EXECUTIVE SUMMARY OF CANCER SURVIVORSHIP: A POLICY LANDSCAPE ANALYSIS DEVELOPED BY THE NATIONAL CANCER SURVIVORSHIP RESOURCE CENTER

SUMMARY

With a growing number of U.S. cancer survivors facing life-altering effects after treatment, a comprehensive, coordinated approach to meeting post-treatment care is critical. The biggest challenges in the delivery of survivorship care are the lack of health care providers to care for survivors, variation in care elements and models, limited evidence base for how to best care for survivors, and lack of adequate reimbursement for clinical services.

BACKGROUND

Cancer patients are now increasingly likely to survive, with nearly 70 percent of patients living five years or more following their diagnoses. Well over one million new cancer patients are added each year to the 13.7 million alive today.

ISSUE

Cancer has become more of a chronic than an acute disease. Appropriate post-treatment survivorship care can increase independent living, positively affect quality of life, and ease the economic burden on the country from a depleted workforce. While the number of survivors is growing, workforce shortages in oncology and primary care are worsening. A challenge to delivering equitable, quality survivorship care is lack of training for the many practitioners needed to appropriately address the physical and psychosocial needs of the cancer survivor.

Cancer patients require health promotion education to prevent occurrence of new or second cancers as well as late effects that may arise as a result of treatment for their primary cancer. Survivors also need ongoing surveillance for recurrence, cancer spread, and second cancers. Survivors have often received multiple modes of treatment from several providers at separate locations, with limited coordination of care between providers. Despite an already strained health care delivery system, quality survivorship care demands improved communication and coordination of care.

RECOMMENDATIONS

- Implement the Affordable Care Act to ensure access to health insurance, coverage and quality care for cancer survivors and expand training and residency programs for health care professionals.
- Support the Comprehensive Cancer Care Improvement Act (CCCIA, H.R. 3705) introduced by Rep. Lois Capps (D-CA) and Rep. Charles Boustany (R-LA) to advance the Institute of Medicine's recommendation for written treatment summaries and survivorship follow-up care plans
- Support the American Cancer Society Cancer Action Network Patient Centered Quality of Life Act to amend the Public Health Services Act to address the symptoms and needs of patients with chronic disease.
- Appropriate research funds to the National Cancer Institute's Office of Cancer Survivorship to expand the evidence base for effective and cost-efficient survivorship care models.

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Cancer Survivorship: A Policy Landscape Analysis

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Cancer patients are now increasingly likely to survive, with nearly 70% of patients living five years or more following their diagnoses.[1] Improved technology and treatments, as well as a focus on prevention and early detection, have made cancer more of a chronic disease rather than an acute condition for many cancer survivors.[2] Well over one million new cancer patients are added each year to the 13.7 million alive today, and a new field of cancer survivorship has developed to address the particular needs of cancer survivors.[3,4]

As a mechanism to assist the development of survivorship practices and policy, the National Cancer Survivorship Resource Center (The Survivorship Center) was funded through a cooperative agreement from the Centers for Disease Control and Prevention (CDC), and exists as a collaborative effort between the American Cancer Society (ACS) and The George Washington University's Cancer Institute (GWCI). The Survivorship Center began as an effort to shape the future of survivorship care and improve the quality of life of cancer survivors. The Survivorship Center utilizes a Socio-Ecological approach, identifying performance indicators and interventions to facilitate change at the individual level, organizational/systemic level, and the societal level. The Center has convened 130 experts in survivorship care representing 52 organizations organized into workgroups to devise a strategic approach to driving change in the delivery and financing of survivorship care.

This paper stems from the work of the Policy and Advocacy Workgroup,[*] and is the first in a series of white papers aimed at identifying and analyzing policy issues surrounding survivorship services. This landscape analysis provides the foundation for the series, synthesizes existing literature, and provides a broad overview of the issues impacting survivorship. A comprehensive article by Marcia Grant and Denice Economou entitled "The Evolving Paradigm on Adult Cancer Survivor Care" in April 2008 serves as an excellent resource and starting point for our analysis.

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History of Survivorship Care in the United States

Survivorship care is rooted in the changing needs of a population affected by a disease that was historically a virtual death sentence.[5] Improvements to care across the cancer continuum from timely screening through personalized treatment have increased survival rates and elicited a need for a new approach to care. Initial efforts in cancer survivorship were catalyzed by survivors themselves and their families and caregivers.[6] National private and government organizations such as the American Cancer Society, The Wellness Community (now The Cancer Support Community), the National Coalition for Cancer Survivorship, the Cancer Leadership Council, the Lance Armstrong Foundation (now LIVE**STRONG**), and the Office of Cancer Survivorship within the National Cancer Institute advanced survivorship goals by conducting research and developing recommendations to change the policy landscape of cancer survivorship.

In 2006, the Institute of Medicine published its seminal report on survivorship, *From Cancer Patient to Cancer Survivor: Lost in Transition*. This report outlined the essential components of survivorship care as: (1) prevention of recurrent and new cancers and other late effects; (2) surveillance for cancer spread, recurrence, or second cancers and assessment of medical and psychosocial late effects; (3) intervention for later conditions arising from cancer and its treatment; and (4) coordination of care between oncology specialists and primary care providers.[7,8] The report continues to serve as the foundation for current survivorship care approaches.

Grant and Economou highlight other reports which have helped to shape the landscape of cancer survivorship. Included among these is the National Coalition for Cancer Survivorship's (NCCS) 1996 report on *Imperatives for Quality Cancer Care: Access, Advocacy, Action & Accountability*. Addressing the mechanisms of health coverage and the quality of cancer care from the perspective of patients for the first time, this report highlights issues that continue to be central to survivorship care 16 years later.[9]

Other major reports and action plans include the Lance Armstrong Foundation (LAF) and Centers for Disease Control and Prevention's (CDC) 2004 *National Action Plan for Cancer Survivorship: Advancing Public Health Solutions*, which identifies the need to "more effectively and systematically provid[e] public health services to cancer survivors."[10] The action plan also includes other necessary elements of survivorship care, including building a research base to improve evidence-based practice, training professionals in a manner conducive to improving delivery of care, and designing programs that comprehensively ensure adequate care in a culturally sensitive and survivor-centric method.[11] Grant and Economou note that this plan was instrumental in delineating coordinated public health initiatives in order to address the numerous physical, psychological, social, and financial issues that survivors face.

Finally, the President's Cancer Panel devoted a chapter to insurance and access issues for cancer survivors in its 2005-2006 annual report, *Assessing Progress, Advancing Change*. Building off of recommendations regarding insurance and access from the previous report period, the Panel identified the need to work collaboratively with legislative, regulatory, and health care

financing authorities to improve survivors' access to quality care. Specifically, it noted the importance of increasing the health insurance coverage rate of the young adult population and exploring creative mechanisms for providing needed services outside of traditional insurance mechanisms.[12]

Though the aforementioned reports are just a few among many, they provide important context for the arena in which survivorship care efforts emerged. Additionally, the 2010 passage of the Affordable Care Act (ACA) included several important provisions that impact cancer survivors, most importantly increased access to coverage and elimination of pre-existing condition exclusions. The ACA also aims to improve fairness, affordability, and efficiency while increasing access to quality care. In this new environment, where quality and cost are of primary importance, it is essential to identify the most critical policy priorities for cancer survivors and opportunities to put them into action.

CHALLENGES IN THE DELIVERY OF SURVIVORSHIP CARE

One Goal, Many Parts

Despite the positive changes that may result from health reform, survivors' health care needs are many, and wide variation in the elements of care that comprise survivorship services remains. Though the IOM report outlined the major components of care, achieving these four goals requires a multitude of services spanning the health care system. Furthermore, although the immediate health status of a cancer patient takes precedence, as he or she transitions into the post-treatment survivor phase, there are numerous physical, emotional, psychosocial, financial, relational, and neurological issues that directly relate to the survivor's quality of life.

To address those issues, key elements of survivorship care must be integrated and understood. First, cancer patients require health promotion education to prevent occurrence of new or second cancers as well as late effects that may arise as a result of treatment for their primary cancer. Second, survivors need ongoing surveillance for recurrence, cancer spread, and second cancers.[13] Third, survivors need monitoring and assessment of pain, distress, and other symptoms or side effects, and for potential late effects and access to early intervention for late effects when they present. Finally, survivors have often received multiple modes of treatment from several providers at separate locations, with limited coordination of care between providers.[14] Despite an already strained health care delivery system, quality survivorship care demands improved communication and coordination of care, particularly as patients move from an intensive period of treatment in which the patients have frequent contact with those involved in the patients' care to a "non-system" with minimal management and few care guidelines for life after treatment.[15]

On top of their primary health care needs, survivors are often grappling with cancer-related pain and other troubling symptoms, concerns about the burdens their cancer has imposed on their family caregivers, and a life that has become defined by a cancer diagnosis. The cost of follow-up care can be devastating even for those with health insurance, and working may be difficult for survivors encumbered by peripheral neuropathy, fatigue, or long term effects of

chemotherapy affecting cognitive functioning. Additionally, the emotional and psychosocial effects of a diagnosis that meets all the critical attributes of a traumatic life event can be especially difficult for cancer survivors: feelings of loss and crisis, fear and anxiety, and personal loss of control over life events may all manifest during and after treatment.[16] Addressing these physical, financial, emotional, and psychosocial needs requires significant communication and coordination between those involved in a survivor's care.

Addressing the Needs of Pediatric and Young Adult Cancer Survivors

Pediatric cancer survivorship represents one of the greatest success stories of health care today. The overall pediatric cancer survival rate is 83%, an impressive improvement to the 58% survival rate of the mid-1970s.[17] Cancer survivors diagnosed as adolescents and young adults (AYAs), however, have seen little improvement in survival rates. Factors contributing to the lack of progress in young adult survivorship include lack of infrastructure to collect data on AYAs, low participation in clinical trials, and varying treatment exposures across different treatment settings – both pediatric and adult care settings.

Adult survivors of pediatric cancer and AYAs are at risk for serious consequences from cancer and its treatment. The Childhood Cancer Survivor Study found that 73.4% of young survivors experience at least one late effect of treatment and approximately 40% endure late effects that are severe, life-threatening, or fatal.[18] The stage of development at which patients experience treatment can also have a critical impact on cognitive, social, educational and vocational late effects of young adults. Some late effects, such as infertility, are of unique concern.

Pediatric cancer survivors are often followed at cancer centers by their oncology team until they reach adulthood. After this time, however, many adult survivors of pediatric cancer no longer receive regular follow-up care. Fortunately, there are a growing number of facilities who offer long-term care for pediatric cancers, including several of the LIVE**STRONG** Survivorship Centers of Excellence as well as the George Washington University Thriving After Cancer Program. A list of clinics providing care for adult survivors of pediatric cancer is available from Lisa Diller's article "Adult Primary Care after Childhood Acute Lymphoblastic Leukemia" in the *New England Journal of Medicine.*[19]

The Children's Oncology Group has developed clinical survivorship guidelines for the ongoing care of pediatric survivors. These guidelines offer a model for adult cancer survivorship care, though data for adult-onset cancer survivors are lacking in comparison to data for pediatric cancer survivors. This is partially due to the low (3-5%) enrollment in adult-onset clinical trials; clinical trials are a standard of care for pediatric cancer treatment, a practice which lends itself to higher enrollment rates.[20] The cancer community also lacks the rich data of a large cohort study for adult-onset survivors similar to that of the Childhood Cancer Survivor's Study.

Acknowledging the Impact of Disparities on Cancer Survivorship

Achieving optimal health after cancer treatment can be difficult for any cancer survivor given the fragmented health care delivery system and poor care coordination, lack of survivorship guidelines, and lack of consensus on who should be delivering which components of care.

However, underserved populations are burdened by additional obstacles that may impede overall quality of life during survivorship, including economic, psychosocial, and cultural barriers.

Poor, underserved individuals who have limited access to health care and medical services often have lower quality of life after cancer, as well as shorter survival rates.[21] The American Cancer Society estimates that survival rates of poor individuals are 10% to 15% lower than those of more affluent cancer patients.[22] The Institute of Medicine (IOM) reports that an individual's health insurance status is the best indicator of how long it will take to access and receive health care; insurance is also a primary determinant in predicting health care quality.[23] While psychosocial support is critical for all cancer survivors to address fear of recurrence and assistance in developing or honing coping skills, underserved populations may experience increased fear, stigmatization, and inadequate economic support that further exacerbate distress.[24] Finally, cultural barriers – including linguistic barriers as well as attitudes and beliefs about health care - can profoundly shape how health care information is interpreted and how the health care system is utilized by a cancer survivor.[25]

Delivering Survivorship Care

Another barrier to promoting quality care for survivors is the variety of models of care and limited evidence about which models are most effective and cost-efficient. Variation can result in a lack of agreement on the essential elements of care and competition for limited resources to improve access to survivorship services. Though different models may be better suited for different patients, a lack of cohesion across the board can be problematic in advancing the field.

Emerging research considers questions related to how best to deliver optimal follow-up care, who should deliver it, in what settings, and according to which guidelines or best practice models.[26] Generally, post-treatment cancer survivor care is limited to monitoring for cancer recurrence and persisting toxicity of therapy by their oncologist.[27] Infrequent communication between oncologists and primary-care physicians is another barrier to adequate survivor care and can result in a lack of PCPs getting the information they need to provide long-term care, which can be especially frustrating for survivors who transition back to their primary care providers.[28]

Lifelong health care is recommended by the IOM for all cancer survivors; however, comprehensive survivor care is sometimes elusive in current practices, and coordinated long-term care is not as widespread as it should be.[29] Several emerging models of survivorship care present a counterbalance to the usual practice, however. The two main categories of survivorship care models, discussed in Oeffinger and McCabe's article "Models for Delivering Survivorship Care," are (1) the community-based shared-care model and (2) the care of adult cancer survivors at academic institutions. The community-based shared-care model, utilized to treat a majority of cancer survivors, allows two or more physicians or care providers of different specialties to address patient care.[30] Typically, a survivor is transferred back to their primary care provider at a predetermined period of time and the oncologist remains on-call as needed.

Care of adult cancer survivors at academic institutions vary widely, but may include a mix of clinical and supportive care combined with research to increase the future evidence base on late effects of cancer, survivor outcomes, and quality of life. Programs may be disease-specific or available to all cancer survivors and vary in the elements of care provided. Some programs are multi-disciplinary and others may be led by an Internist, Physician Assistant or Nurse Practitioner with referral to specialists as needed.[31]

An important communication tool that has emerged, regardless of the model of care, is the Survivorship Care Plan. The new Commission on Cancer accreditation standard requires that a Survivorship Scare Plan be developed by the oncologist to benefit the patient and his or her other providers. This document summarizes crucial information needed for a survivor's long term care, such as the type of cancer and cancer therapy, a list of potential late effects, and recommendations for preventing recurrence and late effects.[32]

Given the complexities of survivorship care combined with existing pressures on primary care, the medical home model may provide a promising option for care of cancer survivors. In this model, the patient is at the center of a medical home, where a health care team provides multifaceted, coordinated care based on a patient's needs.[33] Though a number of medical home models exist, success depends on the medical home's ability to take each patient's case and recruit and coordinate multidisciplinary and specialty services as necessary.[34] For cancer survivors, a medical home can provide a comprehensive treatment plan and other important services for navigating care post-treatment. The relationship between the patient and the provider is paramount in a medical home, which allows for guided management across multiple referrals and services.

Medical homes, however, rely heavily on primary care capacity to care for survivors. The projected shortage of 45,000 primary care physicians by 2020 requires multiple reforms addressed by ACA to expand training and residency and increase retention and satisfaction for primary care providers. Cancer survivorship advocates will need to monitor implementation of these reforms and press for additional approaches to increase overall provider capacity, such as expanding professional training opportunities, state scope-of-practice laws, and increasing efficiency through payment reforms.[35]

Training and Education

Another challenge to delivering equitable, quality survivorship care is lack of training for the many practitioners needed to appropriately address the physical and psychosocial needs of the cancer survivor. Regardless of the model of care, cancer survivorship requires the services of multiple types of providers across systems of care. Oncology providers, including physicians, surgeons, nurses, nurse practitioners, and social workers, must be trained to address the needs of survivors, and they must be equipped with strategies to efficiently coordinate care with primary care providers. Moreover, it is essential that providers such as internists, family practitioners, gynecologists, social workers, and other types of traditional primary care providers be educated about survivors' needs and understand how to collaborate with oncology providers, given the multi-faceted needs of patients.

Training today's providers is only a first step. Due to an aging population and better health care, both of which lead to a growing number of survivors, the need for cancer services will grow immensely. The American Society of Clinical Oncologists has estimated that by 2020 cancer service needs will grow by 48%, while doctors practicing oncology will only increase by 14%;[36] this could result in potentially dangerous care shortages. Oncology nursing shortages are expected to rival those of the physicians, with a projected shortfall of over 1,000,000 nurses and nurse practitioners nationwide by 2020,[37] significantly impacting the quality of care.[38] At the same time, there is a critical shortage of primary care providers,[39] requiring all care providers to employ efficiency even while improving coordination of care.

Specialists' and primary care providers' confusion regarding who should provide which aspects of care for the cancer survivor also reflect the need for training. The Survey of Physician Attitudes Regarding the Care of Cancer Survivors (SPARCCS) study revealed significant differences in primary care providers' and oncologists' knowledge, attitudes, and practices in caring for cancer survivors. The study suggests the need for greater communication between primary care and oncology specialists, training for primary care to increase confidence in caring for survivors, and training for oncologists in appropriately sharing care with primary care providers. Notably, more than two-thirds of the physicians in the study departed substantially from clinical guidelines, reflecting an overuse of non-recommended blood tests and imaging tests and highlighting the need for clear clinical guidance and education.[40]

Strengthening the Evidence Base

Another challenge in the delivery of survivorship care is establishing a solid evidence base to define appropriate quality of care and performance indicators and to help secure appropriate reimbursement for survivorship services. Compared to the outcomes data on long-term and late effects in childhood cancer survivors, there is an extremely limited evidence base for adult-onset survivors, particularly regarding the prevalence of certain late effects, the best ways to treat them, and how to prevent them from getting worse. Current research efforts are hindered by limited funding, although the National Cancer Institute has invested in a dedicated Office of Cancer Survivorship to help partially address this data gap.

Two research priorities critical to advance the field of cancer survivorship include: 1) funding for a large cohort to acquire longitudinal data, modeled after the childhood cancer studies, and 2) infrastructure development, including the revision of databases and registries to incentivize more comprehensive collection of data, as well as analytic tools to retrieve data in a more efficient and effective manner. Improved research efforts will require cooperation between stakeholders such as researchers, clinicians, policy makers, patients and patient advocacy groups, and social service providers to organize the framework and environment necessary to promote personalized, coordinated care for survivors.[41]

Financing Survivorship Care

A final obstacle to the delivery of quality cancer care is achieving consistent and appropriate reimbursement for survivorship services from end of active treatment through the balance of

life. Reimbursement levels for services vary widely, and survivors can have difficulty getting reimbursed for necessary services. Varying definitions of survivorship on the part of payers may lead to a reduction in reimbursements two years after treatment, as well as a reduction in reimbursements for the use of scan technology or screenings for survivors who have been exposed to radiation.[42]

With the implementation of the Affordable Care Act (ACA), the health care delivery and payment system will likely enter a new phase. Recently, the Centers for Medicare and Medicaid Services (CMS) released two new Healthcare Common Procedure Coding System (HCPCS) codes for cancer treatment planning and care coordination, thanks largely to efforts of advocacy organizations like the National Coalition for Cancer Survivorship.[43] While the new code does not guarantee payment, it is an important step toward achieving reimbursement for the time and expertise needed to develop a treatment plan and coordinate care for patients. By describing a common set of services that describe managed care, payers can use the codes to track service delivery and develop new payment strategies. It will be important for cancer providers at the individual and institutional level to actively engage policymakers in discussions around new models of delivery and payment, including the effectiveness of the new HCPCS code, as well as the impact of rolling out Accountable Care Organizations, Medical Homes, and other types of bundled payment options.

The challenges of survivorship care are interconnected. Policy impacts the funding available to the National Cancer Institute and its Office of Cancer Survivorship. The availability of adequate funding impacts the capacity of institutions to engage in research to build the evidence base for improved interventions, clinical guidance development, and care delivery models. Research findings in turn impact the extent to which services are reimbursed.

Conclusion and Next Steps

The growing number of cancer survivors is an extremely positive development; however, the life-altering effects of cancer do not end after treatment ends. Ensuring the overall well-being of survivors requires a comprehensive, coordinated approach to meeting the essential elements of post-treatment care outlined by the IOM and reinforced by LIVE**STRONG** in their recent brief: *The Essential Elements of Survivorship Care.*[44] Some of the biggest challenges in the delivery of survivorship care are the wide variation in the elements of care, the wide variation in the models of the delivery of services, the limited evidence base for how to best care for survivors, and a lack of adequate reimbursement for clinical services. Although the ACA includes many provisions that positively impact the state of survivorship, many challenges remain to securing adequate services and quality care for survivors.

Though today's survivors have many unmet needs, multiple players can come together to insure that the needs of tomorrow's survivors are adequately and comprehensively met. First steps to meeting this challenge are:

- Implement the Affordable Care Act to ensure access to health insurance, coverage and quality care for cancer survivors and expand training and residency programs for health care professionals.
- Support the Comprehensive Cancer Care Improvement Act (CCCIA, H.R. 3705) introduced by Rep. Lois Capps (D-CA) and Rep. Charles Boustany (R-LA) to advance the Institute of Medicine's recommendation for written treatment summaries and survivorship follow-up care plans de
- Support the American Cancer Society Cancer Action Network Patient Centered Quality of Life Act to amend the Public Health Services Act to address the symptoms and needs of patients with chronic disease.
- Appropriate research funds to the National Cancer Institute's Office of Cancer Survivorship to expand the evidence base for effective and cost-efficient survivorship care models.

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