDro, and SPORTDiscus; 1989 to 2004. **Evidence Base**: 8 RCTs and 6 non-randomized control trials. **Cancer Type:** Breast cancer. **Results/Conclusions:** 3 during treatment, 8 post-treatment (3 weeks to 5 years), 3 during and post-treatment. • Exercise interventions (aerobic and resistance training). • Body weight and composition. • 14 studies included in the systematic review; RCTs were rated as moderate quality and control trials rated as weak; mean sample size = 55; 6 to 26 weeks in length. • Body weight and composition were generally secondary endpoints in relation to physical function, fitness, fatigue, and mood. • Most studies indicate significant changes in mood, fatigue, physical function, and fitness, but not body composition or weight. • Changes in body composition and weight compared with other outcomes take longer; hence, the short intervention duration is a possible cause for non-significant results. • None of the studies in the review were designed or sufficiently powered to examine body weight and composition; none specifically recruited overweight breast cancer survivors, used gold-standard measures of body weight and composition, controlled for dietary intake or body size, or employed the type of exercise known to strongly influence body weight and composition.

Author Year (Reference)	Included Reviews
Schmitz 2005 (70)	**Data Sources:** MEDLINE, earliest to 2005. **Evidence Base:** RCTs and quasi-experimental designs (with at least a control group). **Cancer Type:** Primarily breast cancer, but also included patients with other cancers. **Results/Conclusions:** 63% during treatment, 37% post-treatment (conducted separate testing for during and post-treatment). • Any physical activity intervention compared with a parallel control group. • Specific outcomes were not identified. • 32 unique studies were included, with 22 studies rated as high methodological quality. • The majority of the interventions were between 5 weeks and 3 months long, with no follow-up after the end of the intervention. The physical activity prescription was typically for aerobic activity of moderate to vigorous intensity, 2 to 5 times per week, for 20 to 30 minutes per session. • There was evidence of a small to moderate effect of physical activity interventions on cardio-respiratory fitness (weighted mean effect sizes = 0.51 and 0.65 during and after treatment respectively, $p < 0.01$), physiologic outcomes and symptoms during treatment (weighted mean effect size = 0.28, $p < 0.01$ and 0.39, $p < 0.01$, respectively), and vigour post-treatment (weighted mean effect size = 0.83, $p = 0.04$). • Physical activity was well tolerated in cancer survivors during and after treatment. • Limitations include high variability in intervention lengths, substantial loss of subjects in follow-up, substantial variability in outcome measures, and most studies being done in breast cancer and Caucasian populations.
Smedslund, 2004 (71)	**Data Sources:** PsycINFO (to 2003, Week 25), Pubmed (1960 to 2003, Week 25), Embase (1980 to 2003, Week 25), AMED (1985 to June 2003), and Google. **Evidence Base**: 8 RCTs and 5 quasi-experimental designs (must have a control group), **Cancer Type:** Breast cancer, melanoma, prostate, and Hodgkin's. **Results/Conclusions:** Pre- and post-treatment with outcomes in the post-treatment phase. • Interventions included education, social support, psychotherapy, skills training, relaxation, etc. • Outcome: Survival time. • N = 2626 patients. • The total mean inverse-variance-weighted HR was 0.85 (95% CI: 0.65 to 1.11). • Randomized studies (N=8) showed no overall treatment effect (HR: 0.77, 95% CI: 0.56 to1.06). • Non-randomized studies showed no overall treatment effect (HR: 1.00, 95% CI: 0.61 to 1.62). • Interventions using individual treatment (N=3) were effective (HR: 0.55, 95% CI: 0.43 to 0.70). • Interventions using group treatment (N=9) were ineffective (HR: 0.97, 95% CI: 0.73 to 1.27). • Group treatments of breast cancer (N=6) were ineffective (HR: 0.95, 95% CI: 0.69 to 1.31). • Limitations included small diverse studies and the lack of data on select variables (e.g., treatment type).

Note: N = number; RCT = randomized controlled trial, HR = hazard ratio.

Appendix VI: Matrix of Excluded Systematic Review Results

Author Year	Excluded Reviews
Conn 2006	**Data Sources:** MEDLINE, CancerLit, Cochrane Central Register of Controlled Trials, Dissertation Abstracts, PsycINFO, SPORT, HealthStar, Clinical Evidence, and CINAHL; 1970 to 2002. **Evidence Base**: 16 RCTs, 1 quasi-experimental, 13 single-group pre/post- test. **Cancer Type:** All cancers. **Results/Conclusions:** 8 unpublished studies (4 post-treatments), 6 studies during treatments, 6 studies post-treatments,5 studies combined, 5 unclear. • Exercise interventions including center-based and at-home interventions. • Intervention designed to increase resistance, flexibility, or endurance exercise. • Outcomes: Quality of life; psychological outcomes; physical health, including physical function, fatigue, symptoms; body composition and exercise behaviour. • 30 studies included. • The overall weighted mean effect size for two-group comparisons was 0.52 (higher mean for treatment than control) for physical function, 0.35 for symptoms other than fatigue, and 0.27 for body composition. • Modest positive effect sizes were documented for mood (0.19), quality of life (0.14), fatigue (0.11), and exercise behaviour (0.04). • Effect sizes were larger among single-group pre/post design studies. • Effect sizes among control group participants were typically negative and not statistically significant.
De Moor 2008	**Data Sources:** PubMed, 1967-2007. **Evidence Base**: RCTs and quasi-experimental study design. **Cancer Type:** All cancers (primarily head and neck cancers). **Results/Conclusions:** 9 during treatment; 2 post-treatment; 4 childhood cancer survivors. • Psychoeducational and peer-support group smoking cessation and smoking prevention interventions. • Outcomes: Cessation rates, knowledge, decision-making, smoking behaviours. • 3 smoking prevention and 9 smoking cessation interventions. • Smoking-prevention programs showed limited impact on outcomes such as smoking behaviours and decision-making. • Smoking-cessation interventions showed limited impact on cessation rates, with 2 RCTs reporting significant increases in cessation among cancer survivors. • Overall, few studies have evaluated smoking cessation and prevention interventions, study quality is poor, and sample sizes are small.
Demark-Wahnefried 2006	**Data Sources:** MEDLINE and PubMed; 1966 to 2005. **Evidence Base**: 35 RCTs and controlled trials (unclear if all trials included were randomized). **Cancer Type:** All cancers. **Results/Conclusions:** 25 during treatment, 16 post-treatment, 2 during and post-treatment, 1 childhood cancer survivor. • Lifestyle management interventions including exercise, diet-related, and smoking cessation.

Author Year	Excluded Reviews
	• Dietary and physical activity behaviours, and smoking cessation. • 22 exercise interventions; 11 diet-related interventions, 2 diet and exercise interventions, and 10 behavioural-based smoking cessation interventions. • Diet-related interventions were generally successful in promoting changes in dietary behaviours and biomarkers. Most dietary interventions had intensive in-person, individualized counselling sessions delivered by trained nutritionists, and were therefore resource intensive. Less-intensive interventions also showed success when delivered by trained volunteer staff, commercial institutions (i.e., Weight Watchers), or telephone counselling. • Exercise interventions clearly showed many benefits for the cancer survivor. However, most studies evaluated exercise adoption but not maintenance. • Effectiveness of smoking-cessation interventions in cancer survivors is inconclusive, with studies showing very weak effects. • Most studies were conducted with breast cancer and Caucasian patients, the methodological quality of studies was poor, and there was substantial variability in intervention lengths, follow-up, and assessment criteria.
Flynn 2009	**Data Sources:** Cochrane Controlled Trials Register (CENTRAL, up to October 2008), MEDLINE (1950 to October 2008), Embase (1982 to October 2008), CINAHL (1980 to October 2008) and PsycINFO (up to October 2008). **Evidence Base**: 5 RCTs. **Cancer Type:** Gynaecological cancers **Results/Conclusions:** 4 trials during treatment, 1 post-treatment. • Psychological and medical interventions. • Outcomes: Psychosexual dysfunction. • Review included data from 5 studies, comprising a total of 413 patients, examining 5 different interventions. • Studies of a clinical nurse specialist intervention, psychoeducational group therapy and a couple-coping intervention did not show any significant benefit. • Two medical intervention trials (vaginal cream and low-dose brachytherapy) showed some improvements in psychosexual dysfunction. • All the studies were of poor methodological quality. • There was no convincing evidence to support the use of any interventions for psychosexual dysfunction in women treated for gynaecological cancers.
Graves 2003	**Data Sources:** PsycLit, PsycINFO, Dissertation Abstracts International, MEDLINE, and Psychological Abstracts; up to 1999. **Evidence Base**: 38 RCTs. **Cancer Type:** Multiple cancers (28 multiple, 8 breast; 1 melanoma, and 1 gynaecological). **Results/Conclusions:** 34 trials during treatment, 4 post-treatment. • Psychosocial interventions with social cognitive theory (SCT) components to improve quality of life (QOL); SCT components included self-efficacy, outcome expectation, and self-regulation. • Meta-analysis included 38 studies with a total sample of 3216 cancer patients and survivors. • Interventions with more SCT components had significantly larger effect sizes than studies with fewer or no SCT components for the overall analysis ($Z = 3.72$, $p < .01$). • The focused comparisons indicated SCT components were associated with larger effects on global affect ($Z = 4.69$, $p < .05$), depression ($Z = 2.49$, $p < .05$), social ($Z =$

Author Year	Excluded Reviews
	5.69, $p < .05$), objective physical outcomes ($Z = 2.80$, $p < .05$), and specific QOL outcomes ($Z = 2.08$, $p < .05$). • Group treatments had larger effect sizes than individual treatments ($Z = 1.69$, $p < .05$). Inclusion of SCT components did not result in better outcomes for individual treatments. • SCT-based components were not related to improvement in anxiety, coping, overall physical, subjective physical, or functional outcomes. • Several limitations were noted, including lack of standardized measurement of QOL across studies, most studies carried out in Caucasian populations and mostly in North America, and a wide range of intervention lengths studied.
Jacobsen 2007	**Data Sources:** MEDLINE, PsycINFO, CINAHL; 1966 to 2005. **Evidence Base**: 30 RCTs. **Cancer Type:** All cancers (21 breast, 13 multiple, 2 prostate, 2 melanoma, 1 multiple myeloma, 1 gynaecological, and 1 colon). **Results/Conclusions:** 26 during treatment, 6 post-treatment,11 during and post-treatment. • Psychological interventions (telephone counselling, group counselling/support, psychotherapeutic, psychoeducational, cognitive behavioural therapy, stress management). • Activity-based interventions (energy conservation, exercise). • 30 studies included in the meta-analyses; 50% of psychological trials and 44% of activity-based trials rated as fair or better in quality. • Meta-analysis (based on 19 studies) yielded an overall effect size of 0.09 (95% CI = 0.02 to 0.16) favouring non-pharmacological conditions. • Effect sizes were significant but low for psychological interventions and non-activity-based interventions. • Effect sizes of psychological interventions were not significant for patients with breast cancer.
Kirshbaum 2007	**Data Sources:** MEDLINE, Embase, CINAHL, British Nursing Index, and the Cochrane Library; 1985 to December 2004. **Evidence Base**: 9 RCTs, quasi-experimental, case-control, cross-sectional, and case-study. **Cancer Type:** Breast cancer. **Results/Conclusions:**13 during treatment, 10 post-treatment,1 during and post treatment. • Exercise (mostly aerobic, i.e., walking, bicycling; some resistance combined with aerobic). • Physical and emotional health outcomes. • 29 studies (9 RCTs) with small sample sizes. • Experimental and quasi-experimental studies indicated that exercise under structured and measurable conditions has the potential to improve cardiopulmonary function, overall quality of life, global health, strength, sleep, and self-esteem, and reduce weight gain, depression, anxiety, and tiredness. The strongest evidence was benefit of exercise for fatigue. • Limitations included poor methodological quality and poor generalizability. • Most studies focused on populations during treatment, and may not be applicable for the survivorship stage.

Author Year	Excluded Reviews
McNeely 2006	**Data Sources:** Cochrane Controlled Trials Register, MEDLINE, Embase, CINAHL, PsycINFO, CancerLit, PEDro, SPORTDiscus, conference proceedings, clinical practice guidelines, and other unpublished literature sources; up to March 2005. **Evidence Base**: 14 RCTs. **Cancer Type:** Breast cancer. **Results/Conclusions:** 9 During treatments,5 post-treatment. • Exercise interventions (leisure-time physical activity that was performed on a repeated basis over an extended period of time, with the intention of improving fitness, performance or health). • Quality of life, cardio-respiratory fitness or physical functioning, and symptoms (fatigue, body composition, and adverse effects). • 14 studies included with significant heterogeneity and small sample sizes (N = 717). • Study methodology varied significantly, particularly in regard to timing of the exercise intervention, the chosen exercise regimen, and outcomes reported. • Exercise led to statistically significant improvements in quality of life: QOL as assessed by the FACT-G (weighted mean difference [WMD] 4.58, 95% CI 0.35 to 8.80) and FACT-Breast (WMD 6.62, 95% CI 1.21 to 12.03); peak oxygen consumption (WMD 3.39, 95% CI 1.67 to 5.10); fatigue (SMD 0.46, 95% CI 0.23 to 0.70); and increase in physical functioning and well-being (SMD 0.84, 95% CI 0.36 to 1.32). • Pooled results from 4 studies monitoring body weight and BMI showed a non-significant reduction (WMD –0.03 kg, 95% CI –0.44 to 0.38; WMD –0.02, 95% CI –0.09 to 0.05, respectively). • Adverse events included injuries to the back, wrist, shoulder, and lower legs. • Evidence indicates a benefit of exercise for quality of life, physical function, well-being, and fatigue, but not for body mass index or body weight outcomes.
Osborn 2006	**Data Sources:** MEDLINE, PsycINFO and the Cochrane Database; 1993 to 2004. **Evidence Base**: 15 RCTs. **Cancer Type:** All Cancers (6 breast; 7 multiple; 1 colon and 1 prostate). **Results/Conclusions:** 11 During treatment, 1 post-treatment, 3 during and post-treatment. • Cognitive behavioural therapy and patient education. • Outcomes: Depression, anxiety, pain, physical functioning, and quality of life. • N = 1492, age range 18-84. • Cognitive behavioural therapy varied in duration from 4 weekly one-hour sessions to 55 weekly two-hour sessions. PE ranged from a single 20-minute session to 6 weekly one-hour sessions. Follow up ranged from 1 week to 14 months. • Cognitive behavioural therapy was effective for depression (effect size ES) = 1.2, 95% CI = 0.22 to 2.19), anxiety (ES = 1.99, 95% CI = 0.69 to 3.31), and quality of life (ES = 0.91, 95% CI = 0.38 to1.44). • Quality of life was improved at both short-term and (ES = 1.45, 95% CT = .43-2.47) and long-term (ES = .26; 95% CI = .06-.46) follow up. • Patient education was not related to improved outcomes. • Individual interventions were more effective than group interventions.

Author Year	Excluded Reviews
Thorsen 2008	**Data Sources:** PubMed, MEDLINE, Embase, Allied and Complementary Medicine, and PsycINFO **Evidence Base**: 4 RCTs, 2 quasi-experimental. **Cancer Type:** Prostate cancer survivors. **Results/Conclusions:** 2 during treatment; 7 post-treatment. • Physical activity interventions. • Outcomes: Psychological, physical, and functional. • 4 RCT and 2 uncontrolled trials examined effectiveness of physical activity on prostate cancer survivors; mean sample size = 67 (range 9 to 155). • The intervention studies showed promising results for muscular fitness, physical functioning, fatigue, and health-related quality of life. Results for body composition were less conclusive. • Compared with cancer in general, resistance training has most often been studied among prostate cancer survivors. • Prevalence of physical activity in survivors varied between 30% to 70% • Physical activity was predicted by motivational variables such as intentions, perceived behavioural control, and subjective norms. • Sample size and methodological quality was rated as poor; studies were not controlled for confounding variables (i.e., socio-economic status, race, medical morbidity, etc.); studies did not evaluate impact on clinical outcomes (i.e., osteoporosis).
Tremblay 2008	**Data Sources:** MEDLINE, CINAHL, PsycINFO, the Cochrane Library; 1980 to 2006. **Evidence Base**: 10 RCTs, 1 non-RCT, 2 case series. **Cancer Type:** Menopausal breast cancer. **Results/Conclusions:** 3 survivor trials, 10 trials of women with no history of cancer. • Interventions: Psychoeducational interventions (including any education, counselling, cognitive-behavioural therapy (cognitive behavioural therapy), group therapy, psychological intervention, or relaxation techniques). • Outcomes: Vasomotor symptoms – hot flashes. • N = 475 patients. • Five psychoeducational interventions showed improvement in vasomotor symptoms; of nine relaxation studies, five showed improvement in vasomotor symptoms. • Methodological quality of published research was rated as fair to poor.

Note: N = number; RCT = randomized controlled trial.

Appendix VII: Randomized Controlled Trials of Follow-up Interventions

Author Year (Reference)	# of Pts.	Comparisons	Results
Grunfeld 2006 (72)	483 485	Primary care Standard care	Quality of Life - no significant differences detected Patient Satisfaction - NR Psychological Functioning - NR Disease recurrence/Health outcomes - no differences detected (13.2% and 11.2%) - no differences in serious complicated events (3.7% vs. 3.5%) Other – NR
Wattchow 2006 (73)	97 106	Primary care Standard care	Quality of Life - no significant differences detected Patient Satisfaction - no significant differences detected Psychological Functioning - no significant differences detected Disease recurrence/Health outcomes - no differences detected (13.2% and 11.2%) - more FOBT in primary care (rate ratio 2.4, 95% CI 1.4 to 4.4) - more colonoscopies in surgeon care (rate ratio 0.7, 95% CI 0.5 to 1.0) - more ultrasounds in surgeon care (rate ratio 0.5, 95% CI 0.3 to 1.0) Other - NR
Koinberg 2004 (74)	133 131	Nurse-led Standard care	Quality of Life - no significant differences detected Patient Satisfaction - no significant differences detected - satisfied with access to medical centre in standard care (>93%). - patients generally satisfied with medical centre and phone service. Psychological Functioning - no differences in anxiety and depression scores (HADS) Disease recurrence/Health outcomes - no differences detected (13.2% versus11.2%) Other - NR
Moore 2002 (75)	99 103	Nurse-led Standard care	Quality of Life - no differences in EORTC quality of life core questionnaire Patient Satisfaction - Higher in most subscales with nurse-led care at 3, 6, 12 months ($p<0.01$) Psychological Functioning - higher emotional functioning at 12 months with nurse-led care ($p=0.03$) Disease recurrence/Health outcomes - no differences in survival or rates of objective progression - less severe dyspnoea at 3 months with nurse-led care

			(p=0.03) - less peripheral neuropathy at 12 months with nurse-led care (p=0.05). Other - no differences were seen in general practitioners' overall satisfaction - nurses recorded progression of symptoms sooner than doctors (P=0.01). - no differences between groups in the use of resources.
Baildam 2002 (76) (abstract)	525	Nurses-led [a] Standard care	Quality of Life – NR Patient Satisfaction - higher patient satisfaction with nurse-led care (p<0.01). Psychological Functioning - no differences in STAI anxiety scores at first visit or 1 month later - less detection of psychological distress with nurse-led care (47% vs.92%) Disease recurrence/Health outcomes - no differences in the detection of cancer recurrence Other - patients spent more time visiting with nurses than with doctors (p<0.01).
Brown 2002 (77)	31 30	Patient initiated Standard care	Quality of Life - no significant differences between groups Patient Satisfaction - no significant differences detected Psychological Functioning - no differences in psychological morbidity between groups (HADS). Disease recurrence/Health outcomes - arm-symptoms subscale scores higher with standard care compared with patient-initiated follow-up at Time 1 (p = .003) and Time 2 (p = .028). Other - greater reassurance with standard care - convenience was reported as an advantage with patient-initiated follow-up
Helgeson 2000 (78)	200 200	Nurses-led [a] Standard care	Quality of Life – NR Patient Satisfaction - no significant differences detected Psychological Functioning - no differences in HADS scales Disease recurrence/Health outcomes - no differences in medical safety Other - lower mean outpatient cost per patient with nurse-led care on demand - no differences in accessibility
Gulliford 1997 (79)	97 96	Less follow-up Standard care	Quality of Life – NR Patient Satisfaction - NR Psychological Functioning - NR Disease recurrence/Health outcomes - NR Other

			- patients expressed a preference for less versus more follow-up. - no increased use of local practitioner services or telephone triage was detected in those randomised to less frequent follow-up by specialists.
Grunfeld 1996 (80)	148 148	Primary-care Standard care	Quality of Life - no significant differences detected Patient Satisfaction - increase in patient satisfaction over baseline with primary care intervention Psychological Functioning - no significant differences in anxiety Disease recurrence/Health outcomes - no significant differences in clinical outcomes Other - increase in follow-up visits with primary care (3.4 vs. 2.8 visits, $p < .001$) - increase in length of visit (10.5 vs.7.4 min, $p<.001$) with primary care. - costs to patients and health services were lower in primary care ($p<.001$). - no difference in total costs of diagnostic tests - more tests performed in primary care ($p<.001$).

Note: # of Pts = number of patients, NR = not reported, HADS = hospital anxiety and depression scale, STAI = Spielberg State-Trait Anxiety Inventory, EORTC = European Organisation for Research and Treatment of Cancer.
[a] Patient-initiated.

Appendix VIII: Randomized Controlled Trials of Psychoeducational and Cognitive Behavioural Therapy Interventions

Author, Year, (Reference)	# of Pts.	Comparisons	Results
Heidrich 2009 (81)	41 41	Individualized care Standard care	- No significant differences in QOL. - Some measures of symptom distress decreased after the individualized care intervention. - Women with individualized care changed their symptom management behaviours more than controls (p<.05).
Otis Green 2008 (82)	33 in total	Educational sessions Standard care	- No significant differences in QOL. - QOL scores significantly improved from baseline for both groups in psychological well-being (*P* = 0.001), social well-being (*P* = 0.02), and overall quality of life (*P* = 0.001).
Nelson 2008 (83)	27 23	Telephone counselling Standard care	- The intervention yielded significant improvements in quality of life (p=0.011) - Changes in quality of life were significantly associated with an increase in adaptive immunity with a shift of immune system T helper types 1 and 2 (Th1/Th2) bias (p=0.012).
Fillion 2008 (84)	48 46	PSE + physical activity Usual care	- The intervention group showed significant improvement in fatigue, energy level, and emotional distress at 3-month follow-up, and physical quality of life at post-intervention, compared with the control group (p<.05).
Espie 2008 (85)	100 50	CBT Standard care	- CBT was associated with mean reductions in wakefulness of 55 minutes per night compared with no change in usual care group and outcomes were sustained 6 months after treatment. (p<.05). - CBT was associated with moderate to large effect sizes for QOL outcomes, including significant reduction in daytime fatigue (p<.05).
Dirksen 2008 (86)	40 41	CBT Standard care	-- CBT consisted of stimulus control instructions, sleep restriction therapy, sleep education and sleep hygiene. - CBT group had significant improvements in fatigue, trait anxiety, depression and QOL (p < 0.05). - The control group had statistically significant increases in QOL, with a trend suggestive of lower depression at post-treatment.
Bloom 2008 (87)	201 203	Socio-educational Standard care	- The intervention group had greater knowledge about breast cancer, its treatment, and their own health (p = .015), retained more knowledge from pre- to post-test (p=0.044), and increased their physical activity (p=0.036)
Ashing-Giwa 2008 (88)	15 8	CBT Standard care	-Standard care consisted of a survivorship kit with reading material and vaginal lubricant, while CBT also included 6 sessions of problem-focused telephone counselling. - Increases in physical well-being and overall QOL

Author, Year, (Reference)	# of Pts.	Comparisons	Results
			were observed for the intervention group only ($p<0.05$).
Meneses 2007 (89)	129 132	PSE Standard care	- At 3 months, intervention group reported improved QOL, whereas the control group reported a significant decline in QOL. - Although both groups reported improved QOL at six months, significant differences continued to exist between the groups ($p \leq .008$).
Epstein 2007(90)	34 38	CBT Standard care	- Standard care consisted of sleep education and hygiene, whereas CBT also included stimulus control and sleep restriction instructions. - Both groups improved sleep-onset latency, wake after sleep onset, total sleep time, time in bed, sleep efficiency, and sleep quality (based on sleep diaries). - Between-group differences were detected only for time in bed. - Objective measures showed significant pre-to post-intervention changes for sleep-onset latency, wake after sleep onset, total sleep time, and time in bed ($p < 0.008$). - Intervention group rated overall sleep as more improved compared with control group.
Campbell 2007 (91)	12 [a] 18 [a]	Coping skills training (CST) Standard care	- CST produced a moderate treatment effects for QOL related to bowel bother (effect size (ES) = 0.471). - All other differences were non-significant with moderate to high ES for urinary, sexual, and hormonal symptoms. - No significant differences found between treatment and control groups on physical function and mental health subscales of the SF-36 or on scores of self-efficacy. - Partners in the CST groups, compared with the usual care group, reported less caregiver strain, depression, and fatigue, and more vigour, with moderate effect sizes but these differences were not statistically significant.
Gielissen 2006 (92)	50 48	CBT Standard care	- Intervention group reported a significantly greater decrease in fatigue severity (difference = 13.3, 95% CI, 8.6 to 18.1) and in functional impairment (difference = 383.2, 95% CI, 197.1 to 569.2). - Clinically significant improvement for the CBT group compared with the control group was seen in fatigue severity (54.0% vs. 4.0%) and in functional impairment (50.0% vs. 18.0%). - At mean follow-up of 1.9 years, improvements on fatigue severity, functional impairment, and psychological distress after CBT appeared to remain stable (2007).
Bloom 2006 (93)	78 79	Telephone counselling Standard care	- There was a positive intervention effect on mammography maintenance: the odds of being in maintenance were greater in the intervention group than in the control group (OR = 3.6).

Author, Year, (Reference)	# of Pts.	Comparisons	Results
			- Women were more likely to be in mammography maintenance at pre- or post-test if at pre-test they were married (OR = 5.7), employed (OR = 2.3), more worried about breast cancer (OR = 1.4 per unit of scale), or received an annual physical examination (OR = 2.2). - Women under age 40 were much less likely to be in maintenance than were those age 45 and over (age 35 to 39, OR = 0.2; under age 35, OR = 0.07).
Savard 2005 (94)	27 30	CBT Standard care	- Participants who received the insomnia treatment had significantly better subjective sleep indices (daily sleep diary, Insomnia Severity Index), a lower frequency of medicated nights, lower levels of depression and anxiety, and greater global QOL at post-treatment compared with the control group - Therapeutic effects were well maintained up to 12 months after the intervention and generally were clinically significant - Patients treated with CBT had higher secretion of IFN-gamma (cytokines) and lower increase of lymphocytes at post-treatment compared with control patients. - Significant changes in white blood cells, lymphocytes, and IFN-gamma were found at follow-up compared with post-treatment.
Mishel 2005 (95)	244 265	CBT Standard care	- From baseline to post-treatment (10 months) the treatment group had significant increases in cognitive reframing skills, knowledge, and social support satisfaction compared with the control group. - Women in the treatment group rated the helpfulness of symptom information/resources higher than women in the control group - The most pronounced difference was seen in African American as compared to Caucasian survivors
Lane 2005 (96)	20 22	Construct group therapy Standard care	- Significant group-by-time interaction effects on threat, dislocation, and hope scores revealed a change across time for the treatment group more so than control group post-treatment and at 3 months follow-up
Canada 2005 (97)	25 [a] 26	Couples counselling Group counselling	- The intervention group (couples counselling) showed significant improvements in male overall distress ($p < .001$), and male and female global sexual function ($p < 0.0001$ and $p < 0.05$, respectively). Regression towards baseline scores was noted at 6 months follow-up. - Use of erectile dysfunction treatments increased from 31% (baseline) to 49% at 6 months follow-up ($p = .003$) - The intervention did not improve marital adjustment, but mean scores reflected good marital satisfaction at baseline.
Boesen 2005 (98)	131	PSE	- Patients in the intervention group showed significantly less fatigue, greater vigour, and lower

Author, Year, (Reference)	# of Pts.	Comparisons	Results
	131	Standard care	total mood disturbance compared with the controls (P < 0.05) (significant at first follow-up only – 6 months).
Stanton 2005 (99)	184 187 187	Counselling+video+booklet Video+booklet Standard care - booklet	- The video intervention resulted in significant improvements in energy/fatigue at 6 months relative to standard care, particularly among women who felt less prepared for re-entry at baseline (p = .008). - No significant main effect of the interventions emerged on cancer-specific distress, but the counselling intervention prompted greater reduction in this outcome relative to control at 6 months for patients who felt more prepared for re-entry - The costs of the control, video, and video plus counselling arms were $11.30, $25.85, and $134.47 per person, respectively. - The counselling arm was more expensive and less effective than the video for virtually all end points.
Lepore 2003 (100)	84 86 80	Education Education+peer discussion Standard care	- One year post-intervention, men in the education plus peer discussion intervention were less bothered by sexual problems than men in the control group and more likely to remain steadily employed (93.0%) than men who received education (75.6%) or standard care (72.5%) (p < 0.05). - Among non-college graduates, the interventions resulted in better physical functioning than the control group, and more intensive intervention resulted in more positive health behaviours than the control or education groups. - Among college graduates, there were no differences among groups in physical functioning or in positive health behaviours.
Ganz 2000 (101)	37 39	Menopausal assessment Standard care	- The intervention group demonstrated significant improvement ($p < 0.05$) in menopausal symptoms and sexual functioning (p < 0.05). - No significant differences in vitality were detected (p = 0.77).

Note: # of Pts = number of patients; QOL = quality of life; CBT = cognitive behavioural theory.
[a] Couples.

Appendix IX: Randomized Controlled Trials of Lifestyle Management Interventions

Author Year (Reference)	# of Pts.	Comparisons	Results
von Gruenigen 2009 (102)	23 22	CBT+exercise+nutritional counselling Standard care	- There was a significant improvement for self-efficacy related to social pressure (p = 0.03) and restraint (p = 0.02) in the intervention group.
Rogers 2009 (103)	21 20	Physical activity Standard care	- Using a 12-week physical activity intervention (group and home-based), intervention adherence was 99%, and complete follow-up data were obtained on 93% of patients. - Differences favouring the intervention group were reported for accelerometer physical activity counts (p = 0.004), aerobic fitness (p = 0.058), back/leg muscle strength (p = 0.017), waist-to-hip ratio (p = 0.018), and social well-being (p = 0.03). - The intervention group reported a greater increase in joint stiffness (p = 0.04).
Morey 2009 (104)	319 322	Counselling+diet+exercise Standard care	Using a telephone counselling and a mailed print material–based diet and exercise intervention, at the 12-month follow-up, the mean function scores declined less rapidly in the intervention group compared with the control group (p = 0.03). - The mean changes in basic lower extremity function were higher in the intervention group compared with the control group (p = 0.005). - Physical activity, dietary behaviours, and overall QOL increased in the intervention group compared with the control group, and weight loss was also greater (p < 0.001).
Courneya 2009 (105)	82 78 82	Resistance exercise Aerobic exercise Standard care	- At 6-month follow-up, 42.3% were meeting neither exercise guideline, 36.8% were meeting either exercise guideline, and 20.9% were meeting both exercise guidelines. - Seven variables independently predicted the likelihood of meeting exercise guidelines at follow-up including higher pre-trial exercise (p = 0.002), younger age (p = 0.028), breast conserving surgery (p = 0.033), strength improvements (p = 0.028), lower post-intervention fatigue (p =0.067), a more positive attitude (p = 0.086), and lower post-intervention body mass index (p = 0.105).
Cadmus 2009 (106)	25 25 38 37	Exercise program (1) Standard care (1) Exercise program (2) Standard care (2)	- Exercise was not associated with QOL benefits when compared with control in small pilot study. - Exercise was associated with improved social functioning among post-treatment survivors who reported low social functioning at baseline (p < 0.05).
Milne 2008 (107)	29 29	Exercise training program Standard care	- Follow-up data was obtained on 97% of participants and exercise adherence was 61.3%. - QOL significantly increased in the intervention group from baseline to 12 weeks (p < 0.001) and from 12 to 24 weeks (p < 0.001).

Author Year (Reference)	# of Pts.	Comparisons	Results
May 2008 (108)	76 71	Exercise +CBT Exercise	- Cancer survivors' physical fitness increased significantly in both groups from baseline. - No differences between groups were detected. - At 1 year follow-up, QOL and physical activity were significantly and clinically relevantly improved in both exercise groups ($p < 0.001$)
Korstjens 2008 (109)	76 71 62	Exercise+CBT Exercise Standard care	- The effects of multidisciplinary rehabilitation did not outperform those of physical training in role limitations due to emotional problem (primary outcome) or any other domains of quality of life (all $p > 0.05$). - Compared with no intervention, participants in both intervention groups showed significantly and clinically relevant improvements in role limitations due to physical problem (primary outcome; effect size (ES) = 0.66), and in physical functioning (ES = 0.48), vitality (ES=0.54), and health change (ES=0.76) (all $p < 0.01$).
Elkins 2008 (110)	26 22	Hypnosis Standard care	- Hot flash scores decreased 68% from baseline to end point in the hypnosis arm ($p < 0.001$). - Improvements in self-reported anxiety, depression, interference of hot flashes on daily activities, and sleep were observed for patients who received the hypnosis intervention ($p < 0.005$).
Vallance 2007 (111)	94 94 93 96	Exercise materials Pedometer Exercise materials+ pedometer Standard care	- Exercise increased by 30 minutes/week in the standard care group compared with 70 minutes/week in the exercise materials group ($p = 0.117$), 89 minutes/week in the pedometer group ($p = 0.017$), and 87 minutes/week in the combined group ($p = 0.022$). - For brisk walking minutes/week, all three intervention groups reported significant increases when compared with the standard care group. - The combined group reported significantly improved QOL ($p = 0.003$) and reduced fatigue ($P = 0.052$) compared with the standard care group. - Breast cancer-specific materials did not affect exercise or health-related QOL at 6-month follow-up - 71% of participants completed 6-months of follow-up
Mefferd 2007 (112)	47 29	CBT+exercise+diet Standard care	- Significant differences in weight, body mass index, percent fat, trunk fat, leg fat, as well as waist and hip circumference were observed between intervention and control groups ($p \leq 0.05$). - Levels of triglycerides and total cholesterol/high density lipoprotein cholesterol levels were also significantly reduced following the intervention ($p \leq 0.05$).
Matthews 2007 (113)	23 13	Exercise Standard care	- Intervention participants reported a significantly greater increase in walking for exercise than did standard care participants ($p=0.01$). - Objective measures of activity showed that

Author Year (Reference)	# of Pts.	Comparisons	Results
			intervention participants increased their activity levels over time as compared to usual care participants (p≤ 0.04) - No significant changes in body weight/ composition were reported..
Daley 2007 (114)	36 34 38	Exercise placebo Supervised exercise Standard care	- A significant mean difference of 9.8 units was detected in FACT-G favouring exercise therapy at 8 weeks compared to usual care (p=0.004), and in FACT-B, social/family well-being, functional well-being, and breast cancer subscale scores at 8-week follow-up (p < 0.05). - Analyses also revealed a significant difference in physical self-worth scores between exercise therapy and standard care (p = 003) and between exercise-placebo and standard care at 8 weeks (p = 0.005). - Significant differences in mean depression scores between exercise therapy and standard care (p = 0.001) and also between exercise-placebo and usual care (p = 0.001) were recorded. - Aerobic fitness was significantly improved in both exercise groups compared with control (p < 0.05), as well as in clinically meaningful, short-term beneficial effects in QOL.
Bennett 2007 (115)	28 28	Motivational intervention Standard care	- Significant differences in regular physical activities were detected (p < 0.05). - Aerobic fitness, physical and mental health, and fatigue were not different between groups.
Mustian 2006 (116)	10 11	Psychosocial therapy Tai Chi	- The Tai Chi group demonstrated significant improvement in aerobic capacity, muscular strength, and flexibility. (p < 0.05). - The psychosocial therapy group showed significant improvement in flexibility only (p < 0.05).
Demark-Wahnefried 2006 (117)	89 93	Diet and exercise Standard care	- Physical fitness change scores were in the direction and magnitude projected; however significant differences were not detected - Significant differences were detected in the diet quality index (p = 0.03)
Culos-Reed, 2006 (118)	20 18	Yoga Standard care	- Significant differences between the intervention and the control group at post-intervention were seen only in global QOL, emotional function, and diarrhea variables (P <0.05). - There were significant improvements in both the yoga participants and the controls from pre- to post-intervention on a number of physical fitness variables (weight, strength, distance walked, flexibility, and perceived exertion).
Chlebowski 2006 (119)	975 1462	CBT Standard care	- After a median of 60 months follow-up, dietary fat intake was lower in the intervention than in the control group (p < 0.001), corresponding to a statistically significant (p = 0.005), 6-pound lower mean body weight in the intervention group. - 277 relapses were reported in 9.8% of women in the intervention group and 12.4% of women in the control group.

Author Year (Reference)	# of Pts.	Comparisons	Results
			- The hazard ratio of relapse events in the intervention group compared with the control group was 0.76 (95% CI = 0.60 to 0.98, p = 0.077 for stratified log rank and p = 0.034 for adjusted Cox model analysis.
Basen-Engquist 2006 (120)	35 25	Lifestyle exercise Standard care	- The lifestyle group had significantly better performance in the 6-minute walk task than controls (p = 0.005) at 6 months, had positive effects on body pain (p = 0.020) and general health (p = 0.006) subscales from the SF-36, and had a greater motivational readiness for physical activity at 6 months than standard care. - No significant differences were seen between the two groups in the number of minutes of moderate or more intense physical activity or number of days on which they did at least 30 minutes of moderate or more intense activity.
Thorsen 2005 (121)	59 52	Exercise Standard care	- VO2 max significantly increased in patients in the intervention group compared with patients in the control group (p < 0.01). - The fatigue score decreased by 17.0 points in the control group compared with 5.8 points in the intervention group (p < 0.01). - There were no intergroup differences in mental distress or health-related QOL.
Schmitz, 2005 (122); Ohira, 2006	40 39	Exercise Standard care	- The intervention resulted in significant increases in lean mass (p < 0.01), as well as significant decreases in body fat (p= 0.03) and IGF-II (p = 0.02) comparing immediate with delayed treatment from baseline to 6 months. - Within-person changes experienced by delayed treatment group participants during training versus no training were similar. - Over 6 months, the physical (p = 0.006) and psychosocial (p = 0.02) global QOL scores improved in the treatment group compared with the control group. - There were no changes in CES-D scores. - Increases in upper body strength were correlated with improvements in physical global score (p < 0.01) and psychosocial global score (p < 0.01) and Increases in lean mass were also correlated with improvements in physical global score (p < 0.05) and psychosocial global score (p < 0.05).
Sandel 2005 (123)	19 19	Dance+movement Standard care	- FACT-B scores significantly improved in the intervention group at 13 weeks compared with the wait list group (p = 0.008). - The overall effect of the training at 26 weeks was significant (p= 0.03), and the order of training was also significant (p = 0.015). Shoulder range of motion increased in both groups at 13 weeks in the intervention and standard care groups (p = 0.03). - Body Image improved similarly in both groups at 13 weeks and 26 weeks.

Author Year (Reference)	# of Pts.	Comparisons	Results
Pinto 2005 (124)	43 43	Exercise Standard care	- From weeks 1 to 12, a significant increase in mean weekly minutes of exercise (p = 0.0001) and mean exercise steps/week (p = 0.0001) was observed in the intervention group. - A larger percentage of participants reported meeting their goals in the first few weeks (maximum achieved during Week 2). - When comparing change from end-of-intervention (12 weeks) between groups, there was a significant reduction in minutes of exercise at 6 months (p < 0.05), but no decrease in intervention effect at 9 months (p = 0.84). - Post-intervention reductions in fatigue were lost at 6 months (p < 0.01) but remained present at 9 months (p = 0.10). - Exercise fitness improvements were maintained at both follow-up periods (p = 0.30 and p = 0.96). - The intervention effect on vigour was maintained at 6 months (p = 0.19) but was significantly reduced at 9 months (p < 0.05).
Herrero 2005 (125)	8 8	Exercise Standard care	- In response to training, QOL, VO2 max, performance in leg press, and sit-stand test were improved (p ≤0.05). No significant changes were detected in the control group.
Dimeo 2004 (126)	35 34	Exercise Relaxation training	- Physical performance of the training group improved significantly during the program (P=0.01) but remained unchanged in the relaxation group (p = 0.37). - Fatigue and global health scores improved in both groups during the intervention however the difference between scores of the groups were not significant (p = 0.67).
Pinto 2003 (127)	12 12	Exercise Standard care	- Women in the exercise group improved significantly in body image compared with women in the control group. - Reductions in distress were not significant between treatment groups. - There were modest improvements in fitness in the exercise group.
McKenzie 2003 (128)	7 7	Exercise Standard care	- No changes were found in arm circumference or arm volume as a result of the exercise program. - Physical functioning, general health, and vitality domains of the EORTC-QLQ-C30 showed trends toward increases in the exercise group.
Courneya 2003 (129)	28 25	Exercise Standard care	- Peak oxygen consumption increased by 0.24 L/min in the exercise group, whereas it decreased by 0.05 L/min in the control group (p < 0.001). - Overall QOL increased by 9.1 points in the exercise group compared with 0.3 points in the control group (p ≤ 0.001). - Change in peak oxygen consumption correlated with change in overall QOL (*p* < 0 .01).
Courneya 2003 (130)	69 33	Exercise Standard care	- No significant differences between groups for change in the FACT-C were detected.

Author Year (Reference)	# of Pts.	Comparisons	Results
			- Comparing participants who decreased versus increased their cardiovascular fitness over the course of the intervention, revealed significant differences in favour of the increased fitness group for the FACT-C ($p < 0.05$).
Pierce 2002 (131)	1537 1551	Counselling+cooking class Standard care	- At 12 months, the intervention group reported a significantly increased daily vegetable intake, fruit intake, and fibre intake, and energy from fat decreased significantly from 28.6% to 23.7%. - In the control group, dietary intake and plasma carotenoid concentrations were essentially identical to those of the intervention group at baseline and were unchanged at 12 months. - The intervention group achieved and maintained statistically significant changes over 4 years including servings of vegetables (+65%), fruit (+25%), fibre (+30%), and energy intake from fat (-13%) - With a mean 7.3-year follow-up, similar rates of recurrence (16.7% versus 16.9%) and survival (10.1% versus 10.3%) were reported.
Djuric 2002 (132)	12 12 12 12	Weight Watchers (WW) - Counselling with a dietitian WW and counselling Standard care	- Weight change after 12 months of intervention was as follows (mean +/- SD): 0.85 +/- 6.0 kg in the control group, -2.6 +/- 5.9 kg in the WW group, -8.0 +/- 5.5 kg in the counselling group, and -9.4 +/- 8.6 kg in the WW and counselling group. - Weight loss relative to control was statistically significant in the WW and counselling group at 3, 6, and 12 months and only at 12 months in the counselling group. - In the WW groups, weight loss was significantly related to frequency of attendance at WW meetings, and attendance was more frequent in the group that also received counselling. - At 12 months, greater weight loss was associated with significant improvements in overall FACT-An score and in the physical, functional, fatigue, and anemia subscales ($p < 0.05$).
Courneya 2002 (133)	48 60	Group psychotherapy (GP) Exercise+GP	- Significant time by condition interactions for functional well-being, fatigue, and sum of skin folds were detected. - All interactions favoured the exercise+GP group.
Burnham 2002 (134)	6 6 6	Low-intensity exercise Moderate exercise Standard care	- After the 10-week exercise program, the two exercise groups did not differ significantly in the outcome scores, hence the scores for the two intervention groups were combined. - Statistically significant differences in aerobic capacity ($p < 0.001$), lower-body flexibility ($p = 0.027$), decreases in body fat ($p < 0.001$), quality of life ($p < 0.001$) and measures of energy ($p = 0.038$) were detected in the exercise compared with the control group.

Note: # of Pts = number of patients; QOL = quality of life, CBT = cognitive behavioural therapy.

Appendix X: Summary of External Review Comments

Questions

7. The rationale for developing a guideline, as stated in the "Introduction" and "Scope and Purpose" sections of the draft report, is clear.

- Overall, reviewers agree for the rationale as stated.
- Lacking a section called “Scope and Purpose” as referred to in the AGREE II and in the external review questionnaire.

8. There is a need for a pan-Canadian guideline on organization and care delivery structure for adult cancer survivors.

- Overall, reviewers strongly agree with the need of a pan-Canadian guideline.
- There is great disparity between cancer centres to be able to offer and deliver survivorship care. A guideline may help to raise awareness and guide organizations toward quality survivorship care.
- Due to substantial variation with respect to knowledgeable professionals and resources, implementing a standardized care plan/guideline will be difficult.
- Identify the specific professionals and roles to enact the care delivery structure, as well as the linkage between the institutional and community-based system.

9. There is a need for a pan-Canadian guideline on clinical practices for psychosocial and supportive care interventions for adult cancer survivors.

- Large variations exist in the cultures of the cancer centres across Canada. The need for supportive and psychosocial care guidelines will largely depend on the culture of each centre.
- Due to substantial variation with respect to knowledgeable professionals and resources, the implementing a standardized care plan/guidelines will be difficult.
- There is a difference between supportive care and survivorship care. These need to be more clearly defined to determine which we are referring to.
- Fundamentally there is clinical oversight in believing that guidelines should start after treatment. It is critical we accept responsibility for ensuring survivors become educated about their cancer from the point of diagnosis and that we engage them in self-management at all phases of their journey, diagnosis, treatment, and post-treatment. Reinforcing this approach makes common sense from a prevention perspective.
- Include a section on physical therapy services.

10. The literature search described in the draft report is complete (no key studies or guidelines were missed).

- Overall, the reviewers agree with this statement.
- More literature is needed on the issue of the underserved (the poor, illiterate, etc.) and how such guidelines would encompass their socio-economic situation and concerns about support.

- Include literature on cognitive impairment and emotional trauma (PTSD).
- Would like to see from a health systems perspective that the work of Wagner and Bodenheimer has been incorporated. Without a stratified disease management approach in the guideline the health system will continue to struggle with meeting capacity.
- It is important to incorporate living with advanced disease into the survivorship framework, given we know that many may live for years with progressive disease but they want to belong to the survivorship program.
- Add ACSM Roundtable guidelines for exercise in cancer survivors (MSSE July 2010).
- Reconsider the McNeely CMAJ 2006 Meta-analysis on exercise interventions in breast cancer survivors.

11. The evidence described in the draft guideline on organization and care delivery structure for cancer survivorship services is relevant.

- Overall, the reviewers agree with this statement.
- There is some concern with the exclusion of qualitative studies (missing out on important interventions that have not been studied in RCTs).
- Due to low quality ratings of studies, there may be a need for conservative assessment of the evidence
- Identify more clearly why the document uses some research on survivorship care plans in children survivors- needs and outcomes are very different.

12. The evidence described in the draft guideline on clinical practices for psychosocial and supportive care interventions for adult cancer survivors is relevant.

- Overall, the reviewers agreed with this statement
- Concern was expressed with the exclusion of qualitative studies (missing out on important interventions that have not been studied in RCTs).
- Due to low quality ratings of studies, there may be a need for conservative assessment of the evidence.

13. I agree with the methods used to summarize the evidence included in the draft guideline.

- Overall, the reviewers agreed with this statement and felt that the methods used were comprehensive and rigorous.
- The document is very text heavy, the tables are very helpful.

14. The results of the studies described in the draft guideline are interpreted according to my understanding of the data.

- Overall, the reviewers agreed with this statement
- Reconsider the recommendation of including partners in sexual health interventions (Recommendation #5), as the evidence is not strong enough. Perhaps use a different language.

- In recommendation # 3, bullets 3 and 4 contradict each other. Not enough evidence yet to support individual treatment versus group treatment.

15. The draft recommendations are clear.

- Overall, the reviewers agreed with this statement
- Recommendations could be enhanced with additional recommendations on the system structure needed for effective implementation.

16. I agree with the draft recommendations on organization and care delivery structure for cancer survivorship services as stated.

- Overall, the reviewers agreed with this statement.
- Interpretation within the Canadian context would be important.
- Recommendation # 7 needs to be clear about the training/education needed to flag late symptoms.
- It is preferable to have every sentence begin with a command verb. There are some sentences that use the words "should" or "should be" and these words should be removed.
- Additional focus or recommendations are needed on process and assessment; system structure needed for effective implementation.

17. I agree with the draft recommendations on clinical practices for psychosocial and supportive care interventions for adult cancer survivors as stated.

- Overall, the reviewers agreed with this statement.
- Pleased that rehabilitation and sexual health were addressed.
- Highlight the limited evidence, specifically in women's sexual dysfunction (Recommendation #5).
- Lacking is evidence for use of group versus individual interventions. Alter language in recommendations to recognize the lack of evidence.
- Concern that the symptoms and issues that might arise over time as we learn more might not be limited to recommendations # 5 to 8 (sexual health, fatigue, vasomotor, and sleep-wake). Perhaps these could be grouped under one recommendation called "Managing individual related symptoms and concerns" and then list them and provide tactics for each one.
- Include process and assessment.

18. I would feel comfortable having these recommendations applied in my hospital/cancer centre/community programs.

- Overall, the reviewers strongly agreed with this statement.
- Make it clear that there may be need to prioritize depending on the agency.
- There will have to be considerations made regarding provider of services and reimbursement. Systems need to be re-evaluated.
- There is a long way to go to get "buy-in" from all practitioners.

- Pan-system strategies, inter-disciplinary cooperation, and funding for service/program provision need to be addressed.

19. 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)?

- Overall, the reviewers were very likely and likely to make us of the recommendations in the organization and structure of services.
- This is an essential and underserved area of health-care programming.

20. 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)?

- Overall, the reviewers were very likely to make us of the recommendations in the organization and structure of services. The recommendations would be very helpful in informing program development.
- As with other sets of recommendations, this is highly dependent on resources; currently, these types of programs are seen as “nice to have” not “need to have”.

Comments

Among other issues, you may wish to comment on the clarity and completeness of the report, the wording of specific recommendations, the links between the available evidence and the recommendations, and any significant gaps in the recommendations.

- Try to contextualize recommendations more specifically within known Canadian health care structures and processes, for example, the gatekeeper role of family physicians, and building on established pathways for management of other chronic diseases is important to facilitate policy-makers operationalizing concepts into practices/changes in delivery.
- Well written and needed guidelines; concise; very dense; much needed document (8 responses)
- The report is clear, direct, succinct and comprehensive which is what I expect in a guidance document. This is a very useful report. I expect that it will be consulted and cited regularly, and will help shape the direction of work I am leading in psychooncology over the next decade.
- The report is very thorough and focused on professionals. Is it possible to have a consumer-friendly version available?
- Few minor grammatical or word omission errors. A few problems with spacing. In the Methodology section, under Cancer Journey Survivorship Expert Panel, who is a psychosocial oncologist (this is a little confusing - is this a medical oncologist?) In top paragraph on page 18, a study reports that there were no differences in the total costs of diagnostic tests, and that more tests were performed in the primary care setting. This seems to be unusual - perhaps a comment should be made to clarify this. My understanding is that in Canada we use the spelling dietitian rather

than dietician (see Dietitians of Canada) and I would suggest using the Canadian spelling in this document.

- This is a very good start. Unfortunately, the literature is still not very clear. Having a greater rehabilitation presence in cancer services can lead to efficiencies as the focus is on function in addition to disease management. The recommendations are clear in intent but I can foresee many barriers in implementation mostly due to lack of human and financial resources.
- I am pleased to see this move forward. I would like to see more rigorous research in this area as there appeared to be some weak methodology and low sample sizes. Survivorship support is critical and the developing of guidelines is very important, and beyond that is the need to get the cancer community and the public aware and supportive.
- The report is very long, and I honestly did not have the time to read it all. I skimmed it. It looks great. The summaries are very helpful. The low to moderate quality of many of the studies is discouraging.
- With respect to the organization and care delivery recommendations, please consider including language that specifies the Advanced Practice Nurse (whether Clinical Nurse Specialist or Nurse Practitioner) rather than clumping them in under "other health care providers". The role of APNs will be critical in cancer survivorship leaving oncologists and family doctors to see new cancer patients. APNs can and will work collaboratively with physician partners to achieve this. As well APNs possess the knowledge, expertise, skills and abilities to provide care for a wide range of health care needs, including surveillance and work-up of suspected recurrence or new cancers as well as other health issues.
- Excellent document - very readable, informative and recommendations are concrete with applicability to practice; some of the recommendations are quite specific, e.g., exercise - who/what is being recommended to ensure recommendations consistent with new research findings?; no reference to genetic counselling and recommendations for family; literature review didn't include long term impacts on family members, e.g., children of parents with cancer.
- Very comprehensive report - glad to see it. There will be issues with creating SCPs - many challenges with EMRs and compatibility or no EMR and time taken... but they are very much needed.
- Defining survivorship at the point of diagnosis purges the term of substantive meaning, and inhibits strategic use of the survivorship experience in advising necessary interventions. There is a gap between the institutional use of the term and the experience of patients; in addition, there are significant inconsistencies in the use of the term just within the health care system.
- I find it interesting, and confusing, that the NCI definition of survivorship (i.e., from time of diagnosis) is put out as the accepted definition in the beginning, yet the bulk of the guideline deals with survivorship in the post-treatment/follow-up phases. The nomenclature used changes throughout the document until survivorship is simply used. It would be appreciated if it was stated more clearly up front that the guideline is dealing with post-treatment/follow-up survivorship. While the NCI has been accepted by many as an acceptable definition, this definition is also extremely troubling for many people. Many people with cancer do

not feel that they are a survivor when they are in the throws of treatment. They are trying to be a survivor but do not feel they are there, and can be very offended at being referred to as a survivor. Perhaps this complexity could be acknowledged as well.

- This report will be very helpful in planning our programming moving forward.