

M.D. Anderson Breast Cancer Survivor Clinic

by Amanda Patton



Fran Zandstra

Fran Zandstra, RN, MBA, OCN, director of Cancer Survivorship, and Therese Bevers, MD, medical director of clinical cancer prevention at M.D. Anderson Cancer Center in Houston, Tex., recently sat down with *Oncology Issues* to talk about their breast cancer survivorship program.



Therese Bevers

Q. Can you describe the breast cancer survivor clinic underway at M.D. Anderson?

A. Dr. Bevers. We have actually had a breast survivorship program going on for quite a while, but it was rather informal. About three years ago, M.D. Anderson implemented a survivorship initiative. Through that initiative we identified our model of care. We then incorporated the older model of the breast survivorship program into the survivorship model of care that was developed.

This comprehensive model of survivorship care looks at risk stratification by both disease pathology and treatment to predict the resources that the survivor will need. In our model, along with surveillance of the primary disease, we have strategies that address screening and risk reduction for that individual, late effects monitoring and management, and psychosocial screening and referral. It is a consistent model in which we look at those four components of care across the survivorship continuum

A. Zandstra. We've piloted this comprehensive model with survivors of allogeneic stem cell transplant, gynecologic, genitourinary, thyroid, and head and neck cancers. We're now expanding the model to survivors of breast cancer. The components of care are consistent across all survivorship clinics. However, within those components—for example, how you surveil for the disease, the risk-reduction screenings, and the late effects monitoring—are specific to the disease and the treatment modalities the patient has received.

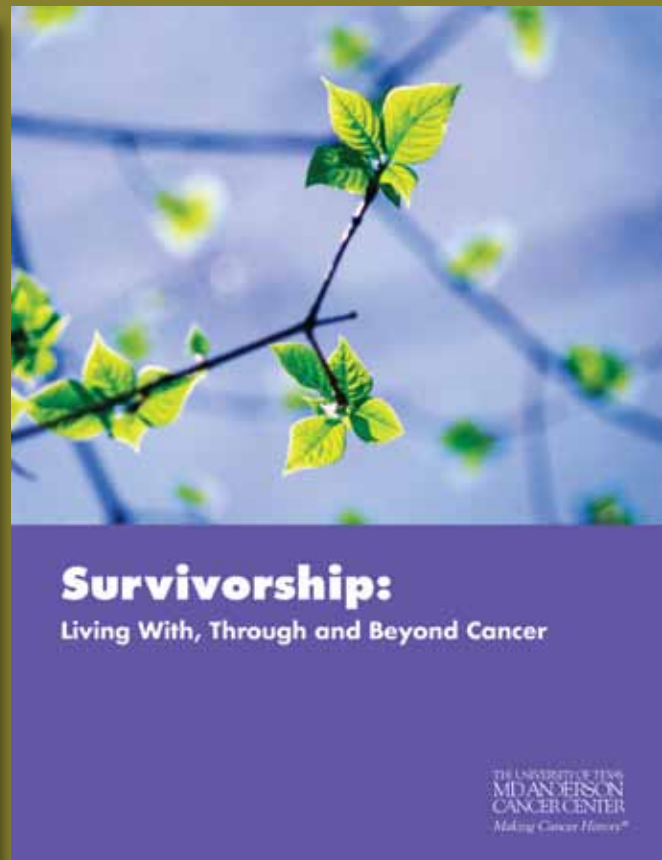
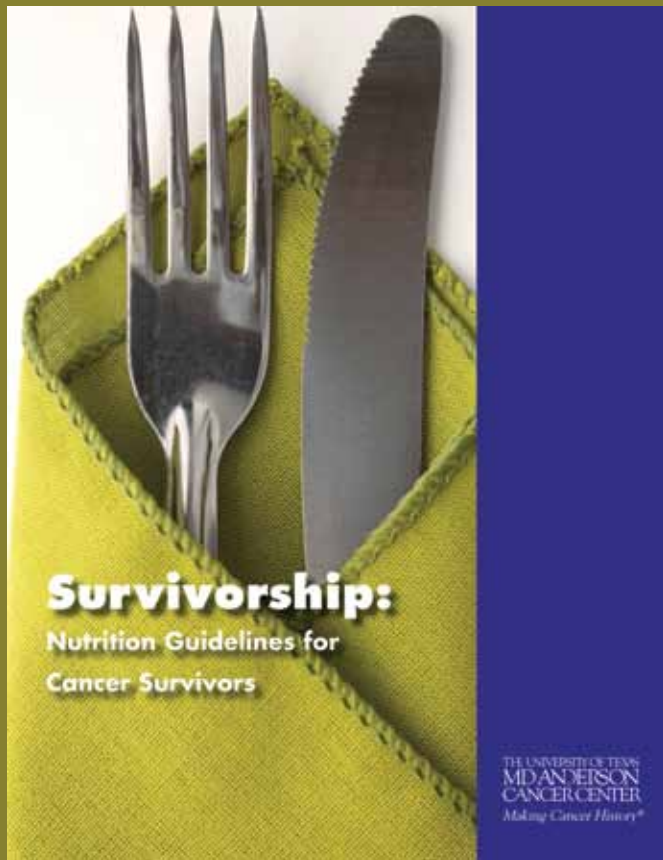
Q. So the need is for disease-site specific survivorship programs if possible?

A. Zandstra. Correct. Survivors of different types of cancers may have very different needs. Within each disease site, patients are risk stratified into three tiers. Tier 1 includes early stage, mono-therapy breast cancer patients—for example, a stage I patient treated with surgery alone. Her risk recurrence is low. She may have other issues that need to be dealt with because of her breast cancer diagnosis, but she is not at risk for the late effects that a survivor of stage III or IV breast cancer treated with intensive chemotherapy [may be at risk for].

A. Dr. Bevers. The risk stratification model is predictive of the multidisciplinary partners with whom that individual survivor may need to have her care coordinated. Within the breast cancer program we have two levels—low risk and high risk. Tier 1 is low risk. Tier 2 and Tier 3 are high risk.

Q. Has the breast cancer survivorship clinic moved out of the pilot phase?

A. Zandstra. It's an established program that we are continuing to refine. We have developed practice algorithms in each organ site that guide the care of our survivors. In addition, we have created a web-based medical summary of care, our Passport Plan for Health, to communicate the



ongoing plan of care to the survivors and their respective community physicians.

Q. *In other words, the Passport Plan for Health is a communication tool between your program and the primary care provider and the survivor?*

A. Zandstra. For the community provider and as a guide for the survivors themselves. The Passport Plan is in an electronic format that is completed at the survivorship visit. The Passport outlines the cancer treatment(s) received and addresses the potential late effects, required ongoing monitoring, cancer screening and cancer risk reduction recommendations, psychosocial issues, and recommended referrals. Many patients really do not have a good understanding of the cancer history, extent of surgery, radiation therapy, or the chemotherapeutic agents they received. In addition, they are at a loss as to what their follow-up plan of care and ongoing care needs are. That's the information contained in the Passport, including the recommendations or patient preferences on where that care will take place—at M.D. Anderson or with their community providers. The Passport Plan for Health is customized to the individual survivor.

Q. *What format do you use for the Passport Plan?*

A. Zandstra. It is an electronic tool that is viewable through a secured website. We develop it in our electronic

medical record [EMR]. We create a document within the EMR that is viewable by the patient and any outside physician or provider that is designated by the patient when she logs in through our secure myMDAnderson portal.

The provider reviews the Passport Plan with the patient in the clinic and provides a copy for her records. The passport is updated each year or as her condition warrants.

A. Dr. Bevers. The Passport Plan is web-based. If a patient should find herself in an area with a provider she has not seen before, she can log in with her own personal ID and show the Passport Plan to that external provider.

Q. *Where is your breast cancer survivor clinic housed?*

A. Zandstra. The breast cancer survivorship program is housed in our cancer prevention center. Again, the breast cancer survivorship program is not our only pilot. We have allogeneic stem cell transplant, GYN, GU, thyroid, and head and neck survivorship programs as well.

Q. *You are piloting disease-site specific cancer survivorship programs for each of those disease sites?*

A. Zandstra. Using the Survivorship Program clinical conceptual framework, the disease-site steering teams define eligibility, conduct literature reviews, and develop disease-specific practice algorithms. The clinical experts are the drivers of the care. Currently Stem Cell Transplant,

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Head and Neck, GYN, GU, and thyroid are housed in their disease-site clinic location. As we mentioned previously breast is in the cancer prevention center.

What we're piloting is a survivorship program including a conceptual framework that continues to be refined as we learn. It is a part of our overall survivorship initiative, establishing survivorship as a distinct phase of the cancer care continuum at M.D. Anderson.

A. Dr. Bevers. To go back to the guidelines. The “front page” of any disease guideline includes those four areas of survivorship care: 1) surveillance screening, 2) risk reduction, 3) late effects, and 4) psychosocial assessment. We then develop guidelines for each of these components that are evidence-based on current literature. Most of the evidence is expert opinion at this point. So each component has a series of guidelines behind it that relate to that particular entity. For example, guidelines for managing bone health for a breast cancer patient would not have hormonal therapies in the same way that the GYN bone health guidelines would—but both might include bone health guidelines.

Q. *How are you staffing this model and, specifically, what role are APRNs playing in transitional care?*

A. Zandstra. Currently, in the disease-site team we employ a partnership model. Low-risk patients are seen by the Cancer Prevention staff (nurse practitioners or physicians). In the case of breast cancer survivorship, high-risk patients are seen by a medical oncologist or a nurse practitioner from the breast medical oncology group, using the guidelines discussed above. Additionally, we have collaborated with endocrinologists to develop bone health guidelines; psychologists related to sexual health counseling; and nutritionists related to nutrition management; and so forth. It is a multidisciplinary approach, and advanced practice nurses play a key role. Through their education curriculum, these professionals have specialized knowledge and skills and are trained in a holistic approach to practice management.

Q. *Does a staff member act as a central point of contact for the breast survivorship program? Is there a central person who coordinates the survivorship service? Are the services coordinated individually for each patient?*

A. Zandstra. As the patient is transitioned to the survivorship program we conduct a review of her health history. Based on this history, she is stratified into either the high-risk breast survivorship group or the low-risk group and then will be scheduled accordingly.

Q. *Who coordinates that activity?*

A. Zandstra. The first step in the process occurs when the patient is identified in the oncology clinic as being a possible candidate for transition to survivorship care. The patient is identified through our institutional database (tumor registry and other enterprise databases), and it's noted on the provider's clinic schedule. When the provider sees that patient in the oncology breast center, the provider then makes the decision about whether this patient is appropriate to transition to the survivorship clinic.

So the short answer is that it is the primary oncologist along with the patient deciding the timing to transition to survivorship care. In doing so, survivorship is presented to the patient as a graduation—*You are doing so well, you are moving from cancer care to survivorship. You are ready to move to the next phase of care.*

This move is made with the acknowledgment and recognition that if any problems arise, the oncologist is always standing ready to take the patient back. Our goal is that patients are seen expeditiously should a problem arise.

Our survivorship program is a formal mechanism to acknowledge that the patient is entering a transition phase, but at the same time, making clear that this move is not just a “hand off.” Patients understand that this step is endorsed by the oncologist as the type of care the patient needs next, and that the communication lines and care lines are not severed.

Patients who are transitioning to the survivorship program are then stratified into low-risk or high-risk groups. A breast leadership group with multidisciplinary representatives has helped to lay out the criteria and the guidelines we use to categorize the patients into that low-risk or high-risk group. The medical director of our breast survivorship program primarily does the stratification assessment. In her absence, Dr. Bevers co-leads risk stratification.

Patients are then scheduled appropriately so when they return—and typically that will be between six months and one year—they are introduced to the survivorship program. That visit includes an introduction to their new provider and a booklet about survivorship, as well as a flyer about other survivorship resources that are available at M.D. Anderson. Patients are then actively involved in the development of the Passport Plan or validation of information that has already been entered into the Passport Plan, and oriented to the approach of this phase of care, which is more of a wellness approach as opposed to a disease approach. For patients, the message is that we are not just focusing on your breast cancer. Of course we will be looking for any problems related directly to that, such as recurrence, but we

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—Dr. Bevers

are also going to look at other aspects of your health. And we discuss those other domains with the patient.

Q. *So at this one-year follow-up visit, what provider is seeing patients in the breast cancer survivorship clinic?*

A. Zandstra. Patients are seeing a mid-level provider or a prevention physician if they are in the low-risk group. Patients in the high-risk group are seen by a breast medical oncologist or a nurse practitioner from the breast medical oncology department.

Q. *Do you have dedicated FTEs that staff the breast cancer survivorship clinic? Or is it a shared job situation in which staff are part-time to the survivorship clinic?*

A. Zandstra. The latter. For the high-risk patient group, the breast medical oncologist dedicates part of her time to patients that are newly diagnosed in active treatment and the survivorship program. The same is true for the advanced practice nurse model. These advanced practice nurses will follow their patients who are survivors down to the prevention center, but they also have days of the week where they are working in the breast center with newly diagnosed patients on active treatment.

Q. *Who heads the breast cancer survivorship clinic?*

A. Zandstra. Our medical director is Dr. P.K. Morrow. Additionally, we have a steering team of multidisciplinary members, including a radiation oncologist, medical oncologist, surgical oncologist, prevention specialist, and representatives from radiology, reconstructive surgery, and hospital administration. The steering team meets monthly or more frequently if there are specific issues. For example, an issue came up related to bone health recommendations. We then had additional meetings that included an advanced practice nurse with specialty knowledge in bone health along with an endocrinologist and a prevention specialist.

We also have a standing provider education meeting twice a month in the Prevention Center, and once a month some segment of the meeting will focus on a survivorship aspect. We usually make it a nurse and provider meeting. We include the clinical nurses too because they are part of the team.

Q. *How many patients are currently involved in the breast cancer survivorship clinic?*

A. Zandstra. We estimate that in our clinical programs we are currently seeing (active patients) 20,000 long-term survivors. Twenty-six percent of those are survivors of

breast cancer. We estimate that our survivor population will grow by seven to nine percent per year.


Q. *Lessons learned that you can share?*

A. Zandstra. I think one lesson we have learned in developing our survivorship initiative here at M.D. Anderson is that we actually had most of the components for the survivorship program in place. However, they were not coordinated or applied consistently for our survivorship population, and the patients were not aware of the different components that were available. For example, we have sexual health services, but it was not something that was uniformly assessed. Survivors are very grateful to be alive and are reluctant to bring up issues they have related to sexual functioning. Much of our work has been bringing resources that are in place to a formalized process and developing communication tools for the patients and providers.

I think mid-level providers, specifically advanced practice nurses, are key patient educators that empower survivors' decision making, raising awareness of survivorship issues and resources available to the individual. We want to provide cancer survivors a comprehensive plan of care that includes educating and counseling them on all the risks and benefits.

Q. *So one message that is transferable to community-based cancer programs is to look at the services they already provide, think about those resources, and draw them together in a distinct way so that patients understand that these cancer survivorship resources are available.*

A. Zandstra. With the special understanding that most community cancer centers will need to make minor tweaks within their programs to make sure that the survivorship focus is embraced by providers and patients.

A. Dr. Bevers. You do not have to be the provider of all survivorship services. I receive calls weekly that say, "We don't have any money or resources for survivorship services." Community cancer centers do not need to provide all of these services. If a program organizes care so that it's consistently addressing survivorship issues with patients and then making community resources available to patients, then cancer survivors will be empowered. It's all focused around the patient. Survivorship care is a wellness model not a disease-focus model 

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