

Evidence-Based Survivorship Care: Current and Future Challenges in Survivorship Research

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Introduction

Although a variety of late and long-term effects from some cancer therapies are known, the science of cancer survivorship care is in its infancy. Guidelines for follow-up care for children and adolescent survivors were first disseminated by the Children's Oncology Group in 2003 (Landier et al., 2004). Although guidelines regarding survivors of adult cancers have been published within the past decade (American Cancer Society [ACS], n.d.; American Society of Clinical Oncology, n.d.; National Comprehensive Cancer Network®, 2019), recommendations for the care of survivors of adult cancers are slow to evolve. Research is sparse to guide best practices for studying groups of survivor populations, models of survivorship care outside of academic centers, health disparities, or long-term biopsychosocial and spiritual consequences of cancer and cancer treatment. This chapter briefly reviews the status of cancer survivorship care, identifies gaps in survivorship care knowledge, and offers recommendations for the future of the science of survivorship care.

Epidemiology

Defining *cancer survivorship* is a challenge. According to some, survivorship begins at diagnosis and continues through the remainder of life (McCabe et al., 2013; National Coalition for Cancer Survivorship, n.d.). Others define *survivorship* as starting when cancer treatment ends, and some reject the term all together (Aiuppa, Hewitt, & Nass, 2018). The conceptual difference between the phase of survivorship beginning at the time of diagnosis and survivorship following curative treatment creates conflict in defining the best time and ways to provide survivorship care, especially to people who are challenged by incurable cancers (Bugos, 2015).

Clearly, challenges differ among individuals, and just as clearly, survivorship issues differ for patients whose cancers are treated with curative intent compared

to individuals who experience cancer as a chronic illness and for people at the end of life. Survivors dealing with chronic cancer often balance hopes of remission with the knowledge that they may not be cured of their cancer and must face the effects of ongoing therapy.

Survivors of curable cancers may experience prolonged recovery and substantial long-term and late effects (Bugos, 2015). Perhaps the divergent experiences, self-identity, and life stories of people with cancer reflect different perceptions of when survivorship begins and whether individuals relate at all to the term *cancer survivor* (McGrath & Holewa, 2012). Questions remain as to how best to describe the experience of living with, through, and beyond cancer, as well as how to provide the necessary supportive care to achieve optimal quality of life for given populations (McGrath & Holewa, 2012).

Survivorship as a Public Health Issue

With increasing numbers of people living longer after cancer diagnosis and treatment, survivorship can be viewed as a result of improving cancer surveillance, early diagnosis, and multimodal treatment of cancer. In this light, it should also be viewed as a public health issue. Public health, the science of protecting and improving the health of people and their communities, achieves its mission through health promotion and disease prevention to improve quality of life (American Public Health Association, n.d.).

Healthy People 2020, a long-term government public health initiative, identified two objectives related to cancer survivorship: to increase the percentage of cancer survivors who live five years or longer after diagnosis, and to improve physical and mental health quality of life among cancer survivors (Moore, Buchanan, Fairley, & Smith, 2015). A recent assessment of organizational implementation of the plan's strategies revealed some success in achieving the plan's goals by leading public health and cancer survivorship organizations. However, it also showed a continuing need to develop clinical practice guidelines, strategies to ensure a quality healthcare workforce, and improvements in translating research to practice (Smith et al., 2013).

In efforts to achieve Healthy People 2020 objectives on cancer survivorship and to advance cancer survivors' quality of life through public health, the Centers for Disease Control and Prevention, in partnership with the Lance Armstrong Foundation (now the Livestrong Foundation), published *A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies*, also known as NAPCS (Centers for Disease Control and Prevention & Lance Armstrong Foundation, 2004). The plan provides a public health road map for improving cancer survivorship care and groups 96 strategies into four public health domains: surveillance and applied research; communication, education, and training; programs, policies, and infrastructure; and access to quality care and services (Moore et al., 2015).

In 2011, Livestrong convened the Essential Elements of Survivorship Care meeting attended by more than 150 stakeholder participants aiming to build consensus on elements of survivorship care that any cancer survivorship program should provide (directly or via referral) to post-treatment cancer survivors (Rechis, Beckjord, Arvey, Reynolds, & McGoldrick, 2011). The meeting consensus recommended five Tier 1, or "must provide," elements (Rechis et al., 2011):

- Survivorship care plan, psychosocial care plan, and treatment summary

- Screening for new cancers and surveillance for recurrence
- Care coordination strategy addressing coordination with primary care and primary oncologists
- Health promotion education
- Symptom management and palliative care

The meeting also recommended another 10 elements as Tier 2, or “high need,” and an additional five elements as Tier 3, or “strive to provide” (Rechis et al., 2011). Post-meeting recommendations support efforts to refine definitions of the essential elements, to conduct research to expand the evidence base supporting the essential elements, and to integrate survivorship care into practice.

The American Society of Clinical Oncology (n.d.) included the Livestrong Essential Elements of Survivorship Care in its online Survivorship Care Compendium, noting that elements of Tiers 1 and 2 mirror the four Institute of Medicine components of survivorship care. To date, there is little indication that research to expand the evidence base to support the essential elements has been conducted and published. The Livestrong report noted one meeting attendee as saying, “Everybody wants to do a survivorship care program, but [they] don’t know the minimum elements that are critical,” and no consensus yet exists on the minimum elements of quality survivorship care programs (Rechis et al., 2011, p. 1).

In response to the call for cancer survivorship guidelines, ACS and the American Society of Clinical Oncology published several disease-specific recommendations for longitudinal care of individual survivors (Resnick et al., 2015; Runowicz et al., 2016). The National Comprehensive Cancer Network also published a guideline for symptom-based survivorship care (Ligibel & Denlinger, 2013).

Moore et al. (2015) developed the Public Health Action Model for Cancer Survivors (PHAM-CS), which combines the NAPCS with the social ecological model. The model outlines strategies to improve cancer survivorship at five levels: policy, community, organizational, interpersonal, and individual survivors. Foundational principles of the PHAM-CS include organizational behavioral change, dissemination and implementation of evidence-based practice, and evaluation of survivorship care and are focused on the four domains of the NAPCS (Moore et al., 2015). Collaboration, evidence-based strategies, culturally aware activity, and innovation are drivers for the model (Moore et al., 2015; Smith et al., 2013).

An example of implementation of the PHAM-CS is the Colorectal Cancer Control Program’s (CRCCP’s) multilevel approach to colorectal cancer prevention (Centers for Disease Control and Prevention, 2015). A social ecological model of health promotion illustrates the complex and dynamic interactions among individuals and environmental factors that determine behaviors, as well as identifies behavioral and organizational leverage points for health promotion within organizations. At the individual level, colorectal screening is beneficial. At the interpersonal level, healthcare providers recommend colorectal screening. At the organizational level, screening reminder systems are enacted. At the community level, public awareness and education campaigns inform community members on the importance of cancer screening. At the policy level, policy decisions are enacted and communicated to the public (e.g., insurance mandates for screening). A comprehensive explanation of this model is found at www.cdc.gov/cancer/crccp/index.htm.

A study by Underwood et al. (2015) assessed the public health approaches to cancer survivorship implemented by National Comprehensive Cancer Control Program grantees in four states and one Native American tribe. These programs

involved surveying for baseline needs and resources and then implementing interventions related to surveillance and communications in South Carolina; using outreach workers for individual and small group education sessions in the Circle of Life Cancer Education Program and connecting survivors and caregivers with available support services in Fond du Lac Band of Lake Superior Chippewa programs; focusing on communication, education, and training in New Mexico; and focusing on peer-to-peer support, policies, and infrastructure in Vermont (Underwood et al., 2015).

An interprofessional shared-care model implemented in the Netherlands included personalized follow-up care based on principles of person-centered care designed to empower survivors and support self-management and organized according to a risk-based approach (Loonen et al., 2018). Such an approach acknowledges the heterogeneity and significance of late effects and the consequent need for specialized cancer survivorship care clinics.

Survivorship care must reflect community needs, existing services, workforce, and available resources, as well as prioritize efforts to identify strategies to coordinate care and address known gaps. Efforts to create survivorship care must be devised to meet the needs of the community it serves. As such, no one model will meet the needs of all survivors in heterogeneous communities; however, Loonen et al. (2018) suggested their universal model of care works for all survivors and in different healthcare systems.

Health Equity and Cancer Survivorship

Despite efforts to advance cancer survivors' quality of life through public health, outcomes are disparate. In the United States, cancer occurs in every population group; however, the disease has a disproportionate impact on certain groups (National Cancer Institute [NCI], 2018a, 2018b). Frequently described disparities result from differences in racial and ethnic background, socioeconomic status, age, sexual orientation, gender, and geographic location (NCI, 2018a, 2018b; Polite et al., 2017; Smith & Hall, 2015). Increasingly, disparities in health insurance coverage and financial toxicity from cancer and cancer treatments are reported (see Chapter 13).

Funding from the Centers for Disease Control and Prevention supports research to examine disparities in access to care. Findings identified breast cancer survivors, lower-income African American survivors, survivors needing psychosocial care, and underinsured or uninsured individuals and families as groups not receiving appropriate surveillance and support after cancer treatment (Smith & Hall, 2015). Other chapters in this book include more detailed information about disparities.

Racial and Ethnic Disparities

Outcome disparities for racial and ethnic minorities are well documented and often attributed to advanced stage of cancer at diagnosis. However, when controlled for stage of cancer at diagnosis, survival disparities persist, and in the case of colon cancer, the stage-specific disparities are worsening (Polite et al., 2017). Disparities exist in colorectal screening among racial and ethnic groups, with Spanish-speaking Hispanics less likely to be screened than Whites or English-speaking Hispanics. In general, when insurance status, age, disease severity, and health status are similar to

non-Hispanic Whites, racial and ethnic minorities tend to receive health care of lower quality (ACS, 2019).

Socioeconomic Status Disparities

Socioeconomic status has an impact on the ability to purchase health insurance, education, and other factors affecting access to health care (ACS, 2019). People with low socioeconomic status have higher mortality rates than those of higher status (ACS, 2019). People with low socioeconomic status are more likely to smoke and be obese partially because advertisers of unhealthy foods and tobacco often target this population (ACS, 2019). Colorectal cancer mortality rates among those younger than 65 years (premature deaths) are higher in states with low education levels compared to states with higher socioeconomic levels (NCI, 2018a). People with higher levels of education have a lower risk of premature death from colorectal cancer compared to people with less education, regardless of race or ethnicity (NCI, 2018a). Uninsured adults or those insured by Medicare without supplemental insurance have inferior access to quality care and experience worse outcomes (Smith & Hall, 2015).

Age Disparities

The Children's Oncology Group (2018) long-term follow-up guidelines are aimed at survivors of pediatric cancers. Common childhood cancers differ from common cancers in adults. Thus, Children's Oncology Group guidelines differ from the few disease-specific guidelines for adult survivors, leaving little guidance for the long-term care of adult survivors of childhood cancer. As a result, this population often receives care managed by pediatric cancer teams well beyond 21 years of age.

At the opposite end of the life span, older adults face different disparities, as most clinical trials exclude this age group. Adults aged 65 years and older with comorbidities are typically excluded from health behavior change research (Aaronson et al., 2014). The risk of developing comorbid conditions increases with age, potentially increasing healthcare utilization, financial burden from health needs, stress on family care providers, and other burdens commonly linked to chronic illnesses.

Geographic Disparities

Geographic location determines access to quality cancer care, the burden of receiving care, and the distance a person must travel to find it. In the United States, variations in health care for chronically ill, older people depend on the system of care within different regions and hospitals (Goodman, Esty, Fisher, & Chang, 2011). For example, Desmond, Jackson, and Waterbor (2017) found disparities in receipt of survivorship care plans in Alabama, Georgia, and Mississippi. Burris and Andrykowski (2010) identified clinically important disparities in mental health outcomes between cancer survivors in rural and nonrural areas.

Health Literacy Disparities

Health literacy is an essential part of shared decision making and quality health care. The Agency for Healthcare Research and Quality (AHRQ) recommends taking a "universal precautions" approach by assuming all patients may have difficulty comprehending health information and accessing health services (Brega et al., 2015). Cancer survivors reporting lower general health were less likely to have accessed health

information for themselves (Smith & Hall, 2015). Research shows that interventions designed for people with limited health literacy also benefit those with stronger health literacy skills. Clear communication helps people feel more involved in their health care and increases the chances of adhering to treatment plans (Brega et al., 2015).

AHRQ published the *Health Literacy Universal Precautions Tool Kit* (Brega et al., 2015) and *The Patient Education Materials Assessment Tool (PEMAT) and User's Guide* (Shoemaker, Wolf, & Brach, 2013), available through the AHRQ website. The ACS Cancer Action Network (www.acscan.org) supports health equity efforts through advocacy, state and federal legislative efforts, and research so that all Americans may receive access to quality care no matter their race, ethnicity, gender, sexual orientation, income level, or geographic location.

As the measurement of health outcomes moves beyond mortality rates, the number of factors affecting outcomes expands (Polite et al., 2017). The field of health disparities is dynamic, which requires greater cultural competence among healthcare providers. Historic data do not provide a comparison for factors considered to be important today, such as health literacy and sexual orientation. Additional research is needed to articulate specific causes of health disparities among cancer survivors and to provide guidance for evidence-based interventions to reduce or eliminate disparities.

Survivorship Care Research Gaps

Cancer survivors are a heterogeneous group. Individuals and their responses to cancer are unique, just as cancers differ from one another and from person to person. Cancer treatments, adverse effects, and the intensity of long-term and late sequelae, as well as human responses to these experiences, differ for each person. The need for research in all aspects of cancer survivorship is fertile, wide, and diverse. The U.S. government and cancer advocacy organizations have laid a framework for research questions and funding for cancer survivorship issues, but the beginning of scientific inquiry in an emerging field starts with individual stories. Healthcare providers owe a debt of gratitude to people who have lived beyond cancer diagnoses, endured long-term and late effects, and shared their wisdom to advance the art and science of cancer survivorship care. Lessons learned from clinical encounters, patients' experiences, and advocacy efforts of communities and governments led to consensus among experts about ways to approach the diagnosis and treatment of long-term and late effects from cancer and its treatment. The National Comprehensive Cancer Network (2019), American Society of Clinical Oncology (n.d.), and ACS (n.d.) publish diagnosis- and symptom-specific clinical practice guidelines for survivorship care. Guidelines on nutrition and exercise for cancer survivors are also available (Kushi et al., 2012; Laino, 2010).

The science of survivorship care is evolving. The appropriate timing and frequency of screening for new cancers and complications of cancer treatments are unclear. Clinicians and survivors must weigh the risks of second cancers and complications from treatment to determine screening schedules. Clinicians must use established evidence-based associations between therapeutic exposures and late effects to identify high-risk populations that benefit from frequent screening measures (Bhatia, Armenian, & Landier, 2017). Risk-based screening for cancer survivors helps ensure that those at high risk are followed more closely than others (Dood et al., 2018; see Chapter 35).

Little research exists to define the personal host factors that affect an individual's susceptibility to long-term and late effects (Nekhlyudov, Ganz, Arora, & Rowland, 2017). A growing acknowledgment that traditional risk factors fail to explain all late effects has led to increased interest in pharmacogenetics, genetic polymorphisms, changed genetic expression, and other genetic variants that increase risks for toxicities and other late effects. Integration of such knowledge could identify preventive interventions and improve risk assessment strategies and outcomes (Linschoten, Teske, Cramer, van der Wall, & Asselbergs, 2018; Myers, Koleck, Sereika, Conley, & Bender, 2017). But what is the bottom line of this lack of research? Quality survivorship care is not clearly defined.

Clinical trials for cancer survivors present challenges. Small groups of survivors and long latency of complications often prevent randomized controlled trials from determining what modality or timing would be superior in early detection of complications or reduction in morbidity and mortality (Bhatia et al., 2017). Although randomized controlled trials are lacking in cancer survivorship care, the number of published studies about survivorship has risen steadily since the formation of the National Coalition for Cancer Survivorship in 1986 and the National Cancer Institute's Office of Cancer Survivorship in 1996 (Bhatia et al., 2017; Jacobsen et al., 2016; NCI, 2017).

In 2015, the American Society of Clinical Oncology conducted a survey of 699 members who self-identified as conducting research in survivorship in an effort to advance the understanding of gaps in cancer survivorship research (Jacobsen et al., 2016). The survey identified 714 studies: 65% observational and 35% interventional. Study participants were most commonly people treated for lymphoid or hematologic cancers and breast cancer. At the time of diagnosis, most participants were aged 40–65 years, and most were less than two years from diagnosis (Jacobsen et al., 2016).

Jacobsen et al. (2016) identified several key gaps. Much of the research focuses on breast cancer, but other commonly occurring cancers with high survival rates receive less attention. Research about cancer survivors older than 65 years is limited. This is especially important because 60% of cancer survivors are in this age group, and 73% of cancer survivors are expected to be aged 65 years and older by 2040 (NCI, 2016). Research is sparse in survivors who are more than five years after diagnosis, and interventional studies are lacking in survivors of childhood cancers who are currently younger than 21 years. Biologic mechanisms and genetic factors related to recurrence and adverse effects are poorly understood. Additional gaps in research include knowledge to identify essential services, measures to optimize a competent workforce for survivorship care, promotion of optimum care coordination, healthcare utilization, and survivorship care planning.

Provision of formal survivorship care planning processes was one of 10 recommendations from the Institute of Medicine's report *From Cancer Patient to Cancer Survivor: Lost in Transition* and the one that has garnered the most attention (Hewitt, Greenfield, & Stovall, 2006). Research findings indicate that substantial gaps exist regarding the process and outcomes of survivorship care planning. An integrative review of survivorship care plan studies revealed limited evidence of improved outcomes and only sporadic implementation of care planning (Mayer, Birken, Check, & Chen, 2015). This study found only four randomized controlled trials. The strength of evidence in other, mostly observational, studies was low. Mayer et al. (2015) also found substantial variations in research on survivorship care plan content, implementation and dissemination processes, and outcomes. A more recent systematic review of the impact of survivorship care plans on health outcomes and healthcare delivery by Jacobsen et al.

(2018) found little evidence that survivorship care plans improve health outcomes and health delivery but found evidence of increased patient satisfaction with the amount of information received and healthcare providers' implementation of recommended care.

Survivorship Care Models

Survivorship care models vary by survivor populations served, available resources, and the degree of administrative support. Models typically include components for prevention and detection of new cancers, surveillance for recurrence, assessment and intervention for the management of late and long-term effects, and coordination of care between oncology and primary care teams (Hewitt et al., 2006). Risk reduction and health promotion interventions are additional components of survivorship care. The timing of interventions and the value of content to survivors represent additional gaps in the research.

Oncology nurses, nurse navigators, clinical nurse specialists, and nurse practitioners are currently key drivers and providers of survivorship care (DeGuzman, Colliton, Nail, & Keim-Malpass, 2017; Grant, McCabe, & Economou, 2017; Haylock, Mitchell, Cox, Temple, & Curtiss, 2007). Specific roles for nurses in survivorship care are not well defined, but advanced practice nurses—primarily nurse practitioners—manage most survivorship clinics and provide care. In most states, nurse practitioners provide reimbursable care. Nurses in these roles provide programmatic leadership and clinical care and facilitate survivors' transitions to primary care. The role of clinical nurse specialists, whose work in most settings is currently not reimbursed, in survivorship care has the potential to contribute to survivorship program development, quality improvement, clinical expertise and staff development, education, and bridging the gap between research and clinical practice. Oncology nurse and patient navigator roles as well as navigation processes throughout survivorship continue to evolve. Current evidence links navigation personnel and processes to increased patient satisfaction, decreased time from diagnosis to initiation of treatment, improved care coordination, and other contributions to care delivery systems reflected by systems' return on investment in navigation roles (see Chapter 6).

Summary

Looking forward, a robust body of knowledge in these areas of survivorship care is essential to optimally understand the healthcare needs of survivors, identify evidence-based surveillance and follow-up strategies, identify and address unmet needs, and determine ways to reduce occurrence and severity of treatment-related adverse effects among cancer survivors. As new questions emerge, research models for addressing them evolve. In 1985, Dr. Fitzhugh Mullan asserted that survivorship care is a natural and necessary component of the cancer care continuum. Nearly 35 years later, oncology care professionals, current literature and research findings, and recommendations of the National Cancer Policy Board's Committee on Cancer Survivorship all support Mullan's pioneering proposition. Nevertheless, full implementation of comprehensive, and some would say humane, survivorship care is far from complete. Efforts to define, plan, pay for, and provide survivorship care generate new and often unforeseen ques-

tions. What is the role of the oncology team in survivorship care? Indeed, how is an oncology “team” approach defined, created, and maintained? When should survivorship care begin? When does it end? Who should provide it? How is survivorship care supported? Who or what entity pays for it? What components are valuable to different survivor groups and populations? Evidence-based answers to these and other emerging questions will shape the future of survivorship care.

References

- Aaronson, N.K., Mattioli, V., Minton, O., Weis, J., Johansen, C., Dalton, S.O., ... van de Poll-Franse, L.V. (2014). Beyond treatment—Psychosocial and behavioural issues in cancer survivorship research and practice. *European Journal of Cancer Supplements*, *12*(1), 54–64. <https://doi.org/10.1016/j.ejcsup.2014.03.005>
- Aiuppa, L., Hewitt, M., & Nass, S.J. (2018). *Long-term survivorship care after cancer treatment: Proceedings of a workshop*. <https://doi.org/10.17226/25043>
- American Cancer Society. (n.d.). American Cancer Society survivorship care guidelines. Retrieved from <https://www.cancer.org/health-care-professionals/american-cancer-society-survivorship-guidelines.html>
- American Cancer Society. (2019). *Cancer facts and figures 2019*. Retrieved from <https://www.cancer.org/research/cancer-facts-statistics/all-cancer-facts-figures/cancer-facts-figures-2019.html>
- American Public Health Association. (n.d.). What is public health? Retrieved from <https://www.apha.org/what-is-public-health>
- American Society of Clinical Oncology. (n.d.). Survivorship compendium. Retrieved from <https://www.asco.org/practice-guidelines/cancer-care-initiatives/prevention-survivorship/survivorship/survivorship-compendium>
- Bhatia, S., Armenian, S.H., & Landier, W. (2017). How I monitor long term and late effects after blood or marrow transplantation. *Blood*, *130*, 1302–1314. <https://doi.org/10.1182/blood-2017-03-725671>
- Brega, A.G., Barnard, J., Mabachi, N.M., Weiss, B.D., DeWalt, D.A., Brach, C., ... West, D.R. (2015). *Health literacy universal precautions toolkit* (2nd ed.) (AHRQ Publication No. 15-0023-EF). Retrieved from <https://www.ahrq.gov/professionals/quality-patient-safety/quality-resources/tools/literacy-toolkit/index.html>
- Bugos, K.G. (2015). Issues in adult blood cancer survivorship care. *Seminars in Oncology Nursing*, *31*, 60–66. <https://doi.org/10.1016/j.soncn.2014.11.007>
- Burris, J.L., & Andrykowski, A. (2010). Disparities in mental health between rural and nonrural cancer survivors: A preliminary study. *Psycho-Oncology*, *19*, 637–645. <https://doi.org/10.1002/pon.1600>
- Centers for Disease Control and Prevention. (2015). Colorectal cancer control program: Social ecological model. Retrieved from <https://www.cdc.gov/cancer/crcp/sem.htm>
- Centers for Disease Control and Prevention & Lance Armstrong Foundation. (2004). *A national action plan for cancer survivorship: Advancing public health strategies*. Retrieved from <https://www.cdc.gov/cancer/survivors/pdf/plan.pdf>
- Children’s Oncology Group. (2018). *Long-term follow-up guidelines for survivors of childhood, adolescent, and young adult cancers* (Version 5.0). Retrieved from <http://survivorshipguidelines.org>
- DeGuzman, P.B., Colliton, K., Nail, C.J., & Keim-Malpass, J. (2017). Survivorship care plans: Rural, low-income breast cancer survivor perspectives. *Clinical Journal of Oncology Nursing*, *21*, 692–698. <https://doi.org/10.1188/17.CJON.692-698>
- Desmond, R.A., Jackson, B.E., & Waterbor, J.W. (2017). Disparities in cancer survivorship indicators in the Deep South based on BRFS data: Recommendation for survivorship care plans. *Southern Medical Journal*, *110*, 181–187. <https://doi.org/10.14423/SMJ.00000000000000617>
- Dood, R.L., Zhao, Y., Armbruster, S.D., Coleman, R.L., Tworoger, S., Sood, A.K., & Baggerly, K.A. (2018). Defining survivorship trajectories across patients with solid tumors: An evidence-based approach. *JAMA Oncology*, *4*, 1519–1526. <https://doi.org/10.1001/jamaoncol.2018.2761>
- Goodman, D.C., Esty, A.R., Fisher, E.S., & Chang, C.-H. (2011). *Trends and variation in end-of-life care for Medicare beneficiaries with severe chronic illness*. Hanover, NH: Dartmouth Institute for Health Policy and Clinical Practice.
- Grant, M., McCabe, M., & Economou, D. (2017). Nurse education and survivorship: Building the specialty through training and program development. *Clinical Journal of Oncology Nursing*, *21*, 454–459. <https://doi.org/10.1188/17.CJON.454-459>

- Haylock, P.J., Mitchell, S.A., Cox, T., Temple, S.V., & Curtiss, C.P. (2007). The cancer survivor's prescription for living: Nurses must take the lead in planning care for survivors. *American Journal of Nursing*, *107*(4), 58–70. <https://doi.org/10.1097/00000446-200704000-00026>
- Hewitt, M., Greenfield, S., & Stovall, E. (Eds.). (2006). *From cancer patient to cancer survivor: Lost in transition*. <https://doi.org/10.17226/11468>
- Jacobsen, P.B., DeRosa, A.P., Henderson, T.O., Mayer, D.K., Moskowitz, C.S., Paskett, E.D., & Rowland, J.H. (2018). Systematic review of the impact of cancer survivorship care plans on health outcomes and health care delivery. *Journal of Clinical Oncology*, *36*, 2088–2100. <https://doi.org/10.1200/JCO.2018.77.7482>
- Jacobsen, P.B., Rowland, J.H., Paskett, E.D., Van Leeuwen, F., Moskowitz, C., Katta, S., ... Robison, L.L. (2016). Identification of key gaps in cancer survivorship research: Findings from the American Society of Clinical Oncology survey. *Journal of Oncology Practice*, *12*, 190–193. <https://doi.org/10.1200/JOP.2015.009258>
- Kushi, L.H., Doyle, C., McCullough, M., Rock, C.L., Demark-Wahnefried, W., Bandera, E.V., ... Gansler, T. (2012). American Cancer Society guidelines on nutrition and physical activity for cancer prevention: Reducing the risk of cancer with healthy food choices and physical activity. *CA: A Cancer Journal for Clinicians*, *62*, 30–67. <https://doi.org/10.3322/caac.20140>
- Laino, C. (2010). New guidelines for cancer patients from American College of Sports Medicine: Exercising during and after treatment brings health benefits. *Oncology Times*, *32*(17), 16, 18. <https://doi.org/10.1097/01.COT.0000388578.69348.ed>
- Landier, W., Bhatia, S., Eshelman, D.A., Forte, K.J., Sweeney, T., Hester, A.L., ... Hudson, M.M. (2004). Development of risk-based guidelines for pediatric cancer survivors: The Children's Oncology Group long-term follow-up guidelines from the Children's Oncology Group Late Effects Committee and Nursing Discipline. *Journal of Clinical Oncology*, *22*, 4979–4990. <https://doi.org/10.1200/JCO.2004.11.032>
- Ligibel, J.A., & Denlinger, C.S. (2013). New NCCN Guidelines® for survivorship care. *Journal of the National Comprehensive Cancer Network*, *11*(Suppl. 5), 640–644. <https://doi.org/10.6004/jnccn.2013.0191>
- Linschoten, M., Teske, A.J., Cramer, M.J., van der Wall, E., & Asselbergs, F.W. (2018). Chemotherapy-related cardiac dysfunction: A systematic review of genetic variants modulating individual risk. *Circulation: Genomic and Precision Medicine*, *11*, e001753. Retrieved from <https://www.ahajournals.org/doi/10.1161/CIRCGEN.117.001753>
- Loonen, J.J., Blijlevens, N.M.A., Prins, J., Dona, D.J.S., Den Hartogh, J., Senden, T., ... Hermens, R.P.M.G. (2018). Cancer survivorship care: Person centered care in a multidisciplinary shared care model. *International Journal of Integrated Care*, *18*, 4. <https://doi.org/10.5334/ijic.3046>
- Mayer, D.K., Birken, S.A., Check, D.K., & Chen, R.C. (2015). Summing it up: An integrative review of studies of cancer survivorship care plans (2006–2013). *Cancer*, *121*, 978–996. <https://doi.org/10.1002/cncr.28884>
- McCabe, M.S., Bhatia, S., Oeffinger, K.C., Reaman, G.H., Tyne, C., Wollins, D.S., & Hudson, M.M. (2013). American Society of Clinical Oncology statement: Achieving high-quality cancer survivorship care. *Journal of Clinical Oncology*, *31*, 631–640. <https://doi.org/10.1200/JCO.2012.46.6854>
- McGrath, P., & Holewa, H. (2012). What does the term 'survivor' mean to individuals diagnosed with a haematological malignancy? Findings from Australia. *Supportive Care in Cancer*, *20*, 3287–3295. <https://doi.org/10.1007/s00520-012-1453-4>
- Moore, A.R., Buchanan, N.D., Fairley, T.L., & Smith, J.L. (2015). Public health action model for cancer survivorship. *American Journal of Preventive Medicine*, *49*(Suppl. 5), S470–S476. <https://doi.org/10.1016/j.amepre.2015.09.001>
- Mullan, F. (1985). Seasons of survival: Reflections of a physician with cancer. *New England Journal of Medicine*, *313*, 270–273. <https://doi.org/10.1056/NEJM198507253130421>
- Myers, J.S., Koleck, T.A., Sereika, S.M., Conley, Y.P., & Bender, C.M. (2017). Perceived cognitive function for breast cancer survivors: Association of genetic and behaviorally related variables for inflammation. *Supportive Care in Cancer*, *25*, 2475–2484. <https://doi.org/10.1007/s00520-017-3654-3>
- National Cancer Institute. (2016). Office of Cancer Survivorship: Statistics. Retrieved from <https://cancercontrol.cancer.gov/ocs/statistics/statistics.html>
- National Cancer Institute. (2017). About cancer survivorship. Retrieved from <https://cancercontrol.cancer.gov/ocs/about/index.html>
- National Cancer Institute. (2018a). Cancer disparities. Retrieved from <https://www.cancer.gov/about-cancer/understanding/disparities>
- National Cancer Institute. (2018b). Health disparities. Retrieved from <https://cancercontrol.cancer.gov/research-emphasis/health-disparities.html>
- National Coalition for Cancer Survivorship. (n.d.). Our mission. Retrieved from <https://www.canceradvocacy.org/about-us/our-mission>

- National Comprehensive Cancer Network. (2019). *NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®): Survivorship* [v.1.2019]. Retrieved from https://www.nccn.org/professionals/physician_gls/pdf/survivorship.pdf
- Nekhlyudov, L., Ganz, P.A., Arora, N.K., & Rowland, J.H. (2017). Going beyond being lost in transition: A decade of progress in cancer survivorship. *Journal of Clinical Oncology*, *35*, 1978–1981. <https://doi.org/10.1200/JCO.2016.72.1373>
- Polite, B.N., Adams-Campbell, L.L., Brawley, O.W., Bickell, N., Carethers, J.M., Flowers, C.R., ... Pas-kett, E.D. (2017). Charting the future of cancer health disparities research: A position statement from the American Association for Cancer Research, the American Cancer Society, the American Society of Clinical Oncology, and the National Cancer Institute. *Journal of Clinical Oncology*, *35*, 3075–3082. <https://doi.org/10.1200/JCO.2017.73.6546>
- Rechis, R., Beckjord, E.B., Arvey, S.R., Reynolds, K.A., & McGoldrick, D. (2011). *The essential elements of survivorship care: A Livestrong brief*. Retrieved from <https://www.livestrong.org/what-we-do/reports/survivorship/the-essential-elements-of-survivorship-care-a-livestrong-brief>
- Resnick, M.J., Lacchetti, C., Bergman, J., Hauke, R.J., Hoffman, K.E., Kungel, T.M., ... Penon, D.F. (2015). Prostate cancer survivorship care guideline: American Society of Clinical Oncology clinical practice guideline endorsement. *Journal of Clinical Oncology*, *33*, 1078–1085. <https://doi.org/10.1200/JCO.2014.60.2557>
- Runowicz, C.D., Leach, C.R., Henry, N.L., Henry, K.S., Mackey, H.T., Cowens-Alvarado, R.L., ... Ganz, P.A. (2016). American Cancer Society/American Society of Clinical Oncology breast cancer survivorship care guideline. *Journal of Clinical Oncology*, *34*, 611–635. <https://doi.org/10.1200/JCO.2015.64.3809>
- Shoemaker, S.J., Wolf, M.S., & Brach, C. (2013). *The patient education materials assessment tool (PEMAT) and user's guide* (AHRQ Publication No. 14-0002-EF). Retrieved from <https://www.ahrq.gov/professionals/prevention-chronic-care/improve/self-mgmt/pemat/index.html>
- Smith, J.L., & Hall, I.J. (2015). Advancing health equity in cancer survivorship: Opportunities for public health. *American Journal of Preventive Medicine*, *49*(Suppl. 5), S477–S482. <https://doi.org/10.1016/j.amepre.2015.08.008>
- Smith, J.L., Pollack, L.A., Rodriguez, J.L., Hawkins, N.A., Smith, T., Rechis, R., ... Stone-Wiggins, B. (2013). Assessment of the status of a national action plan for cancer survivorship in the USA. *Journal of Cancer Survivorship*, *7*, 425–438. <https://doi.org/10.1007/s11764-013-0276-8>
- Underwood, J.M., Lakhani, N., Finifrock, D., Pinkerton, B., Johnson, K.L., Mallory, S.H., ... Stewart, S.L. (2015). Evidence-based cancer survivorship activities for comprehensive cancer control. *American Journal of Preventive Medicine*, *49*(Suppl. 5), S536–S542. <https://doi.org/10.1016/j.amepre.2015.08.011>