

Advancing Health Equity in Cancer Survivorship

Opportunities for Public Health



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The number of cancer survivors who are members of underserved groups is growing, with members of racial and ethnic minorities predicted to increase significantly by 2030.¹ The *Healthy People 2020* objectives advocate reduced death rates for several cancers, increasing the proportion of survivors living more than 5 years, and improving the quality of life of survivors.² Considerable challenges exist to achieving these goals equitably for all survivors and their families.

Health disparities that impact the general population also manifest among cancer survivors. Disparities are evident by race or ethnicity; income; age; geographic location; and mental, cognitive, or physical disability, or comorbidity status.^{3–7} National frameworks suggest methods to reduce or eliminate health disparities. The National Prevention Strategy⁸ provides five recommendations to eliminate health disparities:

1. ensure a strategic focus on communities of greatest risk;
2. reduce disparities in access to quality health care;
3. increase the capacity of the prevention workforce to identify and address disparities;
4. support research to identify effective strategies to eliminate health disparities; and
5. standardize and collect data to better identify and address disparities.

Several of these recommendations align with current public health strategies to increase health equity among survivors and provide guidance about future activities.⁹

Barriers to cancer screening and treatment, such as limited access to high-quality care, poor patient–provider communication, and insufficient support services, can persist among survivors in post-treatment.^{10–18} These

challenges are often exacerbated if survivors are members of any underserved group. Rural cancer survivors were less likely to have access to comprehensive cancer centers and more likely to retire early and have no disability insurance coverage.¹⁹ Elderly lung cancer survivors were less likely to receive care consistent with guidelines if they were racial or ethnic minorities, had more comorbidities, or had lower income.²⁰ African-American breast cancer survivors reported less access to culturally appropriate post-treatment support services.²¹ Survivors with elevated levels of fear of cancer recurrence were more likely to experience greater depression, decreased sleep quality, increased smoking, and lower health-related quality of life.^{22,23} Survivors reporting lower ratings of general health were more likely to not have accessed health information for themselves, have no family members who searched for information on their behalf, and have lower household incomes.²⁴ These and other barriers may be targeted by public health organizations to reduce inequities among survivors.

CDC Research Portfolio on Health Disparities in Cancer Survivorship

CDC has supported multiple projects over the past 10 years that are consistent with the five National Prevention Strategy recommendations to reduce health disparities. Below, the authors highlight some activities that focused on health disparities in cancer survivorship and outline areas for additional public health efforts.

Strategic Focus on Communities at Greatest Risk

Underserved survivors may have specific barriers to quality care and facilitators thereof. CDC and funded partners have conducted a number of studies that have informed the field about the experiences of survivors at risk for suboptimal outcomes.^{25–27} For example, to improve surveillance behaviors, African-American colorectal cancer (CRC) survivors often benefitted from support from family, religious or faith communities, and other survivors.²⁵ Asian-American and Pacific Islander CRC survivors may need culturally appropriate outreach to increase use of mammography.²⁶ One study

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found that 97% of younger breast cancer survivors were at risk for infertility—highlighting the importance of providing these patients with reliable information to make informed decisions about fertility given its impact on later quality of life.²⁷ More research is needed to identify and address the unique needs of underserved survivors including those exacerbated by age, cognitive status, disability status, or geographic location.

Disparities in Access to Quality Health Care

CDC has collaborated with partners to examine disparate access to care for survivors. Findings suggest that breast cancer survivors, lower-income African-American survivors, survivors needing psychosocial care, and uninsured and underinsured survivors are among the groups not receiving appropriate surveillance or support following treatment.^{28–32} African-American CRC survivors are often non-adherent with annual receipt of surveillance colonoscopies.^{33–35} CDC-sponsored research determined that these survivors often reported being uninformed about the recommended protocol for follow-up surveillance.²⁸ Other work confirmed that survivors are at increased risk for depression and more than 50% of cancer survivors reported no discussions with providers or use of support groups to address psychosocial concerns.^{29,30} Psychosocial distress may result in lower quality of life or detrimental health behaviors, and efforts are needed to identify survivors at higher risk for poor outcomes.³⁶

Another CDC-led study found that about 25% of breast cancer survivors reported non-receipt of appropriate mammography surveillance.³² Additionally, publically insured women were less likely to report receipt of a mammogram than those with a combination of Medicare and private insurance. Adults who are uninsured or insured only by Medicare have worse access to quality care or experience worse outcomes, making understanding the role of insurance in access to quality care important.^{37,38} These studies have highlighted survivors that may need additional assistance in accessing appropriate care, surveillance, and support post-treatment.

Improving the Capacity of the Prevention Workforce

Enhanced collaboration among healthcare professionals is essential to work effectively with cancer survivors. Few providers have a comprehensive discussion with survivors about the importance of improving diet, increasing exercise, or ceasing tobacco use, and enhanced patient counseling is warranted.³⁹ A CDC study found that longer-term survivors sought services from both primary care providers and hematology/oncology specialists.⁴⁰ Some research has reported that survivors who received ongoing care by oncologists only reported the

worse preventive care.⁴¹ Cancer survivors, including those with multiple comorbid conditions, should optimally receive care from providers in various areas, suggesting a need to provide training in cancer survivorship across all specialties. A national framework to achieve several objectives related to multiple comorbid conditions has been created.⁴² Efforts to establish guidelines for the treatment of patients in the U.S. with multiple comorbid conditions, including cancer, are underway.^{43,44}

Exploring Effective Strategies to Eliminate Health Disparities

Strategies to eliminate disparities in cancer survivorship can be implemented at multiple levels. CDC funded research to explore the effectiveness of an established cancer survivorship program with lower-income African-American cancer survivors. Results demonstrated the program was not effective with the study participants and highlighted the urgency to develop programs consistent with the needs of the target community.⁴⁵ Survivorship care plans (SCPs) have been promoted as a potential tool to assist survivors in navigating their post-treatment care and have been recently recommended for implementation by the Commission on Cancer.^{3,46} The evidence base for SCPs, however, is still developing, with some conflicting findings.^{47–50} CDC funded a study to explore the feasibility of and satisfaction with SCPs and has also explored the receipt of SCPs at the national level among diverse groups of survivors. Findings revealed that although well received by survivors, SCPs were time and labor intensive and many survivors reported not receiving treatment summaries and written follow-up instructions.^{51,52} Research is needed to assess the best practices for development, dissemination, and evaluation of these plans or other supportive tools for underserved survivors.

Persistent smoking, overweight or obesity, and physical inactivity remain prevalent among survivors. CDC studies identified poor health behaviors among diverse survivors, including longer-term survivors.^{53–56} In a study of racially diverse breast cancer survivors, whites were more likely to be current smokers, and longer-term African-American breast cancer survivors were more likely to be obese.⁵⁴ Cervical cancer survivors had a greater risk of additional malignancies associated with tobacco use.⁵⁵ Additional research suggested that CRC survivors have higher percentages of obesity and lower levels of physical activity.⁵⁶ These studies provide guidance about specific areas that may be targeted to improve survivor education about and self-efficacy related to optimizing health.

Collect Data to Address Disparities More Effectively

CDC works with partners to develop surveys that collect state- or population-level data to assess the burden of cancer. CDC led the development of a Behavioral Risk Factor Surveillance System module to collect data on survivors. Results from this work provided the first state-level summary of the health behaviors and preventive health practices among adult survivors.⁵⁷ CDC collaborated with multiple partners to provide supplemental funding to the Medical Expenditure Panel Survey to improve the quality of data for estimating the economic burden of cancer survivorship in the U.S., particularly improving national estimates of medical care expenditures for patients of all ages and lost productivity among survivors.^{58,59} CDC and the National Cancer Institute co-sponsored the development and administration of cancer control modules on the National Health Interview Survey. Using these data, researchers compared cancer survivorship trends from 1992 and 2010 and found the number of longer-term survivors increased and fewer survivors reported being denied insurance coverage.⁶⁰ These efforts provide information about disparate health behaviors among survivors, identify unequal economic burdens of survivorship, and uncover trends in survivors' experiences that warrant public health research and programmatic intervention.

The Role of Public Health in Advancing Health Equity in Cancer Survivorship

More research examining disparities among post-treatment survivors is needed.⁶¹ Areas of concentration for public health should include:

1. collection of high-quality data on underserved survivors to identify the unique needs of these subgroups;
2. exploration of the psychosocial, medical, and economic demands produced by the interaction of cancer diagnoses with other chronic conditions;
3. determination of the required composition and training of multidisciplinary survivorship care teams to effectively support underserved survivors;
4. evidence-based development, dissemination, and implementation of effective programs;
5. process, outcome, and cost evaluations of the integration of effective programs into systems; and
6. development of models to promote sustainability and scalability of effective programs for underserved survivors.

The field should endeavor to measure the health disparities among various survivor subgroups and elucidate mechanisms to achieving health equity among these

groups. As the U.S. population ages, the population of survivors will increase and continue to age, increasing both the proportion of survivors with chronic comorbidities and the number of comorbidities per survivor.^{62,63} Research is needed to fully understand the barriers to and facilitators of quality care, the impact of no insurance and underinsurance, and effective methods of outreach to underserved survivors. Efforts similar to the national reports on cancer screening, which identified important screening disparities among population subgroups, should be initiated to systematically document disparities in cancer survivorship.⁶⁴

Underserved cancer survivors will need comprehensive systems to support adherence to surveillance protocols, preventive care, and healthy behaviors, and to inform decisions about pain management, palliation, and end-of-life care. A team-based workforce, including lay navigators, may meet these demands.⁶⁵ However, an assessment of the National Action Plan for Cancer Survivorship suggested additional efforts are needed to rigorously evaluate and translate evidence-based research into practice.⁶⁶

Public health has an important role in the translation of effective programs designed to improve the health outcomes and quality of life of survivors.^{67,68} Meaningful engagement with communities to increase awareness, knowledge, and action to mitigate disparities in post-treatment may benefit from adherence to the tenets of community-based participatory research.^{69,70} The Cancer Prevention and Control Research Network (www.cpcrn.org) is a consortium of academic partners funded by CDC and the National Cancer Institute that conducts community-based cancer-related research across the U.S.⁷¹ This network of researchers, a subset of CDC's Prevention Research Centers (www.cdc.gov/prc/index.htm), collaborates extensively with Federal researchers and has expertise in examining the unique issues of underserved patients.

The dissemination and implementation of programs that are scalable for the population is an inherently public health mission, but so is the development of programs for those often under-represented in population-based initiatives. These programs, designed to address the complex array of factors that contribute to illness and disease, can be among the most effective measures to realize better outcomes among underserved groups.⁷² Investigation of the core components of effective programs and explication of processes and costs may allow CDC and its partners to identify what is needed to successfully integrate evidence-based, targeted programs into systems.^{73–75} The goal of sustainable and scalable programs that promote population-level efforts but also address individual, family, community, and system barriers to health equity across the cancer spectrum is possible.

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