









Evidence Gaps in Cancer Survivorship Care: A Report From the 2019 National Cancer Institute Cancer Survivorship Workshop

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Abstract

Today, there are more than 16.9 million cancer survivors in the United States; this number is projected to grow to 22.2 million by 2030. Although much progress has been made in describing cancer survivors' needs and in improving survivorship care since the seminal 2006 Institute of Medicine report "From Cancer Patient to Cancer Survivor: Lost in Transition," there is a need to identify evidence gaps and research priorities pertaining to cancer survivorship. Thus, in April 2019, the National Cancer Institute convened grant-funded extramural cancer survivorship researchers, representatives of professional organizations, cancer survivors, and advocates for a 1-day in-person meeting. At this meeting, and in a subsequent webinar aimed at soliciting input from the wider survivorship community, evidence gaps and ideas for next steps in the following 6 areas, identified from the 2006 Institute of Medicine report, were discussed: surveillance for recurrence and new cancers, management of long-term and late physical effects, management of long-term and late psychosocial effects, health promotion, care coordination, and financial hardship. Identified evidence gaps and next steps across the areas included the need to understand and address disparities among cancer survivors, to conduct longitudinal studies as well as longer-term (>5 years post-diagnosis) follow-up studies, to leverage existing data, and to incorporate implementation science strategies to translate findings into practice. Designing studies to address these broad evidence gaps, as well as those identified in each area, will expand our understanding of cancer survivors' diverse needs, ultimately leading to the development and delivery of more comprehensive evidence-based quality care.

In 2019, it was estimated that 16.9 million individuals in the United States were cancer survivors, defined as those with a history of a cancer diagnosis; this number is projected to grow to 22.2 million in 2030 (1). The increasing number of cancer survivors is due to the growth and aging of the population, better early-detection strategies, more effective cancer treatments,

and improved supportive care. Published in 2006, the seminal Institute of Medicine report, "From Cancer Patient to Cancer Survivor: Lost in Transition" (2), identified 4 essential components of survivorship care: 1) prevention and detection of new cancers and recurrent cancer; 2) surveillance for cancer spread, recurrence, or additional primary cancers; 3) intervention for

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consequences of cancer and its treatment; and 4) coordination between specialists and primary care providers to ensure that all of the survivor's health needs are met. The Institute of Medicine report also made 10 recommendations that included the need to increase survivorship research with focused initiatives to guide effective survivorship care (recommendation #10). Although progress has been made to advance the science and delivery of survivorship care since the 2006 report, many gaps remain (3). The National Academies' Long-term Survivorship Care After Cancer Treatment: Proceedings of a Workshop, held in 2017, emphasized the need to identify research gaps and strategic research priorities for survivorship (4). Two previous analyses of survivorship research identified gaps that included research focused on survivors of cancer types other than breast, older (aged >65 years) cancer survivors, and longer-term (>5 years since diagnosis) cancer survivors; studies on patterns and quality of survivorship care; and intervention studies (5,6). Thus, in April 2019, the National Cancer Institute (NCI) convened extramural cancer survivorship investigators (both early-stage and experienced), representatives of professional organizations, cancer survivors, and survivor advocates for a 1-day meeting with the goal of generating ideas on evidence gaps in knowledge and practice that need to be filled based on the 4 essential components of survivorship care. Invited extramural investigators were identified from a pool of researchers who had an active National Institutes of Health (NIH) cancer survivorship grant at that time. Other attendees—representatives of professional organizations, cancer survivors, and survivor advocates—were selected based on their experience and involvement in cancer survivorship activities; cancer survivors and advocates to help lead the breakout groups (described below) were identified with the help of the NCI's Office of Advocacy Relations. Participant ideas on critical evidence gaps to be filled in the area of cancer survivorship were then used by NCI staff to enumerate strategic research priorities.

The 53 attendees at the 2019 meeting were diverse in terms of professional discipline, research focus, career stage, and geographic location. Participants were expected to review several seminal publications, including a published manuscript by Rowland et al. (6) describing the 2016 NIH cancer survivorship grant portfolio and reports from 2017 National Academies' workshop (4,7), before the meeting. Attendees were assigned to 1 of 6 breakout groups that separately addressed specific areas of survivorship research: surveillance for recurrences and subsequent new cancers, late and long-term physical effects, late and long-term psychosocial effects, health promotion, care coordination, and financial impact. A cancer survivor and/or advocate introduced each group session and briefly reflected on the topic's importance. A topic expert subsequently offered a concise review of the field, building on the 2017 National Academies' workshop report (4). Finally, building on the Rowland et al. (6) analysis of the 2016 NIH cancer survivorship portfolio, an NCI program director summarized the 2017-2019 NIH portfolio on the assigned topic. Each group was then tasked with addressing 2 key questions specific to their topic area: What are the most important evidence gaps in cancer survivorship care that should be addressed? What are the key next steps to address these gaps?

After the topic-oriented small group meetings, all attendees and facilitators reconvened to review each of the small groups' findings, discuss areas of overlap, and elicit new ideas. Finally, the evidence gaps and key next steps generated by each small group were posted in the room, and an open session allowed

participants to contribute to the brainstorming within and outside their small group.

Within 2 weeks of the meeting, NCI hosted a public webinar (8) that shared with the wider survivorship community the evidence gaps and next steps from the workshop. The webinar was advertised in the NIH Guide, the Federal Register, on Twitter, and through meeting attendees as well as professional and advocacy groups. The interactive 1-hour webinar sought to elicit feedback on the evidence gaps and next steps from the 392 webinar participants while also allowing them to submit new ideas. After the webinar, NCI staff met to review the list of evidence gaps and next steps from both the workshop and the webinar to generate a list of research priorities. This article provides a summary of the identified evidence gaps and key next steps from the workshop and webinar as well as a list of the research priorities generated by NCI staff (Box 1).

Surveillance for Recurrences and New Cancers

Evidence Gaps

Because almost 20% of all new cancers are diagnosed in individuals with a history of cancer (9), integrating surveillance recommendations and identifying those at highest risk for additional primary cancers are critical. There is a need to both identify optimal evidence-based schedules for surveillance of recurrence and progression and to generate better estimates of risk and potential benefit for surveillance practices (10,11). Further, there is a need to review and harmonize surveillance guidelines. Currently, it is not possible to differentiate those with and without a recurrence in Surveillance, Epidemiology, and End Results Program data, limiting our understanding of who is at risk for recurrence. Additionally, gaps in knowledge include understanding recurrence risk in different subgroups of the cancer survivor population, including those defined by age, race or ethnicity, immigrant status, socioeconomic status, sexual identity, and rurality, and improving the recruitment of diverse participants to relevant observational studies and clinical trials examining surveillance (12-17). There is also a need to better identify at-risk populations based on cancer treatment received, particularly with emerging therapies and especially in longer-term survivors. Importantly, many survivors should be getting sex- and age-appropriate cancer screenings and general health preventive care (18), but how this testing should be integrated or prioritized relative to surveillance for recurrence or treatment-related surveillance guidelines is unknown.

Key Next Steps

Key next steps identified during the in-person meeting and strongly endorsed by webinar participants (87% agreed or strongly agreed) included determining optimal surveillance frequency and identifying the risks and benefits for surveillance testing. Creating mechanisms and opportunities for additional funding allowing for longer surveillance periods for existing, relevant clinical trials is also warranted. Enhancing NCI's Surveillance, Epidemiology, and End Results Program cancer registries, state cancer registries, and the National Cancer Database to identify and capture recurrences and additional cancers is needed. Intentional data collection is also needed to obtain more representative surveillance and screening data for those experiencing disparities in cancer outcomes.

Box 1 2019 National Cancer Institute (NCI) Cancer Survivorship Workshop Research Priorities**Surveillance for Recurrence and New Cancers**

- Identify optimal evidence-based schedules for surveillance of recurrence and new cancers
- Generate better estimates of risk and potential benefit of surveillance testing
- Enhance NCI's Surveillance, Epidemiology, and End Results Program, state cancer registries, and national cancer databases to capture recurrence, progression, and new cancers

Management of Long-Term and Late Physical Effects

- Incorporate, in a consistent manner across studies and existing data resources, data collection using common data elements for symptoms, functional status, and comorbid conditions
- Examine the natural history and biosignatures of late and long-term effects by cancer type and treatment
- Utilize theoretical models, such as the chronic disease model, to frame intervention development for preventing and mitigating long-term and late physical effects

Management of Long-Term and Late Psychosocial Effects

- Conduct population-level surveillance for psychosocial sequelae
- Examine psychosocial consequences of or contributors to living with metastatic disease, recurrence, and second malignancies
- Encourage greater uptake of screening for psychosocial risk concomitant with cancer diagnosis, treatment, and/or follow-up care
- Identify social functioning needs of aging cancer survivors

Health Promotion

- Conduct multi-level research studies addressing health behaviors in survivorship care in both oncology and primary care settings
- Integrate existing and emerging digital technologies for tailored health promotion into survivorship care
- Combine basic science with human studies to identify mechanisms and targets for interventions

Care Coordination

- Define key outcomes and measures to assess care coordination
- Develop algorithms for risk stratification and implement tailored care pathways for survivors based on levels of needs
- Evaluate the role of telehealth in coordinating comprehensive survivorship care

Financial Hardship

- In longitudinal studies, characterize risk factors for financial hardship, employment disruption, and other economic effects of cancer and evaluate the effects of financial hardship on daily functioning, clinical outcomes, quality of life, and healthcare utilization
- Leverage existing data sources and novel data linkages to study the economic effects of cancer
- Develop technology to streamline the collection and use of economic data to support financial navigation interventions
- Develop interventions to mitigate the economic effects of cancer, addressing issues at the patient, provider, health system, employer, and policy levels

Cross-Cutting Needs

- Understand and address disparities by including understudied, underserved and vulnerable populations in studies
- Conduct longitudinal as well as longer-term follow-up studies (>5 years)
- Incorporate implementation science expertise in interventions to translate findings from observational studies and efficacy trials into practice
- Develop career development, training and mentoring programs, and other strategies to support cancer survivorship scientists

(continued)

Management of Long-Term and Late Effects: Physical**Evidence Gaps**

Several gaps were identified by stakeholders and include developing profiles of the natural history and identifying relevant biomarkers of late and long-term effects that are common in adult-onset cancers. In addition, few existing studies assessing long-term and late effects have included a noncancer comparison group; therefore, there is limited understanding of the effects of cancer and cancer treatment in the context of normal aging and lifestyle patterns (19,20). Furthermore, there is limited understanding of the underlying mechanisms for many of the observed cancer treatment-related long-term and late adverse physical effects; hypothesized, yet understudied, mechanisms for long-term physical effects include senescence,

inflammation, oxidative stress, or mitochondrial dysfunction. Lack of routine capture of common data elements—such as those related to comorbid conditions or functional impairment, using validated core outcome instruments including patient-reported outcomes (PROs)—has also limited the field (21,22). Interventions to promote self-management of risks and late effects have not been thoroughly tested or disseminated.

Key Next Steps

Next steps identified and strongly endorsed by webinar participants (91% agreed or strongly agreed) included the need for consistent use of validated core measures for common data elements related to symptoms, functional status, comorbid conditions, late and long-term effects, and survivor needs. Profiles of the natural history and biosignatures of late and long-term

effects are needed to identify those at high risk of developing certain adverse effects, and in developing and testing prevention and mitigation strategies. Such studies will also set the stage for the development of guidelines and indicators of care quality. Existing data resources, such as registries and cohort studies, should be leveraged by the inclusion of measures that capture comorbidities, functional status, and symptoms as well as behavioral endpoints such as physical activity, diet, tobacco and alcohol use, and rehabilitation needs (23). Another priority is framing intervention development using a theoretical model such as the chronic care model (24-27). These models are multi-level, patient- and family-focused, and have, at their core, risk reduction, rehabilitation, and self-management support. These interventions should be conducted in diverse populations and community settings.

Management of Long-Term and Late Effects: Psychosocial

Evidence Gaps

Anxiety, depression, and fear of recurrence are common in cancer survivors, and some may experience the symptoms of posttraumatic stress (28-31). A number of gaps were identified pertaining to long-term and late psychosocial effects. First, there is a need for more systematic surveillance of psychosocial sequelae for all cancer survivor populations over the course of the survivorship trajectory, including the regular use of relevant PROs. Despite being common, the prevalence and pattern of key psychosocial effects is not well documented. Further, interventions to increase the uptake of screening for adverse psychosocial effects concomitant with cancer diagnosis, treatment, and follow-up care are needed to intervene at the right time in the right place; this will necessitate the utilization of less-used study designs (eg, stepped-care algorithms, harmonized n-of-1 studies, pragmatic studies), going beyond pilot efficacy trials for preliminary data, and powering studies on a threshold of clinical significance. In addition, given the number of evidence-based interventions (32), more work is needed for implementation of psychosocial interventions in real-world settings such as community oncology or primary care (33,34). Finally, additional research is needed to better understand psychosocial effects in understudied populations, such as those living with advanced cancers, recurrences, or multiple cancers, as well as cancer caregivers.

Key Next Steps

Next steps identified and strongly endorsed by webinar participants (89% agreed or strongly agreed) included conducting population-level surveillance for psychosocial sequelae among cancer survivors, identifying social functioning needs of aging long-term cancer survivors, implementing and integrating psychosocial interventions in real-world settings, and targeting prevention and mitigation strategies based on risk for poorer psychosocial outcomes.

Health Promotion

Evidence Gaps

Health promotion is an important component of survivorship care to prevent or mitigate long-term and late effects, improve

physical and mental function, and maintain quality of life (35-38). A lack of sufficient data on the multi-level drivers or mechanisms of health behavior change, including those for diet, physical activity, weight management, tobacco use, sun protection, and alcohol use, was noted (39,40). Studies of biomarkers that both predict long-term outcomes (including recurrence, late effects, and mortality) and are affected by interventions are needed. Other knowledge gaps include how to deliver the right interventions at the right time, with consideration given to factors such as age, race or ethnicity, sexual identity, and socioeconomic status (41). Although many health promotion activities focus on smoking cessation (42,43), increasing physical activity, and improving diet quality (44), interventions to decrease alcohol use and improve sun protection behaviors in cancer survivors are also needed. Additionally, it was noted that existing studies of health behavior interventions for cancer survivors do not commonly include expertise in implementation science; incorporating such expertise may enhance the translational potential of the research (45-47).

Key Next Steps

Next steps identified and strongly endorsed by webinar participants (87% agreed or strongly agreed) included conducting multi-level and pragmatic research studies that address health behaviors in survivorship care in both oncology and primary care settings. Combining basic science with human studies would be useful in identifying mechanisms and targets for intervention. Integration of existing and emerging digital technologies for tailored health promotion in cancer survivorship care is also needed.

Care Coordination

Evidence Gaps

Given the higher prevalence of multiple chronic conditions among cancer survivors compared with individuals without cancer (48,49) and cancer survivors' ongoing need for medical management along with their cancer care, care coordination is an important aspect of survivorship care (50). Clear processes and care pathways that enhance the sharing of cancer and noncancer follow-up care within and across clinical settings and specialties are critical for information exchange, goal and priority setting, and coordination of care (51,52). Models of care that support risk-stratified care delivery, tailoring or customization of lifestyle and self-management interventions, and rehabilitation are lacking (51,53-67). This may be more of an issue in the United States than in other countries given the lack of a national strategy for the delivery of coordinated care, although care delivery challenges are globally apparent as well (68). These much-needed models of care include those that incorporate telehealth and novel strategies such as group visits to expand access and manage resources, especially for underserved survivors (53,69).

Key Next Steps

Next steps identified and strongly endorsed by webinar participants (86% agreed or strongly agreed) included initially identifying key outcomes and measures to assess quality care coordination. In addition, optimal models to promote stratified care coordination based on level of survivor need should be developed, tested, and implemented. It is also necessary to

identify policies that are effective in incentivizing the provision of coordinated cancer care. Finally, assessment of the role of digital health in care coordination and efforts to support underserved populations are both critically needed.

Financial Impact

Evidence Gaps

Although the initial Lost in Transition report did not specifically mention financial hardship or financial toxicity, increasing attention has been paid to this concept over the past several years (70-72). Financial hardship, which includes problems paying medical bills, experiencing distress about the out-of-pocket costs of care, delaying or forgoing care because of costs, and employment disruption (with the potential for loss of income and employer-sponsored health insurance coverage), has become a major issue for many cancer survivors (73,74). Yet, there are gaps in our understanding of modifiable drivers of financial hardship as well as how financial hardship and its correlates change over time. There is also a lack of information on the associations of provider-, payer-, employer-, and health-care system-level factors and financial hardship (75). This issue may be exacerbated in the United States given the lack of national health insurance and increasing reliance on patient contribution to medical costs (76).

Few interventions have been developed to address risk factors for financial hardship, and few validated tools exist to measure the types and amount of financial hardship or associated outcomes. There is a need for future research in this area, with a particular focus on the needs of certain understudied populations who are particularly vulnerable to financial hardship, including adolescent and young adult cancer survivors, the medically underserved, the uninsured and under-insured, caregivers and family members, and patients with metastatic disease.

Key Next Steps

Next steps identified and strongly endorsed by webinar participants (90% agreed or strongly agreed) include longitudinal studies to understand risk factors for financial hardship, not being able to work full-time or to work at all, and other economic effects as well as the effects of financial hardship on daily functioning, clinical outcomes, quality of life, and health-care use. Studies that leverage existing data infrastructure and data linkages to study economic effects are needed. Likewise, technology should be used to collect economic data and support financial navigation interventions. Interventions to mitigate the economic effects of cancer should address issues at the patient, provider, health system, and policy levels. This work should engage relevant stakeholders and be guided by an implementation science framework to inform data collection and the development of programs that are feasible to implement.

Cross-Cutting Needs and Evidence Gaps

A number of needs or evidence gaps were identified by most or all of the 6 groups. First, stakeholders agreed that there is a need to understand and address disparities by including understudied, underserved, and vulnerable populations in studies. To do so, it is necessary to better educate and engage these populations throughout the research process, from determining what research questions are important to them to communication of study results. Second, groups identified the need for

longitudinal studies to examine survivorship outcomes over time; this includes conducting longitudinal studies on longer-term survivorship issues (ie, among survivors who are 5 or more years since diagnosis). In addition, most groups recommended that implementation science be incorporated into interventions to more effectively translate findings from observational studies and efficacy trials into practice.

To build the survivorship scientist workforce necessary to effectively address these evidence gaps, the groups across the board expressed the need to improve training of new investigators as well as to develop mentorship programs matching more experienced cancer survivorship investigators to those in the early stages of their career. Finally, participants encouraged increasing awareness of opportunities to leverage ongoing studies for cancer survivorship research (77), facilitating efficient use of existing resources while addressing new cancer survivorship questions.

Summary

This meeting convened a wide range of United States-based stakeholders to identify evidence gaps and key next steps for survivorship care, which were used by the NCI to generate a list of research priorities (Box 1). Although these broad survivorship recommendations were developed with the United States health-care system in mind, other survivorship research priorities have been published that are focused on a specific cancer type or types (78,79) or that are oriented toward health-care systems in other countries (80). Nevertheless, there is a need to understand the full spectrum of late and long-term effects of cancer and its treatment experienced by survivors as well as to understand the basic biological and behavioral mechanisms underlying these effects. Strategies and approaches that engage implementation science are vital. Further, expanding existing data resources—by leveraging big data, exploring novel data linkages, building data infrastructure, establishing common data elements, or incorporating PROs—and developing and using novel analytic methods to answer cancer survivorship questions within these resources will be useful. Multidisciplinary teams will be essential to approach survivorship research and care from a holistic perspective while addressing health-care delivery in evolving health-care systems (81,82). There are a variety of current mechanisms and additional opportunities that can add to or extend existing funding to address these evidence gaps and priorities. (For survivorship-specific funding announcements, see <https://cancercontrol.cancer.gov/ocs/funding>.) To deliver more comprehensive, evidence-based, quality care for the growing number of survivors, research to fill these evidence gaps and to address these priorities is urgently needed.

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No new data were generated or analyzed in support of this manuscript.

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