

Evaluating needs and the integrated model

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Who is a survivor? Am I a survivor? Are you a survivor? What does a survivor need? How can community oncologists help? These are among the many questions a community oncologist can expect to hear during the course of treating a cancer patient, from the diagnosis, through the decisions about therapy, at all stages of treatment, and well into aftercare and follow-up. A “patient” used to be someone in active treatment, and a “survivor” was someone who had been free of disease for 5 years. More recently, Ellen Stoval of the National Coalition for Cancer Survivorship noted that the term “cancer survivor” can be used “to describe anyone who has been diagnosed with cancer as well as caregivers and loved ones of those diagnosed with the disease.”¹ Her broader perspective more accurately captures the multifaceted nature of survivorship.

These newly defined survivors will experience psychosocial challenges such as chronic and acute anxiety; profound sadness and despair; depression; concern about treatments, restaging, and recurrence; anger about lingering or acute side effects and the limitations they cause; and a nagging fear of dying from cancer. The ripple effects of these issues vary from patient to patient. Some might cope fairly well, others might have a delayed stress reaction, and for some, the challenges could last a lifetime, but they will all bring their concerns to the community oncology practice, where they present a challenge to a staff that has focused primarily on the medical aspects of the disease. Medical and psychological symptoms have traditionally been dealt with separately: the services for them are provided by different professionals, and insurers reimburse them

separately, but is this a necessary, practical, efficient, or even fiscally sound practice?²

Psychosocial needs usually fall into the following categories: supportive services, coaching, financial assistance, psychiatric and medication support, physical therapy and body therapy, individual and family psychological counseling, and spirituality. These needs can be identified by one of several tools³ and once they have been identified, the appropriate service or services can be sought, often with assistance from support groups and advocates. Cancer patients and survivors may need:

- Financial advice to cope with complex insurance claims, loss of wages, and disability issues;
- Body work help such as yoga, nutrition advice, exercise classes, acupuncture, and massage to nurture and heal the body;
- Coaching and psychological services to help them adjust to the upheaval of their altered lives and to teach them how to cope with the sudden and unexpected challenges resulting from cancer;
- Psychiatric care to properly address the psychotropic medications that are sometimes needed to manage more severe emotions and side effects, such as extreme depression, agitation, or anxiety; and
- Psychotherapy and counseling services to ensure a successful transition for the patient and family members to coping with cancer or adjusting to life after cancer.

Emotionally generated distress may be related to the adjustments a patient must make to accommodate multiple doctor appointments, their changed physical condition, loss of work or reduced income, changes in their life priorities, and shifting social and family relationships as a result of their cancer diagnosis and resulting treatment. These patients and their family members are often labeled as difficult, demanding, threatening, angry, or hysterical by doctors and practice staff. How can a

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A survivor speaks

Going through cancer is not easy at all, and you need all the help you can get.

How do you pick up the pieces after a cancer diagnosis? For me, it took some time. I had to accept what was happening to me; that my body was failing me and that I might die, as difficult as that was. In addition, my particular cancer—cervical—was linked to the sexually transmitted human papillomavirus, so I had to deal with the stigma of having cancer as well as knowing that I had a cancer that was linked to HPV.

I don't think you can ever prepare for having cancer. It just kind of happens. But what you do after the diagnosis is important. Thankfully, I didn't lose my life, but sadly, I lost my fertility at the age of 25. After you accept your diagnosis, you have to fight—for your life. Then you have to rebuild; there is no going back to your previous way of life, so you are left with your “new normal.” It's hard to accept that you will never be the same, but once you do, I promise you can survive and thrive.

By the grace of God, my loving mother, wonderful medical team, and supportive friends, I finished my treatment. I had survived! I still had my ups and downs, but I was so grateful for my second shot at life. I tried relentlessly to get back to normal life, my career, my world—one that didn't include cancer. But it's hard once your body has failed you and you're constantly going for check-ups. The worst part was that I would break down completely at the mere sight of a pregnant woman or a new mom.

My family, friends, and coworkers helped me through this dark time. But I realize now that having more targeted psychosocial support at that time would have made a difference for me and my family. In some communities, it is frowned upon to seek “clinical” help for emotional or psychological issues, but I know and understand now that it doesn't mean you're “crazy.” Going through cancer is not easy at all, and you need all the help you can get.

There is no perfect blueprint for how to do this. You just have to take things day by day. At first, I was hesitant to become an advocate for cancer awareness and prevention, but what I have learned from throwing my all into cancer advocacy has helped heal my broken soul. That doesn't mean that I've moved completely. I still have my bad days, but they are fewer and less frequent and I have learned to better deal with them, whether it's taking a walk or helping navigate a newly diagnosed cancer patient through the medical system. I am finally beginning to understand this “new normal” and have made it work for me.

—Tamika Felder

Ms. Felder is a 10-year cervical cancer survivor and founder of www.tamikaandfriends.org, a volunteer grassroots organization dedicated to the eradication of cervical cancer, and TV host and producer in Washington, DC.

medical staff, limited by time and resources, identify these life-changing issues and find an appropriate and timely solution for them? Can we save some medical costs by identifying and addressing these emotional and social needs in a coordinated continuum of care?

Three primary models can be used to coordinate these oncology-related medical and psychosocial services:⁴ coordinated care, colocated services, and integrated services.⁵ Currently, most medical and mental care is provided through the coordinated outside referral, that is, by different providers at different locations whose only link with each other is through telephone, e-mail, or fax. Although outside referrals require the release-of-information consent form, providers often do not follow up on their referrals and communication between providers is limited, meaning that treatment plans are rarely shared and coordinated.⁴ Services that are colocated in the same building or medical office space are usually better integrated, but the practices are considered to be separate to the extent that consent forms still need to be provided and communication between the practices can be time consuming.

Fully integrated practices that provide psychosocial services in the medical community-based oncology practice are considered the most effective care model for the patient. These oncologists and psychosocial service providers often share exam rooms, have access to the patient data, and can more easily coordinate their care plans and support each other on a continuous basis. There is also growing evidence that the integrated model might be more cost effective.² With the increasing use and popularity of the Internet and video conferencing, experts in telemedicine and telehealth have been developing new delivery styles that could result in even easier and better access to psychosocial services for oncology patients. Survivors, however you define them or they define themselves, can have their physical, emotional, and social needs met in a convenient and effective way. We must continue to work to get providers, survivors, and reimbursers to work together to create an effective, fiscally sound, and efficient interrelationship for the benefit of survivors and providers.

References

1. National Coalition for Cancer Survivorship Web site. Cancer advocates, survivors address the “now what?” stage of cancer. Available at: <http://www.nccn.org/about/news/newsinfo.asp?NewsID=203>. Accessed December 3, 2011.
2. Crane R. Does family therapy reduce health care costs for more than the individual patient? *Clin Child Psychol Psychiatry*. 2011;16:3-4.
3. National Comprehensive Cancer Network Web site. NCCN Guidelines for Supportive Care. Available at: <http://www.nccn.org/about/news/newsinfo.asp?NewsID=203>. Accessed November 18, 2011.
4. Hodgson J, Marlowe, D. The Role of MFT in Healthcare: Models of Collaboration. *Family Therapy*. 2011;10,12-5.
5. Blount A. Integrated Primary Care: Organizing the Evidence. *Families, Systems, & Health*. 2003;21:121-133.