



Winship at the

Developing a community-based program for cancer survivors and caregivers

I have been a nurse practitioner for almost 30 years and a nurse for almost 44 years. I have taken care of cancer patients across the continuum beginning with diagnosis and treatment and transitioning to survivorship and/or hospice. As a family nurse practitioner, I have always viewed my patients as members of a family system and this was never more apparent to me than when I transitioned into cancer survivorship care. Recognizing the role that patients and their families (and families can be defined broadly—the spouse, the child, the grandchild, the neighbor, the church community, or the wider community) play in cancer survivorship is the mantra that guides what I do on a daily basis.

When I first took over the cancer survivorship program at Winship Cancer Institute in 2011, I thought I would spend most of my time on symptom management and palliative care (see “Essential Elements of Survivorship, page 51). I was mistaken. Instead, I spent a good portion of my time and resources on health

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education. For example, one 73-year-old patient came into our survivorship clinic 10 years after his cancer diagnosis. When I asked him the date of his last colonoscopy, the patient said that he’d never had a colonoscopy. He’d always assumed that he would die of his lung cancer, so he didn’t see the need to get a colonoscopy. Of

course, I made the patient a colonoscopy appointment immediately. The last outcome I want is for a patient to survive one type of cancer and then develop a second cancer that can be prevented through a screening test. Heart disease is another area where I spend a lot of time educating cancer survivors. I take a family history of not only cancer but any major causes of death or illness, including heart disease. I work closely with the Emory Cardiology Department, and we hope to establish a formal cardio-oncology program in the near future. Cancer survivorship is not just about cancer—it involves all forms of wellness education.

Getting Started

One of the challenges with developing and implementing a cancer survivorship program is that you must often start from the ground up. While survivorship programs do not all look the same, they must all address common questions:

- What kind of a survivorship care model is the best for the program (i.e., community-based shared care, academic-based comprehensive program, nurse practitioner-led shared care, multidisciplinary programs for high-risk populations)?¹
- When should survivorship care begin?
- Who should coordinate survivorship care?
- What services should survivorship care include?
- Where should survivorship care be given?

There are also common factors to consider before implementing a cancer survivorship program.

- Setting.
- Organizational structure, key stakeholders, and program champions.
- Staffing considerations. Which providers will staff the survivorship clinic and what will their responsibilities be?
- Payment considerations. Certain providers can bill for

WHY SURVIVORSHIP SERVICES?

The oncology community, as a whole, has done a phenomenal job getting patients to the point of survivorship. But when active treatment ends, many patients feel like they've been "dropped" by their oncology providers. At this stage, cancer survivors face the question: "What do I do now?" And they often say: "Give me something to do that I can control." Throughout their cancer journey, survivors lose much of their control. When active treatment is over, survivors want and need to get some of that control back. A comprehensive survivorship program can help do just that.



In addition, cancer survivors often face significant physical and psychosocial issues (Table 1, right), as well as practical and financial challenges. Some may have difficulty working due to the physical and/or emotional after effects of their cancer treatment. Often, these survivors are considered disabled; yet they are capable of and want to work if they have the tools and resources to help. All cancer survivors deal with financial stressors, such as lost wage earnings and high co-payments and deductibles. Right now, as a whole, the oncology community is not doing a great job addressing these practical and financial issues. Again, a comprehensive survivorship program can help in these efforts.

Table 1. Issues that Can Affect Cancer Survivors Post-Treatment

| Physical Issues | Psychosocial Issues |
|-------------------------------------|---------------------|
| Osteonecrosis | Body image changes |
| Fatigue | Sexuality changes |
| Cataracts | Insomnia |
| Early menopause | Depression |
| Infertility | Chronic fatigue |
| Heart disease | Anger |
| Lung disease | Anxiety |
| Increased risk of secondary cancers | Fear of recurrence |
| Cavities and tooth decay | |
| Muscle weakness | |
| Bone and joint problems | |
| Hearing Loss | |
| Osteoporosis | |
| Problems with memory | |
| Pain | |
| Intestinal problems | |
| Dysphagia | |
| Stomatitis | |
| Xerostomia | |
| Hypothyroidism | |
| Stroke | |
| Pituitary dysfunction. | |

survivorship services. For example, nurse practitioners and physician assistants can bill incident-to a physician or independently as defined by insurance carriers when they see patients in a clinic and provide services covered. Will a fee-for-service model be used? If so, how will the program provide survivorship care for patients who cannot afford to pay for services?

- Patient characteristics, such as age, race and ethnicity, cancer type, stage of disease, and other risk-stratification issues.
- The number and type of survivors being served.
- The available healthcare providers, services, and resources.

- Patient population risk of recurrence and level of symptoms following cancer treatment.
- Patient preference regarding the type and source of survivorship care. Do patients want to come back to the cancer program for a survivorship visit after active treatment is completed? Some patients would rather see their primary care provider or oncologist.

No matter the model, the survivorship program should 1) have a positive impact on morbidity, mortality, and quality of life, 2) be able to be implemented across a variety of settings, and 3) be



A two-time survivor of head and neck cancer, Barry exercises under the guidance of his wellness coach, Leila, to combat the de-conditioning he experienced after treatment.

supported by an evidence base or—when an evidence base does not exist—consideration of the express needs of the cancer survivors the program seeks to serve.

Winship Wellness for Living

In 2011 Winship Cancer Institute implemented its *Winship Wellness for Living* program to help patients and their families move from cancer diagnosis, through treatment, and beyond. The program is aptly named because it is not just about surviving—it’s about living and enjoying the best quality of life possible in whatever time patients have. The survivorship model for *Winship Wellness for Living* is evidence-based, providing follow-up care that aligns with Winship’s academic model and improving care coordination with primary care providers (PCPs), as well as with patient preferences and lifestyle. Our survivorship program conducts data collection on measurable outcomes, including:

- The number of referrals to the cancer survivorship program
- The number of patients seen, including data on how survivorship services have positively impacted referring providers’ ability to see more newly diagnosed cancers and fewer follow-ups
- Health outcomes
- Compliance with follow-up care plan
- Self-reported patient satisfaction.

The survivorship program provides education, social support, and medical care for patients and families within the clinical environment and within our local community.

Winship for Wellness has a survivorship clinic visit that is integrated into a long-term survivorship plan using a “shared-care” or “blended” delivery model where survivorship staff works directly with oncologists and primary care providers. The survivorship clinic is held in one of Winship’s four clinical sites in the greater Atlanta area. The survivorship clinic is staffed by a nurse practitioner or physician assistant, as we have found this best meets the needs of the unique patient population served in our academic cancer center. Physicians, physician assistants, dietitians, social workers, and chaplains round out the *Winship Wellness for Living* survivorship care team.

The survivorship team conducts community outreach on topics related to cancer survivorship and prevention, and is heavily involved in survivorship-related research activities.

A Unique Gift

After their daughter was diagnosed and treated for breast cancer in her 20s, the Glenn family established the Glenn Family Fund at Winship Cancer Institute, donating a tremendous amount of money towards breast cancer research. In 2010 the family requested that a small portion of that grant money be used to develop and implement an exercise program for breast cancer

survivors. In considering how best to use this unique gift to the benefit of survivors, we had to assess whether providing an onsite exercise facility—in addition to our comprehensive *Winship Wellness for Living* survivorship program—made sense.

One practical consideration was geographical convenience. Winship Cancer Institute is located close to downtown Atlanta and is in the center of a daily traffic nightmare. Many area cancer survivors do not live in Atlanta. They reside in the surrounding communities, such as Woodstock, Canton, and Newnan. Our survivors expressed that they were not willing to travel to Atlanta for any additional services. So, while patients will come into Atlanta for cancer treatment, they are not going to come into Atlanta to exercise. We knew that any exercise facility had to be close to where our cancer survivors lived. In addition to these geographical challenges, including parking issues, childcare also presented a challenge.

Clearly an onsite exercise facility was not the answer. But the solution was right in our backyard.

Winship at the Y

Winship at the Y—a special program within Winship Cancer Institute’s larger cancer survivorship program, *Winship Wellness for Living*—received a 2013 ACCC Innovator Award.

Winship at the Y is a relatively simple program that can be easily replicated in other communities. It is a formal collaboration (with written letters of agreement) between Winship Cancer Institute and the YMCA of Metro Atlanta, which allows us to reach cancer patients and cancer survivors at home and in their own communities.

When I first reached out to the YMCA about a potential partnership, I fortuitously found that the YMCA already had a program in place called THE COACH APPROACH®, an exercise support process that includes goal setting, overcoming obstacles, and ongoing support. Developed by Jim Annesi, PhD, FAAHB, director of wellness advancement at the YMCA of Metro Atlanta, THE COACH APPROACH is an evidence-based, customized, and comprehensive system of support. While the program had not yet been implemented specifically with cancer patients, it had been applied in work related to disparities and obesity.

The YMCA also had a program through which it could track members, how often they come in, and what services they use or what activities they participate in. (We asked our cancer survivors to participate in that program during their trial membership.)

Another bonus—the YMCA of Metro Atlanta had 18 locations throughout our community.

Our Clinical Trial

Using the Glenn Family grant, in June of 2012 we initiated a clinical trial to examine the effects of physical activity on cancer survivors over a six-month period from 2012–2013. The clinical



A participant in Winship’s exercise study, Ellen works out on the treadmill while her wellness coach, Leila, observes.

trial aimed to identify the:

1. Feasibility of a coach-assisted and community-based exercise intervention targeting breast cancer survivors.
2. Psychological, social, and biological effects of an exercise intervention targeting breast cancer survivors, who have been shown to have high rates of depression, fatigue, and other issues affecting quality of life.
3. Effectiveness of an exercise program for breast cancer survivors for improving physical activity.

The clinical trial enrolled 50 breast cancer survivors from the Winship Cancer Institute into THE COACH APPROACH program. Again with funds from the Glenn Family grant, we paid for all 50 study participants to receive a six-month trial membership at one of 18 YMCA locations in metropolitan Atlanta.

continued on page 52



Winship Cancer Institute's Survivorship Team, pictured here in 2014.

continued from page 50

Before enrolling patients, in my role as Winship's survivorship program director, I went to each location and presented an education program to the wellness coaches on cancer survivorship. I oriented these coaches to what it would be like to work with cancer survivors. Today, this education on cancer survivorship is part of the annual training required for all wellness coaches.

Although we have not yet formally analyzed study data, I would estimate that about 50 percent of the participants on the breast cancer study (or about 25 cancer survivors) took advantage of the YMCA membership and made lifestyle changes by extending their YMCA membership, enrolling at another facility, or continuing to exercise on their own. Publication of the results of the study will be released sometime in early fall 2014.

Growing the Program

Based on the success of the initial clinical trial, we expanded the program to all 18 YMCA locations and began to actively market it in our community. For example, every location now displays

a *Winship at the Y* banner. Because my contact information is included on these banners, I receive a number of phone calls from people who are not patients at Winship Cancer Institute, but who are interested in participating in the program. After obtaining their basic information and telling them to let their physician know they are enrolling in the exercise program, I will refer these individuals to the YMCA of their choice. *Winship at the Y* participants receive a 20 percent referral reduction on YMCA membership. To date, I have referred more than 400 people to the *Winship at the Y* program, the majority of these referrals are Winship patients, but many are from the wider community.

When a cancer survivor is referred into the program, I send an email informing the wellness coach who then contacts the patient to come in to the YMCA for a consult. I do not provide any additional information to the YMCA other than the contact information of the cancer survivor being referred into the program. I do not tell the wellness coaches that the patient has breast cancer or head and neck cancer. When I have a very de-conditioned patient, like some of the head and neck patients after their combined chemo-

therapy and radiation, I may suggest in the email that the wellness coach “start slow” with this particular cancer survivor. I do not share details about the patient’s condition or symptoms. Patients are free to reveal this to the coach at the time of their first visit.

Implementation Tips

One factor that has contributed to the success of our partnership is the fact that the YMCA is a non-profit entity—similar to Winship Cancer Institute and many other ACCC member programs. Cancer treatment can take a big toll on the finances of a

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family. The practical issues of treatment and survivorship can leave a patient and family financially devastated and the last expense they can think of adding is a gym membership. It doesn’t happen often, but the YMCA has been very gracious and able to extend scholarships to many of our cancer survivors. For-profit facilities might not be so generous.

Any cancer program can replicate our success with *Wellness for Living* and specifically, *Winship at the Y*. Here are some tips to help you get started:

- Solicit the input of your cancer survivors and their caregivers.
- Engage the same survivors and caregivers in your vision for the program.
- Start with an operating committee and then consider adding a community advisory group. We used a steering committee that met weekly for many, many months and now meets quarterly.
- Explore the most cost-effective way of delivering survivorship care and programs.
- Set some short- and long-term goals with realistic timelines.
- Look to resources that are already in your community (gyms, YMCAs, church groups, etc.). Some churches have great facilities for their members. Explore all possible partnerships, if you don’t have a YMCA close by.
- Look for opportunities for financial support (if needed) and manage your cost expectations. Do not assume that this type of survivorship program will be resource and time intensive. We were able to get *Winship at the Y* up and


running with the initial seed money from the Glenn family. The only resource needed now is my time, which is paid for under the umbrella of our larger survivorship program.

- Start small and be willing to change direction if your first idea doesn’t work. I have found with cancer survivorship, the program champion must often act as a change agent.

Today, Winship Cancer Institute has become a true partner with the YMCA of Metro Atlanta. Our connection through *Winship at the Y* led us to partner on various cancer awareness initiatives. Last summer we provided more than 1,000 summer campers with “Sun Safety Awareness” programs with the assistance of summer interns at Winship and at the YMCA. This summer we will partner with Project Open Hand and their *Good Measure Meals Program* to reach even more summer campers with activities and snacks that stress eating for wellness and cancer prevention through our *Winship at the Y Cooking with Color for Cancer Prevention* program.

Going Forward

The oncology community does not know everything it needs to know about cancer survivorship. More evidence-based research is needed in survivorship care planning and implementation.

With increasing numbers of cancer survivors, the oncology community will need to develop survivorship programs that address surveillance and screening needs, as well as the monitoring of long-term treatment effects. These survivorship programs do not have to be complex or expensive. Survivorship models will look different, depending on the practice setting, resources available, and the patient population. After effects of cancer therapy may be life-long and vary greatly with individuals and their specific cancers and treatments. Many cancers are now being treated as chronic conditions. So the question really becomes: how do you help these patients live with their chronic conditions? 

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