

Providing High Quality Survivorship Care in Practice: An ASCO Guide



American Society of Clinical Oncology

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The American Society of Clinical Oncology (ASCO) is the world's leading professional organization representing physicians of all oncology subspecialties who care for people with cancer. ASCO's more than 35,000 members from the United States and abroad set the standard for patient care worldwide and lead the fight for more effective cancer treatments, increased funding for clinical and translational research, and, ultimately, cures for the many different types of cancer that strike an estimated 12 million people worldwide each year.

Acknowledgements

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1.0 Key Components of Survivorship Care

Survivorship care is a specific approach taken to address the long-term needs of cancer survivors and includes monitoring for and managing long term and late effects, as well as health promotion. The 2005 Institute of Medicine (IOM) report, *From Cancer Patient to Cancer Survivor: Lost in Transition*, embraces four components of survivorship care: 1) prevention and detection of new cancers and recurrent cancer; 2) surveillance for recurrence or new primaries; 3) interventions for long-term and late effects (hereafter referred to as late effects) from cancer and its therapies; and 4) coordination between specialists and primary care providers (PCPs) to ensure that all of the survivor's needs are met¹.

More specifically, high quality survivorship care includes:

- Surveillance for recurrence
- Monitoring for and managing psychosocial and medical late effects
- Providing screening recommendations for second cancers
- Providing health education to survivors regarding their diagnoses, treatment exposures, and potential late and long-term effects
- Providing referrals to specialists and resources as indicated
- Familial genetic risk assessment (as appropriate)
- Guidance about diet, exercise and health promotion activities
- Providing resources to assist with financial and insurance issues
- Empowering survivors to advocate for their own healthcare needs

In 2011, LIVESTRONG convened the Essential Elements of Survivorship Care Meeting, attended by over 150 community leaders, stakeholders, cancer survivors and advocates, with a goal of building consensus around best practices to address the needs of post-treatment survivors. Consensus was reached on 20 essential elements of survivorship care delivery.

To learn more about the LIVESTRONG Essential Elements of Survivorship Care, visit:

<http://www.livestrong.org/What-We-Do/Our-Approach/Reports-Findings/Essential-Elements-Brief>.
Levels #1 and #2 mirror the four IOM components of survivorship care.



2.0 Getting Started

Building a Survivorship Care Program

As a result of advances in cancer diagnosis and treatment, more people than ever before are surviving the disease. For this reason, survivorship care is now recognized as a unique phase in overall cancer care. This section aims to assist oncologists and other clinicians with implementing high quality survivorship care programs within their practice by explaining the different models of care delivery, addressing potential barriers to implementation, and assisting with the identification of existing and needed resources.

For the purpose of this resource, “program” is defined as the set of services needed to provide survivorship care; it does not require that all related services be provided in one practice setting.

2.1 Models of Long-Term Follow-Up Care

Providing survivorship care requires a variety of approaches to meet the needs of this growing population; and there are several models of care delivery available, all with distinct advantages and disadvantages. The population served and level and type of resources available should be the two principal considerations when determining the model best suited for your practice setting. Cancer survivors are not all alike and their needs vary across a continuum, from those who have few long-term effects from their treatment to patients with chronic conditions or significant treatment-related health issues. Regardless, all survivors require education regarding their own health risks and screening needs.

A brief description of several survivorship care models used today is provided below:

Oncology Specialist Care: Care occurs as a continuation in the oncology setting

Multi-Disciplinary Survivorship Clinic: Care is provided by a specialized long-term effects team in a separate clinic outside of the oncology setting

Disease/Treatment Specific Survivor Clinic: Type and intensity of follow-up care is determined by the cancer treatment received; patients may be directed back to the cancer center for needed services at the direction of the PCP

General Survivorship Clinic: Care is provided by a physician or advanced-practice provider (not multi-specialty) and implemented at a cancer center, community hospital, or private practice

Consultative Survivorship Clinic: Initial follow-up is provided in the oncology setting with an eventual transition to a PCP; patient may be directed back to the cancer center for needed services at the direction of the PCP

Integrated Survivorship Clinic: Care is provided within the oncology setting, which may be located with a cancer center, community hospital or private practice, and may be provided by a physician or advanced-practice provider. Care is coordinated with the PCP and other specialists as needed.

Community Generalist Model: The primary care physician, advanced practice nurse, or internist within the community provides care

Shared-Care of Survivor: Care is coordinated/provided by any combination of specialists and PCP's, nurses, and/or is patient directed

Determining the model of survivorship care delivery that works best for your patient population and practice setting requires consideration of the patient needs and risks, and available resources needed to meet the key components of survivorship care. The models of care delivery described in this Guide offer a variety of methods for addressing the needs of cancer survivors. The fundamental differences in these approaches are in the physical location of care delivery and the type of healthcare practitioner providing the long-term follow-up care. Advantages and disadvantages of each model are detailed in the Table 2.1.

TABLE 2.1: MODELS OF SURVIVORSHIP CARE DELIVERY: :ADVANTAGES AND DISADVANTAGES ^{2 3}

Advantages	Disadvantages
Oncology Specialist Care	
<ul style="list-style-type: none"> • Comfortable for patients and family/caregivers who have developed a relationship with the treating oncologist • Provides continuity of oncology care • Oncologists don't feel they have to "give up" their patients to other providers • Patients at high risk of recurrence are closely followed. 	<ul style="list-style-type: none"> • Focus remains on illness, not wellness • Focus may be on relapse rather than risk-based surveillance and health promotion • Providers may lack time or interest in managing of long-term or late effects • Primary care needs may be unmet
Multi-Disciplinary Survivorship Clinic	
<ul style="list-style-type: none"> • Providers have expertise in long-term and late effects of treatment • Multiple services are provided in one location • Good model for complex patients • Improved survivor knowledge of long-term and late effects • Provides ready access to sub-specialists committed to survivorship care • Easy for survivors • Can include psychological support to complement medically focused oncology care 	<ul style="list-style-type: none"> • Resource and time intensive • Not needed by all survivors • Available to a limited number of patients • May discourage survivors from re-establishing care or initiating care with primary care providers, and thus primary cares needs may be unmet • Can be difficult to coordinate all specialists on the team • Communication and coordination with primary care can be challenging
Disease/Treatment Specific Survivor Clinic Disease/Treatment Specific Survivor Clinic	
<ul style="list-style-type: none"> • Providers have expertise in one particular area • Allows institutions and practices to pilot services with one group of patients • Simple to apply guidelines for surveillance and symptom management • Referral to outside services can be a component • Can focus on psychological support to complement medically focused oncology care 	<ul style="list-style-type: none"> • Limited to survivor populations with large numbers • May focus resources away from other survivor groups with significant needs • May discourage survivors from seeing primary care providers

Advantages	Disadvantages
General Survivorship Clinic	
<ul style="list-style-type: none"> • Provides survivorship services for all groups • Financially more efficient than disease-specific services • Referral to outside services can be a component • Can focus on psychological support to complement medically focused oncology care 	<ul style="list-style-type: none"> • Difficult to have expertise in one clinic across all survivor groups • Difficult to tailor services for specific needs • May discourage survivors from seeing primary care providers
Consultative Survivorship Clinic	
<ul style="list-style-type: none"> • Comfortable for patients and family/caregivers who have developed a relationship with the treating oncologist • Allows continuity of oncology care • Oncologists don't feel they have to "give up" their patients to other providers • Requires few resources • Provides a plan for post-treatment care and follow-up • Empowers patients with knowledge and education 	<ul style="list-style-type: none"> • One-time visit with no follow-up • Limited time to address long-term and late effects • Requires extensive knowledge across survivor groups • Requires providers who can bill for services— not all types of providers may be reimbursed
Integrated Survivorship Clinic	
<ul style="list-style-type: none"> • Provider is a survivorship specialist who is part of the clinical team • Oncologists are readily available to survivors if needed • Survivor receives survivorship-focused care within the oncology setting • Frees up the oncologist to see new patients 	<ul style="list-style-type: none"> • Survivors may expect clinician to provide primary care; primary care needs may therefore be unmet • May be difficult to transition patients to primary care when appropriate • Requires providers who can bill for services

Advantages	Disadvantages
Community Generalist Model	
<ul style="list-style-type: none"> • Focus is on wellness rather than disease • Promotes independence and reintegrates the survivor into primary care 	<ul style="list-style-type: none"> • Limited provider knowledge about long-term and late effects • Requires provider knowledge and education about survivorship issues • Difficult to update providers and survivors as new information becomes available
Shared-Care of Survivor	
<ul style="list-style-type: none"> • Survivor continues to benefit from specialists in managing long-term and late effects • Works well for survivors with ongoing, complicated cancer-related health issues • Survivor continues to benefit from specialists when at highest risk of recurrence • Works well for patients with limited risk of late effects • Focus is on wellness rather than disease • Promotes independence and allows focus on co-morbidities - important in the elderly 	<ul style="list-style-type: none"> • Resource intensive since survivors require time, expertise and a strong infrastructure of communication between specialist and PCP • Often roles are not clearly delineated resulting in care that is omitted or duplicated • May be difficult to identify the PCP and therefore transition patients to primary care when appropriate • Connection to oncology may be difficult to reestablish when problems arise

2.2 Determining the Best Model for You: Conducting a Needs Assessment

The purpose of conducting a needs assessment is not only to identify and address deficiencies, but also to recognize resources that may already be available. The assessment should be conducted as part of the survivorship care program planning process in order to establish a clear picture of what services are readily available to be provided and by whom, and what resources are necessary but not in place.

It is important to understand that the model of care delivery will define what resources are needed, but the needs assessment will help determine which model of care delivery is most feasible for your facility. Further, the patient population served by your facility will significantly define what services are needed within your survivorship care program. The vital first step in the process is to identify the stakeholders needed to most appropriately and fully answer the questions. You are encouraged to include patients or patient advocates in the process to ensure the program will best suit the needs of your survivorship population.

The questions below are designed to assist with the identification of strengths and weaknesses that exist within the practice or care center, and the surrounding community. This information then can be used to develop a strategy to plan and implement a survivorship care program.

1. Oversight of the program should be housed within an integrated but separate entity within the practice to which it will have accountability. Given this, who will have oversight of the program?
2. What services or post-treatment programs are feasible for your facility to provide?
 - a. Medical follow-up care
 - b. Psychosocial services
 - c. Educational opportunities for patients and providers
 - d. Survivorship research
 - e. Palliative care/symptom management
3. Does your practice have access to electronic medical records and/or patient portals through which coordination and education can be conducted? If not, how will coordination of care and communication with the patient and other members of the care team be done?
4. What resources (including physical, personnel and financial) are available to you?
5. What programs or services are already available within your practice or facility? Within your community?
6. Is there clinical staff with the appropriate expertise within your facility? Within your community? If not, is training available?

7. Are there non-clinical skills among staff that can be optimized to support the survivorship care program (i.e., an assistant with strong internet research skills who could help identify resources within the extended community)?
8. What existing programs could be expanded to include post-treatment patients?
 - a. Support groups (disease- or age-specific, or family/ caregiver)
 - b. Patient education opportunities (i.e., online, in-person lectures, individual education during encounters)
 - c. Counseling (psychological and financial)
 - d. Complementary medicine (i.e., yoga, acupuncture)
 - e. Palliative care/symptom management
 - f. Physical rehabilitation
 - g. Sexual/reproductive health
 - h. Genetic counseling
 - i. Nutrition services
 - j. Smoking cessation
9. What patient populations can you serve (pediatric, AYA, adult)?
10. How diverse is the survivor population available for long-term follow-up care (i.e., types of cancer and treatments received)?
11. How many cancer survivors will be cared for in your facility's program?
12. How large is the geographic area served by your facility? Is it convenient for patients to continue to return to the treatment facility?
13. Will the majority of patients treated at your facility have received minimal treatment exposures, or will you have more complex patients (e.g. bone marrow transplant recipients) requiring more intense therapies placing them at greater risk for late and long-term effects?
14. Who will be responsible for providing support to the survivor's extended network of family and caregivers?
 - a. Oncologist
 - b. Nurse practitioner
 - c. Physician assistant
 - d. Primary care physician
 - e. Multidisciplinary team

15. Though care will be on-going throughout the life of the survivor, how will the continued provision of survivorship services be delivered?
 - a. Within your practice
 - b. Mostly referred out but primary coordination of patient care remains internal
 - c. Done as needed on a consultant basis

Depending on the answers to the questions above, your facility may consider one or a hybrid of several of the model types detailed below:

Method of Care Delivery (Services are Provided at the Facility, Referred Out, or Combination)	Consider This Model Type
Care is coordinated/provided by any combination or specialists, primary care physicians, nurses, and/or patient directed	Shared-Care of Survivor
Care is provided by a specialized long-term effects team in a separate clinic outside of the oncology practice setting	Multi-Disciplinary Survivorship Clinic
Care occurs as a continuation in the oncology setting	Oncology Specialist Care
The Primary Care Physician (PCP), advanced practice nurse, or internist within the community provides care	Community Generalist Model
Initial follow-up is provided in the cancer center with an eventual transition to a PCP; patient may be directed back to the cancer center for needed services at the direction of the PCP	Consultative Survivorship Clinic
Type and intensity of follow-up care is determined by type of cancer treatment received; patient may be directed back to the cancer center for needed services at the direction of the PCP	Disease/Treatment Specific Survivor Clinic
Care will be provided by MD, NP, or PA (not multi-specialty) and implemented at a cancer center, community hospital, or private practice	General Survivorship Clinic
Care is provided within the oncology setting, which may be located within a cancer center, community hospital or private practice, and may be provided by an MD, NP or PA. Care is coordinated with the PCP and other specialists as needed	Integrated Survivorship Clinic



2.3 Challenges to Implementing a Survivorship Program ^{3 4 5}

Numerous challenges may exist when implementing a survivorship care program including barriers related to providers, survivors, community resources, and the healthcare delivery system. Although not all may be addressed here, the more common barriers to implementation and potential solutions are highlighted below.

PROVIDER-LEVEL CHALLENGES

Survivorship care is provided by a collaborative care team that includes oncologists, PCPs, and advanced-practice providers (APPs). The movement toward collaborative team care and focus on health maintenance is a new model for the oncology community. The well-being of the survivor requires a level of integrated coordination requiring a cultural shift in approach away from a disease-only focus. However, PCPs, APPs, and even oncology providers themselves may be unfamiliar with the ongoing needs of cancer survivors, including cancer-related health risks, screening guidelines, and risk reduction methods. PCPs and APPs may lack the experience and expertise in managing cancer survivors with complex needs.

There may be limited local resources to assist PCPs and others in the care team with providing follow-up care. Additionally, barriers to communication between the oncology team and the external care team may inhibit the provision of quality survivorship care. A contributing factor is that busy oncology professionals often lack the time to coordinate needed long-term follow-up care. As well, the extended rehabilitation community may lack education and expertise or awareness of cancer survivorship issues.

Solutions

- Regional educational programs can be established to increase provider awareness of survivorship issues and to reorient toward the model of communication, coordination and collaboration.
- Technology (e.g., webinars) can also be helpful to distribute survivorship resources and education.
- Advocating for the development of survivorship programs is important to address provider-level challenges surrounding communication and coordination of care.
- Electronic Medical Records and other technology such as patient portals and treatment summary and care plan documents can also assist in ensuring coordination and communication between the members of the care team.



PATIENT-LEVEL CHALLENGES

At the patient level, additional barriers exist to implementing survivorship care in practice. A significant challenge is that survivors may be asymptomatic or unaware of late- or long-term effects of cancer treatment and may not realize the importance of ongoing care. As well, survivors and their family members and caretakers may be unsure who serves as the lead care coordinator. Many patients desire to feel “cured” and to leave the cancer diagnosis in the past, and fear of another cancer diagnosis or of being diagnosed with a serious late effect of treatment may inhibit a survivor from seeking follow-up care. Conversely, survivors at low risk of recurrence and late effects may overestimate the need for ongoing oncology care and find it difficult to transition to the PCP.

It is important to note that survivors are members of a complex network of individuals including family members and caregivers; all members of the network experience stresses from the cancer diagnosis including depression, job security or work issues, and financial strains which may vary across time.

Solutions

- Healthcare providers should communicate the plan for follow-up care early in the treatment process and clearly define to survivors and their family members and caretakers who will serve as the lead coordinator of care at various stages.
- Survivors should be informed regarding their diagnosis, treatment history, and risk of developing second tumors, and/or late- or long-term effects.
- Information should be presented in an appropriate manner to ensure comprehension (i.e. age, culture, language, and education level).
- Survivors should be kept up-to-date regarding existing and newly available resources.
- Providers must understand that follow-up care is dynamic and the care plan must be fluid to consistently assess and address changing needs of the survivor.



SYSTEM-LEVEL CHALLENGES

At a healthcare system level, a key challenge is the lack of standardized guidance that exists for assessment and management of long-term and late effects, vehicles of communication and medical record technology. Additionally, there are often missing or insufficient support systems in place for transportation and/or paid time off work to help survivors travel distance or time to reach a specialized follow-up care center or provider.

Another challenge is that the healthcare system requires independence and self-advocacy skills in order to effectively navigate it and secure services. Not all individuals are equipped with these abilities and skills.

Variation in insurance provisions and new healthcare system alignments under the Affordable Care Act may hinder the implementation of standard programs of survivorship care, as coverage may continue to vary substantially from patient to patient.

Solutions

- Models of care should be patient-centered so that services provided are appropriate to the level of care required by the individual survivor.
- Outreach programs, resources and guidance can be strengthened, and satellite clinics can be explored to service remote areas to help individuals navigate and access the healthcare system.
- To improve communication and coordination among providers and patients, and between providers, discussions about the transition process should be initiated early. Family members and care takers should all receive education on the transition process.
- Though not all measures may be feasible for some programs, the system of care should be required to respond to outcome measures which are built into the program as it is developed.

FINANCIAL CHALLENGES

Survivors with multiple or complex late effects may be unemployed or underemployed and therefore unable to obtain or afford health insurance, even despite the implementation of the Affordable Care Act. Even those survivors with insurance may face restrictions on coverage with regard to which providers they can see or screenings, tests, and services they can receive. On the provider side, resources may be an issue as well, limiting ability of providers to deliver robust survivorship care.

Solutions

- Determine what resources are in place and how to seek reimbursement for services provided by the physician, advanced practice providers, and front office staff.
- Develop a directory of community resources and referral options for survivors.
- To help patients afford their care, providers can ensure their patients have information regarding government programs for adults with special needs or disabilities.
- Personnel with expertise in financial and insurance issues can be very helpful to patients as well.



3.0 Providing Survivorship Care in Practice

Survivorship care does not just begin at the completion of active therapy. Below are details of what may be done during active cancer treatment as well as steps to transitioning the patient into the period of surveillance and long-term follow-up care.

3.1 What to do during Treatment

Survivorship care should begin at the moment of cancer diagnosis and will provide a better continuity of care by planning for the post-treatment period. The 2005 IOM report, *From Cancer Patient to Cancer Survivor: Lost in Transition*, recommends that patients completing their first course of treatment be provided with a comprehensive care summary and follow-up care plan. Together, these reports make up the Survivorship Care Plan (SCP). ASCO promotes the use of the SCP to enhance communication between the oncology team and patient, and to improve communication and coordination of care between the oncology team and primary care provider.

In addition to developing the treatment summary and care plan, oncology providers should have ongoing discussions with patients about possible late- and long-term effects of treatment.

3.2 Transitioning the Patient

Upon completion of treatment, survivors enter into the initial phase of long-term follow-up care focusing on surveillance and disease-specific care. Patients should transition from this initial phase into survivorship-focused care, concentrating on risk-based screening and health promotion. Determining when, where and which patients are followed will vary depending on individual patient need and the model of care delivery.

LIVESTRONG Cancer Transitions

Cancer Transitions is a six-week evidence-based educational program to support and empower survivors as they transition from active treatment to post-treatment. Though mainly targeted to individuals who have completed their treatment within the last 24 months, the program may benefit survivors at any time in their survivorship beyond 24 months. The program helps participants learn the benefits of exercise, nutrition, emotional support and medical management, and is offered in face-to-face meetings.

<http://www.livestrong.org/What-We-Do/Our-Actions/Programs-Partnerships/Cancer-Transitions>

TRANSITIONS BETWEEN CARE SETTINGS: AN EDUCATION PROGRAM FROM THE ACCC

The Association of Community Cancer Centers (ACCC) released a detailed report regarding the issue of care transition between the hospital cancer program and physician group practices. Within the report, ACCC examined three key areas: 1) the adequacy and completeness of the medical record, 2) the continuity of drug therapy (medication reconciliation), and 3) the communication among providers, such as physicians, nurses, pharmacists, and social workers—both internally (within their own programs) and externally (between the two care settings). <http://www.accc-cancer.org/education/Transitions.asp>

NATIONAL CANCER INSTITUTE PDQ: TRANSITIONAL CARE PLANNING

Information on different considerations when transitioning a patient through the phases of care and important members of the care team to include in the planning.

<http://www.cancer.gov/cancertopics/pdq/supportivecare/transitionalcare/Patient/page2>

Checklist

Below a sample check list is provided to help determine if the appropriate steps have been completed in order to transition the patient to survivorship-focused care.

1. Does the patient have an established relationship with a PCP?
2. Has the SCP been transmitted to the PCP or provider in charge of long-term follow-up care?
3. Have additional resources, such as guidelines, been provided to the PCP?
4. Has patient received the SCP?
5. Has the patient been given the opportunity to review the SCP with a member of the care team?
6. Has the transition of care been clearly communicated to the patient so that s/he understands who will be the lead in coordination of care?

4.0 Measuring the Quality of Survivorship Care

There is increasing focus on of quality improvement with regard to survivorship care services. Outcome measures should be built into the survivorship care program as it is developed so that system of care delivery can respond to areas demonstrating a need for improvement. As efforts to provide survivorship care expand, ASCO and others will continue to develop needed measures of quality in care delivery.

ASCO'S QUALITY ONCOLOGY PRACTICE INITIATIVE (QOPI®)

QOPI is an oncologist-led, practice-based quality improvement program. The program's goal is to promote excellence in cancer care by helping practices create a culture of self-examination and improvement. The process employed for improving cancer care includes measurement, feedback and improvement tools for hematology-oncology practices.

Currently, QOPI includes several measures related to survivorship care, including measures to assess treatment plan and summary taking as well as the preparation and delivery of follow-up care plans. To learn more about QOPI, please visit: <http://qopi.asco.org/program>



COMMISSION ON CANCER ACCREDITATION STANDARDS

In September, 2012, the American College of Surgeon's Commission on Cancer released the Cancer Program Standards 2012 Version 1.1: Ensuring Patient Centered Care outlining the standards that focus on patient-centered needs and bringing an additional focus on the quality of care and outcomes.

These new 2012 standards are to be implemented by 2015 and focus on patient-centered areas, including the provision of treatment and survivorship plans. To achieve or maintain accreditation with the Commission on Cancer, cancer programs must develop and implement a process to disseminate comprehensive care summaries and follow-up care plans to cancer patients completing their cancer treatments.

The full 2012 Standards report is available at: <http://www.facs.org/cancer/coc/programstandards2012.pdf>

NATIONAL CANCER SURVIVORSHIP RESOURCE CENTER

The National Cancer Survivorship Resource Center is a collaboration between the American Cancer Society and the George Washington University Cancer Institute funded by the Centers for Disease Control and Prevention. Its goal is to shape the future of cancer survivorship care and improve the quality of life of cancer survivors as they transition from treatment to recovery. The Survivorship Center has developed resources for cancer survivors, health care professionals, and the policy and advocacy community.

Moving Beyond Patient Satisfaction: Tips to Measure Program Impact is a brief guide detailing indicators and outcome measures that can be used to monitor the success of survivorship programs.

<http://www.cancer.org/acs/groups/content/@editorial/documents/document/acspc-033811.pdf>



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