

How to begin a survivorship program in your community oncology practice

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In 2012, the United States had an estimated 12 million cancer survivors.¹ In November 2005 the Institute of Medicine (IOM) issued a call to action on cancer survivorship for health care professionals to recognize challenges, treat conditions, and support our patients more comprehensively after their diagnosis with cancer.² This support begins with educating patients about their disease and treatment, their follow-up plan, and potential complications. It involves an assessment for potential complications of disease and treatment, and intervention when warranted. Survivorship programs have emerged throughout the country, but the composition of the programs and operational process by which they are implemented are widely varied. There is some divergence about what defines a cancer survivor, though most current programs treat individuals who have undergone early stage disease treatment through palliation. The site of service where survivorship programs are delivered varies from hospital to center to clinic. The structure of the delivery mechanism can be as a consultation, assuming individuals will have usually 1 survivorship visit, or as longitudinal, setting the precedent that patients will follow up at some regular interval for continued survivorship care. The most striking variation in survivorship programs is the depth and breadth of services that they provide to their patients.

Variation in survivorship program delivery

Survivorship programs are implemented at various sites of service. In some large academic centers there are physical structures of bricks and mortar that serve as the hub for a survivorship program. Within these structures dedicated to survivorship,

the patients' nutrition, psychosocial, and medical needs can be met from internal resources that are dedicated to that purpose. There are regulatory incentives that are driving hospitals and larger cancer centers to develop survivorship programs, even if the cancer patient interacts with that hospital physical structure only briefly during their course of cancer treatment and follow up. Many hospitals that seek accreditation through the Commission on Cancer (COC) for their cancer programs have developed navigation and survivorship programs in concordance with 2012 guidelines for future COC standards.³ Some hospitals have implemented these programs in collaboration with community oncology partners. National Cancer Institute–designated community cancer programs will implement some form of survivorship programs as well to maintain accreditation. Many community oncologists have implemented survivorship programs in outpatient clinics, but the mechanisms by which they have developed survivorship programs and the extent to which they are implemented is highly variable. In addition, within community oncology, adoption of survivorship programs is far from universal. As most patients are seen in community oncology practices for their long term follow up, community oncology is the site of service where survivorship care delivery will be critical. Community oncology is where our patients survive and continue their care along the continuum. Until survivorship programs are implemented in a meaningful way throughout community oncology, optimal care along the continuum for cancer patients will be limited.

Models for survivorship care delivery

No universal model for survivorship care delivery exists today, and program models vary signifi-

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cantly.⁴ Among adult cancer survivorship programs, the 2 models that are common are consultant and longitudinal models. The consultant models generally have the goal of one survivorship visit where the survivorship care plan is given to the patient and education occurs about effects of disease and treatment as well as some assessment and education about other services available. The longitudinal model however, disseminates the survivorship plan early on, but continues to follow the patient. Some survivorship programs are also integrated with long-term follow-up clinics and are merged with expected follow-up visits.

Incorporating survivorship programs into a community practice setting

Addressing survivorship appropriately does not require a physical plant for program initiation and implementation, but it does require collaboration and coordination. Survivorship programs can start with a few basic functions that can grow and develop over time. Within community practice, development of a survivorship program could be independent or in collaboration with a local hospital program. Regardless of where the program is delivered or who ultimately manages it, a large determinant of a community program's success lies in the ability to foster inter-organizational collaboration. The community oncologist needs to serve as an advocate to align stakeholders in their motivation to provide for the various resources that our cancer patients need: education about disease, treatment, side effects, and follow up, support services, fertility assistance, coping, nutrition, wellness, assessment and treatment of physical and cognitive impairment, and an assessment of their values as they approach care and life decisions.

Community oncologists can incorporate basic survivorship programs into their practices by identifying workflow processes, using existing survivorship resources, and collaborating within our communities. The degree to which we expand on these basic levels of service will depend on need, practice capability, and available resources. Our ability to provide survivorship services better for our patients stretches our reach in providing care for them across the continuum and helps them reach optimal quality and engagement in their health care.

Our practice's journey to survivorship planning

Over the last 18 months we sought to implement a survivorship program within our suburban oncology practice. In our efforts, we had many partners including a large working group within the US Oncology Network and its survivorship task force, which created a toolkit to structure and facilitate implementation of a survivorship program and had knowledge of the processes of many com-

munity programs throughout the country. Many experts in the field also came to lecture and provide insight into the implementation of their survivorship programs. This helped us prioritize goals for the program and to decide how to begin. Within our clinic, we elected to start our survivorship program with a half day per week clinic facilitated by a midlevel provider and social worker. We facilitated inter-organizational collaboration by establishing a consultant relationship with a nutritionist who was interested in cancer-specific issues, counselors who were interested and willing to provide services at a reduced rate, physical therapists who have been trained specifically in cancer rehabilitation, and local wellness programs that engage fitness professional partners. Lastly, our practice was ready to expand on the services we were currently providing. The timing was right. In hindsight, these were the critical steps we took to operationalize our survivorship program.

Step 1, Identify a champion. . .

. . . and give your champion a team. Within our practice we use midlevel providers. Aside from partnering to provide general patient care they have certain niche training and functionalities within our practice. A midlevel provider was a perfect choice for a champion of this effort. It was easier to block her schedule as needed for the hour-long survivorship care first visits, and she was very excited about driving a program to facilitate good health among our patients. The paradigm for nurses and midlevel providers championing these efforts is well established in many larger centers.⁵ We assembled a team of a midlevel provider, a physician, a program developer, and our social worker, and we met weekly to identify the structure and operational implementation of our program. We also engaged a doctoral candidate in nursing at our local university to help us to identify resources for our survivorship program as part of her educational training. She developed evidence-based educational content to disseminate to patients and to help populate our Web-based educational tool. We met weekly over a period of 8 months, reviewed the relevant literature, invited guest lecturers who were experts in the field, and came up with a plan. We invited potential collaborators for the functions we did not provide internally and shared with them our vision of how we were hoping to improve care and how we would like them to participate in that effort. Because collaborators were involved in the planning process, these stakeholders were aligned toward the common purpose of the program from the onset.

Step 2, Develop an implementation plan

Breast cancer patients comprise a large portion of cancer survivors, as a whole they have significant survivorship



Utility and Design

"Very thorough and easy to follow tool. Nice."—Dawn

Journey Forward's tools are designed to be:

- **Flexible**
They work standalone, with one another, and in conjunction with treatment summaries produced by EHR systems
- **Easy-to-use**
They offer quick forms, integrated BSA and BMI calculators, built-in regimen and document libraries, and other utilities to save time and improve accuracy
- **Produce an easy-to-read, sharable and updatable Care Plan**



FIGURE 1 Excerpt from Sample Survivorship Care Plan for Breast Cancer, Journey Forward.org.⁸

needs and they are abundant within our practice, so we elected to use breast cancer survivors as our initial target population after active adjuvant treatment, with the plan to branch out to other cancer types within 6 months. We initiated the first survivorship visit 2-3 months after initial therapy was complete as this is a time when patients may be more receptive to these issues. The initial consultation with the midlevel provider and often a social worker would last 1 hour. There was also an additional 30-60 minutes in preparation for the midlevel provider before the visit to complete the initial survivorship care plan document. Her schedule was initially blocked for 1 afternoon to allow time for this program and then expanded as needed. The care plan summary, evidence-based follow-up plan, and potential therapy-related toxicities would be covered in that hour in addition to a needs assessment and triage. The patient received a care plan at the time of the visit as well as a list of content and community resources that we had assembled. In addition, there was a general assessment of triage and referral needs for nutrition, exercise, physical therapy, counseling and other services as well as a decision to have the patient follow up for survivorship issues in 3-6 months for higher acuity issues, or 1 year if minimal active issues were identified.

There are resources available that can help the team conceptualize a framework for their practice. This year, the Department of Health and Human Services in combination with the Centers for Disease Control and The Livestrong Foundation collaborated to produce a national action plan that is publicly available.⁶ The American So-

ciety of Clinical Oncology (ASCO) has also recently published a statement that can be helpful in conceptualizing planning for a program.⁴ Part of these considerations will be determined by the goals of your program and availability of existing community resources for collaboration.

Step 3, Use existing resources

These resources would include care plans, applications, community resources, training and content. In initiating our program, we used a care plan that was created by our organization, but there are many survivorship care plans that are publicly available. Similarly, there are many free mobile apps that patients or caregivers can use in survivorship. These plans have many similar key elements, and it may be easier to initiate a program using free publicly available documents instead of creating a new tool.

Survivorship care plans. One universal axiom between survivorship programs is that they all use survivorship care plans.⁷ Many organizations create their own programs, but there are some good ones available online and for free. Three common survivorship care plans that are free, easy to use, and publicly available can be found through Journey Forward,⁸ the ASCO Web site,⁹ and the Livestrong care plan in collaboration with the University of Pennsylvania¹⁰ (Figure 1). They differ in their application to different disease types and in their complexity and ease of completion. If you are contemplating using these for your practice, it would be useful to review them all.

Survivorship mobile applications. There are multiple cancer survivorship applications for mobile devices that are also free and publicly available. They differ considerably in educational content and ability to track symptoms or goals related to nutrition, fitness, and other relevant metrics of survivorship. Free apps that are common include: The Cancer Treatment Support App, developed by Interstate Industries Inc; Pocket Cancer Care Guide, developed by the National Coalition for Cancer Survivorship; My Cancer Manager, supported by the Cancer Support Community; the Cancer.Net mobile, developed by ASCO; Cancer Coach, developed by breastcancer.org (it includes both breast and colon cancer); AYA Healthy Survivorship, developed by CTxCARES; Survivor, developed by UMCG; and the Livestrong CancerGuide and Tracker for the iPad, developed by Livestrong. Many of these cancer survivorship apps link to content, questions, and calendars for appointments. Some have side effect trackers, access to cancer specific podcasts, journal entry, and wellness tracking functionalities (Figure 2).



FIGURE 2 Left, AYA Healthy Survivorship mobile app with evidence-based self-assessment, BMI calculator, children's oncology group health links, resource links, survivorship plan links; and right, ASCO's Cancer.Net tumor-specific mobile application showing some of the app's educational content.

Patient education, support, and programs through existing resources. Web-based tools can often facilitate optimal use of existing resources. This can be facilitated through Web sites that link to content or education program schedules to social media sites available in conjunction with your practice. In this way, instead of developing classes and support groups within our practice, by making the schedule of community activities available through our Web site, we can leverage community activities and facilitate patient engagement in educational and support activities that may benefit them. In addition, this serves to facilitate collaboration with our local cancer organizations.

Provider education. There are free and publicly available sites for provider education that can serve as means to assist in preparation and development of a survivorship program. As practitioners want to improve on their skill set of addressing survivorship issues, they can access educational content and training. Cancer survivorship training education can be found at the Cancer Survivorship training Web site in addition to sites by the National Comprehensive Cancer Network, ASCO, the NCI, and Livestrong. Some groups have created other libraries of educational content, such as the Pink Ribbon Survivors Network.

Step 4, Facilitate collaboration

As community oncologists, our ability to be effective advocates for our patients often rests in optimizing collaboration between community stakeholders. Do an assessment of your community resources. Do you have the ability to partner with nonprofit organizations that want to provide education and support within your commu-

nity? To what extent can your local hospital become involved? How will you meet the needs of nutrition support, counseling, fitness, education, and physical therapy? Will these be structured relationships, and can you get special functions or discounts for your patients?

Each community is unique. Within our community, we began by offering classes on nutrition, exercise, sexual health, financial health, and so on. The classes we offered were poorly used. We decided that a better plan would be to leverage community resources. We have cancer support communities locally that provide classes and oncology content education in addition to a local breast cancer resource center that also provides classes and education. By educating our patients about community resources, we were able to optimally collaborate and build partnerships. Our local hospital has also partnered in facilitating education and in having physical specialists trained in cancer rehabilitation and lymphedema. We have negotiated low-cost rates with a team of counselors to meet the needs of our patients. A nutritionist comes to our office to counsel patients at a reduced rate. Our social worker has been instrumental in facilitating these collaborations. Collaboration must also be facilitated by optimally communicating with all referring providers. Ensuring that all involved providers get a copy of the survivorship care plan gives each provider a summary of the disease, treatment, anticipated follow up, and target areas for intervention.

Step 5, Know how to bill

It is a truth about our small oncology practices that if we cannot demonstrate return on investment for any programmatic initiative, uptake will be modest and our reach will be short. We have to be able to bill for these services to be able to provide them on a larger scale. To accomplish this, we demonstrated a sustainable business plan for implementation of this program. The billing is for time spent using survivorship V codes.

Summary

With these basic steps, a community oncologist can begin to implement a survivorship care plan within their practice. They are the first steps on a path to improve our comprehensive care when active treatment is over. This program will evolve over time and be specific to the needs of your own community. Our ability to offer this service within our communities will improve care for the majority of cancer patients as community practice remains the mainstay of cancer care delivery. Offering these services to patients in their communities means that we will provide higher quality of care, help them survive, live well, and position them to embrace wellness.

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