

THE LIVESTRONG ESSENTIAL ELEMENTS OF SURVIVORSHIP CARE: DEFINITIONS AND RECOMMENDATIONS

Background

On September 15 and 16, 2011, LIVESTRONG invited national experts in the field of cancer survivorship care to participate in the Essential Elements of Survivorship Care Meeting (Essential Elements Meeting) in Washington, DC. The goal of the meeting was to build consensus among key stakeholders on the essential elements of survivorship care that any effective cancer survivorship program must provide (directly or via referral) to post-treatment cancer survivors. It is important to note that the goal of the meeting was not to identify specific guidelines or standards for delivering care (e.g., surveillance for recurrence conducted at particular time points).

Meeting attendees included 150 community leaders, researchers, health care providers, professional organizations, cancer survivors and cancer survivor advocates to build consensus on identifying these essential elements of survivorship care. Through a series of consensus-building activities, meeting participants agreed upon a prioritized list of the essential elements of survivorship care.

What Is an Essential Element of Survivorship Care?

Prior to the Essential Elements meeting, several steps were taken to ensure a successful outcome. The first step in the process of identifying essential elements of survivorship care required developing a working definition for an “element of survivorship care” and the criteria that an element must meet in order to be deemed “essential.”

Definition of an Element of Survivorship Care and Criteria for Inclusion

An element of survivorship care is a descriptor of some component of health care that is:

- discrete enough to be actionable (i.e., provides enough information to communicate how the element might function as part of survivorship care); and
- not overly prescriptive (i.e., does not include specific directions on implementation because specific needs will vary significantly across survivor populations and survivorship care settings).

The criteria for an element to be deemed an essential element of care is as follows:

- has a positive impact on morbidity, mortality and/or quality of life for all cancer survivors;
- can be implemented across a variety of care settings; and
- is supported by an evidence base that exists in cancer survivorship or exists in other related health domains or, when an evidence base does not exist, the element embodies one of the following:
 - addresses the expressed needs of cancer survivors;
 - has been agreed upon through consensus of the provider community; or
 - can be tested through further research.

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Universe of Elements

Once these important terms were defined, the next step was to create an expansive list of all possible elements. The universe of elements of survivorship care was organized using the framework outlined by the Institute of Medicine's Lost in Transition report for categorizing the four elements of survivorship care: Prevention, Surveillance, Intervention, and Coordination.¹

This universe of elements was created using the following four steps:

1. A targeted literature review and a review of the survivorship programs in the LIVESTRONG Survivorship Center of Excellence Network (Network) and other comprehensive cancer centers. The RAND Corporation, on behalf of LIVESTRONG, conducted these reviews, which identified 81 elements of survivorship care delivery.
2. Review and feedback conducted by the Network on the list of 81 elements. This review and feedback expanded the universe to 101 elements of survivorship care delivery.
3. Review and feedback conducted on the list of 101 elements from the Essential Elements Meeting Advisory Committee (Advisory Committee) and the Network. This review and feedback condensed the universe to 45 elements of survivorship care.
4. Final review and feedback conducted on the list of 45 elements of survivorship care from the Network and the Advisory Committee to confirm that the final universe was still exhaustive but also an actionable list of elements for the purposes of achieving consensus on essential elements of survivorship care at the Essential Elements Meeting.

Narrowing the Universe

During the Essential Elements Meeting, groups of six to eight individuals were seated at tables where they participated in a total of five consensus-building sessions. These sessions were based on a modified version of the Delphi Process, with the goal of narrowing the essential elements list to 20.² The Delphi Process offers advantages over less systematic methods of building consensus by using structured round table discussions and iterative brainstorming sessions. The modified Delphi Process used at the Essential Elements Meeting, as described more thoroughly below, involved multiple iterations of individually selecting and ranking elements gleaned from group discussions. Stakeholders were seated at each table from varying groups to incorporate multiple perspectives. During the process of narrowing the list of essential elements, a tier system was created to assign each individual element to a tier. This tier system was intended to classify the elements to ensure that the most critically identified needs could be implemented with a common priority across settings. Further clarification of each element, along with suggested clinical examples, is provided in the accompanying text.

¹ Hewitt M, Greenfield, S., & Stovall, E. From Cancer Patient to Cancer Survivor: Lost in Transition. In: Academies IOM NRCN, (ed). Washington, D.C.: National Academies Press; 2006.

² Brown, B. Delphi Process: A Methodology Used for the Elicitation of Opinions of Experts. ASTME Vectors 3(1). Available at: www.rand.org/pubs/papers/206/P3925.pdf.

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The Essential Elements

Tier 1 Consensus Elements

All medical settings *MUST* provide direct access or referral to these elements of care.

- Survivorship care plan, psychosocial care plan and treatment summary
- Screening for new cancers and surveillance for recurrence
- Care coordination strategy that addresses care coordination with primary care physicians and primary oncologists
- Health promotion education
- Symptom management and palliative care

Tier 2 High-Need Elements

All medical settings *SHOULD* provide direct access or referral to these elements of care for high-need patients and to all patients when possible.

- Late effects education
- Psychosocial assessment
- Comprehensive medical assessment
- Nutrition services, physical activity services and weight management
- Transition visit and cancer-specific transition visit
- Psychosocial care
- Rehabilitation for late effects
- Family and caregiver support
- Patient navigation
- Educational information about survivorship and program offerings

Tier 3 Strive Elements

All medical settings should *STRIVE* to provide direct access or referral to these elements of care.

- Self-advocacy skills training
- Counseling for practical issues
- Ongoing quality-improvement activities
- Referral to specialty care
- Continuing medical education

Definitions

The detailed definitions of the Essential Elements presented here are intended to address meeting participants' concerns about the terms used and to provide insight into how the elements might be implemented in clinical care. Participants noted significant overlap between some elements, as well as confusion over the intent behind some elements. Additionally, participants noted that elements inherently linked were nonetheless placed in different tiers. For example, care coordination appears in Tier 1, the successful execution of which often involves referral to specialty care, which does not appear until Tier 3.

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This document is organized along the three tiers and each definition includes three parts.

- 1) The definition of the element.
- 2) Recommendations for how that element might be implemented. The recommendations include what might constitute the basic and enriched levels of care necessary for successful implementation. It is important to note that the delivery of the essential elements should not be limited or restricted only to the care described within the two levels of basic and enriched. Indeed, it is understood that the provision of a spectrum of care between those levels is possible.
- 3) A list of related elements. A list of related elements after each definition highlights other essential elements that may be integral to implementing the element of care in question.

In many cases, providers outside the oncology center or the survivorship program can and should be responsible for providing some of the types of care or recommended services described in this document.

Limitations and Future Needs

It should be noted that a strong evidence-base that demonstrates the efficacy of many of the essential elements in improving survivors' health outcomes is still needed. For that reason, published guidelines concerning many of the elements of survivorship care delivery do not exist. Meeting participants who conduct research and have clinical practices in real world settings identified and prioritized the essential elements. As the field continues to develop an evidence base to support specific aspects of survivorship care delivery along with evidence-based clinical guidelines, expert opinion and consensus can still inform current practice.

The majority of meeting attendees were from the United States, thus the Essential Elements represent elements perhaps most fitting to survivorship care in the U.S. health care environment. While the Essential Elements are intended to be generalizable for most people in the United States, we do recognize that the elements may not always be appropriate or effective in providing care for special and underserved populations – namely for adolescent and young adults, rural residents, and people whose sociocultural background might present difficulties toward integrating into and using of the U.S. healthcare system. With that in mind, we encourage the reader to consider the examples that have been provided with each definition as either a minimal level of care provision for any institution or as an example of what could be provided in an "ideal" or truly comprehensive survivorship program if resources allowed and such services were available. We hope that with the advancement of survivorship research and a close attention to health equity within this research, survivorship care and the essential elements can evolve to better serve these populations.

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Achieving consensus on a list of 20 Essential Elements of survivorship care marks significant progress; however, it is important to note that some elements – many of which were widely acknowledged to be extremely important in post-treatment survivorship – are not included on the list. For example, meeting participants felt strongly about including fertility services as a component of survivorship care but did not select these services as an essential element; many thought it should be addressed before the post-treatment phase of the cancer care trajectory. Additionally, while genetic testing received strong support, some participants felt that this element will not be “essential” until more progress is made in genomic science. Meeting participants agreed on the importance of having a program of research associated with survivorship care delivery but recognized that some care delivery settings may face significant challenges to participate actively in research. Finally, meeting participants indicated that when any assessment of survivors takes place, there should be a corresponding set of available resources to address the needs identified in that assessment.

Elements that were not identified as essential should not be considered unimportant or irrelevant to survivorship care. **LIVESTRONG** believes that all elements considered at the Essential Elements Meeting play a role in providing optimal survivorship services and that none of the elements should be eliminated from ongoing discussion about the provision of post-treatment care. Prioritizing elements of survivorship care delivery with a large group of experts and stakeholders has started a process for ensuring systematic, optimal delivery of care. Our hope is that the list of Essential Elements provides valuable guidance for existing survivorship care efforts and a starting point for those working to design and implement comprehensive survivorship care.

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DEFINITIONS

TIER 1: CONSENSUS ELEMENTS

Survivorship Care Plan, Treatment Summary and Psychosocial Care Plan

A **survivorship care plan**, developed from a patient-specific treatment summary and including medical and psychosocial components, informs the survivor and the clinicians involved in the care of the survivor. Important components of the survivorship care plan include information regarding treatment exposures and potential long-term or late effects, such as medical and psychosocial complications and their signs and symptoms.

Basic level: At a basic level, the survivorship care plan includes recommendations for screening for the surveillance of recurrence, second cancers and other medical and psychosocial long-term or late effects. These recommendations are based on information in the treatment records, including cancer diagnosis, date of diagnosis and treatments received (chemotherapy with names of drugs, surgery, radiation to include fields of radiation, and other cancer directed therapies). The survivorship care plan specifies healthy behaviors important to survivor recovery and in reducing health risks, and psychological, social and functional complications frequently seen in survivors. The care plan should identify resources within the survivor's community to address these potential complications. Examples of domains to be included are cancer surveillance and monitoring, screening for other cancers, cardiac monitoring, bone health, fertility, fatigue, sleep disturbance, pain, depression, cancer related distress, anxiety, physical activity and weight maintenance and tobacco cessation. This could be accomplished by completing of the LIVESTRONG Care Plan powered by Penn Medicine's OncoLink (www.livestrongcareplan.org), and augmented by resources in the survivor's community or referral to LIVESTRONG navigation services.

Enriched level: At the enriched level, the survivorship care plan should include all basic level recommendations, as well as an enriched treatment summary with information about cancer diagnosis, date of diagnosis and treatments received, including chemotherapy with names of drugs, surgery, radiation to include fields of radiation and other cancer-directed therapies. Information about stage and tumor characteristics, doses of cardio toxic drugs and radiation

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dosage, major complications, persistent symptoms, comorbid conditions, and psychosocial, genetic, familial and socio-demographic risk factors are included in the treatment summary. The survivorship care plan specifies healthy behaviors important in survivor recovery and in reducing health risks and psychological, social and functional complications frequently seen in survivors. The survivorship care plan could identify resources within the survivor's community to address these potential complications. In addition, tailoring the care plan with direct recommendations and referrals and having the capacity for follow up on implementation of the care plan are important inclusions. This could be accomplished with Journey Forward Care Plan or a specific institutional enhanced care plan.

Related elements: psychosocial assessment; psychosocial care; care coordination strategy; late effects education, transition visit.

Screening for New Cancers and Surveillance for Recurrence

Screening for new cancers and surveillance for recurrent disease requires a clinical evaluation that includes a complete history (including family history) and physical examination, as well as diagnostic tests and/or imaging that detects new cancers or cancer recurrences at the earliest stage. However, there are inadequate data-based guidelines to direct clinicians in surveillance monitoring for most cancer diagnoses. Screening guidelines for new cancers are often evidence based and available from authoritative organizations. Guidelines, when available, include recommendations for specific tests and the frequency of those tests.

Basic level: At a basic level, screening for new cancers and surveillance for recurrent disease should assure that appropriate screening tests are discussed and recommended, and that they will be provided by an appropriate provider if not done within the survivorship program.

Enriched level: At an enriched level, screening and surveillance could include an extensive clinical evaluation with a complete history and physical examination—and when indicated, a rectal examination, clinical breast and testes examination, female pelvic exam, skin examination and/or eye examination. Depending on evidence-based or consensus guidelines, it also could include imaging and laboratory tests to screen for specific to certain cancers. It is

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important to note that the frequency and appropriate screening tool for every cancer has not yet been established, and that screening that has been shown to not improve outcomes is *not* recommended.

Related elements: survivorship care plan; care coordination; comprehensive medical assessment; health promotion.

Care Coordination Strategy

A **care coordination strategy** refers to an organizational process or procedure consistently applied to help facilitate the sharing of information among the survivor, the primary oncology team, the primary care provider and any other providers of care for the survivor (not limited to physicians, nurse practitioners, or physician assistants). A care coordination strategy specifically provides guidance for what services or activities should be included as part of survivorship care and who is responsible for overseeing this care. The 2006 IOM Report could be used as a template to delineate plans for monitoring for recurrence, surveillance for second cancers, managing late and long-term effects, addressing preventive care and managing comorbidities, including psychosocial care.³ A care coordination strategy is important for all survivors, particularly for those who do not receive a transition visit.

Basic level: At a basic level, a care coordination strategy should include:

- asking or prompting a survivor during a clinic visit to identify the other members of their health care team;
- maintaining updated contact information for this team in the medical record;
- providing specific guidance to the survivor on who they should include on their health care team; and
- developing a treatment summary and survivorship care plan that should be shared with all providers of their health care.

³ Hewitt M, Greenfield, S., & Stovall, E. From Cancer Patient to Cancer Survivor: Lost in Transition. In: Academies IOM NRCN, (ed). Washington, D.C.: National Academies Press; 2006.

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Enriched level: At an enriched level, a care coordination strategy for survivorship includes, from the time of initial diagnosis, automated completion of a treatment summary and survivorship care plan document into an integrated electronic health record system with the ability to document and correspond in real time with all members of the survivor's health care team.

Related elements: survivorship care plan; treatment summary; transition visit; referral to specialty care.

Health Promotion Education

Health promotion is the process of enabling people to increase control over; and improve their health. **Health promotion education** refers to activities and/or programs that contribute to a survivor's knowledge to facilitate informed decisions relating to preserving and improving health from cancer diagnosis and beyond.

Basic level: At a basic level, health promotion education should include primary prevention education that covers reducing risk factors and increasing protective lifestyle behaviors (i.e. tobacco cessation, weight management, physical activity and limiting alcohol consumption). Health promotion education also should address secondary and tertiary prevention by providing information about early detection of other diseases (i.e. chronic diseases, such as osteoporosis, heart disease and diabetes). This care can also be addressed by referring survivors to other educational programs if not provided in the specialty setting.

Enriched level: At an enriched level, health promotion education could include basic level primary, secondary and tertiary prevention education described above that is tailored to cancer type, stage of diagnosis, age at diagnosis, comorbidities, treatment received, and stage of survivorship. Additionally, resources and links at the health system and community level for behavior change and/or sustaining healthy lifestyles could be provided to survivors in well-planned health promotion education programs. Education could include, but is not limited to, smoking cessation, nutrition, exercise, physical rehabilitation, weight management, substance abuse programs, and cancer/chronic disease screening recommendations and screening programs (such as health fairs and free screening clinics).

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Related elements: survivorship care plan; treatment summary; late effects education; nutrition services, physical activity services, and weight management; family and caregiver support; self-advocacy skills training.

Symptom Management and Palliative Care

Symptom management and palliative care refers to care that prevents and relieves suffering and, therefore, improves the quality of life for people with a history of cancer. Such care includes early identification (screening), assessment, and managing of physical and psychosocial symptoms and spiritual distress across the entire cancer trajectory.⁴

Basic level: At a basic level, symptom management and palliative care should include relief from pain of treatment and treatment-related long-term and late effects (i.e., neuropathy, chronic pain syndrome). It should also include managing symptoms related to ongoing therapy (i.e. treating hot flashes in men and women on hormonal therapy).

Enriched level: At an enriched level, symptom management and palliative care could include an individual evaluation of symptoms of pain and distress by a trained professional as a direct service, which may be integrated into or separate from a comprehensive medical assessment or psychosocial assessment. Educational materials should be provided and care should offer relief and treatment—including information about evidence-based complementary and alternative medicine when appropriate—of all long-term and late effects from cancer treatment. The care coordination strategy should include how these issues will be addressed.

Related elements: survivorship care plan; treatment summary; late effects education.

⁴ Modified from the definition of palliative care by the World Health Organization (www.who.int/cancer/palliative/definition/en/, Accessed on 3/22/12).

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TIER 2: HIGH-NEED ELEMENTS

Late Effects Education

Late effects education refers to education for survivors and providers on identify and managing possible late and long-term medical and psychosocial side effects that may impact quality of life and functional outcomes.

Basic level: At a basic level, late effects education should include: 1) a general review of the common after-effects from cancer and its treatment; and 2) questions that cancer survivors should ask their providers who are administering follow-up care. The general review of late effects should include definitions and examples of the following: fatigue, endocrine effects, incontinence, infertility, learning and memory problems, lymphedema, neuropathy, osteoporosis, pain, sexual dysfunction, risk for second cancers, organ damage (especially heart), premature aging and early onset of chronic diseases, such as diabetes and heart disease.

Enriched level: At an enriched level, late effects education should include basic level education described above and could include information that is risk adapted to the survivor's cancer type, stage of diagnosis, age at diagnosis, comorbidities, treatment received, and stage of survivorship.

Related elements: survivorship care plan; treatment summary; health promotion education; rehabilitation for late effects.

Psychosocial Assessment

A **psychosocial assessment**, which can range from symptom screening to comprehensive evaluations, refers to a systematic evaluation of the psychosocial distress experienced by people with a history of cancer.

Basic level: At a basic level, a psychosocial assessment should include screening for distress using the NCCN Distress Thermometer. When distress is present, a follow-up assessment of emotional, practical, and family needs, etc. should be conducted and needs should be

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discussed. If such services are not available within the survivorship program, it should be addressed by an appropriate provider.

Enriched level: At an enriched level, a psychosocial assessment could include an individual evaluation of distress by a trained professional as a direct service, which may be integrated into or separate from the psychosocial assessment. Educational materials should be provided and referrals made to services to address psychosocial needs. The care coordination strategy should include how these issues will be addressed.

Related elements: survivorship care plan, psychosocial care plan, and treatment summary; comprehensive medical assessment; psychosocial care; counseling for practical issues.

Comprehensive Medical Assessment

A **comprehensive medical assessment** should be conducted to identify the palliative services needed to address persistent symptoms and dysfunctions related to a survivor's cancer treatment, as well as to detect secondary health problems that may be a result of cancer treatment. In addition, it is essential to consider and plan for integrating this care into any treatments for comorbid conditions that may be unrelated to cancer (i.e., diabetes and heart disease).

Basic level: At a basic level, a comprehensive medical assessment should include a self-report questionnaire that reviews common long-term symptoms after cancer treatment such as fatigue, pain, neuropathy, sleep, depression, fear of recurrence, and physical limitations. A review of systems that includes consideration and integration of care for major comorbidities, such as diabetes and cardiovascular risks, is also needed. A complete physical exam is necessary and must be assured if not completed at the survivorship visit. A survivorship visit occurs when a patient visits health care providers and receives immediate survivorship care and information about future care needs.

Enriched level: At an enriched level, the most efficient strategy to accomplish a comprehensive medical assessment is through a self-report questionnaire that reviews a broad range of symptoms along with a review of systems. The self-report should be reviewed by the health care

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provider and be the focus of clinical questions and medical evaluation, which includes a complete physical examination and integration of the survivorship care plan with any comorbid conditions that may be unrelated to cancer.

Related elements: symptom management and palliative care; late effects education; psychosocial assessment; care coordination strategy; health promotion.

Nutrition Services, Physical Activity Services and Weight Management

To promote longer lives, empower survivors and provide them with optimal quality of care, survivorship services should be aimed at increasing survivors' knowledge of the importance of **nutrition, physical activity, and weight management**. Services should provide guidelines for meeting personalized health behavior goals, including resources that educate survivors on what constitutes a healthy diet, how to maintain a healthy weight; and as well as physical activity guidelines. Referrals to these services are integral to survivorship care.

Basic level: At a basic level, nutrition, physical activity, and weight management services should include an assessment of diet, exercise patterns and body mass index (BMI) as part of the self-report and medical assessment. The provider should offer relevant educational materials and referrals to community and online resources to achieve goals of regular exercise, weight control and healthy nutrition.

Enriched level: At an enriched level, nutrition, physical activity, and weight management services could include measurement of height and weight to calculate BMI and an individual evaluation of regular patterns of exercise and eating habits by trained professional(s) as a direct service, which may be integrated into or separate from the comprehensive medical assessment. Educational materials should be provided and referrals made to appropriate services for weight management, physical training and exercise programs as needed. The care plan should suggest strategies to set goals in each area needing improvement and the means to achieve these goals. The care coordination strategy should address how these issues will be addressed.

Related elements: survivorship care plan, health promotion education, late effects education.

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Transition Visit and Cancer-Specific Transition Visit

A **transition visit and cancer-specific transition visit** refer to the allocation of health care provider resources specifically devoted to preparing individuals to move to the next stage of cancer care once active treatment is completed. A care coordination strategy should be established as a component of this visit. Activities are directed at reviewing information about the cancer diagnosis, treatment and prognosis and putting into place a plan to coordinate the provision of medical care moving forward. Activities involved in the cancer-specific transition visit are directed primarily at identifying and reviewing the elements of care related to the surveillance of the primary cancer, monitoring and following up on late and long-term effects of treatment and managing symptoms. Activities involved in a transition visit also include recommendations regarding screening for new cancers, providing a plan for ongoing preventive health care and managing co-morbid conditions, which may necessitate coordinating care or referring to another type of care provider. Transition visits of any kind should include an assessment of the survivor's understanding of these needs, as well as a psychosocial assessment and recommendations. Information about the plan of care is shared between and among the survivor and relevant health care providers.

Basic level: At a basic level, once active treatment is completed a transition visit and cancer-specific transition visit should be conducted by a physician, nurse practitioner or physician's assistant. The survivor and primary care physician should get a summary of the treatment received and oncology team contact information so the survivor and/or the primary care provider can reestablish contact with the oncology provider team if needed.

Enriched level: At an enriched level, a transition visit and cancer-specific transition visit could include a visit with a multidisciplinary team of providers who compile treatment summary information and provide guidance regarding the plan of care moving forward after a comprehensive medical assessment. A psychosocial provider of care is part of the multidisciplinary medical team.

Related elements: survivorship care plan, psychosocial care plan, and treatment summary; care coordination strategy; comprehensive medical assessment.

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Psychosocial Care

Psychosocial care refers to individualized care that addresses a broad range of psychological, emotional, cognitive, behavioral and social issues associated with the cancer experience.

Basic level: At a basic level, psychosocial care should include information on topics such as stress management, and access to support groups and referrals to appropriate professionals accessible in the institution of care or within the community setting.

Enriched level: At an enriched level, psychosocial care should include information mentioned in the basic level and could include an individual evaluation of psychosocial distress by a trained professional as a direct service. This may be integrated into or separate from a comprehensive medical assessment. Educational materials should be provided and referrals made to services for psychosocial issues. The care plan should suggest strategies to set goals for each area needing improvement and the means to achieve these goals. The care coordination strategy should include how these issues will be addressed.

Related elements: survivorship care plan, psychosocial care plan, and treatment summary; psychosocial assessment; comprehensive medical assessment; family and caregiver support; counseling for practical issues.

Rehabilitation for Late Effects

Rehabilitation for late effects should include consultation and treatment in the areas of physical therapy, pain and palliative care, nursing, psychology, social work, psychiatry, neuropsychological testing, cognitive rehabilitation and occupational therapy.

Basic level: At a basic level rehabilitation for late effects should include referral to a trained professional to evaluate of late effects so that educational materials can be provided and referrals made to treatment services. The care plan should suggest strategies to set goals for each area needing improvement and the means to achieve these goals.

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Enriched level: At an enriched level, rehabilitation for late effects could include an individual evaluation of late effects by a trained professional as a direct service, which may be integrated into or separate from a comprehensive medical assessment. Educational materials should be provided and referrals made to services for late effects. The care plan should suggest strategies to set goals for each area needing improvement and the means to achieve those goals. The care coordination strategy should include how these issues will be addressed.

Related elements: survivorship care plan, psychosocial care plan and treatment summary; health promotion education; symptom management and palliative care; psychosocial assessment; psychosocial care; referral to specialty care.

Family and Caregiver Support

Family and caregiver support refers to supportive activities for family members and caregivers of people with a history of cancer.

Basic level: At a basic level, family and caregiver support should include direct access or referral to supportive activities for family members and caregivers of people with a history of cancer, including educational approaches for children of survivors; practical education for caregivers regarding activities such as medication management, dressings, wound care, self care, etc.; spousal support groups; spousal education; and bereavement support.

Enriched level: At an enriched level, family and caregiver support could include basic level educational services, as well as professional evaluation of an individual's the need for support. This direct service may be integrated into or separate from a psychosocial assessment. Educational materials should be provided and referrals made for support services. The care coordination strategy should include how these issues will be addressed.

Related elements: health promotion education; psychosocial care; educational information about survivorship and program offerings.

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Patient Navigation

Patient navigation refers to individualized assistance offered to cancer patients, their families, and their caregivers to help overcome health care system barriers and facilitate timely access to quality medical and psychosocial care.⁵ For post-treatment survivors, navigation can help with things such as addressing late effects, getting support for emotional needs, finding resources for practical concerns, and identifying and securing an appointment with a primary care provider or other specialty referral.

Basic level: At a basic level, referral to lay patient navigation services should be ensured if requested by a patient or caregiver. The lay patient navigator may assist in providing resources upon request for specifically identified services (i.e. referral and access to community resources).

Enriched level: At an enriched level, culturally competent patient navigation services could include integrating trained navigation care specialists into a transition visit, such that navigation is a part of every survivorship visit and is a part of implementing the survivorship care plan. At this level, follow-up care appointments are made with the help of the patient navigator. A patient navigator would help verify that a treatment summary and care plan is in place and help make follow up appointments with specialty survivorship services, such as a community-based physical activity and nutrition program.

Related elements: survivorship care plan, psychosocial care plan, and treatment summary; family and care giver support; counseling for practical issues; transition visit or cancer-specific transition visit; care coordination strategy; referral to specialty care.

Education Information about Survivorship and Program Offerings

Educational information and resources about survivorship and program offerings should be provided to support the transition from active care to survivorship. Information can be provided in a variety of modalities (i.e. in-person, online, group or class, written, etc.).

⁵ C-Change. What is Cancer Patient Navigation? Washington, DC: C-Change 2009. Available online at: www.cancerpatientnavigation.org. Accessed on 7/30/2012.

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Basic level: At a basic level, educational information and resources about survivorship and program offerings should include direct access or referral to educational materials and local resources.

Enriched level: At an enriched level, educational information and resources about survivorship and program offerings could include materials that are tailored to be culturally and linguistically appropriate. Additionally, this could include direct access to activities such as courses on survivorship issues, “Survivors’ Day” events, or other opportunities that engage survivors.

Related elements: survivorship care plan, psychosocial care plan, and treatment summary; health promotion education; family and care giver support; counseling for practical issues; referral to specialty care.

TIER 3: STRIVE ELEMENTS

Self-Advocacy Skills Training

Self-advocacy skills training refers to training to enhance survivors’ knowledge and empower them to become active participants in managing their health care.

Basic level: At a basic level, self-advocacy skills training should include referral to self-management programs in the health care system or community and/or referral to health professionals trained in health behavior and self-management, such as case managers, psychologists or social workers.

Enriched level: At an enriched level, self-advocacy skills training could include direct access to self-management training, group medical visits for survivors to support self-management skills, the addition of self-management topics and strategies to ongoing local support groups, patient access to records, and recommendations on electronic medical record health portals to support informed decision-making about survivorship and health. This could happen in conjunction, or separately from other educational offerings and trainings for survivors.

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Related elements: survivorship care plan, psychosocial care plan, and treatment summary; health promotion education; family and caregiver support; counseling for practical issues.

Counseling for Practical Issues

Counseling for practical issues refers to guidance and services that target practical matters, such as finances, legal issues, insurance, school, work, and family roles and role changes for survivors with a history of cancer and/or families. This counseling can be offered to anyone whose life has been affected by cancer.

Basic level: At a basic level, counseling for practical issues should include direct access or referral to counseling on an as-needed basis for financial issues, legal assistance, education support (scholarships, etc), employment training, family therapy, and learning new family roles.

Enriched level: At an enriched level, counseling for practical issues could include an individual evaluation of practical needs by a trained professional as a direct service, which may be integrated into or separate from a psychosocial assessment. Educational materials should be provided and referrals made to services for identified practical needs. The care coordination strategy should include how these issues will be addressed.

Related elements: family and caregiver support; educational information about survivorship and program offerings; self-advocacy skills training.

Ongoing Quality Improvement Activities

Ongoing quality improvement activities for survivorship in healthcare settings involves the intentional allocation of resources devoted to identifying clinical or organizational benchmarks of success in providing of coordinated cancer survivorship care within a health care system, assessing of key systemic gaps and targets for improvement, and routinely administering and reviewing of small-scale tests to close identified gaps. Quality improvement activities can be quantitative or qualitative. Results of quality improvement activities may be shared with

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organizational stakeholders and have implications for reimbursement or professional certification.

Basic level: At a basic level, ongoing quality improvement activities for survivorship could be used to track the number of patients seen in the oncology treatment setting who have a primary care provider or to track the compliance of patients receiving recommended health care screenings over time, such as annual preventive health care exams with a primary care provider.

Enriched level: At an enriched level, ongoing quality improvement activities should include benchmarks for quality care as defined by an organization and made clear to all staff within an organization and made publicly available. Quality improvement activities are initiated by and receive (salary) support from the leadership within a health care setting who are trained in quality improvement methodology. Results of quality improvement activities are reported regularly to stakeholders upon request, and participating institutions demonstrate accountability for progress over time. For cancer care, oncology practices participate actively in a “medical neighborhood” into coordinating cancer care and partnering with primary care Patient-Centered Medical Homes that are certified by the National Committee for Quality Assurance. Programs may survey survivors using a standardized scale of care coordination—such as Cancer Care Coordination Questionnaire for Patients⁶—to assess and address the program’s effectiveness.

Related elements: continuing medical education; care coordination strategy.

Referral to Specialty Care

Referral to specialty care involves implementing a mechanism at the site of primary medical care that facilitates the provision of evaluating and assessing the medical, psychosocial or spiritual needs of the survivor. Referral is dependent upon an initial screening of these needs and upon timely communication and complete sharing of necessary information with the referred provider.

⁶ Young JM, Walsh J, Butow P, Solomon MJ, & Shaw J. Measuring Cancer Care Coordination: Development and Validation of a Questionnaire for Patients. *BMC Cancer* 2011 11:298.

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Basic level: At a basic level, referral to specialty care should include an order placed in an electronic or other medical record for a service that would benefit the survivor and that has been recommended by the medical team. It also could include a referral to a phone- or online-based patient navigator or community-based program to help identify additional resources that meet an individual's needs. An example includes a health care provider who fills out a request for consultation with a clinical psychologist to evaluate and provide care for an individual for whom anxiety symptoms have been prevalent and current treatment has not proven effective at reducing symptom burden.

Enriched level: At an enriched level, referral to specialty care could include a mid-level nursing health care provider who screens survivors at the time of their survivorship clinical assessment, discusses this assessment with the primary oncology team and facilitates a person-to-person referral for services. An example includes referring a head and neck cancer survivor who has limited range of motion of his head to a physiatrist.

Related elements: survivorship care plan, psychosocial care plan, and treatment summary; care coordination strategy; symptom management and palliative care; psychosocial assessment; comprehensive medical assessment; patient navigation; rehabilitation for late effects.

Continuing Medical Education

Continuing medical education refers to the institutional encouragement, tracking, and provision of institutionally-affiliated providers' participation in accredited continuing medical education about survivorship. Various providers can participate in this education, including primary and specialty care physicians, allied health professionals, nurse practitioners, mental health professionals and other health professionals.

Basic level: At a basic level, continuing medical education should include participation in survivorship awareness education. Providers of survivor—such as primary and specialty care physicians, allied health professionals, nurse practitioners, mental health, and other health professionals—should be encouraged to enroll. Additionally, providers who routinely see survivors should participated frequently (at least annual) in survivorship educational

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opportunities. These opportunities include, but are not limited to, Grand Rounds; case reviews such as Tumor Boards that feature survivorship; local seminars and lectures; relevant continuing medical education opportunities; and conferences such as the Biennial Cancer Survivorship Research Conference, American Psychosocial Oncology Conference, Centers for Disease Control and Prevention Cancer Conference, and Society of Behavioral Medicine Annual Meeting.

Enriched level: At an enriched level, providers should participate in basic level opportunities. Additionally, organizations and institutions with capacity and expertise in cancer survivorship are encouraged to develop new opportunities for medical education credit/units for the health professionals listed above. These opportunities include training newer practitioners at the onset about survivorship care.

Related elements: ongoing quality-improvement activities.