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Breast cancer survivorship care: a narrative review of challenges and future directions

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Background and Objective: Breast cancer (BC) is the most prevalent cancer among women worldwide. With a growing number of BC survivors (BCSs), the number of survivors who require high-quality survivorship care is increasing. Various recommendations have been proposed for survivorship care plans (SCPs). However, globally, limited progress has been made to implement these recommendations consistently in cancer care centers. This review explores the gaps and challenges that exist in BC survivorship care (BCSC) and proposes future directions for improving survivorship care for patients and the healthcare system.

Methods: Current literature on BCSC was searched using PubMed and Google Scholar. The search strategy utilized a combination of keywords related to BCSC, gaps in survivorship care, and health promotion. Retrievable and English articles from January 2000 to March 2024 were included in the review.

Key Content and Findings: Despite the large number of guidelines and recommendations on best BCSC practices, only a small number of these have been translated into clinical practices that help streamline patient care. There are many gaps to the provision of high-quality survivorship care, all of which negatively affect patient outcomes. Some of these gaps include but are not limited to: the limited role of primary care providers (PCPs), lack of coordination of care, lack of evidence-based research, insufficient data on health promotion, and challenges implementing comprehensive care.

Conclusions: These findings indicate the need for a holistic and personalized approach to BCSC. The importance of implementing a multi-disciplinary and coordinated approach to survivorship care has been emphasized. This includes further involvement of PCPs, through increased training for PCPs in survivorship care. Despite available models of survivorship care, further research is needed to determine optimal BCSC that improves patient outcomes while decreasing the strain on the healthcare system. Additionally,

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technology can play a beneficial role in survivorship care, especially through telehealth and artificial intelligence (AI). Nonetheless, further research is needed on BCSC.

Keywords: Breast cancer survivorship care (BCSC); gaps; health promotion; risk stratification; future directions

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Introduction

Background and rationale

Over the past 20 years, the prevalence of breast cancer (BC) has been steadily increasing. In 2022 alone, BC caused 670,000 deaths globally, and was reported as the most common cancer in women in 157 of 185 countries (1). Recent advances in early detection and breakthrough innovations in treatment strategies have increased the 5-year survival rate of women with early-stage BC to 90% (2). The continuing improvement in survival rate is contributing to an increase in the size of the BC survivor (BCS) population. This large and growing population of survivors requires comprehensive and high-quality care to attend to long-term effects of BC diagnosis and treatment (3,4). Furthermore, survivors may experience specific challenges, and survivorship trajectories can be impacted by treatment-related side effects, such as physical problems, psychological distress, cognitive impairments, and impaired social and work reintegration (5,6) that need to be addressed. Additionally, survivors still have general health needs, such as managing chronic preexisting or ensuing conditions that can complicate care (2).

The 2006 Lost in Transition report from the Institute of Medicine (IOM) recommended providing comprehensive care to patients after a cancer diagnosis (7). Recommendations included preventing and surveilling for recurrence and new cancers, surveilling and managing the physical and psychosocial effects of cancer and focusing on health promotion and preventative care (7). Since then, there have been many efforts to improve the quality of survivorship care and promote comprehensive supportive care that meets survivors' needs.

One such effort was initiated by Nekhlyudov and colleagues (8), who developed an evidence-based quality of cancer survivorship care framework. The framework was intended to serve as a foundation to determine key components of survivorship care. The purpose of this framework was to inform the identification and

development of quality metrics to measure and improve care for survivors (7). This model can be used to determine various areas of cancer survivorship and measure the success of various survivorship models. The framework proposed by Nekhlyudov and colleagues outlines the five major domains that pertain to cancer-related and general care needs for cancer survivors, including prevention and surveillance for recurrence of new cancers, health promotion and disease prevention, and surveillance and management of physical effects, psychosocial effects and chronic medical conditions (8). To adhere to these domains, it is important to perform surveillance and prevention-focused visits, implement risk-reducing strategies, tailor assessment and care plans based on the type of cancer and treatment, and implement a multidisciplinary approach to survivorship care (8). This framework was selected for this review, as it provides an overview of the different domains of quality cancer survivorship care, as well as other individual and social factors that should be considered when providing cancer survivorship care to patients.

The framework stresses that each domain plays a role in patient outcomes, and that the domains are interconnected, synergistically impacting survivorship care. However, these domains are influenced by various factors, including individual, interpersonal, organizational, community, and policy factors (8). For example, individual and socio-ecological factors, such as sociodemographics, health literacy, patient involvement in their own health, cancer type, and phase of survivorship influence the quality of survivorship care. Contextual domains of the health-care delivery system also influence quality of care, including clinical structure, communication and decision making, care coordination, and patient and/or caregiver experience. The outcomes of survivorship care can be measured by the patient's quality of life, metrics on healthcare utilization (emergency services and hospitalizations), costs, and mortality rates (8). By understanding how these domains and factors influence survivorship care, patient outcomes can be improved, minimizing the burden placed on the

healthcare system. Therefore, it is essential to consider these factors and domains when diagnosing and providing survivorship care to BCS.

Globally, various survivorship initiatives have been implemented by cancer organizations, and recommendations have been proposed for survivorship care plans (SCPs) (8). However, limited progress has been made to implement these recommendations consistently and uniformly in cancer care centers worldwide (8). The traditional specialist-led follow-up model of survivorship remains the most prevalent care model (9). These practices are heavily focused on surveillance and the detection of recurrence which often fail to adequately address survivors' concerns (9). Although various survivorship models exist, only a few have been integrated into the healthcare system. Implementation is often delayed by various factors such as limited resources, communication, care coordination, survivor engagement, planning, and flexible services (10).

BCS often face challenges in managing the physical, social, cognitive, and psychological effects that result from BC and associated treatments (2). This demonstrates the need for holistic, personalized survivorship care models, which prioritize various aspects of care, from preventing recurrence of cancers, to equipping patients with the skills needed to manage the physical and psychosocial effects of cancer treatment. There is also a need for comprehensive care, by planning aftercare to improve outcomes for BCS, while efficiently using healthcare resources. This ensures additional economic and resource burdens are not placed on the already strained healthcare system (8).

Furthermore, primary care providers (PCPs) are being encouraged internationally to accommodate patients in need of survivorship care close to home and to stabilize healthcare costs (11). However, the role of PCPs in cancer survivorship has been limited, partly due to a lack of training in survivorship care among PCPs (10).

Objectives

Although recommendations on BC survivorship care (BCSC) have been proposed for many years, it is common for these recommendations to not be translated into practice. There are limited reviews focused on the current gaps in BCSC, and directions for future research. Therefore, the aim of this study was to (I) synthesize the existing literature to identify the gaps in BCSC globally; and (II) provide directions for future research in BCSC approaches. These directions can help guide interventions

that address the long-term physical, emotional and social issues faced by BCS, ensuring a comprehensive approach is used to provide survivorship care to patients. We present this article in accordance with the Narrative Review reporting checklist (available at <https://apm.amegroups.com/article/view/10.21037/apm-24-78/rc>).

Methods

Current relevant literature on BCSC was identified via searches from January to March 2024. PubMed and Google Scholar were searched to identify articles focused on BC survivorship. Websites of international, national, and regional cancer organizations, including National Institute of Health (NIH), American Society of Clinical Oncology/American Cancer Society (ASCO/ACS), National Comprehensive Cancer Network (NCCN), and Canadian Family Physicians were consulted as secondary sources. The keywords used in the search included [breast cancer survivorship care] OR [breast cancer survivors] AND [gaps] OR [primary care] OR [survivorship care plan] OR [health promotion] OR [risk-stratified]. Articles were chosen in the time frame of January 2000 to March 2024. Articles were included in the review if they were retrievable and in the English language. Included articles focused on BC survivorship, including gaps in care, incorporation of primary care, health promotion, and/or risk-stratified care. Articles focused on general survivorship were also included as supporting evidence for the gaps and future directions of BCSC. Evidence was then sorted into current challenges in BCSC, risk-stratified care, and future directions. Following the collection of evidence, the results were used to identify gaps in the literature and provide recommendations for future research. The search strategy was summarized (*Table 1*).

Challenges in survivorship care

Several gaps in the provision of high-quality BCSC have been identified, including the limited role of PCPs, lack of coordination of care, lack of evidence-based research, insufficient data on health promotion, and challenges with the implementation of comprehensive care.

The role of PCPs

Traditionally, survivors have relied on oncologists for ongoing medical care following active treatment (12).

Table 1 The search strategy summary

Items	Specification
Date of search	January–March 2024
Databases and other sources searched	PubMed, Google Scholar, Cancer organization websites
Search terms used	[breast cancer survivorship care] OR [breast cancer survivors] AND [gaps] OR [primary care] OR [survivorship care plan] OR [health promotion] OR [risk-stratified]
Timeframe	January 2000–March 2024
Inclusion criteria	Articles were selected if they were retrievable, were in the English language and were focused on survivorship care
Selection process	Conducted by four individual researchers, consensus was reached by a fifth researcher (M.A.)

However, oncologist-led care presents challenges such as time constraints and difficulties maintaining contact with survivors going through life-phase transitions (13,14). Furthermore, given the recent increase in prevalence of BC, cancer centers are overwhelmed with active patients. As a result, follow-up care for BCS has shifted to be a responsibility of PCPs (15). However, many PCPs are not equipped to manage this due to a lack of survivorship training (16). A study found that of the physicians, nurse practitioners, and physician assistants surveyed, the majority were uncomfortable providing these services themselves, citing reasons such as insufficient training, poor communication, and unclear role expectations (16). There is a clear lack of knowledge and training on cancer survivorship care in the training pathway of PCPs (17,18), despite cancer being a leading cause of death globally. In surveying the recent curriculum of the largest Canadian medical school, only a minority of all lectures (28%) discussed a cancer-related topic, 12% of educational sessions were taught by an oncologist, and only 2% of clerkship clinical electives were selected in oncology (19). Furthermore, only 9.2% of family medicine residency training programs in the USA reported having a cancer survivorship program/curriculum (20). This demonstrates a clear need for integration of survivorship training into PCP curriculums as primary care-led models can provide an improved holistic and proactive continuity of care, as well as improve individual patient support (21).

PCPs play a critical role in enhancing the satisfaction of care and well-being of BCS and patients have reported equivalent or higher satisfaction with PCP-led care models, compared to others (10,20). Even though PCPs are well-suited to deliver quality survivorship care when properly trained, there is a clear need to mitigate barriers to enable

and support the use of primary care-led models (15,20). These barriers include knowledge gaps on the standard of care for survivors, low health literacy and medical mistrust, lack of timely information and communication from oncologists, and access to care (14,22–26).

Furthermore, these barriers are exacerbated by constraints to the limited amount of time PCPs can spend with each patient due to high patient volume, making it difficult to provide complete and adequate information (14,17,22,27). As such, to promote the shift of BCS care into a primary care-led model, there is a need to increase and strengthen cancer survivorship education and training for PCPs, providing more survivorship resources for PCPs, and improving cross-disciplinary communication with other specialists (27).

Coordination of care through SCPs

A key practical gap in patient care is the lack of communication and care coordination between physicians (14,18,22,25,26). Communication is especially critical between PCPs and oncologists, as effective communication is directly related to improved coordination of care (17,28). However, there is still a lack of evidence on the frequency and the ideal means of communication between PCPs and oncologists (17). Proposed methods to improve this communication include the integration of electronic medical records across health systems and increased communication between providers using email, paper documentation, virtual and in-person meetings, and phone calls (17,22,29). Another method that demonstrates promise is the implementation of treatment summaries and SCPs. Despite the limited evidence and evaluations surrounding SCPs, the implementation of these plans

is the second highest recommendation for adult cancer survivorship care from the IOM (30,31). SCPs provide enhanced coordination of care through comprehensive documentation of active treatment and clear instructions for post-treatment follow-ups (32-36). SCPs are also associated with better management of late and long-term effects, fewer post-treatment concerns, lower distress, and overall higher satisfaction of care (32,34,37-39). As such, it is critical to develop SCPs early in treatment, ensuring the plan is accessible to all providers and delegates specific tasks to each, thus helping to overcome communication barriers and ensuring that patients' needs are met (2).

Research in survivorship care

There is a key lack of evidence-based research providing support for the most effective survivorship model, creating a barrier in the implementation of many models of care (10,40). There is also a lack of evidence surrounding the structural and process barriers of survivorship care, how each model of care affects survivors' health outcomes, and the evaluation, costs, and benefits of current existing SCPs (41). Furthermore, most of the literature on survivorship care is based on analyses of existing datasets/surveys, leading to limited information in areas such as benefits of various models of care and alternatives to existing models of care (40). This creates barriers in determining which survivorship care model is best for improved outcomes (40). There is also a lack of research in the geriatric population, despite making up a majority of cancer survivors (42). Furthermore, there is limited understanding of the prevalence and pattern of psychosocial effects, despite anxiety, depression, fear, and posttraumatic stress being extremely common among women with BC (43,44). To improve this, there is a need for population-level surveillance for cancer survivors with psychosocial symptoms, as well as improved availability of psychosocial resources and interventions (43,44).

Health promotion

Health promotion and education play key roles not only for BC prevention, but also in BCSC. Specifically, maintaining a lifestyle conducive of physical activity, healthy weight maintenance, and reduced substance use (e.g., smoking, alcohol), lowers the risk of BC recurrence (15). Health promotion can also mitigate long-term and late effects, improve physical and psychosocial symptoms, and maintain quality of life (43). However, despite these

recommendations, BCS are still not receiving adequate care and health education. One key barrier to this is the lack of knowledge provided to oncologists regarding health promotion, as many survivors rely on their oncologists for medical care, with many oncologists reporting being unfamiliar and uncomfortable with health promotion due to a lack of training (45). There is also a gap in the promotion of preventive health measures such as screening. One study discovered that over the course of 4 years, 65% and 40% of BCS did not undergo screening for colorectal and cervical cancer, respectively (46). To mitigate this, PCPs and other healthcare providers (HPs) can also play a key role in ongoing BCSC, thereby allowing for a multidisciplinary and holistic approach to survivorship care (43). Therefore, future research should focus on education regarding the mechanisms of health behaviors for HPs of various disciplines, including oncologists, PCPs (43) and pharmacists (47). A study performed by Mullan *et al.* (48) found that a 2-hour workshop which aimed to facilitate the use of behavior change techniques by health professionals resulted in increases in knowledge, descriptive and subjective norms, perceived behavioral control and intention (48). Furthermore, future research should focus on the integration of digital technologies designed for health promotion (43). Another recommendation is the integration of a new healthcare position, a health promotionist, which will fill in the gap for the neglected priority of health promotion and will educate survivors on improving their health behaviors (46).

Risk-stratified survivorship care

Personalized survivorship care aims to uphold high-quality, patient-centered care, potentially reducing costs and ensuring more equitable care delivery, especially for patients facing accessibility challenges (49). One form of personalized care is risk-stratified care which places cancer survivors into different care pathways based on their needs and the HPs required (50). As shown in *Figure 1*, survivors are categorized into low, medium, or high complexity groups based on factors such as the effects of ongoing treatments, risk of recurrence and late effects, functional capacity, mental health, and social context (49,51,52).

Survivors with low complexity are considered to have a low risk of recurrence, mortality, and long-term effects post-treatment (49). They typically have minimal immediate care needs and are well-suited for self-managed care pathways, with periodic follow-ups by PCPs for symptom management, lifestyle guidance, and guidance on when to

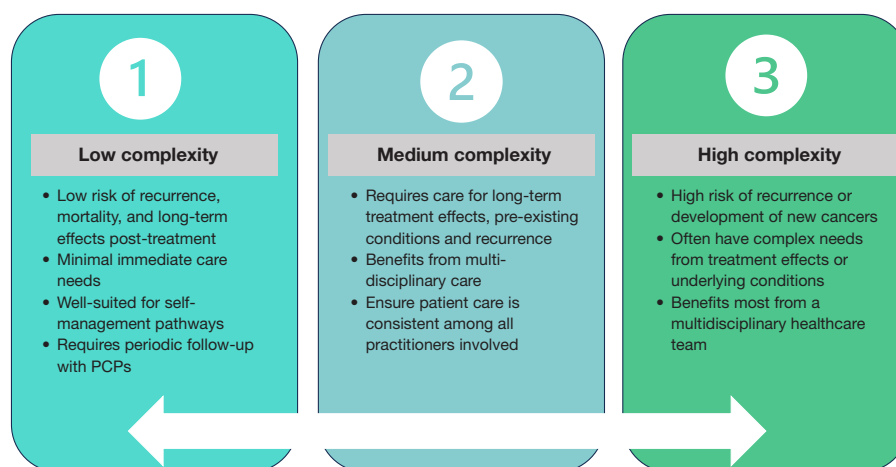


Figure 1 Summary of the categorization of risk stratification care, based on low, medium, and high complexity. PCPs, primary care providers.

consult an oncologist if recurrence signs arise (45,49,52). In contrast, survivors requiring care for long-term treatment effects, pre-existing conditions, and recurrence (which is at a higher risk compared to low-complexity patients) are categorized as medium-complexity (49). These patients benefit from multidisciplinary care involving PCPs, oncologists, psychologists, dietitians, and other specialists if they present with comorbidities. Additional specialists may be necessary for comorbidities, with shared-care models facilitating communication between community providers and patients (49,53). Since comorbidities are common with cancer, it is crucial to communicate and adjust SCs accordingly to ensure patient care is consistent between all HPs involved (53). Finally, survivors with a high risk of recurrence or the development of new cancers, alongside complex needs from treatment effects or underlying conditions are placed in the high-complexity group (49). These patients benefit the most from a multidisciplinary healthcare team coordinating comprehensive care and managing long-term treatment effects (49,52). This approach involves specialists from various fields and may include patient-centered medical homes to address medical, social, and mental health needs (49,52). Transitioning high-complexity survivors from oncology to PCPs for survivorship care, within a coordinated medical home framework, enhances their overall care experience.

These pathways include supported self-management with remote monitoring of tests and results, coordinated care led by PCPs, and complex care management by a multidisciplinary team for patients with significant needs (52).

The choice of pathway is a collaborative decision between patients and HPs, allowing for adjustments as needs evolve (52). Key features of these pathways include remote monitoring, rapid re-access protocols, comprehensive needs assessments and care plans, treatment summaries, patient education on self-management, and access to support services such as psychological, nutritional, and physical activity counseling (52,54). In addition to PCPs, telehealth technology (55) can help bridge communication gaps between care providers. However, this technology could be improved, and challenges such as access to technology and provider availability in remote areas need to be addressed. Additionally, further research is needed to elucidate the implementation of telehealth into multidisciplinary cancer survivorship plans.

Limitations and future directions

The main limitation of this narrative review is that it was not possible to conduct a systematic review or meta-analysis due to the wide variety of content under the topic of survivorship care. However, this review was able to summarize the current literature on BCSC. Based on the variety of articles and topics discussed in this review, future directions can be provided for future research and care for BCS. These future directions aim to provide a starting point that can be researched in the future to further enhance the quality of care provided to BCS.

Although there have been advancements in BCSC, there is a clear need for further research and investigation into

implementing recommendations on survivorship care. The traditional survivorship model has depended on oncologists for ongoing medical care following active cancer treatment, however, this presents with time constraints and challenges maintaining long-term care. Additionally, the rise in the number of BCS has overwhelmed this traditional oncology-led model, minimizing personalized care to survivors. Current evidence suggests a need for more personalized and comprehensive survivorship care that focuses on the patient as an individual. This can be achieved through personalized stratified pathways of care in which the type of care provided is determined by factors such as the cancer type, treatment, current symptoms, and present concerns, as well as the risk of long-term and late effects (56). Patient-centered care can enhance the quality of care provided and improve clinical outcomes. Furthermore, having a personalized approach to survivorship care allows patients' priorities to be met, which has been shown to increase self-efficacy and self-management of care, increase their adherence to health promotion strategies, decrease suffering and symptom burden, and improve their quality of life (57). As discussed, one method of personalized care is risk stratification, which provides survivors with the resources they require based on the complexity of their needs. In 2023, the World Health Organization (WHO) published a package of interventions for rehabilitation of malignant neoplasm, which focuses on resource stratification to improve survivorship rehabilitation care (58). Despite progress in this area, further research is needed on risk-stratified care.

The lack of coordination and communication between physicians is evident, despite research supporting that increased communication results in overall higher satisfaction of care. Therefore, alongside a personalized approach to survivorship care, a multidisciplinary survivorship model should be implemented. Current literature demonstrates the benefit of multidisciplinary models for patient outcomes, while reducing burden on the healthcare system (11,59). This should be used in conjunction with the risk-stratified model, to improve efficiency in survivorship care, while focusing on patient-centered care (60). Additionally, a crucial component of multidisciplinary care is ensuring care is coordinated between PCPs and specialists. However, there is limited survivorship training for PCPs, preventing PCPs from providing quality survivorship care. It is paramount to increase the engagement of PCPs through more survivorship training, giving them the resources necessary to provide survivorship care to patients to allow for this

model of care. The benefits of integrating primary care into survivorship care are clear, including the enhanced continuity and satisfaction of care (20).

Another suggestion is to utilize technologies, such as telehealth. The use of telehealth has increased substantially in the United States, especially during the coronavirus disease 2019 (COVID-19) pandemic. Research has shown that telehealth can be used to improve health care access and quality, patient-provider communication, and health outcomes (7). Since the pandemic, models of cancer care have been adapted using telehealth and remote patient monitoring technologies. These models have incorporated community resources, primary care, and allied health disciplines, as well as clinics, to help keep cancer survivors away from acute care hospitals as much as possible. These changes have been adopted successfully globally, and it is believed that these changes can be integrated with routine cancer care even after the pandemic (10). One specific technology that can be implemented is artificial intelligence (AI) which has demonstrated increased motivation of patient-reported outcomes (PROs), reduced fatigue and pain levels, improved quality of life, and improved physical activity (61). AI is a growing area in BCSC, however, more research is needed on the impacts of AI in BCSC, as current research is limited to small population sizes and single-center trials.

The long-term feasibility of the survivorship care model must be considered to prevent further strain on the healthcare system. Shared-care and multidisciplinary models have demonstrated efficacy for the healthcare system (42). However, more research is needed to determine which model of survivorship care is most effective, which caters to patients' needs, while minimizing the administrative and financial burden placed on the healthcare system.

These suggestions are summarized in *Figure 2*. Implementing these changes will allow for a more holistic and patient-centered approach to BCSC, which will not only benefit patients but the healthcare system as a whole.

Conclusions

With the rise in the number of BCS, it is paramount to continue developing BCSC worldwide. By training PCPs to provide survivorship care to BCS, the burden placed on oncologists can be minimized, allowing for long-term follow-up care for BCS. This can be achieved through multidisciplinary and personalized models of survivorship care, through risk-stratified care, allowing patients to

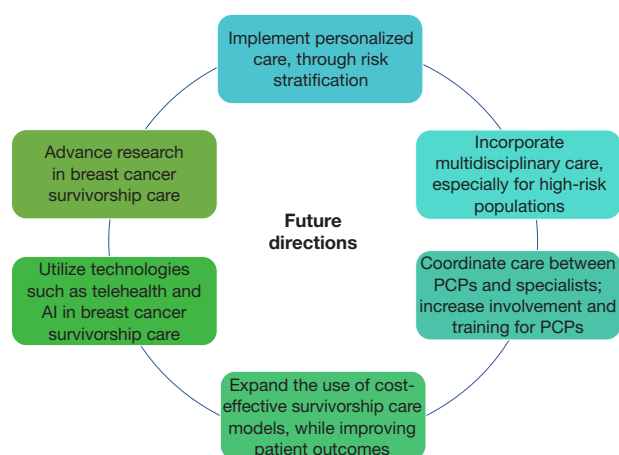


Figure 2 Summary of future directions for BCSC. AI, artificial intelligence; PCPs, primary care providers; BCSC, breast cancer survivorship care.

benefit from individualized care that is tailored to their needs based on where they are in their survivorship journey. Newer technologies such as telehealth and AI should also be explored and implemented into survivorship care to improve access and quality of survivorship care. Specifically, these technologies should be tested in BC survivorship clinics, as there is limited evidence of their utility in BCSC.

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