

## Viewpoint

# Status of Cancer Survivorship Care: Should We Not Improve?

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Cancer mortality has significantly decreased due to screening, early detection, improved diagnostics, treatments, and supportive care.<sup>1</sup> Worldwide, an estimated 28.4 million new cancer cases are projected to occur in 2040.<sup>2</sup> Cancer survival in the United Kingdom has doubled in the past 40 years from 24 to 50%.<sup>3</sup> By 2040, we expect around 26 million cancer survivors in the United States of America.<sup>4</sup> The total global cancer survivor population, including Asia, could be over several million. Undoubtedly, every healthcare provider will encounter a cancer survivor in their practice. The care of cancer survivors is often uncoordinated, incomplete, and tends to be fragmentary. Significant improvements in cancer survivor care are necessary in most parts of the developing world by implementing the core essentials of cancer survivorship care, such as ASCO, ESMO, National Academies of Sciences, Engineering and Medicine, and National Cancer Survivorship Resource Center (The Survivorship Center).<sup>5–7</sup>

We summarize this topic through a set of questions and answers. The core essentials of cancer survivorship care will be outlined, and finally, we will discuss a few methods of its implementation in our region.

## What Is Cancer Survivorship?

This term has been there for several decades and recently achieved greater attention as more and more individuals live with and beyond cancer. It is a phase of the cancer continuum that begins with prevention and risk reduction, cancer screening, diagnosis, treatment, survivorship, and then carries on to the end-of-life care. Cancer survivorship focuses on the health and life of an individual diagnosed and living with and beyond cancer through the end of life.<sup>8</sup> It covers cancer's physical, psychosocial, and economic issues beyond the diagnosis and treatment phases. Survivorship includes issues related to getting health care and follow-up treatment, recognition of late effects of treatment and management, detection of second cancer, and promotion of quality of life.

## Who Are Cancer Survivors?

The term cancer survivor is used in various ways and sometimes confuses. For most caregivers, the focus is often on those who have completed active treatment, but an individual is considered a cancer survivor from the time of diagnosis through the balance of his or her life. There are many types of survivors, including those living with cancer and those free of cancer. The term is meant to capture a population of those with a history of cancer. We must understand that the term may or may not resonate with specific individuals.

Cancer survivors can include those who are cancer-free after treatment for the remainder of life. Cancer survivors are cancer-free but has one or more late severe complications. Cancer survivors remain cancer-free for many years but then develop late recurrence. Cancer survivors then develop many other new second and third primary cancers. Cancer survivors also suffer from intermittent periods of active disease, requiring treatment, or those living with cancer continuously with or without treatment, without a disease-free period. It is important to emphasize that specific individuals do not wish to use cancer survivors as a term to describe themselves or their experiences.

## Survivorship Facts and Figures

According to the American Cancer Society, currently over 16.9 million cancer survivors live in the United States; the number is projected to grow 26 million by 2040.<sup>4</sup> There are over 12 million cancer survivors in the European Union.<sup>9</sup> In the rest of the world, an approximate estimate would be several additional million. The growing survivor population is due to many factors, including an aging population, screening tests, early detection, improved treatments, outcomes, and supportive care.

Cancer survivors are mostly 65 years of age or older, with ~64% of the cancer survivor population. Nevertheless,

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younger survivors, those below age 50, account for 10% of the population.<sup>4</sup> Older survivors are more likely to have morbid medical conditions like heart disease, chronic obstructive pulmonary disease (COPD), chronic kidney disease (CKD), and diabetes, thus requiring additional consideration when planning for long-term survivorship care, including the need for care coordination. Disparities in cancer survivorship do exist. Cost, access to treatment, and follow-up are the most important reasons.

The increasing survivor population has widespread implications for the healthcare system. This growing population is too large for oncology providers to care for them alone. It comprises an older population with complex medical needs and a population that requires coordinated care from oncology providers, primary care providers, and other specialists. In the Western world, primary care providers are getting prepared to directly care for cancer survivors and share and coordinate care with other healthcare professionals.

## Areas of Focus in Cancer Survivorship Care

► **Table 1** presents the areas that should be considered when caring for any cancer survivor.<sup>10</sup> Usually, it starts with focusing on preventing and detecting recurrences and new cancers. This is often the main focus of oncology specialists. This may include clinical visits with taking history of symptoms, physical examination, laboratory testing, and imaging. Next follows the evaluation and treatment of the physical effects of cancer and its treatments. These effects may include surgery, chemotherapy, hormonal treatment, immunotherapy, targeted agents, and radiation therapy. The knowledge and experience of recognizing the physical effects of cancer and its treatments are strengths of oncology providers. However, we suggest primary care providers equip themselves with this knowledge by self-learning survivorship programs.

Healthcare providers should ask survivors about physical symptoms that they are experiencing; healthcare providers should be on the lookout for specific symptoms and problems that may occur as a result of treatment and be sure to evaluate and treat these when they are diagnosed. This may require referral to specialists who are best equipped to provide such care. Similarly, healthcare providers must focus on the psychosocial effects of cancer and its treatment. This may include psychological issues such as depression, anxiety, and fear of recurrence. Also, issues on finances, employment and school, and interpersonal issues such as relationships with loved ones, sexuality, and intimacy are relevant. Again,

**Table 1** Core essentials of survivorship care

- |  |
|--|
| 1 Prevention or detection of recurrences and new cancers                       |
| 2 Evaluation and treatment of physical effects of cancer and its treatment     |
| 3 Evaluation and treatment of psychosocial effects of cancer and its treatment |
| 4 Evaluation and treatment of chronic medical (noncancer) conditions           |
| 5 Health promotion and disease prevention                                      |

healthcare providers must ask survivors about symptoms they may be experiencing and find ways to treat them. This may be with medications, psychotherapy, or other means. Referral to specialists may be needed.

Most cancer survivors are older and may have chronic medical conditions prior to diagnosis. These must not be ignored and are given the appropriate attention. This may mean ensuring that survivors continue to see their primary care provider and/or other specialists and that attention is placed on making sure that they adhere to treatment recommendations for these medical conditions. Taking stock of medications being taken is essential. Finally, attention to health promotion and disease prevention is necessary for cancer survivorship. This includes exercise, a healthy diet, reducing alcohol use, quitting smoking, and getting the appropriate preventive care, including vaccinations. While focusing on these areas, it is essential to pay attention to the overall healthcare environment in which the patients are receiving their care and be sure that communication, decision making, coordination of care takes place and that the needs of each patient are being considered, of evident importance is that the patient or individual factors are clearly emphasized. Stress may not need to be placed on all of these areas equally. They must be considered and addressed if needed for each patient individually.

## Who Should Provide Cancer Survivorship Care?

Cancer survivors are traditionally taken care of by oncology care providers. There is general reluctance from primary care providers to follow patients with a history of cancer. Oncology care and primary care address different aspects of care. Oncology-centered care is cancer-focused. It includes much attention on cancer, surveillance, and recurrence. Other conditions, or comorbidities, are often not the focus of oncology-centered care.

On the other hand, primary care is focused on general well-being, including care for chronic conditions and disease prevention. Considering the long-term and late effects of cancer and its treatment and psychosocial care directed toward the effect of cancer may or may not be adequately addressed by either oncologists or primary care providers. It may depend on their knowledge, training, and confidence in providing cancer survivorship care for primary care providers.

There are benefits and challenges to oncology-centered and primary-centered care.<sup>11–14</sup> Providers have differing familiarity and training. Oncology providers are more experienced than primary care providers in offering cancer-related care. Cancer survivors often have more confidence in their oncology providers regarding survivorship care, especially after building a relationship during their cancer treatment. This can create a loop where survivors seek out oncology providers first rather than their primary care providers. This also creates fewer chances for primary care providers to gain survivorship care experience.

On the other hand, primary care providers have more experience caring for heart disease, COPD, CKD, or diabetes. Oncology providers are not equipped to provide such general care, including regular screenings and tests for comorbidities. This can create a gap where patients continue to see their oncology provider for all care but do not receive the necessary screening tests or treatment for these medical conditions.

Nevertheless, most cancer survivors need to return to primary care, even though they may be reluctant. Cancer survivors have more trust established with their oncology providers and have negative concerns that primary care providers may not be able to provide survivorship care. There is also a lack of clear communication about the plan for survivorship care. One important strategy is to communicate clearly with survivors about expectations for post-treatment survivorship care. It is also essential that the primary care providers remain involved even during cancer treatment. As treatment winds down, survivors can work with their providers to properly develop their posttreatment care plans.

### What Happens When Treatment Ends?

Survivorship care consists of many moving parts across multiple providers. Several recommended models for survivorship care have been recently proposed, including shared care, risk-stratified, or personalized care. Regardless of the model, providers must communicate across specialties. Survivors should feel empowered and be included as members of their care team to ask questions, make suggestions, and communicate freely with their providers. Survivors receive regular screening and surveillance for both cancer and late effects, and they also receive disease management for chronic conditions and counseling and support for healthy lifestyle behaviors like smoking cessation, diet and nutrition, and physical activity.<sup>15,16</sup>

Unfortunately, the reality is typically fragmented survivorship care. Providers do not usually communicate across settings through electronic health records or written communication. It can be challenging for providers to navigate the relationships between survivors and their oncology providers. Additionally, oncology providers lack training and education for general care, while primary care providers lack training and education for cancer-specific care. This mismatch in confidence and skills can impact the quality of care provided. It can also be confusing for survivors because it is unclear who has responsibility for what care. For example, who is supposed to do cancer screening for other cancers? Expectations for cancer survivorship care are changing, and the cancer survivor population continues to grow. These are all factors to consider when caring for survivors and working toward less fragmented care.<sup>17</sup>

### Strategies for Primary Care Providers

There are several practical tips to improve survivorship care in primary care settings.<sup>15</sup> Ask patients about their cancer

history, including their personal and family members' histories. Request oncology treatment records and survivorship care plans and document treatment and care need in the electronic health record. Participate in formal, for example, continuing medical education and informal training to increase understanding of cancer-related, chronic, and late effects. Learn how to co-manage patients during active treatment and ongoing oncology-based follow-up care. Participate in educational activities to increase comfort and skills in providing follow-up care for patients with cancer who are transitioned from oncology care. Refer patients who previously received extensive cancer treatment and/or those experiencing chronic and late treatment effects for specialized survivorship care. Work toward supporting patients who are doing well in self-managing their health outside of surveillance visits. And lastly, build bridges with oncology to understand survivors' risk and ongoing healthcare needs,

### Strategies for Oncology Care Providers

There are several strategies for oncology care providers to improve survivorship care in their settings.<sup>16</sup> These include promoting survivors' transition back to primary care. Examination of current patient rosters, clinic utilization patterns, and new patient visits lots and consider shifting care of low-risk low needs survivors to primary care. Begin to triage patients who need specialized follow-up care to survivorship clinics. From the time of diagnosis, communicate to patients that they will be expected to continue to be followed by their primary care provider and likely transition back to their primary care provider or a follow-up cancer survivorship clinic after treatment ends. Reinforce expectations about follow-up by ongoing communication throughout cancer treatment. Survivorship care plans for every cancer survivor should be completed as treatment ends—work toward supporting patients who are doing well in self-managing their health outside of clinic visits. Build bridges with primary care to better equip primary care providers with information that they need to care for their patients who are cancer survivors, coordinate care, and facilitate referrals back to oncology if needs arise.

### Conclusions

As the cancer survivor population grows, primary care providers and oncology care providers will need to be well equipped to care for cancer survivors' complex healthcare needs and think about referrals to necessary subspecialists. The care needs include long-term and late effects, psychosocial needs, and healthy lifestyle behaviors. Primary care providers and oncology providers need to build bridges to equip each other so that their patients receive the best care.

#### Compliance with Ethical Principles

No ethical approval is required.

#### Data Availability

Not applicable.

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**Conflict of Interest**  
None declared.

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