

Creating a community-based, patient-centered cancer survivorship program

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A report from the Institute of Medicine in 2005¹ marked a watershed in the thinking about cancer patients and their long-term needs as survivors when it argued for oncology programs in the United States to address the unmet needs of cancer survivors at the community practice level. Cancer care in the United States has tended to focus on the more immediate aspects of the active treatment, limiting our long-term concerns for the patient's well-being. Indeed, as a community oncologist in the early part of my career, 2 decades ago, I considered cancer patients "finished" with their cancer and back to "normal" soon after their last acute toxicity ended.² These days, our profession as well as patients and society as a whole have come to understand that the needs of cancer patients continue into well into survivorship, which can span years or even decades. These concerns should be addressed and accommodated through comprehensive, community-based survivorship programs.

Survivorship needs can be viewed as,

- Management of immediate toxicities of treatment,
- Intermediate issues of re-integration into one's employment and social milieu, and
- The longer-term management of fertility, sexuality, organ system dysfunction, and psychosocial issues of acceptance, among others.

The community survivorship program can guide its outpatient components to integrate these stages into the immediate posttreatment period. Programs can be created to transition these phases from one step to the next.

In this article, I plan to look at the rationale for having a community-based, patient-centered survivorship program, the practical components of such a program, and to offer some "how to"

advice. My personal perspective is derived from my experiences in a community-based practice.

An oncologist-driven venture

Survivorship programs in a local community allow the physician and associated cancer-care professionals to care for survivors beyond the typical office visit setting. Having the oncologist as a leader in this trend toward survivorship programs allows the physician to guide the process and bring credibility to the survivorship movement as a whole. The incorporation of survivorship care into the mainstream of practice may help us get health insurance coverage for aspects of survivorship care that currently are often overlooked.

From my own experience, when physicians enter into a multidisciplinary process, the physician is often given considerable authority to guide the planning and implementation processes. Physician involvement could help introduce the survivorship program earlier in the patient's active treatment, which may make it easier for both the physician and the patient when the patient transitions to posttreatment follow-up. Traditionally, posttreatment surveillance for the practicing oncologist consisted of office follow-up with the patient for an indefinite period of time. We now consider multiple issues well beyond the scope of the office visit such as the spiritual, emotional, and financial challenges as important issues for survivorship care.

The players

A recent article identified an expected shortage of oncology care providers in the United States in the near future.³ In a survey of primary care physicians,⁴ only 24% of respondents said they provided survivorship care; most (82%) believed that the guidelines for doing so were not well defined, and 47% said they had not been adequately prepared to provide cancer survivorship care. Given these two

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A survivor speaks

'Just how much of your professional background is helpful when you find out it is "you" that is the cancer patient?'

Compared with many, I was the lucky one. I was completely taken by surprise that evening when my dermatologist called with the disturbing biopsy report. A routinely removed cyst showed an unusual malignancy, and I was being referred to a head and neck surgeon. A head and neck surgeon? I was confused. As a health professional I did not understand why I was being handed off to an otorhinolaryngologist. So, I did what any educated health professional who has worked in the cancer prevention field for many years would do ... I went to the internet. From the internet, to cancer nonprofit and voluntary agencies, and finally on to the professional oncology literature.

Oh, I learned quite a bit about my suspected salivary tumor but as I devoured as much information as I could stand, it was supplanted with new questions. At some point, I made the conscious (and rather surprising) decision to stop this search for answers and leave it to my physicians. From further examinations, to scans, and eventually to surgery, and on to follow-up, the final pathology report revealed an unusual squamous cell tumor and not the typical salivary tumor as was suspected. I was very fortunate as my prognosis was good, and with each successive examination by both surgeon and dermatologist, I felt more confident that I would make the "cancer survivor" list.

What I was not expecting, however, was that despite the excellent treatment and care I received, I still have plenty of *new* questions and concerns. Becoming a cancer survivor does not mean an end to your treatment path, but the beginning. And as I soon discovered, I was pretty much on my own moving forward. This is precisely why programs in survivorship are rapidly taking hold in the oncology and health profession community. As a health educator, I am now discussing the role my profession can play in working with oncologists to assist, inform, and reintegrate other cancer survivors into their family, societal, and professional roles. Community survivorship programs as outlined by Dr. Fisher are pivotal in meeting the continuing needs of cancer patients and survivors and provide opportunities for health educators, like myself, to participate as team members.

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realities, an active community-based survivorship program would relieve some of the follow-up demands on community oncologists, cater to the needs of the survivors, as well as play a role in bringing the program into the mainstream of cancer care.

From a practical standpoint, creating a survivorship program should include personnel and lines of care that are already in place in most communities. The oncologist would be well served to use a "buy-in" from local hospitals and outpatient cancer-care programs. Other members of the survivorship task force should include all physician disciplines within the local cancer-care program, the local hospital cancer-care committee, oncology nurses, navigators, social services staff, and allied health professions that complement cancer care. The latter group would include providers of physical therapy, lymphedema therapy, occupational therapy, and pastoral care, as well as nutrition counselors, exercise physiologists, and local nonprofit organizations and national organizations with a local presence. It is also advisable to have individual cancer survivors who are energetic activists as part of this team to complement the professionals who guide the survivorship program.

Existing outpatient services would be best incorporated as contributors to a survivorship program, rather than taking over these services into the new, larger authority.⁵ Hopefully, within short order, the allied health professionals in a community-based survivorship program will understand the broader implications of their participation to allow the survivorship program to gain credibility.

Once a community oncology survivorship program has been established, funding can become an ongoing issue for sustainability. Most programs can be maintained with existing team members serving in a voluntary capacity. Each community may have appreciative survivors who would be willing to donate money or services to maintain the survivorship program. Completing grant proposals will likely take up time and increase the workload for local foundations or corporations, given the often stringent requirements for the proposals.

Practice-based to the community at large

The relative novelty of a comprehensive, practice-based survivorship program creates the opportunity to market the program to the community at large. Inviting cancer survivors who received their active cancer treatment at a different location can boost the reputation of the program in the eyes of the invited survivor and the community at large. When creating a survivorship program, this opportunity should be an acknowledged goal, especially where start-up funding from hospital and nonprofit foundations can be solicited. Hospital systems may be interested in the enhanced reputation created from "cancer wellness" survivorship programs.

A survivorship program also creates the opportunity for research from a number of perspectives. Statistical records and analysis of patient demographics, diagnoses,

disease stage, specific survivorship programs that have been used, and subsequent patient quality of life are worthy indicators of a survivorship program's success. Those data may be suitable for publication in a professional journal, and certainly would be appropriate for inclusion in the program's annual report. In addition, the collection of such data may improve the fundraising opportunities that are needed to maintain the financial viability of a program.

From the research perspective, an analysis of the participants of a survivorship program compared with demographically matched nonparticipants may yield survival and quality of life data worthy of academic publication. One could focus on specific programs offered survivors, type of malignancy or cancer treatment, or specific individual demographic to study. As new programs are added to a survivorship program, it may be possible to study the impact of new programs on survivors' quality of life, compared with patient controls whose participation preceded the new interventions.

Keep your eyes on the survivor

Although there may be institutional gains from having a community oncology survivorship program, one should not lose sight of the fact that the program exists to serve the individual survivor. Much has been written about the needs of the cancer survivor and the support community. To ensure that the program is consistently patient centered, one should focus on the patient's healing, recovery, and growth as she or he journeys from active treatment and the management of toxicities, to re-integration into

family, social, and professional units, and management of fertility, sexuality, and psychosocial issues. With this in mind, the oncologist can maintain involvement with the patient, overseeing both the program at large and the way in which the program serves the patient.

Trends in cancer care are toward the need for an active survivorship program. A community-based oncology survivorship program can be created from existing resources within most community oncology practices. A simple structure will likely yield a successful program that can create promotional, clinical research, and funding opportunities. Although it can be easy to misplace the individual cancer patient's needs in the larger structure of the survivorship program, one should remember that the goal is to create a patient-centered program and that the earlier the planning begins, the greater the likelihood of improving patient outcome.

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