

# The Embedded Nurse Navigator Model





## *A novel approach to providing survivorship care in a community cancer center*

### **In Brief**

There are more than 14 million cancer survivors in the United States, a number that is expected to grow exponentially due to an aging population and improved methods for early detection and treatment.<sup>1</sup> In an effort to provide survivorship care to these patients, many cancer programs have implemented a survivorship clinic model, typically led by a nurse practitioner with physician oversight. This approach to survivorship care is not without its limitations, however. This article describes another approach—the embedded nurse navigator model—developed at the Helen F. Graham Cancer Center and Research Institute at Christiana Care in Newark, Del.

Cancer survivors often experience physical and psychosocial long-term and late effects after treatment ends.<sup>2</sup> Long-term effects include fatigue, peripheral neuropathy, pain, and cognitive changes that may manifest during treatment and continue well beyond the end of treatment.<sup>3</sup> Late effects of therapy, such as cardiac dysfunction, pulmonary fibrosis, lymphedema, and secondary malignancies, can occur as late as 20 years post-treatment.<sup>3</sup> As newer chemotherapeutic agents are integrated into treatment, unanticipated side effects may emerge.

In addition to physical challenges, studies have shown an increased risk of psychosocial distress in cancer survivors who:<sup>4,5</sup>

- Are younger
- Have inadequate socioeconomic resources
- Have limited access to care
- Have communication barriers
- Exhibit underlying co-morbid illness
- Have a history of psychiatric disorders.

Psychosocial adjustments to life after cancer can include difficulty concentrating, anxiety, insomnia related to these issues, depression, and post traumatic stress disorder.<sup>4,5</sup> In 2006 Vachon and colleagues reported that even though approximately one-third of individuals with cancer experience some psychosocial distress, only about 10 percent of these individuals receive therapy to address their distress.<sup>4</sup> In a survey of more than 3,000 cancer survivors, 98 percent of respondents indicated that they experienced continued concerns as a result of cancer treatment.<sup>5</sup> Of these same respondents, 75 percent indicated a fear of recurrence, followed by depression and/or sadness (65 percent), while 53 percent reported low energy, sleep disturbance, and difficulty concentrating.<sup>5</sup> In 2013 Ness and colleagues identified these top five concerns of cancer survivors:<sup>2</sup>

- Fear of recurrence
- Fatigue
- Living with uncertainty
- Managing stress
- Sleep disturbance.

**Table 1. Survivorship Care Models & Features**

FEATURES	MODEL			
	EMBEDDED	CONSULTATIVE	MULTI-DISCIPLINARY CLINIC	INTEGRATED CARE
Individualized and personalized care and resources	✓	✓	✓	✓
On-site consultation at time of scheduled appointments to avoid travel to multiple locations at different times	✓			
Point of contact for questions or concerns post-treatment	✓			✓
Impromptu referrals	✓			
Comprehensive physical examination performed by a mid-level provider of the survivor's primary oncology team		✓	✓	✓
Multiple providers are available and provide follow-up care at the same visit; usually based on diagnosis			✓	

Cancer survivors also identified social isolation, intimacy issues, spiritual concerns, alterations in body image, and sexuality as causes of distress.<sup>2,6</sup>

The American Society of Clinical Oncology (ASCO) describes the stages of survivorship as acute, extended, and permanent.<sup>7</sup> The acute phase describes the time frame from diagnosis through initial treatment. The extended time frame is the period immediately after treatment is completed. The permanent phase is a longer time frame—usually measured in years.<sup>7</sup>

### Survivorship Care Models & Features

As there is no “one size fits all” model of delivering survivorship care, the oncology community has developed multiple models for survivorship programs. These models include a consultative model, a multidisciplinary clinic model, and an integrated care model (see Table 1, above). Adult follow-up programs traditionally focus on a medical model. In this model, cancer survivors are usually seen by a mid-level provider from their primary oncology team who performs a physical examination and assesses patients for long-term and late effects of treatment. The provider makes

referrals for additional services to programs within the facility or to resources in the community.<sup>8</sup>

A consultative model employs a one-time comprehensive visit for cancer survivors at the end of treatment, which reviews the therapy received and recommendations for health promotion and surveillance.<sup>8,9</sup> Additional consultations with ancillary support services, such as rehabilitation and psychosocial counseling, can be recommended and the ongoing care continues to be provided by the cancer survivor’s oncology team.<sup>8,9</sup>

In a multidisciplinary clinic model, multiple providers are available during the cancer survivor’s scheduled appointment time. This model was the first developed, and is still used today, in pediatric survivorship programs.<sup>8</sup> Because this model is usually costly and resource intensive, it may not be feasible for adult survivorship programs.

In an integrated care model, cancer survivors remain under the care of their primary oncology team; however, care is usually delivered by a mid-level provider from the cancer care team. Care may then be transitioned to the cancer survivors’ primary care providers at a specific interval.<sup>8</sup> To ensure a successful transition, primary care providers must be given the necessary information

to provide ongoing surveillance for long-term and late effects of cancer treatment.

With each of these models, however, cancer survivors will need an additional post-treatment appointment to review long-term and late effects of treatment, health promotion, and surveillance recommendations.

### Developing a New Model of Survivorship Care

After publication of the 2006 Institute of Medicine (IOM) report highlighting the unmet needs of cancer survivors,<sup>10</sup> the Helen F. Graham Cancer Center and Research Institute conducted a baseline assessment of the physical and psychosocial needs of cancer survivors and providers in the community.<sup>11</sup> This assessment revealed several key points.

First, cancer survivors wanted more individualized education, versus a class or seminar format, on the potential physical and psychosocial long-term and late effects of the treatment that they received.

Second, cancer survivors indicated that it was difficult to know which healthcare providers they should contact in times of need; therefore, many did not seek assistance. This finding highlighted the importance of screening cancer survivors for distress. Our team could not assume that cancer survivors would tell us the issues that they face. Instead, our team believed that we needed a structured and standardized distress assessment.

Cancer survivors also expressed feeling disconnected from their treatment team after active treatment was completed.

Finally, cancer survivors expressed a desire to have follow-up appointments scheduled conveniently in the same location, thus avoiding travel to multiple facilities at different times.<sup>11</sup>

From our cancer survivors, our team has learned that survivorship is not a linear process, but a journey. Healthcare providers who deliver care to cancer survivors should provide consistent, continuous education and evaluation to address the ongoing challenges these individuals face over time. Based on these findings, our team revised our survivorship services.

### The “Embedded Model”

Based on our baseline assessment results, our team piloted a program in the Radiation Oncology Department where the nurses met with cancer survivors during their final week of treatment to discuss the challenges of life post treatment. In addition, nurses provided cancer survivors with written educational materials and information on available support services.

Next, to build our survivor-centered approach to care and with support from the NCI Community Cancer Centers Program (NCCCP), the Helen F. Graham Cancer Center and Research Institute hired a full-time survivorship nurse navigator dedicated to meeting the needs of our cancer survivors. The survivorship nurse navigator position is located within the Radiation Oncology

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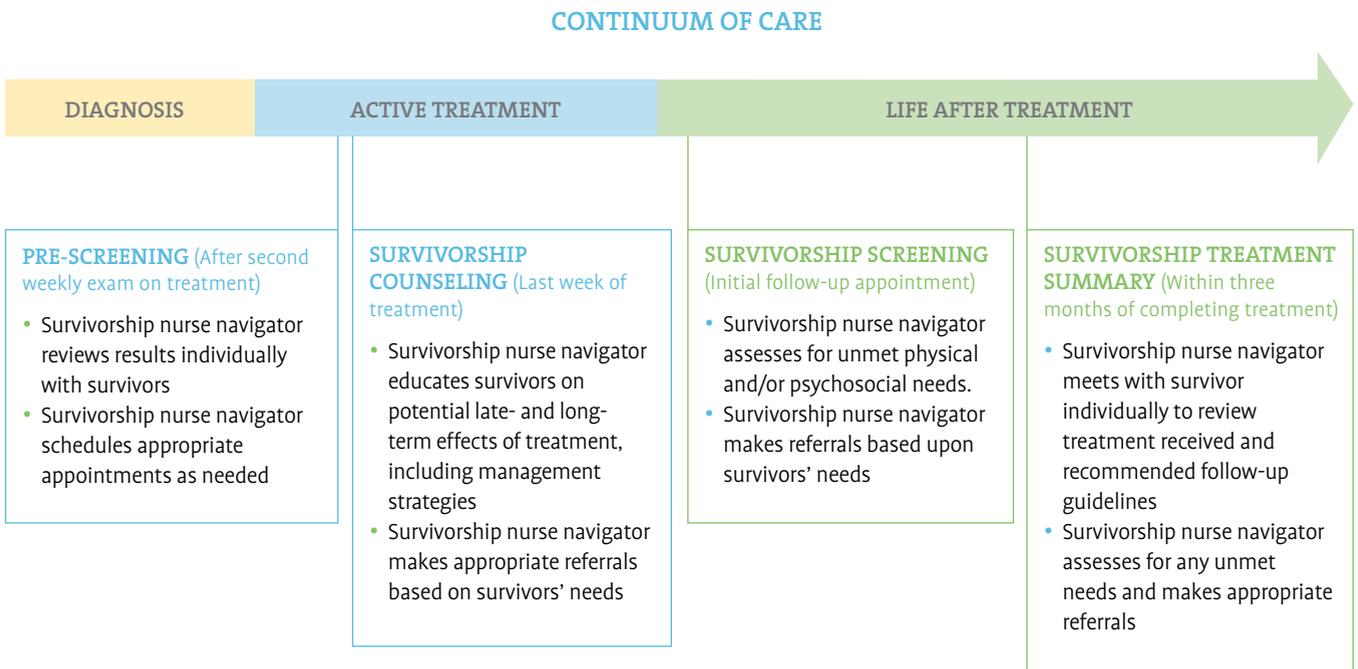
Department since radiation therapy tends to be the end point for the most common types of cancers that we treat (i.e., breast and prostate). Initially, the survivorship nurse navigator met with breast cancer survivors during their last week of treatment; however, feedback from cancer survivors and staff indicated that it would be more beneficial for survivors to meet with the survivorship nurse navigator earlier in their radiation treatment to establish a relationship and provide timely intervention.

In an effort to establish a consistent way to triage those who may need additional support, cancer survivors complete a psychosocial distress screening tool two weeks after beginning radiation therapy (see Figure 1, page 40). This process aligns with the 2012 Commission on Cancer (CoC) standard 3.2, which mandates that cancer programs screen their survivors for psychosocial distress. Cancer survivors who screen positive for psychosocial distress or request more information regarding programs and services are seen by the survivorship nurse navigator at the time of their established daily radiation treatment. Interestingly, it has been our experience that screening for psychological distress also predicts which cancer survivors will tend to struggle with physical late and long-term effects of treatment. In other words, if patients test positive for distress, they are more likely to struggle with long-term effects of treatment.

Currently, the survivorship nurse navigator meets individually with breast and prostate cancer survivors as they near the end of treatment, counsels them on the potential long-term physical and psychosocial effects that may occur, and suggests management strategies. During this meeting, cancer survivors receive written information about support services and programs available within the Helen F. Graham Cancer Center and Research Institute, as well as resources within the community.

Because the survivorship nurse navigator is embedded in the Radiation Oncology Department, she is often asked to meet with

**Figure 1. Timeline of Survivorship Treatment**



cancer survivors who are receiving treatment for other cancers, such as lymphoma, lung, head and neck, and colorectal cancer. Although these cancer survivors may continue with other treatment once they complete radiation therapy, they benefit from the early intervention and support that the survivorship nurse navigator provides. It also allows the navigator to introduce the concept of survivorship and review the survivorship program services that are available to these patients.

Unless contacted earlier by the patient, the survivorship nurse navigator meets with cancer survivors at their established first follow-up appointment with the radiation oncologist. Having the navigator meeting during the same visit provides the convenient scheduling patients cited in our baseline assessment. During this visit, cancer survivors complete a quality of life (QOL) questionnaire that assesses how they are coping with the most common physical and psychosocial side effects of cancer treatment, including fatigue, cognitive changes, body image concerns, anxiety, and fear of recurrence. Based on their individual responses to the follow-up QOL survey, cancer survivors may be referred to additional support services and programs, such as:

- A support group
- Individual counseling with a health psychologist
- A mind/body/spirit program (i.e., yoga and/or meditation)
- Social work
- Cancer rehabilitation
- Consultation with a dietitian.

At this appointment, cancer survivors are offered the opportunity to receive a treatment summary and survivorship care plan. If the patient opts to have these tools created, the survivorship nurse navigator will prepare both documents and present them to the patient at a face-to-face follow-up visit. The survivorship care plan provides a synopsis of the treatment that patients received as a result of their cancer diagnosis along with evidence-based follow-up recommendations.

For those cancer survivors interested in receiving a survivorship care plan, the survivorship nurse navigator obtains written consent from cancer survivors for release of medical information to access their medical records. When the survivorship care plan is completed, the survivorship nurse navigator contacts patients to schedule an appointment to review their survivorship care plan. The survivorship nurse navigator uses this individual appointment as an opportunity to:

1. Review evidence-based follow-up guidelines
2. Assess physical and psychological concerns
3. Educate cancer survivors on the importance of continued surveillance and health promotion.

Cancer survivors receive a copy of their survivorship care plan and are encouraged to share this information with their primary care provider and other specialists involved in their care. A copy of the survivorship care plan is also scanned into the patient's

electronic health record (EHR) for review by other members of his or her healthcare team.

Although the Commission on Cancer sets the survivorship care plan as a standard and several cancer advocacy groups recommend that cancer survivors receive a summary of the treatment that they received, we have found that more than half of patients decline the summary when it is offered.<sup>12</sup> Some cancer survivors ask, “Why do I need this when my doctor has this information?” Others state, “I don’t want to be reminded of what I went through.” In some instances, cancer survivors have become very emotional upon reviewing the information provided in the summary. Some of our cancer survivors have not returned messages left to schedule an appointment to review their treatment summary; others have received a survivorship care plan, but do not remember having received one. Although we offer treatment summaries and care plans to all of our cancer survivors, it has been our experience that patients can—and often do—decline to receive this information.

### Closing Thoughts

The goal of our survivorship program is to help cancer survivors transition to life after treatment. Since implementing the survivorship nurse navigator role in October 2010, this team member has met individually with more than 1,400 cancer survivors. Patient satisfaction survey results are overwhelmingly positive regarding the role of the survivorship nurse navigator and the information that is provided. Physician and ancillary staff satisfaction survey results reveal that the survivorship nurse navigator role has benefitted their patients. In fact, staff had even requested that a survivorship nurse navigator assist survivors who had completed treatment prior to the program implementation.

The transition from active treatment to survivorship care is now being recognized as a distinct phase of the cancer care continuum.<sup>10</sup> Although payers do not currently reimburse for survivorship services, other cancer programs have addressed this funding issue by obtaining grant support. To optimize the IOM’s triple aim approach to healthcare,<sup>13</sup> the goal of our survivorship program is two-fold:

- To empower survivors to take responsibility for ongoing surveillance and preventive care.
- To foster a more collaborative approach between the survivors’ oncology team and their primary care providers as patients transition their care back to their primary care provider. This includes providing these clinicians with the information and education needed to recognize and manage long-term side effects. 

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*management strategies. Scott Siegel, PhD, is a licensed psychologist and the director of Psychosocial Oncology & Survivorship at the Helen F. Graham Cancer Center & Research Institute within the Christiana Care Health System in Newark, Del.*

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