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Comprehensive cancer control: promoting survivor health and wellness

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Abstract

Purpose—As of 2016, an estimated 15.5 million cancer survivors were living in the United States and the number of cancer survivors is expected to increase to 20.3 million by 2026. Numerous clinical studies have shown that comorbidities, such as obesity and diabetes, and unhealthy lifestyle choices, such as physical inactivity and heavy smoking, negatively influence overall quality of life and long-term survival of cancer survivors. Accordingly, survivorship programs seek to focus on overall wellness, including symptom management, monitoring for late effects of treatment, monitoring for recurrence, helping patients adapt healthy behaviors, and quality of life. This paper provides a broad overview of public health efforts to address the needs of cancer survivors.

Methods—To describe a range of examples of survivorship initiatives in comprehensive cancer control, we analyzed documents from comprehensive cancer control programs and coalitions and solicited detailed examples from several national partners.

Results—Comprehensive cancer control programs, coalitions, and partners are undertaking myriad initiatives to address cancer survivorship and building upon evidence-based interventions to promote healthy behaviors for cancer survivors across the country.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflicts of interest.

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Conclusion—A coordinated public health approach to caring for the growing population of cancer survivors can help address the long-term physical, psychosocial, and economic effects of cancer treatment on cancer survivors and their families.

Keywords

Comprehensive cancer control; Cancer survivorship; Health promotion; Public health

Background

A cancer survivor is a person diagnosed with cancer, from the time of diagnosis throughout the person's life [1–4]. As of 2016, approximately 15.5 million cancer survivors were living in the United States [5, 6]. The number of cancer survivors is expected to increase to 20.3 million by 2026 [5–7]. Additionally, in 2016, 64% of cancer survivors had lived 5 years or more, 40% had lived 10 years or more, and 15% had lived 20 years or more since diagnosis [8]. Myriad factors can contribute to poor long-term medical and psychosocial outcomes for cancer survivors. Numerous clinical studies have shown that comorbidities, such as obesity and diabetes, and unhealthy lifestyle choices, such as physical inactivity and heavy smoking, negatively influence long-term survival and overall quality of life of cancer survivors [9–14]. Concomitantly, cancer survivors themselves report behavioral, medical, and health care access challenges that also may negatively affect their health and quality of life [15, 16]. For example, during their transition from diagnosis to acute and long-term care, cancer survivors commonly report difficulties accessing quality care, understanding and following post-treatment guidelines, and finding resources to help manage side effects that result from their treatment [17, 18]. Additionally, studies have found that approximately 15% of cancer survivors report being current smokers, nearly a third of survivors report not engaging in regular physical activity, almost two-thirds lack a summary of their cancer treatment, and almost a quarter report not having any instructions on how to best proceed with follow-up care [15]. These findings underscore the need for initiatives to support lifestyle changes that may contribute to cancer survivors' overall disease-free and long-term survival [7, 19].

Since 1998, the Centers for Disease Control and Prevention's (CDC) National Comprehensive Cancer Control Program (NCCCP) has supported collaborative cancer control and prevention efforts. CDC currently funds Comprehensive Cancer Control (CCC) programs in all states, the District of Columbia, six U.S. Associated Pacific Islands and Puerto Rico, and eight tribes or tribal organizations to not only prevent cancer, but also to address the needs of cancer survivors in their respective jurisdictions [20]. A cancer coalition, vital to the work of the NCCCP, is a state, tribal or territorial-specific group that consists of a diverse partnership of people representing public health (including cancer and other chronic disease) programs, cancer survivors, clinical providers, employers, advocacy organizations, faith-based organizations, community-based organizations, academia, professional associations, and other interested parties [20–23]. The cancer coalition is charged with using data to write the cancer plan and subsequently supporting the implementation of evidence-based initiatives and interventions to help cancer survivors live longer, healthier lives [20, 24]. Cancer plans include evidence-based interventions addressing primary prevention, screening, diagnosis, treatment, survivorship,

and health disparities [25]. Within cancer survivorship specifically, cancer plans guide the work of the NCCCP coalitions to help cancer survivors make healthy lifestyle choices, such as quitting smoking, eating well, and increasing physical activity, which, in turn, may lead to reductions in cancer morbidity and mortality [11, 15, 26, 27]. Cancer coalitions also work to make systems-level changes to increase the availability of patient-centered interventions, such as patient navigation (PN) and community health worker (CHW) services [22, 28].

This paper provides a broad overview of a coordinated public health approach to addressing the needs of cancer survivors. In particular, we describe various NCCCP activities related to promotion of healthy behaviors for cancer survivors in the United States, including sources of data that inform survivorship activities, and examples of NCCCP and survivorship initiatives. We also provide examples of initiatives carried out by the Comprehensive Cancer Control National Partnership (CCCNP), which is a collaborative group of national organizations well positioned to assist NCCCP awardees with their activities.

National Comprehensive Cancer Control Program survivorship activities

Cancer survivor national- and state-level data sources—Long-term data collected on the cancer survivor population have improved the understanding of the needs of cancer survivors [8, 13, 29, 30]. These data are instrumental in developing effective program activities that are responsive to and supportive of cancer survivors. Every person affected by cancer has a unique experience; data drawn from these experiences can help the NCCCP, local cancer coalitions, and other collaborators identify unmet needs in communities and develop meaningful programs in their states, tribes, and territories.

Data on cancer incidence for 100% of the U.S. population are collected from state cancer registries, supported by CDC and the National Cancer Institute (NCI) (<https://gis.cdc.gov/Cancer/USCS/DataViz.html>). Nationally representative population-based surveys, such as CDC's National Health Interview Survey (NHIS) (<https://www.cdc.gov/nchs/nhis/index.htm>) include questions on cancer survivorship, which can provide information on the demographics, health behaviors, health status, health care engagement, and financial status of cancer survivors. The Behavioral Risk Factor Surveillance System (BRFSS) (<https://www.cdc.gov/brfss/index.html>) provides similar information but in a state-specific manner, which is particularly helpful for local NCCCP planning. Table 1 provides examples of cancer survivor questions included in NHIS and BRFSS. Cancer survivorship data are also available from data collected as part of accreditation surveys, such as the publically available National Cancer Database (<https://www.facs.org/quality-programs/cancer/ncdb>), and long-term cohort studies that focus broadly on health outcomes, such as the Nurses' Health Study and the Health Professionals Follow-Up Study [31, 32].

State, territorial, and jurisdictional programs and coalitions of the NCCCP use data from many of these sources to identify unmet needs in their population of cancer survivors and to develop survivorship programs and initiatives that address those needs. They may also access additional local sources of data to help cancer planning.

National Comprehensive Cancer Control Program survivorship initiatives—Cancer survivorship is a priority of the NCCCP [33]; accordingly, programs are expected

to initiate at least one intervention in survivorship per year and describe the implementation and impact of interventions to CDC as part of standard reporting requirements. To ascertain the types of survivorship activities of NCCCP awardees, we examined examples of cancer survivorship activities reported to CDC by NCCCP awardees between 2015 and 2017. We also reviewed products developed by programs, such as NCCCP Success Stories (<https://www.cdc.gov/cancer/ncccp/state.htm>). We identified numerous themes and topics in this high-level review, such as tobacco cessation services for cancer survivors, nutrition and physical activity, psychosocial care and mental health, survivorship care plans, palliative care, and PN and CHW efforts. We describe our findings for each of these areas in detail below and briefly discuss the relevance of each to cancer prevention and control.

Tobacco cessation services for cancer survivors—Continued tobacco use after a cancer diagnosis is associated with increased mortality, negative effects on cancer treatment, and increased risk for a recurrence or developing a second primary cancer [34]. Studies have shown that approximately 9 years after diagnosis, 9.3% of all survivors were current smokers [35]. For cancer survivors who are smokers, quitting smoking can improve prognosis and can increase long-term survival [34, 36, 37]. Our review showed that several programs (Michigan, Indiana, South Dakota, Washington, and Kansas) collaborated with state tobacco cessation programs to focus cessation efforts on cancer survivors, including offering tobacco cessation training to providers at cancer treatment centers. Additionally, the Iowa Cancer Consortium brought coalition members and partners together at the 2016 Iowa Cancer Summit to raise awareness of the importance of tobacco cessation services for cancer survivors. In 2017, the Comprehensive Cancer Control Program (CCCP) at the Iowa Department of Public Health (IDPH) and the Division of Tobacco Use Prevention and Control (TUPC) at IDPH partnered with the Iowa Cancer Consortium to do a survey of cancer centers to learn more about what would be useful for them in terms of Quitline materials and Quitline/tobacco cessation educational opportunities. After the survey was completed, CCCP and TUPC collaborated to get Quitline materials (both educational materials and promotional materials) mailed to 46 organizations including cancer centers or clinics and community organizations, e.g., predominately African American churches across Iowa.

Second-hand smoke also puts cancer survivors at risk [34]. To address this, the Louisiana Cancer Coalition (LCC) collaborated with community-based organizations to propose a comprehensive smoke-free law for indoor worksites and public places, including bars and casinos, which passed unanimously in 2015 [38]. This collaborative work, initiated by the LCC, highlights the importance of partnerships in ensuring healthy work and leisure areas for cancer survivors.

Nutrition and physical activity—Maintaining a healthy weight is associated with reducing cancer risk and recurrence [39]. Overweight and obesity are associated with at least 13 different types of cancer. These cancers make up 40% of all cancers diagnosed [30]. NCCCP awardees and coalitions have demonstrated their commitment to creating opportunities to understand the needs of and provide opportunities for enhanced nutrition and physical activity among cancer survivors [40]. In our review, we found that the Kansas

Comprehensive Cancer Control Program partnered with the Kansas Senior Farmer's Market Nutrition Program to encourage survivors to consume fresh, local fruits, and vegetables. They also partnered with the LIVESTRONG at the YMCA program to provide cancer survivors resources to help them increase physical activity. Similarly, to understand the unique nutrition and physical activity needs of cancer survivors, the Indiana Comprehensive Cancer Control Program surveyed cancer survivors in its state to measure cancer lifestyle factors, among other variables. Results helped the program and the state cancer coalition (the Indiana Cancer Consortium) prioritize and tailor information related to engaging in healthy behaviors for survivors in Indiana, which they disseminated via links on the Indiana Cancer Consortium website.

Psychosocial care—Cancer survivors often experience physical, practical, emotional, and existential challenges that indicate a need for psychosocial support. Over time, survivors may have difficulty managing the long-term side effects of cancer treatment and may also experience anxiety, depression, and fear of recurrence [41]. Psychosocial support encompasses a wide range of activities, including individual and family counseling, psychoeducational and support groups, and peer support [41]. The Vermont cancer coalition developed a peer-to-peer support program called *Kindred Connections*. The *Kindred Connections* program has demonstrated its success in meeting the complex needs of cancer survivors looking for support in rural Vermont communities. The cancer coalition has continued to identify appropriate community partners to expand the program to other areas of Vermont. Additionally, the Hawaii Comprehensive Cancer Control Coalition (HCCCC) Quality of Life Action Team worked with cancer survivors, patient navigators, CCCNP organizations, hospitals, and community organizations to host the *Journey Together: The Quality of Life Cancer Survivorship Conference*. This conference brought 200 cancer survivors, caregivers, oncology professionals, and community organizations together to discuss life after cancer treatment.

The Iowa Cancer Consortium (ICC) addressed a particular psychosocial concern of many cancer survivors: adverse effects to sexual functioning resulting from cancer treatment [42]. A cancer survivor member of the ICC is featured in a video, *After Cancer: Solutions for Sexual Health*, sharing personal challenges with sexual intimacy, resources for other survivors, and tools for providers. Additionally, the ICC leveraged resources from diversified funding for the *All of Me: Prioritizing Sexual Health in Iowans Impacted by Cancer* project that aims to improve sexual health care after cancer by promoting continuing education credit opportunities for providers and developing resources for cancer survivors. Educating providers in assessing sexual functioning in all cancer survivors and offering psychosocial/ psychosexual counseling where indicated is especially important in addressing this often-ignored psychosocial concern [42].

Survivorship care plans—Survivorship care plans (SCPs) are a vehicle for communicating information to providers and survivors about needed interventions to optimize survivors' quality of life. SCPs provide a complete record of a cancer patient's cancer history, treatments given, the need for future check-ups and cancer tests, possible long-term effects of the treatment, ideas for staying healthy, and contact information for

key health care providers [43, 44]. SCPs were a major focus of NCCCCP efforts, including activities such as developing SCPs, assessing usage of SCPs, delivering SCPs to patient populations, and assessing strengths and limitations related to using registry data to auto-populate SCPs. Florida's Department of Health focused on the dissemination of SCPs by developing a process to refer cancer survivors to tobacco cessation services by compiling various SCP models. South Dakota successfully increased the number of SCPs distributed at three health system-based cancer centers using electronic health records in conjunction with cancer registry data.

Palliative care—Palliative care aims to improve the quality of life of cancer patients through the prevention and relief of suffering and treatment of pain and physical, psychosocial, and spiritual concerns [45, 46]. Palliative care efforts in our review included state-mandated palliative care advisory committees/councils (Kansas and Indiana), cancer survivor distress screening (South Carolina), and assessing provider knowledge gaps in palliative care and corollary training (Kansas). Specifically, the Kansas Cancer Partnership and Kansas NCCCCP awardees supported the End-of-Life Nursing Education Consortium Project by leveraging resources from the University of Kansas Medical Center to identify palliative care issues across the state and develop strategies to expand the reach and impact of provider training to the rural settings throughout the state. As a result of these efforts, they developed and implemented provider training courses remotely, allowing further expansion of reach and impact to rural regions of the state.

Patient navigation and community health worker efforts—Many grantees have used PN/CHW networks and models to enhance health care delivery and improve patients' continuum of care by filling gaps in the health system. Some grantees developed PN toolkits and promoted certification, while others expanded existing PN and/or CHW networks to maximize reach and impact of these efforts. For example, Indiana worked with the George Washington University Cancer Center (GWCC) to develop a customized PN/survivorship training for PNs and CHWs across the state. Indiana promoted this training to establish an active base of trained PNs and CHWs statewide and provided tools and resources to support PNs and CHWs.

Collaborations with national partners to enhance survivor initiatives

As clinicians have begun to provide clinical follow-up care to address the needs of cancer survivors, including physical, psychosocial, and emotional needs, many national organizations [47] have identified ways in which they can partner to provide resources, evidence, and data to support and inform this work. The following are examples of three activities undertaken by several of the CCCNP organizations focused on cancer survivorship (Table 2).

National Cancer Survivorship Resource Center—Launched in 2010 through a significant investment from the CDC, the National Cancer Survivorship Resource Center (the Survivorship Center) provides resources for patients and families, cancer clinicians and policy decision-makers. These resources were designed to help increase provider capacity to care for cancer survivors. Resources for clinicians include clinical cancer follow-up care

guidelines for cancer survivors of breast, prostate, colorectal, and head and neck cancer; a 10-module e-learning series for primary care providers about caring for cancer survivors; and a toolkit with disease-specific survivorship checklists and tips for clinicians and patients. The Survivorship Center also developed patient- and caregiver-facing materials relevant to cancer survivorship [48]. Resources such as the *Life After Treatment Guide* were developed to help prepare cancer survivors and their caregivers for discussions with their health care team and provide information about managing health and wellness after treatment.

LIVESTRONG at the YMCA—The LIVESTRONG Foundation has worked with YMCA of the USA and a group of expert advisors to gather best practices related to physical activity for cancer survivors. The program meets the American College of Sport Medicine’s exercise guidelines for cancer survivors [49, 50]. Collectively, the YMCA of the USA is one of the nation’s largest, not-for-profit providers of health and well-being programs and is generally accessible to the public, since approximately 80% of U.S. households are within five miles of a YMCA [49]. The Texas and Pennsylvania cancer coalitions have received funding from CDC to deliver or expand the program with YMCA sites located in their respective states. Researchers from Yale Cancer Center and Dana-Farber Cancer Institute conducted a study to demonstrate the impact of the LIVESTRONG at the YMCA program. The study found that LIVESTRONG at the YMCA improves survivors’ overall quality of life, improves fitness, decreases their cancer-related fatigue, and helps them meet or exceed recommended amounts of physical activity [49].

Cancer Support Community Cancer Experience Registry—Since 2013, the Cancer Experience Registry (the Registry), a program of the Cancer Support Community, has provided an online forum for cancer survivors to share their experiences, identify the issues that affect their lives, access resources, and learn from each other. It is open to anyone who either has been diagnosed with cancer or provides care to a cancer patient. The Registry documents insights from cancer patients across the cancer experience spectrum, illuminates key areas that affect patients’ lives, and informs stakeholders, such as cancer coalitions, looking for data to inform cancer plans and identify needs for broad system change. The Registry includes self-reported data on demographics, cancer-related distress, quality of life, side effects of treatment and symptom management, financial impact, and work-related experiences.

Data from the Cancer Support Community’s Registry showed that among 2,827 respondents analyzed in the 2017 Cancer Experience Registry Report, the main physical concerns were eating well and getting enough nutrition (62%, $n = 1,752$), exercising and being physically active (55%, $n = 1,554$), fatigue (50%, $n = 1,414$), and sleep problems (46%, $n = 1,300$). Emotional concerns included worrying about the future (53%, $n = 1,498$), struggling with body image and physical appearance (42%, $n = 1,187$), difficulties thinking clearly (42%, $n = 1,187$), worrying about family and friends (41%, $n = 1,159$), and disruption to everyday life (41%, $n = 1,159$). Additionally, 44% ($n = 1,243$) of respondents reported moderate to very serious concern about the financial impact of cancer, with 30% ($n = 846$) reporting that they depleted their savings because of treatment costs [51]. Data such as these are useful for

cancer programs and cancer coalitions in deciding where to focus their resources and energy to best meet the needs of cancer survivors.

Future directions

The NCCCP is embarking on numerous initiatives to enhance quality of life for cancer survivors as they face physical, psychosocial, and socioeconomic challenges. Programs are engaging in activities related to tobacco cessation, nutrition and physical activity, psychosocial care and mental health, survivorship care plans, palliative care, and PN/CHW efforts. Similarly, cancer coalitions are focusing on helping survivors eat better, exercise more, never take up or quit smoking, drink alcohol in moderation, and use positive coping techniques. Together, programs and coalitions are also supporting health care providers who care for long-term survivors to focus on wellness, symptom management, monitoring for recurrence, and monitoring late effects of cancer treatment.

In an effort to maximize the impact of individual efforts of NCCCP, awardees, and their cancer coalitions, the CCCNP prioritized healthy behaviors for cancer survivors as an area of focus in 2017. The CCCNP Healthy Behaviors for Cancer Survivors Work Group developed a matrix of national resources (<http://bit.ly/HealthyBehaviorsTool>) to support NCCCP initiatives and is currently developing an action plan to guide their work in helping cancer coalitions address survivor-focused initiatives. Increased adoption of practice- and evidence-based, sustainable, survivorship activities across the NCCCP and its partners has the potential to increase not only survivors' adherence to treatment and follow-up [52] care, but also their duration and quality of life [53–56].

The interrelated survivorship activities and initiatives of the NCCCP awardees, their cancer coalitions, and the CCCNP described in this paper constitute the coordinated public health approach to improve wellness among cancer survivorship population, called for in 2005 [57]. This 20-year collaboration has made progress toward delivering high-quality cancer survivorship care and toward achieving some cancer-related Healthy People 2020 [58] objectives, such as decreasing the proportion of adult cancer survivors who are smokers and increasing physical activity among cancer survivors [58–60].

Despite these gains, there are still areas of need in cancer survivorship and cancer survivorship care. For example, relative survival rates differ among subpopulations of survivors [59, 61], and it is difficult to assess rates for some groups known to have higher behavioral risk factors for cancer such as LGBTQ [62]. Additionally, the proportion of adult cancer survivors who are obese is increasing [59], underscoring an increased need for programs and resources focused on the nutrition and physical activity of cancer survivors, as described in this report. As well, compared with individuals without a cancer history, cancer survivors have greater health care expenditures and more financial difficulties, including bankruptcies [53, 63, 64]. In 2017, the National Academies of Sciences, Engineering, and Medicine hosted a workshop on long-term survivorship care after treatment that arrived at several goals for the next decade, including affordable, accessible, and equitable survivorship care; holistic care of survivors; integration of psychosocial services into standard survivorship care; and focusing on the needs of cancer caregivers [53]. NCCCP awardees, their cancer coalitions, and the CCCNP aim to continue their strong commitment

to cancer survivorship, which is demonstrated by the activities reported here. Future efforts of these entities may focus on developing and supporting evidence-based programs and initiatives to improve survivor wellness, caregiver coping, and health care provider education.

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Sample cancer survivorship questions from 2017 Behavioral Risk Factor Surveillance System and 2016 National Health Interview Survey

Table 1

Data source	Question
Behavioral Risk Factor Surveillance System ¹	How many different types of cancer have you had?
	At what age were you told that you had cancer?
	What type of cancer was it?
	Are you currently receiving treatment for cancer?
	What type of doctor provides the majority of your health care?
	Did any doctor, nurse, or other health professional ever give you a written summary of all the cancer treatments that you received?
	Have you ever received instructions from a doctor, nurse, or other health professional about where you should return or who you should see for routine cancer check-ups after completing your treatment for cancer?
	With your most recent diagnosis of cancer, did you have health insurance that paid for all or part of your cancer treatment?
	Were you ever denied health insurance or life insurance coverage because of your cancer?
	Did you participate in a clinical trial as part of your cancer treatment?
National Health Interview Survey ²	Do you currently have physical pain caused by your cancer or cancer treatment?
	Have you ever been told by a doctor or other health professional that you had cancer or a malignancy of any kind?
	What kind of cancer was it?
	How old were you when it was first diagnosed?
	How long have you had cancer?
	Have you had a mammogram during the past 12 months? During the past 12 months, have you had any test done for colon cancer?

1. <https://www.cdc.gov/brfss/index.html>

2. <https://www.cdc.gov/nchs/nhis/index.htm>

Table 2

Cancer survivorship resources through the National Cancer Survivorship Resource Center, LIVESTRONG at the YMCA, and the Community Cancer Experience Registry

Source	Resource	Brief description	Website/link
National Cancer Survivorship Resource Center	Cancer Survivorship Clinical Care Guidelines and links to download the guidelines app	Clinical care guidelines for cancer survivors of breast, prostate, colorectal, and head and neck cancer. Available as full guidelines for download; abridged version available as an app	https://www.cancer.org/health-care-professionals/national-cancer-survivorship-resource-center.html
	Cancer Survivorship e-Learning Series for Primary Care Providers	Provides no-cost continuing medical education units for primary care providers to learn more about caring for individuals who have had cancer	http://bit.ly/PCPE-Learning
	The National Cancer Survivorship Resource Center Toolkit: Implementing Clinical Practice Guidelines for Cancer Survivorship Care	Includes the <i>Prescription for Cancer Information</i> , a tear-off pad for clinicians to provide key resources to patients	http://bit.ly/NCSRCToolkitFull
LIVESTRONG at the YMCA	LIVESTRONG at the YMCA information page on the LIVESTRONG Foundation website	Includes program overview, video, and program site locator	https://www.livestrong.org/ymca-search
	LIVESTRONG at the YMCA information page on the YMCA of the USA website	Includes program overview, video, and program site locator	http://www.ymca.net/livestrong-at-the-ymca
Cancer Support Community Cancer Experience Registry	The Cancer Experience Registry	Online community for those affected by cancer to share their experiences, identify issues that affect their lives, access resources, take surveys, and learn from each other. Reports published on findings of surveys administered within the registry document the experiences of both survivors and caregivers	https://www.cancerexperienceregistry.org/