Closing the Gap

Developing an AYA Cancer Survivorship Center

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The adolescent and young adult (AYA) cancer survivor population, ages 15 to 39 as defined by the National Cancer Institute,[1] faces many barriers and challenges in its journey from diagnosis to survivorship. For example, AYA cancer survivors experience poorer outcomes[1] and have a lack of access to insurance. This scenario is particularly true in the state of Texas, which has an overall uninsured rate of 25 percent.[2] Other barriers facing AYA cancer survivors include:

- Life challenges and changes during the adolescent and young adult developmental period, such as starting careers or families and making independent medical decisions.
- Incomplete knowledge about cancer treatment and its consequences because of their age at diagnosis.
- A lack of survivorship care plans and treatment summaries. It was not until 2005 that these tools were first recommended by the Institute of Medicine.[3] The American College of Surgeons Commission on Cancer did not require survivorship care plans and treatment summaries until its 2012 accreditation standards.[4]

- Late effect(s) from cancer treatment and the possibility of developing chronic conditions later in life.
- A lack of awareness of the preventive guidelines for secondary cancers.
- A lack of recognition about the importance of educating their current medical team about their history with cancer.

A New Care Paradigm: The Seton Cancer Survivor Center

The Seton Healthcare Family, a not-for-profit healthcare system, provides services for adults in 11 counties of central Texas, and for pediatric patients in 46 counties. The Seton network is comprised of 11 hospitals and numerous ambulatory clinics throughout the service area.

Childhood cancer survivors are seen in the LIVE**STRONG** Childhood Cancer Survivorship Center at Dell Children's Medical Center, part of the Seton Healthcare Family. But as pediatric patients aged into their late 20s and 30s, no formal program existed to transition them into an adult-survivor care setting. Recognizing that adolescents and young adults in central Texas had unmet needs—specifically, access to post-treatment survivorship services, Seton built upon the success of its pediatric program to address this gap and created the Seton Cancer Survivor Center for adolescents and young adults in 2011, with funding from LIVE**STRONG**.

Today, the Seton Cancer Survivor Center cares for post-treatment cancer survivors, ages 18 to 39, residing in our 11-county service area of central Texas—regardless of diagnosis or where the patient received treatment. We chose this age range specifically so that patients under 18 years of age would continue to receive care in a pediatric center.

Staffed by two FTE staff, in addition to a medical director, and with an annual budget of approximately $150,000, the Seton Cancer Survivor Center offers a range of services to address the four components of survivorship: coordination, intervention, surveillance, and prevention. We created a system of support, centering on the AYA patient and a medical home that includes:

- Clinical navigation
- Clinical care
- Provider and patient education.

Clinical Navigation

Clinical navigation is the entry point and foundation for AYA survivors. At the Seton Cancer Survivor Center, an RN clinical nurse navigator focuses on the medical issues related to cancer survivorship. With a signed release of information request, the nurse navigator first obtains medical records from the clinic or hospital where the patient was treated and then develops a written treatment summary and survivorship care plan. Next, the nurse navigator schedules a visit with the patient to review the treatment summary and survivorship care plan and assess for any other needs, including medical care and psychosocial and practical needs. The nurse navigator looks closely for issues that may create barriers for patients in fulfilling their care plans.

At the Seton Cancer Survivor Center, we have developed a shared navigation model with the assistance of LIVE**STRONG**. Our RN nurse navigator provides clinical navigation, and the LIVE**STRONG** Navigation Center in Austin, Tex., helps to address patients' psychosocial and practical needs, such as help with insurance, counseling, and cooking classes, as well as many other services.

Our nurse navigator helps each patient establish care in a medical home for his or her primary care needs, as well as for survivorship screening and surveillance. To provide patient-centered care and choice in medical providers, patients have the option of obtaining survivorship care through the Seton Cancer Survivor Center. If this is not possible—due to lack of insurance coverage—the nurse navigator will provide the survivorship care plan and treatment summary to the patient's primary care physician. The nurse navigator is available to the young adult survivor to coordinate care among specialists, the primary care provider (PCP), and the Seton Cancer Survivor Center.

Clinical Care

AYA survivors scheduled for survivorship care at the Seton Cancer Survivor Center are seen by an internal medicine physician who is well versed in late effects of chemotherapy and

radiation, as well as current surveillance practices. The survivorship clinical program takes place in the physician's private practice, with support from the nurse navigator along with consultation, when needed, from a medical oncologist that treats adult cancer patients or from a pediatric hematologist/oncologist. Care is focused on screenings and surveillance, along with overall health and well-being. Many survivors view this visit as an annual "survivorship check-up"—a time to revisit and update their survivorship plan and to make arrangements for screening and follow-up on other recommendations for a healthy survivorship. For patients who choose to have their survivorship care through their PCP, a copy of their treatment summary and survivorship care plan, along with a matrix of recommended screenings, is sent to the PCP.

Complementing the Seton Cancer Survivor Center care is our connection to the other resources in our system, including the Seton Heart Institute and the Seton Brain and Spine Institute, among others. For example, we are able to connect AYA survivors with Seton cardiologists that have received additional education on chemo- and radiation-related cardiomyopathies, and we are working toward a specific cardio-oncology program.

Education & Training for Providers, Survivors, & Caregivers

Through a grant from the Cancer Prevention and Research Institute of Texas (CPRIT), Seton Cancer Survivor Center developed an educational program, *After Cancer Care Ends Survivorship Starts for Adolescents and Young Adults (ACCESS-AYA)*, to support primary care providers, community nurses, and other healthcare providers who see AYA cancer survivors in their practices. This educational program consists of:

- Online CME and CNE credit options
- Provider seminars
- Brief detailing sessions known as Prompt Evidence Assessment and Review of the Literature Service (PEARLS).

The goal is to reach providers online, in person through traditional seminars, or in person at their practice sites by delivering PEARLS in 15-minute sessions. Because the nurse navigator tracks each patient's PCP, we can generate a list of providers to target our offered educational programming.

In addition to provider education, the ACCESS-AYA program has specific goals to provide education to AYA cancer survivors and their family members and caregivers. We have created a series of "video diaries" through which AYA survivors share their cancer and survivorship experiences. These video diaries are available on the Seton Cancer Survivor Center's website (*www.seton.net/survivorship*). The ACCESS-AYA project provided input and support for the development of an iPhone app, *AYA Healthy Survivorship*, which was developed by Texas A&M School of Rural Public Health CTxCARES program, a CDC-funded cancer control and prevention program. The app allows survivors to assess their health habits, get daily tips, and begin to create a survivorship care plan.

Referrals

Patients are referred to the Seton Cancer Survivor Center from four sources:

1. Transition from the LIVE**STRONG** Survivorship Center at Dell Children's Medical Center
2. Transition from treatment at Shivers Cancer Center at University Medical Center Brackenridge
3. Referrals from community providers
4. Self-referrals.

LIVESTRONG Survivorship Center at Dell Children's Medical Center. Our nurse navigator visits the pediatric center to meet the young adult patient and family to seamlessly transition their care to the Seton Cancer Survivor Center. This introductory meeting allows the nurse navigator to establish rapport and trust with the patient and family, as well as educate them about the services provided by the Seton Cancer Survivor Center. The patient's treatment summary and survivorship care plan—already developed by the pediatric clinic—transfer over to the Seton Cancer Survivor Center.

Shivers Cancer Center at University Medical Center Brackenridge. Shivers Cancer Center, an ambulatory clinic of the University Medical Center Brackenridge and the only indigent cancer care clinic in central Texas, is an additional referral source to the Seton Cancer Survivor Center. As patients complete their active treatment, a health promoter prepares a treatment summary and survivorship care plan, using ASCO care plan templates and the online LIVESTRONG Care Plan, and writes a cover letter to the patient's PCP with specific recommendations for follow-up. The treatment nurse navigator and treating oncologist then review all the materials and sign the care plan and cover letter, respectively; a survivorship transition session is then scheduled with the patient. At this

session, AYA patients meet with their treatment nurse navigator, the health promoter, and the Seton Cancer Survivor Center survivorship nurse navigator. This session is designed to:

- Educate patients and their families about the next phase of their cancer journey and survivorship
- Review the survivorship care plan
- Allow the patient and family to meet the Seton Cancer Survivor Center navigator who will help them from this point on.

Patients Outside of the Seton Healthcare Family. Our third method of enrolling AYA survivors is to reach out to PCPs, specialists, community oncologists, and the community at large to find survivors who have not received a treatment summary and survivorship care plan, and/or are not engaged in any kind of long-term follow-up from their cancer treatment. To do so, we routinely meet with various physician practices, hospital staff, nurses, clinic administrators, and others to educate about the program and share with them how they may refer patients to the Seton Cancer Survivor Center.

Self-Referrals. Currently, a small number of survivors arrive at the Seton Cancer Survivor Center through self-referral or referral from friends or family members who have heard of the program through word-of-mouth, media coverage, or the Seton website. We anticipate the number of self-referrals will grow as we work with more cancer survivors and develop additional programs and public outreach.

In less than one year, we have enrolled 88 patients in navigation services. Close to 80 percent of patients are established with a primary care provider and medical home and our nurse navigator continues to assist others with establishing care.

Among the metrics we monitor are:

- Percent of patients established with a primary care provider and medical home within 12 months of enrolling in navigation (currently 88 percent)
- The percent of patients provided a treatment summary and survivorship care plan within three months of enrolling in navigation (currently at 90 percent)
- The percent of patients that implement a wellness activity within 12 months of enrolling in navigation services (33 percent at 6 months of data collection).

Barriers

One of the biggest challenges we face is recruiting patients who completed treatment years before survivorship centers developed. This population may not have received information on the importance of survivorship—long-term follow-up, screening, and surveillance. Patients may have a mindset that once treatment is completed, they are done with cancer. We strive to overcome this through our community outreach and educational programming to survivors through our ACCESS-AYA program.

Some AYA survivors face a gap in insurance coverage. Those without insurance are concerned about accruing large medical debts, especially since they may have outstanding bills from their treatment. Thanks to the LIVESTRONG grant funding, our nurse navigation services, including the provision of treatment summaries and survivorship care plans, are completely free of charge to survivors. While navigation seeks to reduce or eliminate barriers to care for patients, we want to reduce or eliminate barriers to patients enrolling in the Seton Cancer Survivor Center by informing patients at the start that our navigation services are free of charge.

Keys to Success

Several critical success factors came together to create the Seton Cancer Survivor Center, including:

- A physician interested in providing long-term follow-up care to AYA cancer survivors
- A health system executive leader committed to the continuum of cancer care services
- A provider community that sees the benefits of cancer survivorship services
- An existing infrastructure that allowed adaptation to include survivorship
- The initial grant from LIVESTRONG that allowed the program to get up and running
- The CPRIT grant, which supports provider and patient education.

Our future plans include carrying out a research agenda that includes some short- and long-term research projects in collaboration with The University of Texas at Austin, and with The University of Texas Southwestern Medical Center and Simmons Cancer Center, among others.

We will continue to build on the success of our adolescent and young adult program to offer survivorship services and navigation to patients ages 40 and above, closing the cancer survivorship continuum of care gap in central Texas. OI

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