Helping Cancer Survivors in Transition

Cancer survivors in the U.S. currently number 17 million, with that number expected to climb to 26 million within the next 20 years. As defined by the National Cancer Institute, cancer survivorship care focuses on the health and life of a person following initial treatment through the end of life. It covers the physical, psychosocial, and economic issues of cancer, beyond the diagnosis and initial treatment phases.

Sylvester Survivorship Celebration on August 3, 2019 at Marlins Park.

Sylvester Comprehensive Cancer Center, part of the University of Miami Miller School of Medicine, leads a survivorship program that currently serves more than 750 adult patients. Breast, colorectal and gynecological cancers are among the most common diagnoses.

Frank J. Penedo, Ph.D., professor of psychology and medicine, and associate director for Cancer Survivorship and
Translational Behavioral Sciences, has been interested in cancer survivorship for more than two decades.

“With unprecedented growth in the number of cancer survivors due to advances in early detection and treatment, a major objective is to help them live their best possible lives,” Dr. Penedo said.

Dr. Penedo’s vision for the survivorship program at Sylvester includes:

• Collaboration among clinicians and scientists across multiple disciplines to foster exceptional cancer survivorship care and research

• Implementation of evidence-based, state-of-the-art survivorship care that is informed by the latest research

• Provision of integrated multidisciplinary services across the University of Miami Health System to promote continuity of comprehensive care and avoid fragmentation of services

**Benefits of Cancer Survivorship Care**

A 2005 report from the National Academy of Sciences highlighted the need for coordinated and comprehensive care for patients, following their completion of primary cancer treatment. The report stated that care should effectively addresses physical, psychosocial and financial concerns. It also recognized that after treatment, many survivors were “lost in transition.” Although their lives were forever changed by their cancer experience, there were few services tailored to meet their special needs and guide them through the transition to follow-up care, management of treatment...
related side effects, and surveillance for recurrences or secondary cancers.

Since then, Sylvester and other cancer centers across the country have developed comprehensive programs to address the physical, social, emotional and economic issues impacting patients and their loved ones as they transition from initial treatment.

“It is a time where they need the most direction. At Sylvester, our physicians and staff understand the importance of this period in a patient’s journey. Our cancer survivorship program is tailored to meet the needs of each individual patient and keep them connected to Sylvester and the resources we provide to support them during this time,” explained Jessica MacIntyre, APRN, executive director of clinical operations at Sylvester.

Frank J. Penedo, Ph.D.

Dr. Penedo cited a number of issues that may create stress and anxiety for patients, both during and after treatment: symptom burden like fatigue, treatment- and cancer-related side effects, fear of cancer recurrence, strain on interpersonal relationships, and intimacy issues, especially with
reproductive cancers.

For 71-year-old Donna Rick, key interventions through the Sylvester survivorship program provided significant improvements in her life. Rick was diagnosed with mucosal cancer in 2018. She had surgery to remove her septum, part of her cheekbone, and 33 small tumors in her neck. Following surgery, she had radiation therapy for a month and began receiving monthly immunotherapy in June 2019.

Side effects from Rick’s treatments included dry mouth and damage to her taste buds. With little interest in eating, she lost more than 80 pounds over several months.

Through the survivorship program, Rick was referred to a dietitian. She was thrilled to learn through the dietitian about a special product made from fruit that makes food taste better.

“You eat a wafer, and it enhances your taste buds,” Rick said. Since then, she is eating more, and her weight loss has leveled off.

A nurse practitioner at Sylvester gave Rick a pamphlet on survivorship, plus she received a calendar of events with activities for cancer patients. Her cancer is rare, but she found a Sylvester-sponsored group near her home in Deerfield Beach that invites people with all types of cancer to come together to talk about their experiences.

To make cancer care for Rick and other patients as seamless as possible, multiple disciplines will come together monthly to coordinate programmatic efforts for the care of cancer
survivors.

Disciplines include psychology, psychiatry, physical medicine and rehabilitation, physical therapy, nutrition, palliative care, geriatrics and others.

Dr. Penedo said, “We are also in the process of creating specialized interdisciplinary clinics that provide evidence-based care, including lifestyle and wellness needs, to address issues such as diabetes and obesity, geriatric oncology, physical rehabilitation, cardio-oncology and others in close collaborations with multiple disciplines that address unique needs of our survivors. We will also be expanding other existing programs that are well aligned with our survivorship care vision, such as the Stem Cell Survivorship Clinic.”

The clinic provides comprehensive evaluation, treatment and follow up for cancer recurrence, new or subsequent cancers, and intervention for other illnesses caused by cancer and its treatment with coordination of care among health care providers.

Research Drives Care Improvements
Since Dr. Penedo’s arrival in 2018, Sylvester has expanded its translational behavioral research in cancer survivorship, including systematic screening of symptoms and toxicities, and coordination with supportive oncology programs such as psychology and nutrition services that can assist patients with managing challenges of their survivorship journey.

“Our survivorship clinical programs also provide opportunities for research that, in turn, will inform and improve clinical care,” Dr. Penedo said. “It’s kind of like a feedback loop
where we can evaluate the added value of survivorship care to patient-reported outcomes, such as quality of life and treatment satisfaction, while optimizing efficiencies within care delivery.”

Examples of new programs delivering improvements are:

- **Patient-Reported Outcomes (PROs).** A new program being piloted with gynecologic oncology patients seeks patient input before a scheduled visit. Patients complete assessments on a smartphone or computer via UChart, the patient health management portal. This program, called UHealth PRO (Patient-Reported Outcomes), allows the cancer team to track and triage patients as they complete the assessment and report issues including emotional distress; pain, fatigue or other physical symptoms; nutritional needs; and practical needs, such as assistance with transportation or finances. An English version of the assessment was rolled out in fall 2019; a Spanish version will follow in January 2020.

- **Patient Portal Tool Box.** Using technology to assess symptoms and needs and to identify patients who would benefit from psychosocial interventions such as those offered by Sylvester’s supportive oncology services is another focus for the survivorship program. Initiatives are also being developed to provide education and support conveniently to patients using their patient portal. “We want to provide patients with the opportunity to access evidence-based programs that may help them deal with stressors, engage in relaxation techniques, and learn skills to manage their survivorship experience without the added burden of coming for a visit unless it is necessary,” Dr. Penedo explained.
Further, Dr. Penedo and his research team are testing the utility of cultural adaptations that deliver counseling and tools to different ethnic groups in a sensitive and culturally informed manner. “We want to culturally tailor the tool kit to address the unique needs and experiences of our communities,” he explained. “We are currently looking at cultural adaptations of evidence-based treatments for Hispanic prostate and breast cancer survivors. Our hypothesis is that culturally adapted treatments will have better results than standard treatments that do not consider the role of culture, such as extended family and illness perceptions.”

Assessing the Impact
“We know we can improve quality of life, and studies are beginning to show we can improve treatment satisfaction when we have these systems in place,” Dr. Penedo said.

Researchers also will be evaluating whether Sylvester’s survivorship efforts as a whole are having an impact on the health system, such as reducing hospital and urgent care visits, readmission rates and length of stay.

Dr. Penedo continued, “What’s most rewarding is the patient-centeredness of what we do. Patients want to be engaged and active participants in their care. The survivorship services we provide engage and empower patients and their families as active participants in their care and follow-up.”

If you are interested in pursuing survivorship research or advancing clinical care, please contact ICS. To learn more about cancer survivorship research, call 305-243-3329 or email SCCCSurvivorshipResearch@miami.edu.
To learn more about cancer survivorship care, call 305-243-4922 or email SCCCSurvivorship@miami.edu.