

Future Directions in Cancer Survivorship and Aging

A Special Report from the National Cancer Institute

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Declining cancer deaths ... More survivors living longer ... An exciting time in cancer research and care ...

Although these statements may sound like echoes of what we've been saying for several years, they're not. The landscape of cancer research and care is constantly changing – and for the better.

It's difficult to think of any part of the landscape that is the same as it was even 10 years ago. Tremendous progress has been made against cancer: medical advances are occurring at a rapid pace; a plethora of new drugs have been developed; industry is continuing to increase its investment in

developing additional treatments; cancer death rates are continuing to decline for most cancers; and one of the biggest indicators of progress we have seen – the number of long-term (longer than 5 years) cancer survivors is growing. This progress further underscores the importance of NCI's Office of Cancer Survivorship, established in 1996 in recognition of the growing number of cancer survivors and the need for more research to better understand and meet their unique needs.

Expanding population of older cancer survivors

The population of cancer survivors aged 65 and older is expected to continue to grow

at an unprecedented rate over the next few decades. This will be driven not by the number of new cancers in this demographic group, which is not expected to increase, but, instead, largely by the graying of the overall population in the United States. By 2040, when researchers estimate the total number of cancer survivors in the United States will have increased from the 17 million it is today to 26 million, this population of older survivors is expected to represent three-quarters of all survivors.

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The fact that people are living longer after a cancer diagnosis is certainly cause for celebration. At the same time, given that nearly two-thirds of cancer survivors are age 65 and older, we are now facing a new challenge – an inadequate understanding of long-term and older survivors' unique healthcare needs and how best to address them.

More opportunities for older survivors to participate in clinical trials

One reason for this gap in knowledge is the limited research that has been conducted on older cancer survivors, as clinical trial criteria often render these survivors ineligible to enroll in trials. In recent years, we have been encouraging NCI-funded researchers to relax the use of upper age limits in adult treatment trials to accommodate participation of older survivors with active disease.

Discussions are also underway to relax additional restrictive eligibility criteria, such as current use of medications to treat coexisting health conditions. Because older people, and older cancer survivors in particular, are more likely to have multiple chronic diseases, lifting that restriction would result in many more opportunities for older survivors to enter clinical trials and receive cutting-edge therapies for their cancer. It would also provide evidence-based data that would enhance researchers' and clinicians' ability to determine age-appropriate cancer treatment protocols, as well as optimal ways to disentangle and manage the competing medical conditions that can affect health outcomes and quality of life.

Lost in transition

The transition from active cancer treatment to continuing care is a critical period for cancer survivors and one to which we must give added attention, particularly since survivors are living longer and requiring longer follow-up care. During this period, cancer survivors can sometimes feel lost as they find themselves treading the unknown waters of post-treatment care.

NCI offers a very useful resource for cancer survivors, as well as for family members, friends, healthcare providers, advocates, and researchers – the Cancer Information Service (1-800-4-CANCER). One of NCI's best kept secrets, CIS is a contact center where anyone can call in and talk to a trained information specialist about cancer-related questions and concerns. The center provides free and confidential information and support, in both English and Spanish, and in language that is understandable, which may not always be the case when talking to medical specialists, given the highly scientific and complex nature of cancer research and care. In addition to providing personalized responses to a range of cancer questions, CIS can help people find cancer clinical trials, and quit smoking.

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As researchers and healthcare providers dealing with a growing population of aging survivors, we are also grappling with unknowns. One area that we don't yet have sufficient understanding of, and consequently no consistent guidelines for, is the optimal length of follow-up and frequency of screenings for surveillance of longer-term survivors for cancer recurrence and additional cancers.

For many cancer survivors, the fear of cancer recurrence or of developing another cancer is very real. That fear is likely to be even greater in older survivors, given that the risk of other cancers increases with age.

One in five new cancers in the United States occurs in someone who has had a cancer before. Overall, cancer survivors have about a 15-percent greater risk of developing another primary cancer during their lifetime. However, risk varies according to the type of cancer at first diagnosis, treatment received, and age at diagnosis. Childhood cancer survivors, for example, have a higher risk because of the treatments they received and their age at the time of the first cancer.

NCI's Healthcare Delivery Research Program leads the institute in research to improve the delivery of cancer-related care. Again, we have much to learn in terms of how to implement optimal continuing care for cancer survivors, especially older cancer survivors. Given the health complexities of the aging survivor, the ideal post-treatment care would involve a team of providers that includes oncologists and geriatricians, many of whom are primary care practitioners, delivering comprehensive, coordinated

care.

Some older cancer survivors have experienced frustration when their healthcare providers have treated them simply as part of a cadre of older patients with multiple coexisting conditions that include cancer, rather than as a distinct group of patients with unique needs as a result of their cancer. Both survivors and providers have expressed concerns over inadequate communication and coordination among the members of a survivor's healthcare team and lack of clarity regarding who is providing which components of follow-up care.

We recognize and appreciate the advocacy community's push for treatment summaries and survivorship care plans to help address this lack of communication and coordination. These documents are meant to be shared with the cancer survivor, primary care providers, and the rest of the healthcare team to help guide the conversation and transition from active treatment to continuing care. This is an area where implementation research will be beneficial in understanding how to encourage practitioners to develop and make use of these documents.

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Long-term and late effects

The increasingly longer lives of cancer survivors overall is an enormous source of hope. At the same time, we recognize the importance of quality of life. Transition from treatment to continuing care, fear of recurrence and new cancers, management of pain and other effects of cancer and its treatment, concerns about employment, changes in relationships and caregiving, financial hardships, access to healthcare – these are among the myriad issues cancer survivors face that affect quality of life and health outcomes.

NCI has identified a broader examination of management of long-term and late effects – one that encompasses psychosocial and economic effects, in addition to physical effects – as a research priority. We know, for example, economic hardships and limited access to healthcare are key factors leading to less healthcare utilization and poorer outcomes. The rise in numbers of long-term survivors necessitates the development of new models of healthcare delivery that ensure all cancer survivors can obtain integrated physical, psychosocial, health promotion, and financial services as part of their continuing and coordinated care program.

We must also ensure that these services are accessible to everyone, regardless of

where they live. Many survivors do not live in large urban areas near major cancer research centers. NCI is expanding availability of clinical trials and cancer care delivery research into smaller communities, where most survivors receive their care. Through funding for NCI-designated cancer centers to develop and strengthen rural cancer control research capacity, and the NCI Community Oncology Research Program, we are making screening, surveillance, treatment, symptom management, and supportive care more accessible, enabling survivors in rural and underserved areas to get the kind of care they need without having to travel outside the communities in which they live.

Working together to move cancer survivorship science forward

Clearly, the rapid growth of an older cancer population is very gratifying. It has also brought with it an opportunity for us to pursue many unanswered questions about how to deliver optimal continuing care to this group.

NCI continues to convene meetings with a variety of survivorship stakeholders who have different perspectives on cancer survivorship and aging issues. These meetings foster discussions, identify gaps in survivorship care, and develop research agendas that prioritize the most pressing issues for cancer survivors and the growing population of aging survivors. Our goal is to have these collaborations help guide the future direction in cancer survivorship and aging research, so that we can improve the outlook and quality of life for all cancer survivors.

Since 1994, the National Cancer Institute has written an exclusive annual report for *Coping's July/August Celebration* issue.

This article was published in *Coping® with Cancer* magazine, July/August 2019.
