Survivorship care models for breast cancer, colorectal cancer, and adolescent and young adult (AYA) cancer survivors: a systematic review

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Abstract

Background Well-elucidated survivorship care models are pertinent in the long-term management of cancer survivors. This review aims to update existing literature and evaluate the key components of such models with a focus on breast, colorectal, and adolescent and young adult (AYA) cancer survivors.

Methods The PubMed electronic database were searched comprehensively for relevant publications in English through February 2017. Additional manual searches were conducted for reference lists and official guidelines published by oncology societies. Included studies addressed the correct cancer type, elaborated on each model's structure and provided patient-related outcome data to support its model's effectiveness if applicable.

Results Among the 25 included studies, six articles described survivorship models applicable to all cancer types, and the remaining focused on breast cancer ($n = 10$), colorectal cancer ($n = 3$), and AYA cancer survivors ($n = 6$). Shared-care model was largely described for all cancer types whereas multidisciplinary model predominated for AYA cancer survivors. Upon evaluation, these models described the essential components of survivorship care fairly well except for the care coordination component. Also, the definition of time points of care was vague and noncomprehensive.

Conclusion The reviewed survivorship model studies were comprehensive but were limited by a lack of existing rigorous evaluation efforts to assess their effectiveness. This review further provided valuable recommendations for future methodological evaluation of such models. This review has highlighted care coordination as an area for improvement and emphasized the importance of obtaining data on the effectiveness of these survivorship models to ensure satisfactory quality of life and health outcomes.

Keywords Cancer survivors · Survivorship model · Breast cancer · Colorectal cancer · Adolescents and young adults

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Introduction

With greater advancements in detecting and treating cancers, lifespans of cancer survivors are extended where up to two thirds are estimated to survive more than 5 years after their cancer diagnoses [1]. Thus, survivorship care provision is an area of increasing importance to manage survivors' late side effects, compromised physical functional status, and psychosocial issues [2]. To systematize survivorship care, proposed survivorship care models are typically characterized by the description of treatment summaries, care plans, and care services [3]. The Institute of Medicine (IOM) further delineates the essential components of an ideal model: measures to prevent and surveillance methods to detect new or recurrent cancers; appropriate interventions to manage side effects; and

defined pathways that specify care coordination or distribution between specialists and primary care physicians (PCPs) [4, 5].

Given a heterogeneous cancer survivors population, general care models may not be adequate in addressing the optimal risk-stratification strategies, surveillance methods and long-term side effects management for all cancer types. Therefore, contextualizing care models to homogenous subgroups is warranted for the purpose of clinical implementation. When considering cancer diagnosis-specific care models, existing evidence-based surveillance plans were largely developed for breast and colorectal cancers due to their high prevalence and favorable survival rates [1, 3, 6]. Additionally, adolescents and young adults (AYA) with cancer diagnoses made between 15 and 39 present collectively as a distinct subgroup where survivorship care is driven by the pertinent need to ensure close monitoring of long-term health status beyond primary cancer remission due to an elevated risk of morbidity and mortality after 40 years old [7, 8]. This need is complicated by a great susceptibility to follow-up loss and the complex psychosocial issues accompanying transition to adulthood. They are then likely to reap significant benefits from a structured survivorship care model that promotes life-long practices to maximize the quality of their survival [7].

Existing reviews on survivorship models are largely limited by their lack of contextualization [3, 9–11]. Consequently, there is a lack of robust evaluations of models in assessing their appropriateness for clinical use. This systematic review then aims to address this research gap by (i) updating studies on survivorship care models with additional focus on breast, colorectal and AYA cancer survivors and (ii) conducting preliminary evaluation of these models. Subsequently, this review can shed light on the key metrics required to assess essential elements of survivorship care models for future consideration.

Methods

Search strategy

Through PubMed (inception to February 2017), we searched comprehensively and systematically for English literature on survivorship care models that were general or specific to breast cancer, colorectal cancer and AYA with cancers. To enhance the robustness of our search, we manually reviewed reference lists of studies retrieved by electronic search. Additionally, we conducted a manual search for official guidelines drawn up by the respective oncology societies.

We assembled extensive search terms to capture all potentially relevant articles. A series of search terms was dedicated to contextualizing the type of cancer of interest. For general cancer, variations of the word “cancer” like “neoplasm (MeSH terms)” would be paired with “breast,” “colorectal” or

“bowel,” “adolescents and young adults” to yield studies on the specific cancer types. These terms were subsequently combined with survivorship-related terms like “survivorship,” “survivorship model,” “survivorship care model,” and “survivorship models of care and ‘survivorship service.’” We reviewed the abstracts and retrieved the full-text articles that met the inclusion criteria for further review.

Study selection

We included studies that met the following criteria: (i) addressed the correct type of cancer including general cancer survivors of any age, special focus on breast, colorectal, and AYA cancer survivors in remission and (ii) reported on principles and framework supporting a model’s structure. Considering current lack of consensus over the type of study designs appropriate for examining survivorship care models, we did not impose strict restrictions on the study designs and we have included clinical practice guidelines [3].

We excluded studies that focused on: (i) designing survivorship care plans (SCPs) only; (ii) assessing effectiveness of interventions without adequate description of their implementation in terms of the specific services provided and the healthcare providers’ involvement; (iii) examining cost-related issues; (iv) reporting one-time intervention/program without follow-up; (v) studying attitudes, perspectives and feelings of healthcare providers or patients without accompanying model structure; and (vi) describing needs assessments instead of overarching care principles.

Eligibility assessment was performed by two investigators (K.Y. and T.N.). A single investigator performed the initial review and selected relevant studies before sending the same set of search results to another investigator (T.N.) for independent validation according to the eligibility criteria outlined.

Data extraction

One reviewer (K.Y.) appraised and extracted relevant information from the selected articles. Data items included the study design, cancer survivors of interest, study objective with respect to survivorship care, model characteristics, outcomes if any, and the conclusion or significance of study. Model characteristics referred to information pertaining to the model type, major components, parties involved (healthcare providers, patients), and the presence of inter-professional collaboration. We adopted the following terms to characterize the type of models described in the studies [12]. First, a shared-care model is defined as a care transition from oncology specialists to primary care provider generalists. Second, a multidisciplinary care model is defined by the provision of specialized care by a dynamic team of healthcare professionals largely based in cancer centers [12]. Humanistic outcomes data extracted (e.g., quality of life and satisfaction with care

measures) were related to change in cancer survivors' health status after direct involvement in the care model elucidated.

The study characteristics extracted were critically summarized in tabular form and stratified by cancer diagnosis into all cancer types and specifically breast, colorectal and AYA cancers. However, we did not assess the methodological quality of each study due to the diverse underlying study designs and types. We further formulated an evaluation criteria addressing the models' limitations and reinforcing the desirable features of an ideal survivorship model. The criteria were primarily based on the four principles outlined in the IOM report: prevention, surveillance, intervention, and care transition [4]. We examined the adequacy of each model's components in terms of its treatment of SCPs, clear definition of care delivery time points, and consideration of risk stratification. We also sought to delineate the roles of both healthcare providers and survivors in the long-term care management and to provide suggestions on the types of outcomes required to establish clinical utility of such models.

Results

Search results

Figure 1 summarizes the search process and results. We identified 566 and 7 citations from the electronic database and other additional records, respectively. After removing 35 duplicates, we screened the titles and abstracts of 538 articles before retrieving the full text of 39 articles. Subsequently, 14 articles were excluded with reasons. Eventually, 25 articles were included in our analysis. Articles dated from 2006 to 2017 and were either general or contextualized in Australia, Canada, Europe, Italy, South Korea, and the USA.

Study characteristics

Among the 25 included articles, 6 provided descriptions of survivorship frameworks that are applicable for all cancer types (Table 1) [3, 5, 13–16], 10 articles focused on breast cancer survivors (Supplementary Table 1) [17–26], 3 articles focused on colorectal cancer survivors (Supplementary Table 2) [27–29], and 6 articles focused on AYA cancer survivors (Supplementary Table 3) [7, 30–34]. Notably, four articles on all cancer types, seven articles on breast cancer survivors, two articles on colorectal cancer survivors, and all articles on AYA cancer survivors were published after the latest systematic review in 2014.

General survivorship frameworks

Multidisciplinary care and shared-care models were the two major types of models described in studies. They provided the skeletal structures for subsequent applications to specific

cancer groups. The multidisciplinary care model is characterized by a dedicated team of healthcare professionals such as physicians, nurses, social workers, psychologists, counselors, and other allied health practitioners providing a range of health services [5, 13]. This model is largely restricted to cancer centers with an emphasis on multidisciplinary collaboration. One study reported a 76% satisfaction level among cancer survivors for the emotional support services provided by the multidisciplinary care team in Australia [13].

In the shared-care model, cancers are regarded as chronic diseases where survivors are transitioned from oncology specialist care to PCPs for long-term management. Three studies suggested using risk stratification to facilitate this process [5, 14, 16]. Survivors identified as “high risk” would be subjected to more extensive co-management by oncologists and PCPs. To ensure a smooth care transition, another study proposed the creation of centralized information sharing system to enhance clinical data sharing across tertiary and primary care settings [15]. Additionally, further education, training, and certification of PCPs were highlighted to be pertinent in increasing this model's feasibility [15, 16].

Under both model types, nurses were described to have a dual and flexible role in care provision. In the multidisciplinary model, they could act as care coordinators to conduct needs assessment and to make referrals [13]. In the shared-care model, they could serve as an intermediary between oncologists and PCPs to ease care transitions [5, 14].

Survivorship care models for breast cancer survivors

Three studies that described multidisciplinary care model focused on rehabilitation. Two studies collectively discussed a prospective surveillance model that can be integrated into the multidisciplinary model [18, 26]. This model defined multiple care phases with respect to a surgery intervention. Routine screenings of upper extremity impairment, pain, fatigue, function, and weight were necessary monitoring efforts to detect warning clinical signs for early intervention. Health promotion focusing on exercise was recommended. Hence, exercise and rehabilitation professionals, psychiatrists, physical and occupational therapists should be engaged to manage the physical and functional impairments. Another study introduced a new healthcare party—a specialized breast nurse—to be fully involved in a survivor's follow-up from diagnosis in specialized rehabilitation facilities [24].

For shared-care models, five studies reported recommendations according to the IOM components [4, 19, 21, 22, 24, 25]. Key surveillance areas include annual contralateral mammography with ultrasound, annual mammography and lipid screening. The long-term events that require continual assessment and management include cardiovascular health, cognitive function, osteoporosis, pain, neuropathy, lymphedema, distress, depression, anxiety, sexual function, fertility, and

Fig. 1 Flow chart showing search methodology and selection criteria

premature menopausal signs. Psychosocial services should be provided together with preventive health measures on exercise, nutrition and smoking cessation. Risk evaluation and genetic counseling were also highlighted to identify women with high risk for recurrence or with genetic predisposition due to familial history [22]. Furthermore, for survivors with receptor-positive breast cancers, one study reported a hormone therapy reassessment referral system to refer survivors back to consults with oncologists periodically to follow-up on their hormone therapy regimen [23].

Two studies further emphasized the importance of survivors' self-empowerment in survivorship care [17, 20]. Follow-up frequency and duration, together with the choice of model type should be individualized [17]. Using the self-management strategies proposed by one study, integrated cognitive behavioral strategies and internet-based interventions were utilized as education tools to improve fatigue, insomnia and quality of life with a survival advantage of 4.9% [20].

Survivorship care models for colorectal cancer survivors

Studies on colorectal cancer survivors were mainly guidelines and were similar in their consistent adoption of the shared-care model with recommendations targeting the IOM components. As 30–50% of survivors are expected to experience relapse, surveillance was a central issue addressed by all studies [29]. PCPs play a pivotal role in conducting regular screening and physical assessment with care coordination maintained via SCPs. Intensive follow-up was proposed to screen for recurrent cancer through scheduled colonoscopy, and other secondary primary cancers occurring in breast, cervix, prostate, genitourinary tract, skin, and lung. In particular, carcinoembryonic antigen monitoring was unanimously recommended to detect for recurrence signs. Health promotion and side-effects management of cognitive function, pain, neuropathy, distress, anxiety, depression and fertility coincided with the management of

Table 1 Characteristics of studies on general survivorship care models

Author (year)	Setting	Objective	Model characteristics		Parties involved (healthcare providers, survivor)	Collaboration	Outcomes	Conclusion/significance
			Type	Main components				
Cadet et al. (2016) [13]	Cancer survivors in Bloomhill Cancer Center (BCC), Australia	Describe evidence-based principles of holistic care and identify opportunities for service provision	Multidisciplinary care model	<ul style="list-style-type: none"> • SCP • Regular needs assessment • Services: exercise, yoga, meditation, touch therapies, acupuncture • Community engagement activities 	<ul style="list-style-type: none"> • Survivor is empowered to self-manage own health • Care is chiefly led by skilled cancer nurses who coordinate care through assessment, support, needs identification, and referral • Allied health practitioners: psychologists, counselors, dieticians, and exercise physiologists • Other parties: social support groups 	Collaborations with public, private and community.	<ul style="list-style-type: none"> • 67% were satisfied with their first contact • 77% were satisfied with their first meeting with the cancer nurse specialist • Over 90 and 76% were very satisfied or satisfied with the touch therapies and emotional support, respectively • Needs: areas of mindfulness, nutrition information, and emotional assistance 	Early success of BCC interventions offers other countries a framework for the provision of cancer supportive care.
COSA guidelines (2016) [14]	Cancer survivors in Australia	Define critical components of cancer survivorship care	Shared-care model	<ul style="list-style-type: none"> • SCP: main concerns and actions for surveillance, management, and rehabilitation • Risk-stratified care • Services: needs assessment, services directory, referral pathways, Telehealth • Community engagement programs to support survivors' self-management • Services: monitoring for 	<ul style="list-style-type: none"> • Survivors self-manage through self-monitoring and are stratified according to risk • Care for low-risk survivors are led by PCPs with remote monitoring • Care for moderate- and high-risk survivors are led by specialists, nurses and allied health practitioners while supported by PCPs • Other parties: community support groups 	Collaborations between various healthcare providers are facilitated and encouraged, in order to allow timely access to necessary services and to ensure appropriate follow-up.	No outcomes were evaluated.	The proposed model depicts stages, factors, and processes to be considered in planning, developing and adapting survivorship services.
Lim et al. (2016)	Cancer survivors	Explore issues and provide	Shared-care model	<ul style="list-style-type: none"> • Services: monitoring for 	<ul style="list-style-type: none"> • Treatment and acute care are managed by 	Collaborations between healthcare providers in	No outcomes were evaluated.	Study adapted of key concepts from chronic

Table 1 (continued)

Author (year)	Setting	Objective	Model characteristics		Parties involved (healthcare providers, survivor)	Collaboration	Outcomes	Conclusion/significance
			Type	Main components				
[15]	in South Korea	suggestions for developing a Korean survivorship care model		recurrence, comorbidities management, nutrition management, and psychosocial counseling	specialists whereas long-term survivorship care is led by certified PCPs	tertiary and primary settings are based on a centralized clinical information sharing system.		care model to construct a Korean survivorship care model.
Nekhlyudov et al. (2017) [16]	Cancer survivors in USA	(i) Assess survivorship models described in literature. (ii) Focus on integrating PCPs into survivorship care	Shared-care model	<ul style="list-style-type: none"> SCP: developed by oncologists and transitioned to PCPs Risk-stratified care determined 5 years after initial treatment 	<ul style="list-style-type: none"> Survivors are stratified according to risk Care for low-risk survivors are led by PCPs with noncancer-focused care Care for intermediate- and high-risk survivors are co-managed by oncologists and PCPs Other parties: nurse practitioners, case managers (nurses and social workers) assist in care transition to PCP 	PCPs' involvement in cancer treatment and communication with the oncology team is encouraged.	No outcomes were evaluated.	PCPs can actively learn from oncologists and should be trained to be involved in survivorship care across various settings.
Oeffinger et al. (2006) [5]	Cancer survivors in the USA	Discuss models of survivorship care in both community and academic settings	Shared-care model (community--based and institution--based)	<ul style="list-style-type: none"> SCP: developed upon treatment completion to include information on cancer diagnosis, stage and treatment SCPs are regularly updated according to changes in recommendations on surveillance and management of late effects Needs assessment: physical, emotional 	<ul style="list-style-type: none"> Long-term care is led chiefly by PCP with oncologists providing guidance and consultations Other parties: nurse practitioners in cancer centers can act as intermediary for a few years before formal transition. 	Collaboration between oncologists and PCPs is maintained through PCPs and consults. Nurse practitioners can also be engaged.	<ul style="list-style-type: none"> No outcomes were evaluated. Proposed outcomes for future studies: mortality, morbidity and health-related quality of life (SF-36, EORTC, FACT) 	Study provided a general framework for shared-care model but are limited in its unpredictable scalability and lack of clinically relevant evaluation.
			Multidisciplinary care model	Long-term follow-up	Care team: trained physicians on	Care is mainly focused within the multidisciplinary care	No outcomes were evaluated.	

Table 1 (continued)

Author (year)	Setting	Objective	Model characteristics		Parties involved (healthcare providers, survivor)	Collaboration	Outcomes	Conclusion/significance
			Type	Main components				
Viswanathan et al. (2014) [3]	Adult-onset cancer survivors	Systematic review describing existing and proposed models of survivorship care	<ul style="list-style-type: none"> Shared-care model Multidisciplinary care model 	<p>The review focused on evaluating existing models presented in literature through August 2013.</p>	<p>survivorship, oncology nurse practitioners, social workers, psychologists, administrators, and a network of consulting physicians.</p> <ul style="list-style-type: none"> Shared-care model: care is co-managed by oncologists and PCPs Multidisciplinary care model localized within cancer centers: care led by oncologists or nurses 	<p>team with PCP playing a supplementary role.</p> <p>Care coordination across care settings and within care teams in cancer centers is encouraged.</p>	<ul style="list-style-type: none"> Reported outcomes on models reviewed Proposed outcomes for future studies: quality of life, satisfaction surveys, adherence, and resource utilization 	<p>Studies on survivorship care models are largely heterogeneous with limited supporting evidence on their effectiveness.</p>

Abbreviations: COSA, Clinical Oncology Society of Australia; EORTC, European Organization for Research and Treatment of Cancer; FACT, Functional Assessment of Cancer Therapy; GP, general practitioner; PCP, primary care physician; SCP, survivorship care plan; SF-36, Item-36 Short Form Survey

breast cancer survivors. Long-term effects specific to this survivor group include bowel movements, dental and urinary health. The 2016 ASCO guidelines proposed further research in managing these effects since current evidence could be improved [27].

Survivorship care model for AYA cancer survivors

Among six studies, two studies alluded to a shared-care model while the rest described a multidisciplinary care model. This observation was understandable given that the complex psychosocial needs of this survivor group due to the unique developmental stage warrant a team of diverse healthcare professionals. Specifically, these psychosocial supportive services should be directed at reintegrating survivors back to their normal lives or workforce by addressing developmental implications, social relationships and spiritual needs [30, 33].

In light of the large spectrum of possible cancers implicating this survivor group, long-term effects management should be specific to exposure. For instance, dental examination is recommended only for survivors with prior chemotherapy and radiation exposure [31]. Nevertheless, some common areas of management include endocrine disorders, cardiomyopathy, pulmonary fibrosis, and secondary malignant neoplasms [7]. Vaccinations, fertility-preserving facilities and the standard health promotion areas on exercise and nutrition are also recommended [30–32].

Despite the diverse range of cancers, three studies utilized risk stratification to guide care provision [7, 30, 32, 33]. For example, annual phone follow-up was performed in the low-risk group, whereas dedicated programs compromising of neurological and psychophysical rehabilitation were available for the high-risk group [32]. Age-based assessment tools and education were also emphasized to provide age-appropriate referrals [33]. Furthermore, multiple studies promoted survivors' enrolment into clinical trials as long-term medical and psychosocial outcomes are currently limited [30–32].

Lastly, the demonstration of respect for survivors' autonomy is crucial in empowering them to make informed decisions of their own survivorship care [30, 32, 34]. Initiatives can be categorized into active engagement and constructive environment creation. The former includes self-advocacy skills training and communications through technology with care providers [30, 32]. It can be further subjected to creative explorations like photography course, exhibitions, singing songs, and novel writing sessions as implemented in a Milan institution [32]. The appropriate care environment for AYA cancer survivors include age-dedicated spaces, facilities like gyms and classrooms, the creation of friendly and welcoming physical inpatient and outpatient environments [32, 34].

Evaluation of survivorship care models

Table 2 summarizes the model evaluation results. We excluded two studies from this evaluation due to their focus on reiterating models already presented in other literature [3, 7]. Seven studies reported multidisciplinary model, thirteen studies reported shared-care model, and three studies provided recommendations for follow-up care without explicit reference to any model structure.

Majority of the multidisciplinary care models described in studies addressed the IOM components fairly well except for care coordination between specialists and PCPs [5, 18, 24, 26, 33, 34]. Due to the focus on a dedicated care team in cancer centers, PCPs only played a supplementary role in acute conditions management without significant involvement in survivorship care. Follow-up time points were also poorly delineated, with only explicit recommendations made to the transfer of survivors from primary oncologist to multidisciplinary care team 1 to 2 years after treatment completion [5]. The use of SCPs was moderate possibly due to a diminished need to relay clinical information to PCPs. As this model is highly survivor centric, majority of the models highlighted a focus on survivor's self-management. However, only limited precise strategies were described.

Similar to the multidisciplinary care model, the shared-care models described in the studies were also adequately compliant to the IOM recommendations. The performance in the care coordination component was better due to more extensive engagement with PCPs to distribute the care burden. The value of PCPs was emphasized in the management of colorectal cancer survivors since mortality manifests more often from general causes that would benefit from consistent PCPs' holistic care [29]. Therefore, SCPs' construction emerged as a highly important element to facilitate care transfers. In general, several studies agreed that SCPs should be initiated by an oncologist with each cancer survivor upon treatment completion. Each SCP should include a treatment summary, expected late side effects, types of monitoring and surveillance parameters, relevant contact information, and outstanding survivor-identified needs. Clear definition of time-points is crucial to facilitate this care transition. However, differing recommendations were observed where one study recommended a transition to be made 1 to 2 years after treatment completion and another suggesting a 5-year period instead [5, 16]. Nevertheless, screening schedules for both breast and colorectal cancer survivors were clear and agreeable [25, 28, 29].

Overall, the definition of the time points of care was vague and incomprehensive across both model types. Nonetheless, the literature provided valuable information on risk stratification and the significance of care continuity. Risk stratification is a refining strategy that can be employed in both model types. The proposed method of assessing risks obtained information on the complexity and exposure of cancer treatment,

Table 2 Evaluation of models elaborated in included studies

Author (year)	IOM recommendations			Model components			Relevant parties		Special needs of specific cancer population	Outcomes measured
	Prevention of new/recurrent cancers	Surveillance for new/recurrent cancers	Intervention for complication of cancer	Coordination between specialists and PCP	Survivorship care planning	Time-points of care	Risk stratification	Focus on PCP		
Multidisciplinary model										
Cadet et al. (2016) [13]	✓	×	✓	×	✓	×	×	×	General	✓
Oeffinger et al. (2006) [5]	✓	✓	✓	✓	✓	✓	×	✓	General	×
Gerber et al. (2012)	✓	✓	✓	×	✓	✓	×	×	Breast cancer survivors are predisposed to physical impairments like pain, fatigue, upper-extremity dysfunction, neuropathy, weakness, joint arthralgia, osteoporosis, and lymphedema	×
and Stout et al. (2012) [18, 26]										
ESMO guidelines, Senkus et al. (2015) [24]	✓	✓	✓	×	×	✓	×	×	Risk of relapse among breast cancer survivors differ according to cancer's receptor status	×
Magni et al. (2016) [32]	✓	×	✓	×	×	×	✓	×	• Care for AYA survivors should be patient-centered to acknowledge their level of autonomy and maturity	✓
									• Clinical trials are limited for this group	
Victorian AYA Cancer Service guidelines, Palmer et al. (2008) [33]	✓	✓	✓	✓	✓	×	✓	×	Many AYA patients experience a loss of continuity when their care change from active treatment to surveillance in the survivorship stage	×
Ramphal et al. (2011) [34]	✓	✓	✓	✓		×		×	The psychosocial state of AYA survivors largely determine	×

Table 2 (continued)

Author (year)	IOM recommendations		Model components				Relevant parties		Special needs of specific cancer population	Outcomes measured
	Prevention of new/recurrent cancers	Surveillance for new/recurrent cancers	Intervention for complication of cancer	Coordination between specialists and PCP	Survivorship care planning	Time-points of care	Risk stratification	Focus on PCP		
Shared-care model										
COSA guidelines (2016) [14]	✓	✓	✓	✓	✓	✓	✓	✓	General	×
Lim et al. (2016) [15]	×	✓	✓	✓	×	×	×	✓	General	×
Nekhlyudov et al. (2017) [16]	✓	✓	✓	✓	✓	✓	✓	×	General	×
Oeffinger et al. (2006) [5]	✓	✓	✓	✓	✓	✓	✓	×	General	×
CMAJ guidelines, Grunfeld et al. (2005) [19]	✓	✓	✓	✓	×	×	×	✓	PCPs have an important role in managing breast cancer survivors through regular follow-up surveillance before care escalation	×
Luetka-Flude et al. (2015) [21]	✓	✓	✓	✓	✓	×	×	×	Care transition should be smooth and complete so that breast cancer survivors do not feel abandoned	×
ASCO guidelines, Runowicz et al. (2016) [22]	✓	✓	✓	✓	✓	×	×	✓	Breast cancer history is a risk factor for recurrence and genetic counseling should be considered	×
Rushton et al. (2015) [23]	✓	✓	✓	✓	✓	×	✓	✓	Care coordination between PCP and specialists can be further improved with a standardized	✓

Table 2 (continued)

Author (year)	IOM recommendations			Model components			Relevant parties		Special needs of specific cancer population	Outcomes measured
	Prevention of new/recurrent cancers	Surveillance for new/recurrent cancers	Intervention for complication of cancer	Coordination between specialists and PCP	Survivorship care planning	Time-points of care	Risk stratification	Focus on PCP	Focus on survivors	
Sisler et al. (2016) [25]	✓	✓	✓	✓	✓	✓	×	✓	discharge process from cancer centers Breast cancer has high survival rates that will benefit from long-term proper survivorship care provision	×
ASCO guidelines, El-Shami et al. (2016) [27]	✓	✓	✓	✓	✓	×	×	✓	Focus of managing colorectal cancer survivors should extend towards managing long-term side effects	×
Jorgensen et al. (2015) [28]	✓	✓	✓	✓	✓	✓	×	✓	• Surveillance for cancer recurrence is a key element of follow-up care for colorectal cancer survivors • Other aspects of managing long-term effects should be further considered	×
ESMO guidelines, Labianca et al. (2013) [29]	✓	✓	✓	×	✓	✓	×	✓	Majority of colorectal cancer survivors die of other causes. Thus, general and preventive health issues are pertinent. AYAs have high survival rates and thus, medical, neuro-cognitive, and psychosocial late effects require ongoing assessment and surveillance	×
COSA guidelines, CanTeen (2015) [30]	✓	✓	✓	✓	✓	✓	✓	✓		✓

Table 2 (continued)

Author (year)	IOM recommendations			Model components			Relevant parties		Special needs of specific cancer population	Outcomes measured
	Prevention of new/recurrent cancers	Surveillance for new/recurrent cancers	Intervention for complication of cancer	Coordination between specialists and PCP	Survivorship care planning	Time-points of care	Risk stratification	Focus on PCP	Focus on survivors	
Undefined model/recommendations for follow-up care										
Chopra et al. (2014) [17]	✓	✓	✓	✓	×	×	×	×	✓	×
Knobf et al. (2015) [20]	×	×	×	×	×	×	×	×	✓	✓
NCCN guidelines [31]	✓	✓	✓	×	✓	×	×	×	×	×

Abbreviations: ASCO, American Society of Clinical Oncology; CMAJ, Canadian Medical Association Journal; COSA, Clinical Oncology Society of Australia; CT, computerized tomography scan; ESMO, European Society for Medical Oncology; PCP, primary care physician; SCP, survivorship care plan

survivors' needs assessment tools, age, coexisting noncancer comorbidities and accessibility to PCPs [14, 16, 23, 32, 33]. Furthermore, care transition from oncologists to PCPs or multidisciplinary care team should be smooth to avoid abandonment sentiments among survivors [21].

Discussion

This review updated and extended current literature by delineating the specific and definitive survivorship care needs among breast, colorectal, and AYA cancer survivors. The evaluation of studies on survivorship care models revealed care coordination and clinical outcomes determination as areas for improvement. Furthermore, it highlighted the imminent challenge to objectively provide appropriate metrics and a structured evaluation framework to assess such models for clinical applications. Therefore, this paper proposed and discussed plausible recommendations below for methodological evaluation by synthesizing key approaches to evaluate the adequacy of each model's components (Table 3).

The lack of a robust evaluation framework could be attributed to an over-fixation on the four essential care components flagged out by IOM without an equal devotion to assess its feasibility. A 2011 study reported that the IOM recommendations were not fully followed and realized in practice due to limited time and special resources required for preparation and delivery [35]. Besides considering the fulfillment IOM components, information on feasibility and resources required are also critical for evaluation. Therefore, these IOM components should be jointly evaluated with the actual patient-relevant outcomes to determine the adequacy of survivorship care planning and services. They include services targeting cancer prevention, cancer recurrence surveillance, and the management of long-term complications. With respect to the SCPs constructed in the model, they could be assessed using justified criteria either by employing validated tools like the scorecard for breast cancer survivors or seeking experts' consensus through the Delphi method [36, 41]. The cancer-specific SCP templates provided by ASCO could serve as valuable references for further streamlining and discussion [42, 43]. Lastly, for AYA cancer survivors, the level of participation in clinical trials and related research activities should be considered [32, 34].

Besides services provision, the efficiency of care coordination need to be assessed to support the implementation of the shared-care model. As healthcare professionals, cancer survivors and the healthcare system or institutions are all involved in this transition phase, evaluation metrics should cover all three perspectives. The possible holistic assessment framework proposed was adapted from the Care Coordination Measures Atlas [44]. Existing studies conducted on oncologists' attitudes showed that they were not in favor of a shared-

care model as they were unconvinced of PCPs' skills to manage late effects and screenings [45, 46]. Conversely, PCPs possessed more positive attitudes towards shared-care model and they were the most confident in performing breast and colorectal cancer follow-up and in providing psychosocial support. Despite PCPs' confidence in such surveillance services, the study also noted that PCPs had a greater tendency to utilize routine use of nonrecommended blood and imaging testing [46]. From the perspective of cancer survivors, both studies conducted in 2009 and 2015 reported unfavorable perceptions of PCPs' delivery of survivorship care and their inadequate communication with oncologists [37, 38]. An effective care coordination would then need to remediate these disparate perceptions across all parties.

Potential strategies to enhance care coordination are elaborated as follows. Firstly, oncologists should extend their knowledge to PCPs actively to establish agreeable care standards [16]. Secondly, PCPs should feel more empowered and confident in delivering care following an increasing number of primary care-specific guidelines. A study showed that the strongest predictor of PCPs' willingness to partake in shared-care model was prior involvement in similar cancer surveillance, indicating that experience accumulation is a key factor [45, 47]. Thus, PCPs should be given exposure and training opportunities preferably under the guidance of an experienced oncologist in the incipient stage. Lastly, the unchanged unfavorable perceptions of PCPs among survivors over the years underscored a need for both oncologists and PCPs to assure these survivors of their competencies and build meaningful rapport. Thus, survivors' perceptions of PCP survivorship care delivery should also be a key area to monitor for ascertainment of care quality [38].

Although the included studies elaborated on the utility of risk stratification and provided examples of low- and high-risk survivor characterization, there was a lack of a formal criterion established to guide this process. A formal criterion should address the number and severity of risk factors for adverse outcomes, the significance of these risks in survivors' perceptions, the availability of effective interventions, and the associated economic implications [48]. Currently, risk stratification strategies are based on risks of cancer recurrence or treatment complications without considering the risks of poor psychosocial in the long-term management [47]. Furthermore, the choice of specific risk factors for the stratification tool needs to be supported by established risk-minimization strategies. The modified version of the Wilson-Junger criteria was proposed to gauge the value of each possible risk factor identified for this purpose [48]. The study further recommended a combination with routine needs assessment using validated instruments in the primary care settings [49]. These needs items and risk factors are complementary and when examined collectively, the established criterion for risk stratification should be evaluated for its effectiveness in reducing clinical

Table 3 Recommendations for methodological evaluation of survivorship care programs

Evaluation aspects	Recommendations
Evaluating the adequacy survivorship care planning and services	
Treatment summaries and survivorship care plan	<ul style="list-style-type: none"> Assess the comprehensiveness of Survivorship Care Plans' (SCPs) contents using an appropriate and justified metric. <ul style="list-style-type: none"> The metric can be developed for generic or specific cancers via experts' consensus using the Delphi method and existing SCPs templates endorsed by ASCO [34, 35]. For breast cancer survivors, a 32-item scorecard is available as a validated and reliable tool [33]. Measure oncologists' compliance rates to providing services outlined in SCPs and their satisfaction levels with this tool.
Survivorship care services on cancer prevention, recurrence surveillance, and management of cancers' complications	<ul style="list-style-type: none"> Corroborate provided services and screening schedules with recommendations outlined in major practicing guidelines (e.g., ASCO, CMAJ, ESMO, etc.). Special attention should be paid to addressing cancer-specific late effects (e.g., bowel issues in colorectal cancer survivors). Determine survivors' participation levels in clinical trials, especially for the AYA cancer group. Determine survivors' satisfaction and participation levels in the psychosocial support services and fertility preserving facilities. Measure survivors' compliance rates to the scheduled screenings and follow-up visits.
Evaluating the adequacy other components	
Care coordination	<ul style="list-style-type: none"> Conduct evaluation of experiences with care coordination from three perspectives [36]. Patient or family perspective: <ul style="list-style-type: none"> Satisfaction levels with the care transfer from oncologists to PCPs Presence of any sense of abandonment by healthcare professionals Reports on confusion, hassle or unnecessary care (e.g., laboratory tests, procedures, hospitalizations) Currently available instrument(s): Consumer Assessment of Healthcare Providers and Systems (CAHPS) Healthcare professional(s) perspective: <ul style="list-style-type: none"> Evaluate oncologists' levels of trust in PCPs' competency in delivering survivorship care Evaluate PCPs' confidence in delivering survivorship care Reports on confusion or hassle (e.g. time spent on coordinating referrals) Currently available instrument(s): Care Coordination Measurement Tool (CCMT) Healthcare system representative(s) perspective: <ul style="list-style-type: none"> Extent of healthcare utilization by survivors (e.g., referral rates from PCPs to oncologists, hospital re-admissions) Assess quality of care through analysis of electronic health records or administrative data Determine the costs of survivorship care with care transfer Currently available instrument(s): Assessment of Chronic Illness Care (ACIC)
Risk stratification and needs assessment	<ul style="list-style-type: none"> Determine if regular psychosocial needs assessments are conducted for cancer survivors or their families with reliable and validated instruments [37]. If a risk stratification tool is used to guide survivorship care pathways, determine if the tool possess the following characteristics: <ul style="list-style-type: none"> Includes risk factors pertaining to cancer recurrence risk, adverse effects, psychological wellness, and social functioning Provides justification for the choice of risk factors based on the existence of effective management strategies (e.g., using the Wilson-Junger Criteria) [38] Evaluate the effectiveness of the risk-stratification tool by tracing the cancer recurrence rates, adverse or undesirable event rates predisposed by the risk factors examined, psychosocial problems occurrence rates, and the efficiency of healthcare resources allocation to the various risk groups.
Measuring clinical and patient-related outcomes	
Survival advantage	<ul style="list-style-type: none"> Compare the mortality rates between cancer survivors undergoing structured survivorship care program and those without.
Symptom burden	<ul style="list-style-type: none"> Trace improvements in symptoms following survivorship care provision based on clinician-administered scales or patient-reported outcomes. For example, changes in severity of chemotherapy-induced peripheral neuropathy can be evaluated via the following tools [39, 40]: <ul style="list-style-type: none"> Clinician-administered grading scales: NCI Common Terminology Criteria for Adverse Events and Total Neuropathy Score (developed by Johns Hopkins University) Patient-reported outcomes: EORTC QLQ-CIPN20 questionnaire, FACT/COG Neurotoxicity questionnaire and Patient Neurotoxicity Questionnaire (PNQ).
Health-related quality of life	<ul style="list-style-type: none"> Ascertain the validity of the instruments used to obtain patient-reported outcomes. The instrument should be either validated in the general population of cancer survivors or in subgroups of cancer-specific survivors. For the breast cancer survivors, specific examples of validated instruments include generic questionnaire SF-36 and cancer-specific EORTC and FACT questionnaires. For the colorectal cancer survivors, one of the instruments commonly used in existing literature is the FACT questionnaire. For the AYA cancer survivors, no consensus exists for the use of any specific instrument. Thus, an instrument validated among cancer survivors can be employed as an alternative (e.g., QOL-CS questionnaire). Future research should be conducted to develop and validate a questionnaire specific to this age group.
Economic outcomes	<ul style="list-style-type: none"> Measure the direct costs of survivorship care under the specific delineated program (e.g., consultation costs, cost of services). Measure the indirect costs of participation in survivorship program (e.g., absenteeism, loss of work days). Evaluate the cost-effectiveness of the survivorship program if robust estimates of costs and reliable effectiveness data are available.

Abbreviations: ASCO, American Society of Clinical Oncology; AYA: adolescents and young adults, typically defined as 15 to 35 years old; CMAJ, Canadian Medical Association Journal; COG, Gynecologic Oncology Group; EORTC, European Organization for Research and Treatment of Cancer; ESMO, European Society for Medical Oncology; FACT, Functional Assessment of Cancer Therapy; NCI, National Cancer Institute; QOL-CS, Quality of Life–Cancer Survivor; SF-36, Short Form Health Survey

recurrence rates and psychosocial problems occurrence rates as well as in enhancing the efficiency of healthcare resources allocation [47].

Evident from the model evaluation results, patient-related outcomes were not routinely reported among the included studies. Nevertheless, they provided insights on the types of outcome measures that are useful to assess a model's clinical effectiveness. They include improvement in mortality, morbidity and survivors' satisfaction of provided services [3, 13]. Measures of health-related quality of life proposed were either generic questionnaires or cancer-specific tools [5]. While such tools were not designed principally for cancer survivors, their utility could be justified by supporting validation studies among cancer survivors. For example, the Functional Assessment of Cancer Therapy (FACT) was validated among long-term breast cancer survivors and used significantly in existing literature on colorectal cancer survivors [39, 50, 51]. For the AYA cancer survivors, no consensus exists over the appropriate tool for this survivor group [40]. Therefore, instruments designed for cancer survivors in general should be considered instead for this cancer group. One such example would be the Quality of Life Cancer Survivor (QOL-CS) developed by City of Hope National Medical Centre [52]. Other clinical outcomes to be determined include level of symptom burden and economic evaluations based on direct and indirect cost-estimations [5]. For instance, the improvement of chemotherapy-induced peripheral neuropathy among cancer survivors could be assessed using clinician-administered neuropathy grading scales or patient-reported outcomes obtained from quality of life instruments such as the EORTC QLQ-CIPN20 questionnaire [53].

A limitation in our review relates to the inclusion criteria selected for our review. As there is a lack of standardized definition for “survivorship care model,” we have attempted to address this ambiguity by expanding our search to all types of study designs that have provided variations of survivorship care services and programs before categorizing them into the multidisciplinary or shared-care model domains. Additionally, models targeting AYA cancer survivors may potentially benefit from a clearer specification of the time of diagnosis to differentiate acute survivorship needs within the AYA years and long-term follow-up care into late adulthood.

Conclusion

This review on survivorship care models showed that the shared-care model was prominent in all cancer types, except for the AYA cancers where multidisciplinary care model predominated. Results of the preliminary models' evaluation demonstrated a lack of existing rigorous evaluation efforts to assess the desirability or effectiveness of such models. In response, this review contributed to the proposal of possible

metrics for methodological evaluation of survivorship care programs by considering the relevance of structural components and the value of clinical outcomes. Future studies can supplement these recommendations in the areas of risk stratification strategies and health-related quality-of-life assessments in the AYA cancer survivors group.

Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

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