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# **Public Health's Future Role in Cancer Survivorship**

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#### Introduction

Despite modest reductions in the incidence rates for many cancers in recent years,<sup>1</sup> the absolute number of people who will be diagnosed with cancer and the number of cancer survivors are expected to increase substantially over the next few decades in the U.S., due to changing demographics, an aging population, and improvements in survival.<sup>2–4</sup> Advances in treating childhood cancer have led to an increase in the number of adolescents and young adults who are cancer survivors, and the late effects of treatment can be substantial in this age group.<sup>5</sup> Most cancer survivors, however, are older than age 65 years.<sup>6</sup> The number of adults aged 65 and older is projected to increase in the U.S. from 48 million in 2015 to 74 million by 2030.<sup>7</sup> In the war on cancer, cancer survivors are often wounded warriors with long-term sequelae needing to be managed together with other chronic conditions, such as hypertension, cardiovascular disease, and diabetes.<sup>8–10</sup> In addition, cancer survivors may be at risk of developing other primary cancers because of shared etiologic risk factors or the consequences of radiation therapy or chemotherapy.<sup>11,12</sup> The complex needs of the continually growing number of cancer survivors cannot be fully met by the current healthcare system.<sup>13–16</sup>

CDC has used interdisciplinary approaches to address the public health needs of cancer survivors for more than a decade.<sup>17</sup> This article highlights some of the future directions suggested by the research and programmatic activities described in this special supplement to improve the health of cancer survivors and the communities in which they live.

## The Critical Importance of Collaborations

Partnerships and coalitions with public and private sector organizations are essential for effective public health program implementation. Moore and colleagues described the Public Health Action Model for Cancer Survivorship to illustrate how various partners can collaborate across multiple levels to improve survival and quality of life for cancer survivors. This approach is used by CDC's National Comprehensive Cancer Control Program (NCCCP), which provides a coalition-based approach to cancer prevention and control in all 50 states, the District of Columbia, seven tribes and tribal groups, and seven U.S. Associated

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Pacific Islands/territories. The majority (94%) of these cancer coalitions are currently working in their communities to address the public health needs of cancer survivors. <sup>20,21</sup> A recent assessment of the implementation of the National Action Plan for Cancer Survivorship revealed that 64% of NCCCP grantees include these strategies in their program action plans. <sup>20</sup> As examples, Underwood and colleagues <sup>21</sup> described activities being undertaken by grantees under CDC's NCCCP to address cancer survivorship. In addition, CDC also provides a number of smaller programs to support implementation of NCCCP survivorship priorities, as described by Buchanan et al. <sup>17</sup> This includes support for the National Cancer Survivorship Resource Center, and the opportunities to continue to build on and add to the Center's resources are tremendous.

### Meeting the Needs of Specific Survivor Populations

Evidence gained from the experiences of NCCCP and other programs demonstrate how specific population needs can be met. As one current example, CDC funds a consortium of national networks for populations experiencing tobacco use and cancer-related outcomes. An emphasis on smoking cessation is important because 35% of cancer survivors aged 18–44 years in 2012 continued to smoke, compared with 22.7% of the general population. These networks convene stakeholders from across the country to provide guidance and resources for public health programs to reduce tobacco- and cancer-related disparities in racial/ethnic minority populations; populations with mental illnesses; lesbian, gay, bisexual, and transgender populations; and populations in rural and low-SES communities. These networks are composed of stakeholders with invaluable insights, and they should be heavily engaged as activities move forward to address the unique health needs of cancer survivors from disparate populations.

Smith and Hall<sup>23</sup> summarized how cancer survivorship research activities at CDC are aligned with the five recommendations of the National Prevention Strategy for reducing health disparities and outlined areas where public health could advance health equity in cancer survivorship. For cancer survivors who face social, economic, and environmental disadvantages, access to quality health care can be limited. In addition, these same disadvantages can exacerbate the long-term physical, emotional, psychological, and financial consequences of the cancer diagnosis. Public health is uniquely positioned to reach and assist populations of underserved survivors.

Johnson-Turbes and colleagues<sup>24</sup> shared findings from an evaluation of an innovative online intervention aimed at African-American women who had been diagnosed with breast cancer before age 45 years. This evaluation highlights the importance of working in partnership with community representatives to be culturally appropriate, and suggests a cost-effective approach for reaching special groups of younger cancer survivors.

Hall and Smith<sup>25</sup> summarized the decade-long implementation of a research agenda at CDC to understand the information needs of men who are newly diagnosed with localized prostate cancer. The body of collaborative research they described revealed the need for health communication products and decision tools to assist men, their spouses, and their physicians with conversations about treatment choices. The goal is to allow men to make decisions

based on their values and needs. Consistent with the Public Health Action Model for Cancer Survivorship, <sup>19</sup> this research also demonstrated the importance of recognizing the multilevel perspectives of the decision-making triad of the patient (survivor), caregiver (interpersonal), and provider (organizational). Hall and Smith also discussed uncertainty about the appropriate protocol for active surveillance for African American men. Community–clinical partnerships and community-based participatory research may be valuable to ensure that the needed research is designed for dissemination and implementation at the outset.

### **Expansion of Data on Survivors for Public Health Action**

In the Public Health Action Model for Cancer Survivorship, <sup>19</sup> surveillance and applied research are levers that can facilitate change as well as one of the four public health domains of the National Action Plan for Cancer Survivorship. <sup>26</sup> Ryerson et al. <sup>27</sup> described the substantial progress that has been made to enhance the ability of cancer registries to address this data need. Restricted registry data, including recently collected data on comparative effectiveness from ten registries belonging to the National Program of Cancer Registries, is now available to researchers through the Research Data Center of the National Center for Health Statistics. <sup>28</sup> Several innovations to expand the use of cancer registry data demonstrate opportunities for central cancer registries to contribute in new ways to cancer survivorship initiatives at the state and community levels. Continued work is needed to fully capitalize on the existence of a nationwide system of cancer surveillance in this country.

The data presented by Guy and colleagues<sup>29</sup> on out-of-pocket healthcare expenditures among younger cancer survivors point to the urgent need for increased efforts at multiple levels to address the economic impact of healthcare expenditures on cancer survivors and their families. Other authors have called for increased discussions between physicians and patients about "financial toxicity" as a side effect of treatment.<sup>30</sup> Communication at the level of the individual survivor and provider may be particularly useful when providing information to those who are uninsured or underinsured. Actions taken at the population level, however, are likely to have greater impact.<sup>31</sup> Removal of financial barriers to the receipt of needed medical care and preventive health services may require changes at the policy level.<sup>32,33</sup> For policy considerations, cost expenditure data such as that provided by Guy et al. can be extremely useful to decision makers.<sup>34</sup>

#### **Disease Prevention and Health Promotion After Treatment**

Activities of NCCCP include efforts to institutionalize the use of survivorship care plan standards that not only summarize a survivor's treatment care but also provide descriptive follow-up plans to improve the survivor's health and quality of life. CCC coalitions are powerful networks with the capacity to work with a number of clinical and community partners to ensure cancer survivors access to medical homes for post-treatment services as well as support for community programs to facilitate healthy behaviors.

New data on barriers and facilitators to adherence to major guidelines for health promotion and cancer prevention among long-term colorectal cancer survivors are now available from the Prevention among Colorectal Cancer Survivors study.<sup>35,36</sup> The findings from Hawkins

and colleagues<sup>35</sup> suggest the need for a comprehensive, multilevel approach to promote greater awareness of dietary guidelines, including limiting alcohol, among cancer survivors and their providers. Rodriguez and colleagues<sup>36</sup> reported that, compared with those who reported no exercise, survivors who reported exercise at levels below recommendations had higher scores for physical and overall health-related quality of life. This finding lends support to broader efforts to promote modest increases in physical activity, such as walking.<sup>37</sup> In addition, having two or more comorbid conditions was significantly associated with lower mean scores for physical, mental, and overall health-related quality of life. This latter finding suggests potential value in partnering with other disease-specific programs to address the health of cancer survivors in the context of multiple morbidities.<sup>38,39</sup>

Buchanan et al.<sup>40</sup> examined the prevalence of cognitive impairment among breast cancer survivors and the level of support received for these symptoms. These findings point to a need for greater recognition of the importance of psychosocial issues among younger breast cancer survivors and referral and care for psychosocial problems. Broader community-level support is needed for those who are experiencing neurocognitive effects from chemotherapy and hormone therapy.

#### Conclusions

Preventing premature death and disability among people with a history of cancer, similar to other chronic diseases, requires addressing risk factors at both the individual and population levels and increasing collaborations between clinical and community preventive services. <sup>41</sup> The considerable progress achieved in implementing the public health strategies in the National Action Plan for Cancer Survivorship<sup>26</sup> has depended on numerous partnerships at the national, state, and local levels. NCCCP programs have demonstrated tremendous capacity and potential for planning and implementing evidence-based interventions to address many of the unmet needs of cancer survivors. These programs can bridge clinical and community resources to support the full implementation of survivorship care planning as well as chronic disease self-management.

Although much progress has been made, more needs to be done, especially as cancer survival rates continue to increase.<sup>3,4</sup> More progress also is needed in primary cancer prevention, to reduce the number of new cancer cases.<sup>42</sup> CDC and its partners must reinvigorate efforts to gather data to assess the needs of survivors from their own point of view to inform programs, policies, and practices. Through the application of public health data and surveillance systems, the translation of population-based research for public health action, and the lever-aging of new and existing partnerships at the national, state, and local levels, innovative approaches can be identified, evaluated, and implemented to improve the lives of cancer survivors.

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