


Cancer Survivors, Oncology, and Primary Care Perspectives on Survivorship Care: An Integrative Review

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Abstract

Purpose: Evidence-based models of cancer survivorship care are lacking. Such models should take into account the perspectives of all stakeholders. The purpose of this integrative review is to examine the current state of the literature on cancer survivorship care from the cancer survivor, the oncology care team, and the primary care team perspectives. **Methods:** Using defined inclusion and exclusion criteria, we conducted a literature search of PubMed, PsycINFO, CINAHL, and Scopus databases to identify relevant articles on the stakeholders' perspectives on cancer survivorship care published between 2010 and 2021. We reviewed and abstracted eligible articles to synthesize findings. **Results:** A total of 21 studies were included in the review. Barriers to the receipt and provision of cancer survivorship care quality included challenges with communication, cancer care delivery, and knowledge. **Conclusion:** Persistent stakeholder-identified barriers continue to hinder the provision of quality cancer survivorship care. Improved communication, delivery of care, knowledge/information, and resources are needed to improve the quality of survivorship care. Novel models of cancer survivorship care that address the needs of survivors, oncology teams, and PCPs are needed.

Keywords

oncology, primary care, shared care, survivorship

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Introduction

An estimated 16.9 million Americans, most over the age of 65, were living with a history of cancer as of January 2019.¹ By 2030, the number of cancer survivors in the United States is expected to exceed 22 million.¹ This trend is primarily fueled by advances in early detection and treatments.² However, survival comes with its own challenges. Many survivors suffer from multiple comorbidities and have complex medical and psychosocial needs.^{3,4} In addition to quality of life (QOL) concerns, survivorship care can be complex and fragmented.⁵ For survivors of cancer, the completion of treatment does not mark an end to their cancer experiences.⁶ Survivorship care may include follow-up surveillance, management of late and long-term adverse treatment effects, healthy living recommendations (diet, physical activity, tobacco cessation, other

cancer screening), and comorbidity management.⁵ Continued relationships with the healthcare system are often needed to manage long-term survivorship care.⁷

Current models of cancer survivorship care often fail to meet survivors' physical, psychosocial, and informational needs.⁸ Such needs are compounded by the challenges of a

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fragmented healthcare system where coordination and communication between different medical specialties are often challenging. Evidence suggests that the implications of fragmentation of care can result in greater spending, delays in treatment, prevention, and surveillance for recurrences and new cancers and comorbid conditions.⁹ Initially, post-treatment follow-up and surveillance may primarily be provided by oncologists; however, this places a heavy burden on the oncology team.^{10,11} By contrast, a full transition to primary care physicians (PCP) can also create burden and PCP care delivery constraints. In addition, PCPs may have limited knowledge and formal training on survivorship care.^{6,7,12,13} Cancer survivors often develop strong emotional bonds with the oncology team and may prefer to be followed by their oncology team for cancer surveillance and management of late and long-term treatment effects, as well as preventative care.¹⁴ Historically, systems have not coordinated care ongoing between primary care and oncology throughout treatment, which can exacerbate survivors' hesitancy to return back to primary care following cancer care.

The purpose of this integrative review is to examine the literature on cancer survivorship care from the perspectives of the cancer survivor, the oncology care team, and the primary care team. Findings will be used to understand knowledge gaps, identify potential barriers to the provision of cancer survivorship care, and inform improvements to current survivorship care delivery models.

Methods

This integrative review was conducted using methods proposed by Russell¹⁵ and Toronto and Remington.¹⁶ Integrative reviews are used to represent the state of the research literature on a given topic, identify central issues in an area, and identify future research and practice implications.^{15,16} The method was selected for this review to provide a more holistic approach to understanding stakeholder perspectives of cancer survivorship care. The 5 stages of the integrative review were used: problem formulation, literature search, data evaluation, data analysis, and presentation.

Problem Formulation

This review was undertaken due to the longstanding, persistent challenges in communication, care delivery, and knowledge during cancer survivorship.¹³ Our specific review questions include the following: (1) What are the overall perspectives of various stakeholders on the provision of cancer survivorship care? (2) What are the barriers to the provision of cancer survivorship care from the stakeholders' perspectives? The National Cancer Institute's (NCI) Office of Cancer Survivorship defines a "cancer survivor" as an individual from the time of cancer diagnosis through

the balance of life and recognizes that there are many phases of cancer survivorship, including those living with cancer and those free of cancer.¹⁷ This definition was used to guide our review to include the various challenges associated with this extended period, ranging from Acute to Extended to Permanent Survival.¹⁸

Literature Search and Data Evaluation

A comprehensive, computerized search of the literature in Medline (PubMed), PsycINFO, CINAHL, and Scopus was conducted in August 2021. The search was restricted to English language articles published from 2010 to 2021. Search keywords included "Shared Care Model," "Cancer Survivorship," "Oncology," "Oncology Nursing," "Oncology Advanced Practice Nurse," "Primary Care," "Patient," and "Survivor." MeSH terms for Medline and CINAHL included "Oncology," "Primary Care," and "Survivorship."

As proposed by Russell¹⁵ and Toronto and Remington,¹⁶ data evaluation involves the appraisal of the relevance of the selected literature. Publications were selected for full-text reviews by a screening of titles and abstracts. Full-text articles were selected for inclusion based on the following criteria: (1) any cancer type; (2) any phase of cancer survivorship based on NCI definitions; (3) articles that focused on one or a combination of stakeholder perspectives on the provision of cancer survivorship care; and (4) studies conducted in the United States. Exclusion criteria included: (1) editorials and case studies; and (2) studies conducted outside of the United States. We chose to exclude studies conducted in other countries in an effort to focus on cancer survivorship care delivery within the United States healthcare delivery system. Published systematic reviews and other narrative reviews were accessed for their reference lists. Two investigators (ML, VS) reviewed all articles for inclusion, and discordant reviews were discussed until consensus was reached.

Data Analysis and Presentation

All articles selected for final review were read by 2 reviewers (ML, VS). Data abstraction was completed using a predetermined data document. Extracted study characteristics include first author, year of publication, study aim, stakeholders involved, sample size, cancer type(s), phase of cancer survivorship based on NCI definitions, and study design. Articles were categorized by survivor, oncology, and/or primary care perspectives. All articles that focused on one stakeholder alone were counted as one article, while those that included multiple stakeholder perspectives were counted once for each of the stakeholders that were included. To identify findings related to the provision of cancer survivorship care, all 21 articles were reviewed and coded for

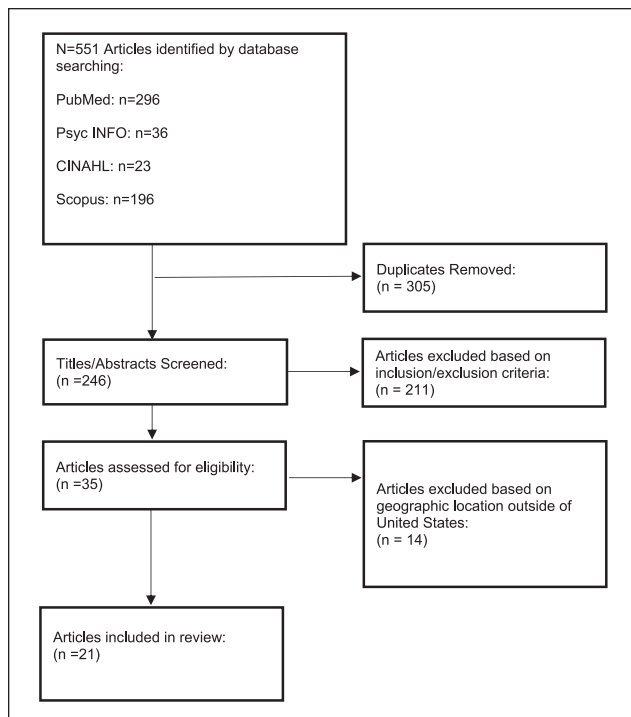


Figure 1. Search and study selection flow chart.

themes relevant to care provision (ML, VS). Discordant codings were discussed until consensus was reached.

Results

The flow chart of search and selection procedures is depicted in Figure 1. A total of 551 articles were identified in the initial search. Of this total, 305 were excluded after accounting for duplication, leaving 246 articles that underwent title/abstract screening. After title/abstract screening, 211 articles were excluded, leaving a final of 35 for full-text review. After a full-text review, 14 articles were excluded, yielding a total of 21 articles (3.8%) that met the inclusion criteria. Of the 21 eligible articles, 12 articles (57%) addressed cancer survivor perspectives (see Table 1). Of note, 8 out of the 12 articles (67%) focused on cancer survivors exclusively. A total of 10 articles (48%) addressed the oncology care team's perspective (oncologists and oncology nurses); none of the articles targeted oncology perspectives exclusively. Finally, 12 articles (57%) addressed the primary care team's perspective (57%); only 3 articles (25%) were exclusive to primary care.

Overall Summary of Findings

Key study characteristics for the 21 articles are presented in Table 1. For articles that included cancer survivor perspectives, the most common cancer type is breast and colorectal.

Many articles included multiple cancer types that were not specified. The most common phases of cancer survivorship were the extended phase and the permanent phase. The majority of articles were qualitative studies; of note, 4 articles described findings from randomized trials on survivorship care planning and care delivery.

Findings by Survivorship Care Provision Themes

Survivor Perspectives

For the 12 articles that either focused exclusively or included survivor perspectives, 3 overarching themes emerged. They included communication (11/12; 91.7%), cancer care delivery/post-treatment care (11/12; 91.7%), and a lack of information/limited knowledge (10/12; 83%).

Communication. The theme of communication from the survivor's perspectives was primarily focused on barriers. These barriers ranged from lack of timely communication, poor communication/information from the medical team, transparency of out-of-pocket costs, and a need for consistent advice from multidisciplinary care team members. Many studies reported the need for care coordination as survivors often experienced instances of issues in relaying information to both primary care and oncology care teams. Additionally, survivors reported the need for consistent advice from providers as confusion over conflicting instructions often occurred.

Care delivery. Survivors reported a lack of confidence in their general practitioner's knowledge and ability to provide cancer survivorship care, and dissatisfaction with health providers for reasons such as unresponsiveness and dismissiveness. Extended wait times for follow-up appointments, tests, and lack of access to services also posed problems to post-treatment care from the survivor's perspective. Additionally, patients faced instances of delaying or canceling treatment due to the financial toxicity associated with survivorship care. According to the NCI, financial toxicity is defined as the problems a survivor faces related to the cost of medical care that may lead to debt and bankruptcy, which can negatively affect a patient's quality of life and access to care.⁴¹

Limited knowledge. Overall, survivors expressed a lack of information in multiple facets of their post-treatment follow-up care. The unmet informational needs were focused on cancer treatments, treatment-related side effects/toxicities, diet, healthy living, recurrence, follow-up, long-term effects of treatment, and when to see their providers in the future. In addition, survivors perceived a lack of clarity on the PCP's role in their cancer care, further

Table 1. Characteristics of Studies Included in the Review (Organized by Stakeholders).

Author	Study aim	Stakeholder	Sample size	Cancer type(s)	Survivorship phase ¹⁹	Study design	Themes
Mollica et al ¹⁹	Investigate factors associated with patient-reported care coordination scores of cancer survivor Medicare beneficiaries ²⁰	Survivor	Survivors: n = 14646	Prostate, breast, colorectal, lung/bronchus, uterine/cervical, bladder, melanoma, head/neck, renal, non-Hodgkin lymphoma	All	Cross sectional	Communication care delivery knowledge
Hudson et al ²¹	Examine the perspectives of patients on care preferences and their physicians' roles in their cancer follow-up care	Survivor	Survivors: n = 42	Breast, prostate	Extended, permanent	Qualitative	Communication care delivery knowledge
Palmer et al ²²	Evaluate the outcomes of breast cancer survivors that received a standardized survivorship care plan visit	Survivor	Survivors: n = 139	Breast	Extended	Quasiexperimental	Communication care delivery knowledge
Wallner et al ²³	Test a multi-level intervention aimed at improving the delivery of team-based survivorship care	Survivor	Survivors: n = 66	Breast	Extended	RCT	Communication care delivery knowledge
Bazzell et al ²⁴	Pair cancer survivors with available evidence-based interventions or resources that improve survivor quality of life via a shared care model	Survivor	Survivors: n = 52	Multiple, not specified	All	RCT	Communication care delivery knowledge
Hong et al ²⁵	Review the discourse between cancer survivors and providers about out-of-pocket spending	Survivor	Survivors: n = 1433	Multiple, not specified	Extended, permanent	Qualitative	Communication care delivery
Kapoor and Nambisan ²⁶	Determine feasibility of an online survivorship care plan tool	Survivor	Survivors: n = 51	Breast	All	RCT	Communication care delivery knowledge
Thom and Benedict ²⁷	Address the effect of financial toxicity on factors such as psychological well-being, coping self-efficacy, and cost-coping behaviors in cancer survivors	Survivor	Survivors: n = 140	Multiple, not specified	Extended, permanent	Qualitative	Communication care delivery knowledge
Shen et al ²⁸	Assess the perceptions of primary care physicians' communication with oncologists and their communication needs	Primary care	PCPs: n = 128	Information not provided	N/A	Mixed-methods	Communication care delivery
Dixit et al ²⁹	Understand the knowledge and attitudes of primary care physicians and their preferences for care models for breast and colon cancer survivors	Primary care	PCPs: n = 220	Breast and colon	N/A	Cross sectional	Communication care delivery knowledge
Skinner et al ³⁰	Evaluate the perspectives of primary care innovators treating patients	Primary care	PCPs: n = 10	Information not provided	N/A	Qualitative	Communication care delivery knowledge
Virgo et al ³¹	Explore barriers perceived by primary care physicians and medical oncologists on cancer survivorship care over 5 years post-treatment	Primary care oncology	Oncologists: n = 1130 PCPs: n = 1072	Breast and colorectal	Permanent	Qualitative	Communication care delivery knowledge

(continued)

Table 1. (continued)

Author	Study aim	Stakeholder	Sample size	Cancer type(s)	Survivorship phase ¹⁹	Study design	Themes
Potosky et al. ³²	Compare primary care physicians and oncologists regarding their knowledge, attitudes, and practices for follow-up care of survivors	Primary care oncology	Oncologists: n = 1130 PCPs: n = 1072	Breast and colon	Extended, permanent	Qualitative	Communication knowledge
Hebdon et al. ³³	Explore the perspectives of healthcare team members on cancer survivorship care using shared mental models	Survivor primary care oncology caregivers	Oncologists: n = 3 PCPs: n = 2 Survivors: n = 5 Caregivers: n = 6 RNs: n = 3	Information not provided	N/A	Qualitative	Communication care delivery knowledge
Dulko et al. ³⁴	Assess the process of survivorship care plan completion and to survey	Survivor primary care oncology	Oncologists: n = 17 PCPs: n = 39 Survivors: n = 58	Breast and colorectal	All	Mixed-methods	Communication care delivery
Forsythe et al. ³⁵	Examine physician-reported practices on cancer survivorship care	Primary care oncology	Oncologists: n = 1130 PCPs: n = 1021	Breast and colorectal	Extended, permanent	Qualitative	Communication care delivery knowledge
Hahn and Ganz ³⁶	Evaluate the cancer survivorship programs at four health care organizations	Primary care oncology nursing	N/A	Multiple, not specified	All	Qualitative	Communication care delivery knowledge
Klabunde et al. ³⁷	Assess the self-reported roles of primary care physicians and oncologists in provision of survivorship care for patients within 5 years of completing cancer treatment	Primary care oncology	Oncologists: n = 1125 PCPs: n = 1014	Information not provided	Extended	Qualitative	Communication care delivery knowledge
Forsythe et al. ³⁸	Compare oncologist provision and primary care physician receipt of treatment summaries and follow-up plans and evaluate associations between primary care physician receipt of such documents and survivorship care	Primary care oncology	Oncologists: n = 1130 PCPs: n = 1020	Multiple, not specified	All	Qualitative	Communication care delivery knowledge
Balashramanian et al. ³⁹	Characterize surveillance patterns for cancer survivors	Survivor primary care oncology	Oncologists: n = 24 PCPs: n = 41	Colorectal	Extended	Cross sectional	Care delivery knowledge
Rocque et al. ⁴⁰	Describe the patient and provider factors that impact decision-making in treatment of metastatic breast cancer	Survivor oncology	Oncologists: n = 11 Survivors: n = 20	Breast	Extended	Qualitative	Communication knowledge

compounding the survivor's confusion on matters related to their follow-up care.

Oncology Perspectives

For the 10 articles that either focused exclusively or included oncology perspectives, 2 common themes were identified: communication (9/10; 90%) and care delivery (8/10; 80%). Approximately one-third of the oncology articles included perspectives from oncology nursing teams (3/10; 30%), contributing a unique point of view to the overall oncology perspective.

Communication. Similar to survivors, the oncologists and oncology care teams experience significant obstacles to communication. The critical barrier is the lack of communication with PCPs regarding survivorship care. Oncologists/oncology teams also perceived communication barriers with survivors in some cases, specifically with language barriers that pose challenges in transferring information on survivorship care.

Care delivery. As a result of the communication barriers, several concerns related to care delivery and post-treatment care were reported. These include concerns regarding general preventive healthcare responsibility, duplicated care, requests from survivors for unnecessary testing, and insurance restrictions on tests or treatments. The oncology care teams also expressed difficulties in transferring care responsibilities and finding the time and resources needed to provide personalized survivorship care plans.

Oncology nursing perspective. Of the articles reviewed, one-third included perspectives from registered nurses, nurse practitioners, and advanced practice nurses. Nurses expressed challenges with both communication and care delivery. In terms of communication, nurses reported a lack of systematic referrals from either oncology or primary care teams to survivorship care nurses. Additionally, nurses voiced continuous efforts to make survivorship care plans more patient-friendly in order to meet varying literacy levels of patients. For care delivery, nurses expressed that they were often tasked with completing survivorship care plans. However, they reported insufficient organizational resources, such as time, staff, money, and training to support their role in some cases. In addition, there were often inconsistent institutional systems to facilitate care plan completion (ie, electronic templates embedded in electronic medical records).

Primary care perspectives

For the 12 articles that either focused exclusively or included primary care perspectives, 3 underlying themes

were identified: communication (11/12; 92%), care delivery (11/12; 92%), and limited knowledge (10/12; 83%).

Communication. For primary care teams, a common communication obstacle was the lack of consistent updates on survivor prognosis throughout the course of treatment. Primary care teams report being informed of their survivor's cancer diagnosis; this is often followed by a long period of communication gap during treatment. Consequently, primary care teams expressed concerns with the quality and fragmentation of care associated with the lack of communication across medical specialties.

Care delivery. Concerns regarding care delivery were prevalent in the primary care perspective and were focused on follow-up and comorbidity management. For the primary care team, the quality of oncology follow-up care remains a concern as the primary care responsibility of managing certain aspects of care is often not clearly defined. The primary care team also reported a lack of training on how cancer treatments can further exacerbate comorbidities. Consequently, there are concerns about the quality of comorbidity management. For example, survivors undergoing treatment for lung cancer with chronic obstructive pulmonary disease as a comorbid condition may experience exacerbated symptoms.⁴² Instances such as this can cause complication in the decisions made in the course of comorbid condition treatment due to the limited consensus on how to manage comorbidities in the context of cancer.

Limited knowledge. Primary care teams report a lack of or insufficient formal training on cancer survivorship care. Consequently, PCPs reported limited knowledge on the principles of cancer survivorship care and on management guidelines. Areas of deficiency in knowledge and training included the frequency/types of cancer surveillance and the long-term effects of cancer treatments.

Discussion

Since the introduction of the U.S. Institute of Medicine's 2006 seminal report, "From Cancer Patient to Cancer Survivor: Lost in Transition," a range of research has been carried out to better address the unique needs of cancer survivors.⁴³ This report outlined the vital components of survivorship care and recommended the development of a survivorship care plan to improve communication and coordination between oncologists and PCPs. Nearly a decade and a half later, many of the same stakeholder-identified barriers to the delivery of quality survivorship care remain. Persistent challenges remain in areas such as timely communication between medical specialties, unmet informational/training needs, and challenges in coordinating care responsibilities between medical specialties. Notably, PCPs

reported a lack of communication from the oncology team after being notified of a patient's cancer diagnosis. The provider-to-provider communication voids are often filled by survivors themselves, with many serving as the communication "bridge" between providers on their treatments and surveillance plan. Although most PCPs view survivorship care as an important component of their work and agree with the importance of their role in survivorship care, more research is needed to understand why persistent barriers exist for PCPs. A viable strategy is to design cancer survivorship research with PCP involvement and engagement. The review also revealed support for caregivers as an unmet need from the survivor's perspective.

Many of the reported challenges continue to focus on the time and resources needed to complete a survivorship care plan. This result may be associated with previous survivorship care accreditation guidelines from the American College of Surgeons' Commission on Cancer (CoC), which required the completion and provision of a care plan. Published systematic reviews and meta-analyses found that care plans alone do not improve the quality of care delivery and coordination following treatment.⁴⁴ Accreditation guidelines, including those from the CoC, have since been revised to emphasize the development of robust survivorship programs rather than achieving a threshold percentage for the receipt of a survivorship care plan document.⁴⁵ Future research should focus on stakeholder perspectives on developing comprehensive survivorship care programs to improve communication and care coordination. Additionally, research should encourage the integration of primary care and oncology care throughout care delivery to foster equally strong relationships among patients and all of their providers.

The findings of this review were consistent with those of recent systematic reviews on the topic.⁴⁴⁻⁴⁶ Calls for more defined roles in cancer follow-up care, improved and timely information sharing, and protocols for survivorship care were also highlighted in these systematic reviews. Importantly, an understudied area of research is the critical perspectives on the challenges faced by oncology nurses as integral members of the cancer survivorship care team, a point further revealed in our findings. As vital members of the care team, oncology nurses participate in survivorship care; advanced practice nurses (ie, nurse practitioners, clinical nurse specialists) are often leading survivorship care efforts, either working alone or collaborating with interdisciplinary teams. Nurse-led care coordination and communication can potentially reduce care fragmentation after cancer treatments, and research is needed to test interventions and programs that include oncology nurses as crucial care team members.⁴⁷ With advances in treatments such as immunotherapies, the field of cancer survivorship has expanded its focus to address the care for survivors living longer with advanced and metastatic cancers. Research is

needed to test models of comprehensive survivorship care for these populations, including care delivery research that addresses the preferences of survivors and providers and care team integration of primary care in partnership with subspecialists.¹⁹ Finally, our review found a noticeable lack of evidence on the support person/family caregiver's perspectives on cancer survivorship care; only one of the studies included in this review included this population.

A potential model of cancer survivorship care that may address the needs of all stakeholders is the Self-Management Shared Care Model.⁴⁸ The model fosters transdisciplinary collaboration among oncologists, oncology nursing, and primary care teams, with a focus on care coordination among medical specialties and communication between survivors and providers. Survivors are coached on the principles of self-management, which aims to empower and enable them through goal-setting, identifying challenges, and developing an action plan to overcome challenges. The model also leverages supportive care expertise (ie, dietitians, rehabilitation, psychology/psychiatry) for a more comprehensive survivorship care approach.^{49,50} Evidence from other countries suggests that in breast cancer survivors, the shared care approach improved receipt of timely follow-up screening, decreased waiting time to receive oncology care, and freed up clinician time by shifting resources to survivors with more complex needs.⁵¹ Implementation of the self-management shared care model will likely be more complex in the United States due to diverse care delivery systems, and more evidence is needed on its effectiveness in the United States healthcare system.⁴⁷

Limitations

While the review was guided by an integrative review framework^{15,16} and used a methodological approach, we did not focus on the quality/level of evidence. Additionally, the review was limited to studies conducted in the United States and articles published in the English language, potentially excluding stakeholder perspectives published in other languages and countries with different healthcare systems. We acknowledge that much of the existing evidence on cancer survivorship care delivery is from Canada, Australia, and Europe; however, this was beyond the aim and scope of the review.

Conclusions

Persistent barriers in providing quality cancer survivorship care exist from the perspectives of survivors, the oncology team, and PCPs. These barriers included the need for improved communication, delivery of care, knowledge/information, and resources for the provision of quality survivorship care. Research is needed to test the impact of

novel models of care that address the needs of survivors, oncology teams, and PCPs. The design of comprehensive cancer survivorship care program and research should include the perspectives of all stakeholders, including oncology nurses and family caregivers.

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References

1. Miller KD, Nogueira L, Mariotto AB, et al. Cancer treatment and survivorship statistics, 2019. *CA Cancer J Clin.* 2019;69(5):363-385. doi:10.3322/caac.21565
2. Siegel RL, Miller KD, Jemal A. Cancer statistics, 2019. *CA Cancer J Clin.* 2019;69(1):7-34. doi:10.3322/caac.21551
3. Granger CL, Parry SM, Edbrooke L, Denehy L. Deterioration in physical activity and function differs according to treatment type in non-small cell lung cancer - future directions for physiotherapy management. *Physiotherapy.* 2016;102(3):256-263. doi:10.1016/j.physio.2015.10.007
4. Cavalheri V, Jenkins S, Cecins N, et al. Impairments after curative intent treatment for non-small cell lung cancer: a comparison with age and gender-matched healthy controls. *Respir Med.* 2015;109(10):1332-1339. doi:10.1016/j.rmed.2015.08.015
5. Pratt-Chapman M, Simon MA, Patterson AK, Risendal BC, Patierno S. Survivorship navigation outcome measures: a report from the ACS patient navigation working group on survivorship navigation. *Cancer.* 2011;117(15 Suppl):3575-3584 (Erratum in: *Cancer.* 2012;118(21):5450). doi:10.1002/cncr.26261. .
6. Rubinstein EB, Miller WL, Hudson SV, et al. Cancer survivorship care in advanced primary care practices: a qualitative study of challenges and opportunities. *JAMA Intern Med.* 2017;177(12):1726-1732. doi:10.1001/jamainternmed.2017.4747
7. Reed SC, Walker R, Ziebell R, et al. Cancer survivors' reported discussions with health care providers about follow-up care and receipt of written care plans. *J Cancer Educ.* 2018;33(6):1181-1188. doi:10.1007/s13187-017-1228-1
8. National Academies of Sciences, Engineering, and Medicine; Health and Medicine Division; Board on Health Care Services; National Cancer Policy Forum. *Long-Term Survivorship Care After Cancer Treatment: Proceedings of a Workshop.* National Academies Press (US); 2018.
9. Nekhlyudov L, Mollica MA, Jacobsen PB, Mayer DK, Shulman LN, Geiger AM. Developing a quality of cancer survivorship care framework: implications for clinical care, research, and policy. *J Natl Cancer Inst.* 2019;111(11):1120-1130 (Erratum in: *J Natl Cancer Inst.* 2021;113(2):217). doi:10.1093/jnci/djz089
10. Alfano CM, Mayer DK, Bhatia S, et al. Implementing personalized pathways for cancer follow-up care in the United States: proceedings from an American Cancer Society-American Society of Clinical Oncology summit. *CA Cancer J Clin.* 2019;69(3):234-247. doi:10.3322/caac.21558
11. Alfano CM, Jefford M, Maher J, Birken SA, Mayer DK. Building personalized cancer follow-up care pathways in the United States: lessons learned from implementation in England, Northern Ireland, and Australia. *Am Soc Clin Oncol Educ Book.* 2019;39:625-639. doi:10.1200/EDBK_238267
12. O'Malley D, Hudson SV, Nekhlyudov L, et al. Learning the landscape: implementation challenges of primary care innovators around cancer survivorship care. *J Cancer Surviv.* 2017;11(1):13-23. doi:10.1007/s11764-016-0555-2
13. Nekhlyudov L, O'malley DM, Hudson SV. Integrating primary care providers in the care of cancer survivors: gaps in evidence and future opportunities. *Lancet Oncol.* 2017;18(1):e30-e38. doi:10.1016/S1470-2045(16)30570-8
14. Pollak KI, Arnold RM, Jeffreys AS, et al. Oncologist communication about emotion during visits with patients with advanced cancer. *J Clin Oncol.* 2007;25(36):5748-5752. doi:10.1200/JCO.2007.12.4180
15. Russell CL. An overview of the integrative research review. *Prog Transplant.* 2005;15(1):8-13.
16. Toronto C, Remington R. *A Step-by-Step Guide to Conducting an Integrative Review.* Springer; 2020.
17. Statistics, Graphs, and Definitions | Division of Cancer Control and Population Sciences (DCCPS). Cancercontrol.cancer.gov. 2022. <https://cancercontrol.cancer.gov/ocs/statistics>
18. Park ER, Peppercorn J, El-Jawahri A. Shades of survivorship. *J Natl Compr Canc Netw.* 2018;16(10):1163-1165. doi:10.6004/jnccn.2018.7071
19. Mollica MA, Falisi AL, Geiger AM, et al. Survivorship objectives in comprehensive cancer control plans: a systematic review. *J Cancer Surviv.* 2020;14(2):235-243. doi:10.1007/s11764-019-00832-3
20. Mollica MA, Buckenmaier SS, Halpern MT, et al. Perceptions of care coordination among older adult cancer survivors: a SEER-CAHPS study. *J Geriatr Oncol.* 2021;12(3):446-452. doi:10.1016/j.jgo.2020.09.003
21. Hudson SV, Miller SM, Hemler J, et al. Adult cancer survivors discuss follow-up in primary care: 'not what i want, but maybe what i need'. *Ann Fam Med.* 2012;10(5):418-427. doi:10.1370/afm.1379
22. Palmer SC, Stricker CT, Panzer SL, et al. Outcomes and satisfaction after delivery of a breast cancer survivorship care plan: results of a multicenter trial. *J Oncol Pract.* 2015;11(2):e222-e229. doi:10.1200/JOP.2014.001404
23. Wallner LP, Abrahamse P, Gargaro JG, et al. Improving the delivery of team-based survivorship care after primary

- breast cancer treatment through a multi-level intervention: a pilot randomized controlled trial. *Breast Cancer Res Treat.* 2021;189(1):81-92. doi:10.1007/s10549-021-06257-w
24. Bazzell JL, Spurlock A, McBride M. Matching the unmet needs of cancer survivors to resources using a shared care model. *J Cancer Educ.* 2015;30(2):312-318. doi:10.1007/s13187-014-0708-9
 25. Hong YR, Salloum RG, Yadav S, Smith G, Mainous AG 3rd. Patient-provider discussion about cancer treatment costs and out-of-pocket spending: implications for shared decision making in cancer care. *Value Health.* 2020;23(12):1592-1598. doi:10.1016/j.jval.2020.08.002
 26. Kapoor A, Nambisan P. Personal decision support for survivor engagement: formulation and feasibility evaluation of a conceptual framework for implementing online cancer survivorship care plans. *BMC Med Inform Decis Mak.* 2020;20(1):59. doi:10.1186/s12911-020-1073-8
 27. Thom B, Benedict C. The impact of financial toxicity on psychological well-being, coping self-efficacy, and cost-coping behaviors in young adults with cancer. *J Adolesc Young Adult Oncol.* 2019;8(3):236-242. doi:10.1089/jayao.2018.0143
 28. Shen MJ, Binz-Scharf M, D'Agostino T, et al. A mixed-methods examination of communication between oncologists and primary care providers among primary care physicians in underserved communities. *Cancer.* 2015;121(6):908-915. doi:10.1002/cncr.29131
 29. Dixit N, Burke N, Rodriguez G, et al. Knowledge and self-efficacy for caring for breast and colon cancer survivors among safety net primary care providers. *Support Care Cancer.* 2020;28(10):4923-4931. doi:10.1007/s00520-019-05277-z
 30. Skinner D, Franz B, Howard J, Kelleher K, Crabtree BF. The politics of primary care expansion: lessons from cancer survivorship and substance abuse. *J Healthc Manag.* 2018;63(5):323-336. doi:10.1097/JHM-D-16-00030
 31. Virgo KS, Lerro CC, Klabunde CN, Earle C, Ganz PA. Barriers to breast and colorectal cancer survivorship care: perceptions of primary care physicians and medical oncologists in the United States. *J Clin Oncol.* 2013;31(18):2322-2336. doi:10.1200/JCO.2012.45.6954
 32. Potosky AL, Han PK, Rowland J, et al. Differences between primary care physicians' and oncologists' knowledge, attitudes and practices regarding the care of cancer survivors. *J Gen Intern Med.* 2011;26(12):1403-1410. doi:10.1007/s11606-011-1808-4
 33. Hebdon MC, Abrahamson K, Griggs RR, McComb SA. Shared mental models of cancer survivorship care. *Eur J Cancer Care.* 2018;27(2):e12831. doi:10.1111/ecc.12831
 34. Dulko D, Pace CM, Dittus KL, et al. Barriers and facilitators to implementing cancer survivorship care plans. *Oncol Nurs Forum.* 2013;40(6):575-580. doi:10.1188/13.ONF.575-580
 35. Forsythe LP, Alfano CM, Leach CR, Ganz PA, Stefanek ME, Rowland JH. Who provides psychosocial follow-up care for post-treatment cancer survivors? A survey of medical oncologists and primary care physicians. *J Clin Oncol.* 2012;30(23):2897-2905. doi:10.1200/JCO.2011.39.9832
 36. Hahn EE, Ganz PA. Survivorship programs and care plans in practice: variations on a theme. *J Oncol Pract.* 2011;7(2):70-75. doi:10.1200/JOP.2010.000115
 37. Klabunde CN, Han PK, Earle CC, et al. Physician roles in the cancer-related follow-up care of cancer survivors. *Fam Med.* 2013;45(7):463-474.
 38. Forsythe LP, Parry C, Alfano CM, et al. Use of survivorship care plans in the United States: associations with survivorship care. *J Natl Cancer Inst.* 2013;105(20):1579-1587. doi:10.1093/jnci/djt258
 39. Balasubramanian BA, Jetelina KK, Bowen M, Santini NO, Craddock Lee S. Surveillance for colorectal cancer survivors in an integrated safety-net health system in the United States. *Int J Care Coord.* 2018;21(1-2):26-35. doi:10.1177/2053434518764634
 40. Rocque GB, Rasool A, Williams BR, et al. What is important when making treatment decisions in metastatic breast cancer? A qualitative analysis of decision-making in patients and oncologists. *Oncologist.* 2019;24(10):1313-1321. doi:10.1634/theoncologist.2018-0711
 41. "NCI Dictionary of Cancer Terms." National Cancer Institute, National Institutes of Health. <https://www.cancer.gov/publications/dictionaries/cancer-terms/def/financial-toxicity>
 42. Raviv S, Hawkins KA, DeCamp MM Jr, Kalhan R. Lung cancer in chronic obstructive pulmonary disease: enhancing surgical options and outcomes. *Am J Respir Crit Care Med.* 2011;183(9):1138-1146. doi:10.1164/rccm.201008-1274CI
 43. Institute of Medicine. *From Cancer Patient to Cancer Survivor: Lost in Transition.* Institute of Medicine; 2005.
 44. Hill RE, Wakefield CE, Cohn RJ, et al. Survivorship care plans in cancer: a meta-analysis and systematic review of care plan outcomes. *Oncologist.* 2020;25(2):e351-e372. doi:10.1634/theoncologist.2019-0184
 45. Lisy K, Kent J, Piper A, Jefford M. Facilitators and barriers to shared primary and specialist cancer care: a systematic review. *Support Care Cancer.* 2021;29(1):85-96. doi:10.1007/s00520-020-05624-5
 46. Klemanski DL, Browning KK, Kue J. Survivorship care plan preferences of cancer survivors and health care providers: a systematic review and quality appraisal of the evidence. *J Cancer Surviv.* 2016;10(1):71-86. doi:10.1007/s11764-015-0452-0
 47. Buerhaus P, Donelan K, DesRoches C, Lamkin L, Mallory G. State of the oncology nursing workforce: problems and implications for strengthening the future. *Nurs Econ.* 2001;19:198-208.
 48. Parry C, Kent EE, Forsythe LP, Alfano CM, Rowland JH. Can't see the forest for the care plan: a call to revisit the context of care planning. *J Clin Oncol.* 2013;31(21):2651-2653. doi:10.1200/JCO.2012.48.4618
 49. Bertelsen JB, Refsgaard J, Kanstrup H, et al. Cardiac rehabilitation after acute coronary syndrome comparing adherence and risk factor modification in a community-based shared care model versus hospital-based care in a randomised controlled trial with 12 months of follow-up. *Eur J Cardiovasc Nurs.* 2017;16(4):334-343. doi:10.1177/1474515116666781
 50. Vaccaro L, Shaw J, Sethi S, et al. Barriers and facilitators to community-based psycho-oncology services: a qualitative study of health professionals' attitudes to the feasibility and acceptability of a shared care model. *Psychooncology.* 2019;28(9):1862-1870. doi:10.1002/pon.5165
 51. MacMillan Cancer Support. *Evaluation of the Transforming Cancer Follow-Up Programme in Northern Ireland Final Report.* MacMillan Cancer Support; 2019.