

Models of care for post-treatment follow-up of adult cancer survivors: a systematic review and quality appraisal of the evidence

D. Howell · T. F. Hack · T. K. Oliver · T. Chulak · S. Mayo ·
M. Aubin · M. Chasen · C. C. Earle · A. J. Friedman ·
E. Green · G. W. Jones · J. M. Jones · M. Parkinson ·
N. Payeur · C. M. Sabiston · S. Sinclair

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Abstract

Purpose The impact of cancer and cancer treatment on the long-term health and quality of life of survivors is substantial, leading to questions about the most appropriate configuration of services and models of care for follow-up of post-primary treatment survivors.

Methods A systematic review and quality appraisal of the health literature for structure of services and models of follow-up care for post-treatment survivors was identified through a search of guideline sources and empirical databases including MEDLINE, EMBASE, PsycINFO, the Cochrane Library, CINAHL, and EBSCO from 1999 through December 2009.

S. Mayo
Faculty of Nursing, University Health Network,
Toronto, ON, Canada

T. F. Hack
Faculty of Nursing, University of Manitoba,
Winnipeg, MB, Canada

T. F. Hack
Patient and Family Support Services, Cancer Care Manitoba,
Winnipeg, MB, Canada

T. K. Oliver
Department of Oncology, McMaster University,
Hamilton, ON, Canada

T. Chulak
Nutrition Sciences, ParticipACTION,
Toronto, ON, Canada

M. Aubin
Department of Family Medicine and Emergency Medicine,
Université Laval,
Quebec, QC, Canada

M. Chasen
Palliative Care Program, University of Ottawa,
Ottawa, ON, Canada

M. Chasen
Palliative Rehabilitation and Survivorship, Elisabeth Bruyere
Research Institute and Ottawa Regional Cancer Foundation,
Ottawa, ON, Canada

C. C. Earle
Health Services Research Program, Cancer Care Ontario and the
Ontario Institute for Cancer Research,
Toronto, ON, Canada

A. J. Friedman
Cancer Patient Education and Survivorship, University Health
Network,
Toronto, ON, Canada

A. J. Friedman · E. Green
Cancer Care Ontario,
Toronto, ON, Canada

G. W. Jones
Peel Regional Oncology Programme, Credit Valley Hospital,
Mississauga, ON, Canada

G. W. Jones
Department of Radiation Oncology, University of Toronto,
Toronto, ON, Canada

J. M. Jones
Department of Psychiatry, Cancer Survivorship Program,
University Health Network, University of Toronto,
Toronto, ON, Canada

M. Parkinson
Patient and Family Counselling Services, BC Cancer Agency,
Vancouver, BC, Canada

Results Ten practice guidelines and nine randomized controlled trials comprised the evidence base for models of care for adult cancer survivors. Although the evidence base was rated as low quality, nurse-led and primary care physician models of follow-up care were equivalent for detecting recurrence. Consensus also suggests that cancer survivors may benefit from coordinated transition planning that includes the provision of survivorship care plans as part of standard care.

Conclusions Realignment of models of care is identified as a health system priority to meet the supportive care and surveillance needs of a burgeoning survivor population. Further research is needed to evaluate the efficacy of models of care in a broader population of cancer survivors with differing needs and risks. While the evidence is limited, there is research that may be used to guide the configuration of health care services and planning.

Keywords Psychosocial and supportive care · Cancer survivorship · Organization of care · Delivery structure · Care plan · Systematic review

Introduction

The impact of cancer and treatment on the long-term health and quality of life of survivors is substantial, leading to questions about the most appropriate configuration of health care services and models of follow-up care for the post-treatment phase of survivorship care [1, 2]. Post-treatment survivors are at risk for a number of physical and psychosocial sequelae depending on type of cancer, stage, and treatment modality. Survivors may experience chronic pain, fatigue, sleep disturbance, cognitive dysfunction, and ongoing psychosocial issues such as depression, existential distress, fear of recurrence, disturbances in body image and/or self-concept, and changes in their sexual quality of life [3–24]. Late effects may include development of second

cancers, cardiac or pulmonary problems, reproductive system changes, and osteoporosis [25–27]. Long-term employment and financial concerns are also an issue for many survivors, and return to work may be distressing, with some never returning to work [28–31]. The post-treatment effects of cancer require ongoing monitoring and coordinated follow-up care to ensure management of persistent problems and early detection of emerging problems and late or long-term effects.

While several definitions of cancer survivorship exist, 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 impacted by the survivorship experience and are therefore included in that definition [1]. Along the cancer continuum, most of the attention is paid to the diagnostic and treatment stages of care [32]. However, the post-treatment phase of survivorship is now recognized as a distinct phase in the cancer continuum occurring at the end of primary treatment and encompassing the domains of psychosocial and supportive care, health promotion, surveillance and long-term monitoring, and early intervention for late and long-term effects [33]. This phase of care must also be considered in service planning as it is largely neglected in clinical practice, education, and research [32].

A number of landmark reports and publications have put forth recommendations on the service delivery structure and models of care for post-treatment cancer survivors [1, 2, 34, 35]. Four distinct models for follow-up care have been identified including: nurse-led, family physician-led, specialist- or oncologist-led, or shared care [2]. More recently, survivor-initiated models of care for follow-up of survivors have also been identified as a possible approach [36]. Currently, across cancer organizations, variations in models of follow-up care have emerged dependent on local health policy or as a default to the lack of consensus among clinicians and administrators regarding the model of care that is most effective. While a

N. Payeur
Patient and Family Counselling Services, BC Cancer Agency,
Victoria, BC, Canada

C. M. Sabiston
Department of Kinesiology and Physical Education,
McGill University,
Montreal, QC, Canada

S. Sinclair
Manitoba Palliative Care Research Unit, University of Manitoba,
Winnipeg, MB, Canada

S. Sinclair
Faculty of Medicine, Calgary, Alberta, and Spiritual Care Services,
Alberta Health Services, Tom Baker Cancer Centre,
University of Calgary,
Calgary, AB, Canada

D. Howell
Faculty of Nursing,
University Health Network (Princess Margaret Hospital),
610 University Ave,
Toronto, ON, Canada

D. Howell
Psychosocial Oncology and Palliative Care,
Ontario Cancer Institute,
610 University Ave,
Toronto, ON, Canada

D. Howell (✉)
Lawrence Bloomberg Faculty of Nursing,
University of Toronto,
610 University Ave,
Toronto, ON, Canada
e-mail: doris.howell@uhn.on.ca

number of possible models of care have been recommended, systematic reviews to examine the effectiveness of these models of care have not been previously conducted. This knowledge is important to guide evidence-informed health care planning or policy decisions regarding the most effective services or models that should be implemented.

Given the range of issues and support needs experienced by survivors in the post-primary treatment follow-up phase of the cancer continuum, we undertook a systematic review and quality appraisal of the evidence to assess the effectiveness of models of care that can optimize health and quality of life in the post-treatment cancer survivor population. The full systematic review examined both the models of care for survivorship services and psychosocial and lifestyle interventions. In this paper, we report only on the systematic review results that examined service delivery structures and models of care. The specific research question that was addressed in this systematic review was:

- 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, patient satisfaction, psychosocial and supportive care needs, and health-related quality of life.

Methodology

Literature search strategy

Several types of evidence were gathered in this broad systematic review. Primary studies and integrative summaries such as systematic reviews were identified and appraised in the review. Additionally, guidelines developed and used by other health services, nationally and internationally, were also identified to address consensus-based recommendations for which evidence was lacking, such as optimal follow-up periods after treatment and services such as transition planning.

The following electronic databases were searched for evidence: the Canadian Partnership Against Cancer's Inventory of Cancer Guidelines, the National Guideline Clearinghouse, Canadian Medical Association Infobase, MEDLINE (Ovid: 1999 to November 2009), EMBASE (Ovid: 1999 to November 2009), PsycINFO (1999 to November 2009), the Cochrane Library (Ovid: issue 4, 2009), and CINAHL (EBSCO: 1999 to December 2009). Reference lists of related papers were also scanned for additional citations.

The search combined cancer-related terms with terms related to post-primary treatment survivorship, and terms for care delivery or models of care and survivorship services and by study

design for models of care to identify randomized trials. Evidence was selected and reviewed by three trained reviewers. The specific search terms used for the full systematic review were initially identified for MEDLINE and adapted for the other databases. The terms used to search each database are described in more detail in the full technical report available at www.capo.ca.

Study selection criteria

Primary evidence, systematic reviews, and consensus-based guidelines were selected for inclusion in the review if they focused on the post-primary treatment phase of survivorship for adult cancer survivors and: (a) reported on models of care or (b) reported on organization of care or structure of survivorship services from a synthesis of evidence. Studies or guidelines also had to meet additional practice guidelines/standard inclusion criteria and exclusion criteria prior to as follows:

Inclusion criteria

- Be an organizational standard or practice guideline (must show rating of evidence)
- Systematic review (with or without meta-analyses) or randomized controlled trial (RCT) with methods sufficiently described
- We included guidelines that were no more than five years old

Exclusion criteria

- Pediatric cancer survivor populations or those who transitioned from pediatric cancer to adult services
- Pharmacological interventions or diagnostic testing/medical follow-up of cancer survivors
- Qualitative or descriptive studies
- Opinion papers, letters, or editorials

Critical appraisal methods

Critical appraisal methods differed for guidelines, systematic reviews, or randomized controlled trial evidence. The quality of the identified practice guidelines was assessed using the AGREE II instrument [37] by a minimum of two reviewers. Following the AGREE II convention, the quality of the guidelines were assessed based on seven criteria: scope and purpose, stakeholder involvement, rigor, clarity of evidence, presentation, applicability, and editorial independence.

The quality of the RCTs was appraised using the six criteria identified in the SIGN guideline development handbook [38]. The six criteria used to evaluate the quality of randomized trials are shown in Table 4. Based on these standard criteria, the quality of the trials was assessed as poor to moderate due to non-blinding of participants or outcome assessors, poor reporting of randomization procedures, and lack of power to

detect statistically significant differences between treatment groups on the primary outcomes of interest.

Results

Of the total 3,275 citations identified in the search of the literature, ten practice guidelines [1, 39–47] and nine RCTs [36, 48–55] provided the evidentiary base to inform the structure of survivorship services and models of care including sites of care (specialized or integrated), the types of provider, support services, and care processes (e.g., survivorship transition plans) for consideration when planning post-treatment follow-up services.

Models of care and provider type

The ten practice guidelines and quality appraisal are shown in Table 1; the quality of guidelines was assessed as moderate to poor, especially in the domain of rigor of development (i.e., >50 of 100). However, an expert panel agreed to include recommendations from guidelines as they represent consensus from experts in the field that can inform clinical practice. The recommendations relevant to models of care, type of provider, or structure of survivorship services from guidelines before are summarized in Table 2.

Five clinical practice guidelines provided recommendations on some aspect of models of survivorship care [41, 42, 44, 45, 47]. Models of care for post-primary treatment follow-up of cancer survivors included survivorship clinics [41], shared care between oncologists and primary care/family physicians [41], nurse-led survivorship care [41], and multidisciplinary models of care [41, 44]. Four practice guidelines provided recommendations on type of provider to be included as part of the survivorship care team [41, 42, 44, 46]. Two guidelines recommended that an interdisciplinary team including oncology nurses, urology nurses, radiotherapy nurses, dietitians, physiotherapists, psychologists, and sexologists comprise the follow-up care team for survivors [44, 46]. One guideline recommended that comprehensive rehabilitation services be available throughout the entire continuum of cancer care from diagnosis to survivorship [41]. Another guideline reported on the importance of collecting data on health-related outcomes and costs associated with the delivery of cancer survivorship care by various health care providers [42].

Evidentiary support for these recommendations was weak overall and based primarily on consensus. Other considerations included the need for service availability [42]; continuity of care [42, 45]; involvement of appropriate health providers [42, 44, 45, 47]; identification of the goal, frequency, and duration of follow-up visits [44, 45]; and communication between team members to minimize redundancy [47].

RCTs for models of care

Nine RCTs examined models of care for post-treatment follow-up of cancer survivors [36, 48–55]. Trials were in breast cancer [36, 48, 50, 52, 54, 55], prostate cancer [53], lung cancer [51], and colon cancer [49] mostly with low-risk post-surgical or adjuvant breast cancer populations. The primary outcomes of interest that were measured included: health-related quality of life [36, 49, 51]; psychological morbidity such as anxiety, depression, and well-being [36, 49–52]; detection of serious clinical events [48]; and satisfaction with care [49, 50, 52–55]. Secondary outcomes included diagnosis of recurrence or survival rates [48–52, 55], length of follow-up [49, 52, 55], cost [51, 55], and access to medical care and resource utilization [50, 51, 53].

The nine models of care RCTs that were examined are briefly summarized in Table 3. Standard follow-up provided by the oncologist in the cancer center was compared to care provided by either primary care physicians [36, 48, 49] or by nurses [50–53]. Three trials compared conventional follow-up with on-demand or patient-initiated follow-up [36, 52, 53]. In the three trials that compared primary care physician- and oncologist-led follow-up, no differences in quality of life or disease recurrence outcomes were reported [48, 49, 55]. In the four trials with nurse-led follow-up including patient-initiated care in two trials [52, 53], there were no significant differences in quality of life or disease recurrence outcomes when compared with standard oncologist-led follow-up care [50–53]. Patient satisfaction was higher for nurse-led care ($p < 0.01$) in one study [51]. Patient-initiated care resulted in greater patient satisfaction in one trial [52], and one trial [52] reported higher scores for emotional functioning at 12 months with nurse-led care ($p = 0.03$), while another trial [51] reported less detection of psychological distress with nurse-led vs standard oncologist-led follow-up care (47 vs 92 %, $p =$ not reported).

Critical appraisal of RCTs on models of care

The details of the quality appraisal are summarized in Table 4 for the RCTs of models of care included in this review. The quality of the trials ranged from non-assessable [52] to poor [36, 50, 51, 53, 54] or modest quality [48, 49, 55]. Blinding was not possible in most trials due to the nature of the intervention and the reliance on self-reports; however, in one trial, the block size used in random allocation procedures was unknown to study coordinators at the centers [50]. Self-reported outcomes, including quality of life and psychological morbidity, were assessed with validated tools such as the European Organisation for Research and Treatment of Cancer (EORTC)-QLQ-C30 [36, 48, 51, 55], the Medical Outcomes Study-Short Form-12 [49], the Hospital Anxiety and

Table 1 Practice guidelines and critical appraisal: service structure and models of care

Author year (ref)	Disease site	Models of care		Critical appraisal									
		Model of care	Type of provider	Support services	Service structure	Number of reviewers/ AGREE II instrument used:	Scope and purpose	Stakeholder involvement	Rigor	Clarity presentation	Applicability	Editorial independence	Overall assessment [1–7]
NCCN 2010 [39]	Colon	–	–	–	√	4–AGREE II	44.4	50.0	49.5	73.6	22.9	47.9	4.3
NCCN 2010 [40]	Rectal	–	–	–	√	3–AGREE II	53.7	40.7	47.2	83.3	31.9	77.8	5.3
ASPO 2009 [41]	Multiple	√	√	–	√	2–AGREE II	43.0	15.0	3.0	25.0	0.0	50.0	2.5
ACCC 2009[42]	Multiple	√	√	–	√	2–AGREE II	22.0	33.0	0.0	47.0	17.0	4.0	3.5
IOM 2008 [43]	Multiple	–	–	√	√	2–AGREE II	75.0	43.0	65.0	75.0	58.0	50.0	5.5
DACCC 2007[44]	Prostate	√	√	–	–	3–AGREE II	75.9	68.5	54.9	81.5	40.3	30.6	5.3
IOM 2006 [1]	Multiple	–	–	–	√	2–AGREE II	67.0	43.0	46.0	75.0	45.0	46.0	5.0
ASCO 2006[45]	Breast	√	–	–	–	4–AGREE II ^a	68.1	33.3	57.1	69.8	45.8	77.1	5.3
DACCC 2006[46]	Renal	–	√	–	–	3–AGREE II	75.9	68.5	54.9	81.5	40.3	30.6	5.6
CBCI 2005 [47]	Breast	√	–	√	√	2–AGREE II	39.0	53.0	17.0	25.0	2.0	4.0	2.5

Column numbers are percentages

Ref/reference, √ outcome 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 Netherlands: Dutch Association of Comprehensive Cancer Centres, ACS American Cancer Society, CBCI Canadian Breast Cancer Initiative

Table 2 Summary of guideline recommendations for service structure and models of care

Author, year (ref)	Models of care and provider type
NCCN, 2010 [39]	Prescription for survivorship and transfer of care to primary care physician to include summary of treatment, including all surgeries, radiation treatment, and chemotherapy received; describe possible clinical course, including expected time to resolution of acute toxicities, long-term effects of treatment, and possible late sequelae of treatment; include surveillance recommendations; delineate appropriate timing of transfer of care with responsibilities identified.
NCCN, 2010 [40]	Prescription for survivorship and transfer of care to primary care physician to include overall summary of treatment, including all surgeries, radiation treatment, and chemotherapy; describe possible clinical course, including expected time to resolution of acute toxicities, long-term effects of treatment, and possible late sequelae of treatment; include surveillance recommendations; delineate appropriate timing of transfer of care with responsibilities identified for PCP and oncologist.
ASPO, 2009 [41]	Data on health-related outcomes and costs associated with the delivery of cancer survivorship care by various health care 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. 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 patients around their follow-up care is needed.
ACCC, 2009 [42]	<p>Comprehensive rehabilitation services are available to cancer patients and their families through the entire cancer care continuum from diagnosis to survivorship.</p> <p>Each health care discipline is available on staff or by consult to facilitate continuity of care for rehabilitation services. Programs and educational resources for survivors and their families should include:</p> <ol style="list-style-type: none"> 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, as well as psychosocial, spiritual, and financial concerns. Access to information about cancer prevention, early detection, genetics, disease treatment, symptom management, and psychosocial, spiritual, 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 [43]	Every cancer patient within the 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.
DACCC, 2007 [44]	<p>Follow-up may involve various disciplines, such as oncology nurses, urology nurses, radiotherapy nurses, dieticians, physiotherapists, psychologists, and sexologists, depending on the specific problems, symptoms, and needs of the individual patient. 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).</p> <p>If the 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.</p>
IOM, 2006 [1]	<p>Patients completing primary treatment should be provided with a comprehensive care summary and follow-up plan that is clearly and effectively explained. The principal provider(s) that coordinated oncology treatment should write this “Survivorship Care Plan.”</p> <p>Health care providers must be trained to address the health care and quality-of-life issues facing cancer survivors.</p>
ASCO, 2006 [45]	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 PCP, the PCP 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.
DACCC, 2006 [46]	Multidisciplinary coordination is desirable to systematically flag psychosocial problems for the purpose of providing appropriate support.
CBCI, 2005 [47]	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. Psychosocial support should be encouraged and facilitated.

Table 3 Summary of RCTs of models of care

Author, year (ref)	No. of pts.	Comparisons	Population	Follow-up schedule	Quality of life	Patient satisfaction	Psychological functioning	Disease recurrence and complications
Grunfeld, 2006 [48]	483	Primary care physician (PCP)	Breast	3–6 monthly for 3 years then 6 monthly for 2 years to annual.	No significant differences	Not reported	Not reported	No differences in serious clinical events between standard care and primary practice (3.7 vs 3.5 %).
	485	Standard care (oncologist/cancer clinic)		Study duration, 4.5 years from diagnosis				
Wattchow, 2006 [49]	97	Primary care physician vs surgeon-led	Colon post-surgical resection	3 monthly follow-up.	No significant differences	No significant differences	No differences	No differences detected (13.2 and 11.2 %) More FOBT in primary care (rate ratio, 2.4; 95 % CI 1.4–4.4) Patterns of care differed: more colonoscopies in surgeon care (rate ratio, 0.7; 95 % CI 0.5–1.0); ultrasounds in (rate ratio, 0.5; 95 % CI 0.3–1.0)
	106			Study duration, 24 months				
Koinberg, 2004 [50]	133	Nurse-led follow-up on demand	Breast	3 monthly clinical exam for 2 years; every 6 months for 3 years; annual follow-up thereafter. Study duration, 5 years	No significant differences	No significant differences detected. Satisfied with access to medical center in standard care (>93 %). Patients generally satisfied with medical center and phone service.	No differences in anxiety and depression scores (HADS)	No differences detected (13.2 vs 11.2 % standard care). Survival same in two groups. More local recurrences detected during on-demand vs routine (too small).
	131	Standard care (oncologist/cancer clinic)						
Moore, 2002 [51]	99	Nurse-led	Lung	Following primary treatment: nurse telephone monthly compared to 2–3 monthly intervals by oncologist; study duration for 12 months	No differences in EORTC quality of life core questionnaire	Higher satisfaction in most subscales with nurse-led care at 3, 6, 12 months ($p<0.01$, $p=0.05$). No differences were seen in general practitioners' overall satisfaction	Higher emotional functioning at 12 months with nurse-led care ($p=0.03$)	No differences in survival or rates of objective progression. Less severe dyspnea at 3 months with nurse-led care ($p=0.03$). Less peripheral neuropathy at 12 months with nurse-led care. Nurses recorded progression of symptoms sooner than doctors ($p=0.01$).
	103	Standard care (oncologist/cancer clinic)						
Baillam, 2002 [52], abstract	525	Nurses-led ^a standard care (oncologist/cancer clinic)	Breast	Not reported	Not reported	Quality of life–NR patient satisfaction —higher patient satisfaction with nurse-led care ($p<0.01$).	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 %)	No differences in the detection of cancer recurrence. Patients spent more time visiting with nurses than with doctors ($p<0.01$).
Brown, 2002 [36]	31	Patient initiated to cancer clinic	Breast	4–6 monthly clinical exam for 5 years vs request only in patient-initiated	No significant differences	High levels of satisfaction but not significant. Greater reassurance	No differences in psychological morbidity between groups (HADS)	Arm-symptoms subscale scores higher with standard care compared with patient-initiated follow-up at
	30							

Table 3 (continued)

Author, year (ref)	No. of pts.	Comparisons	Population	Follow-up schedule	Quality of life	Patient satisfaction	Psychological functioning	Disease recurrence and complications
		Standard care (oncologist/cancer clinic)		group. Study duration, 12 months		with standard care for women. Convenience an advantage by men		time 1 ($p=0.003$) and time 2 ($p=0.028$)
Helgeson, 2000 [53]	200	Nurses-led ^a	Prostate	Every 6 months by phone for nurse or on demand. Study duration.,3 years	Not reported	No significant differences detected	No differences in HAD scales	No differences in medical safety. Lower mean outpatient cost per patient with nurse-led care
Gulliford, 1997 [54]	97	Standard care (oncologist/cancer clinic)	Breast	3 monthly clinical exam; 4 monthly year 2; 6 monthly for 5 years. Study duration, 16 months	Not reported	Patients expressed a preference for less vs more follow-up.	Not reported	No increased use of local practitioner services or telephone triage was detected in those randomized to less frequent follow-up by specialists.
Grunfeld, 1996 [55]	148	Primary care (oncologist/cancer clinic)	Breast	3–6 monthly for 3 years then 6 monthly for 4 years to annual. Study duration, 18 months	No significant differences	Increase in patient satisfaction over baseline with primary care intervention	No significant differences in anxiety	No significant differences in clinical outcomes: slight excess in hospital mortality in standard care. Increase in follow-up visits with primary care (3.4 vs 2.8 visits, $p<0.001$) and length of visits (10.5 vs 7.4 min, $p<0.001$) with primary care. Costs to patients and health services were lower in primary care ($p<0.001$). No difference in total costs of diagnostic tests but more tests performed in primary care ($p<0.001$)

Ref reference, *No of pts.*, number of patients, *QOL* quality of life, *HS* versus, *HADS* hospital anxiety and depression scale, *STAI* State-Trait Anxiety Inventory, *EORTC* European Organisation for Research and Treatment of Cancer

^a Patient-initiated

Depression Scale [36, 48–50, 52], and the Spielberg Trait Anxiety Inventory [52]. Five of the trials that evaluated patient satisfaction as a primary outcome did not use validated measures [50–54]. However, three studies pilot tested the items with focus groups [51, 53] or provided reliability statistics [50]. Two trials used validated tools to collect patient satisfaction information [49, 55].

The synthesis of effect sizes across the models of care using a meta-analysis approach was not possible given the diversity of models examined and intervention approach. However, the Grades of Recommendation, Assessment, Development, and Evaluation (GRADE) approach has recently emerged as a promising system of grading the quality of evidence for use in the development of clinical recommendations [56]. As seen in Table 5, 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, and there is little evidence that directly answers the questions of interest for differing cancer types. 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.

Site of care

None of the guidelines provided recommendations specifically addressing the site of survivorship care, nor did the RCTs of follow-up interventions specifically explore advantages or disadvantages associated with the site of care. Of the RCTs where follow-up was conducted in the primary care (family physician) office setting with comparisons to oncologist-led care in cancer centers [48, 49, 55], two trials reported no overall differences in outcomes by study group [48, 49], while one study reported increased patient satisfaction over baseline, with more (3.4 vs 2.8 visits, $p < 0.001$) and longer (10.5 vs 7.4 min, $p < 0.001$) follow-up visits with primary care vs specialist care [55].

Structure of care: transition care processes

As shown in Table 2, most of the guidelines provided recommendations on the structure of follow-up care processes including the provision of survivorship transition care plans. Two guidelines recommended the need for written survivorship care plans to prepare survivors for the transition from the active treatment to the post-primary treatment follow-up phase [1, 43]. In addition, it was recommended that survivors be provided with knowledge regarding the adverse late effects that may occur in the survivorship phase [44], new and persistent symptoms to report without waiting for the next scheduled appointment [47], and clear designation of which care provider to contact for emerging problems [44].

Table 4 Critical appraisal of RCTs of follow-up strategies

Author, year [ref]	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 [48]	-	+	-	++	++	++	-	+	-	++
Wattchow, 2006 [49]	+	++	+	+ ^b	+	+	>20 %	+	+	+
Koinberg, 2004 [50]	+	++	- ^a	-	+	+	-	+	+	+
Moore, 2002 [51]	-	+	-	+	+	+	-	-	+	+
Baldam, 2002 [52] ^c	-	-	-	-	-	-	-	-	-	-
Brown, 2002 [36]	+	+	-	+	+	+	<20 %	-	-	-
Helgesen, 2000 [53]	+	+	-	+	+	-	>20 %	-	+	-
Gulliford, 1997 [54]	-	+	-	+	-	-	-	-	+	-
Grunfeld, 1996 [55]	+	+	-	++	++	+	<20 %	+	+	+

Ref reference, ++ well addressed, + adequately addressed, - poorly or not addressed

^aBlock size unknown to study coordinators at centers

^bTrend toward higher education in surgeon follow-up group

^cAbstract

Table 5 Grade evidence summary: structure of care and models of care

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	⊕⊕OO LOW	Low
Site of care								
3	RCT	Serious	Serious	Serious	Serious	None	⊕⊕OO LOW	Low
Type of provider								
13	CPG, RCT	Serious	Serious	Serious	Serious	None	⊕⊕OO LOW	Low
Support services								
4	CPG	Serious	No serious inconsistency	No serious indirectness	No serious imprecision	None	⊕⊕OO LOW	Low
Structural approaches								
8	CPG	Serious	No serious inconsistency	No serious indirectness	No serious imprecision	None	⊕⊕OO LOW	Low
Other								
4	CPG	Serious	Serious	Serious	Serious	None	⊕⊕OO LOW	Low

CPG clinical practice guideline, SR systematic review, RCT randomized controlled trial

Structure of care: preparation of providers

Four guidelines also advocated for ongoing educational opportunities to be provided to members of the survivorship care teams [1, 41–43]. The Association of Community Cancer Centers (ACCC) [42] and the Institute of Medicine (IOM) [1, 43] 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 needs and quality-of-life issues facing cancer survivors.

Moreover, the American Society of Preventive Oncology (ASPO) 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 around their follow-up care is needed [41]. 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 [1, 43].

In addition, it was recommended that organizations providing research funding should support assessment of the implementation of 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 recommendations [43]. Based on the consensus of experts, the ACCC also recommended that resources be allocated to

provide a robust survivorship program and implementation of national standards for survivorship care into program planning, implementation, and evaluation [42].

Discussion

There is consensus, globally, that the traditional model of oncologist and cancer center follow-up care is not sustainable and must be reconfigured to meet the needs of a burgeoning post-treatment survivor population. Additionally, oncologist-led follow-up care may not be necessary for low-risk populations such as women post-adjuvant breast chemotherapy given the equivalence of primary care physicians in detection of recurrence. This systematic review yielded clinical practice guidelines and primary randomized controlled trial evidence that could help to inform health care decision making and policy regarding effective models of care and best practices for structuring post-treatment survivorship services. Although the evidence base is limited, the trials reviewed suggests that nurse-led and primary care physician follow-up care is equivalent in detecting recurrence when compared to oncologist-led care, and patients are satisfied with this approach. Nurse-led care may be a viable option for follow-up care and is being implemented in many leading cancer organizations [57], but these models will also need to ensure appropriate communication with primary care physicians who hold responsibility for the overall health of their population [58]. Most important, the

evidence reviewed suggested that primary care and nurse-led models of care are equivalent in a post-surgical colorectal and prostate populations and following adjuvant treatment for breast cancer. These models of care may not apply to survivors with more complex needs or for whom early detection of disease recurrence requires more specialized follow-up tests available in cancer programs or when specialist physical assessment is required (i.e., gynecologist–oncologists). We did not identify specific models or evidence for shared care models, but these have been shown to be effective in other populations where the needs of patients are complex [59]. These models of care may be important to consider in the call for more risk-based models of care for post-treatment survivors [60]. Risk-based models of care are considered most beneficial for populations who are considered high risk for persistent post-treatment problems and recurrence that requires ongoing monitoring and intervention by oncology specialist teams [61]. The assumption in most models of care is that the primary care physicians will assume their roles in usual cancer screening and surveillance, but this will only occur if effective channels of communication are established [58] and family physicians are provided with specific information regarding the surveillance monitoring required for specific cancers and types of treatment received [62]. Given the diversity of outcomes measured across the model of care studies and that most were focused on breast cancer populations or recurrence end points, further research is needed to establish the efficacy of these models of care for optimizing health and quality of life for post-treatment survivors.

Consistent with the consensus-based guideline evidence reviewed, transition care processes that include written survivorship care plans are important to reduce the distress of transitioning from active treatment to follow-up care. Survivorship care plans guide survivors on the disease surveillance required but must also include the self-regulatory actions they can take for identifying and reporting emerging problems and regaining health. Regardless of the model of care, it is clear that passive dissemination of information or traditional patient education seldom translates into the adoption of health behaviors [62]. Reducing risks of recurrence through health behavior change where there is evidence of effectiveness will be critical to service planning and not just the early detection of recurrence. Additionally, it must be recognized that survivors will require navigated access to multidisciplinary specialists and other physician specialists depending on emerging or expected late effects (i.e., endocrinologists, cardiac specialists). Currently, access to coordinated interdisciplinary teams that can address the broad range of issues experienced by post-treatment survivors inclusive of psychosocial distress is important but untested. While models of care that are effective have been shown in this review, implementation of these in routine care can be challenging and will require an understanding of knowledge to action approaches that are most effective and take into consideration the local and contextual health care environment.

Conclusion

The findings of this systematic review may help to inform policy and decision making regarding the service configurations for follow-up survivorship care that are most appropriate based on the evidence and considering the local health care context and available resources. Clearly, there is a need for further research on how to best structure care for post-treatment cancer survivors that includes examination of the cost-effectiveness of differing models of care including appropriate models of care that address populations considered to be at higher risk.

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