

Review Article

# Cancer Survivorship Care for Adult Survivors of Childhood Cancer: An Adult Based Model Facilitating Multi-Disciplinary Long-Term Follow-Up Care, Education and Research

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## Abstract

As the number of adult survivors of childhood cancers continues to grow, the challenges of long-term follow-up (LTFU) care escalate. When adult survivors of childhood cancer are followed in a pediatric oncology setting their care can be fragmented, leading to barriers for both providers and patients. To address the need for continued LTFU care as survivors age out of the pediatric medicine arena, the STAR (Survivors Taking Action & Responsibility) Program was established in June of 2001 within an adult oncology setting at the Robert H. Lurie Comprehensive Cancer Center of Northwestern University. The 11-year old program currently has over 320 survivors enrolled (ages 19-60, all diagnosed at 21 years of age or younger). The program's three main foci are (1) comprehensive, long-term follow-up clinical care, (2) patient/family education and (3) research. The STAR team includes a general internal medicine physician, a clinical health psychologist, and an advanced practice nurse with expertise in childhood cancer and late effects from cancer therapy. The program facilitates referrals to specialty care as appropriate. Patient-oriented events allow opportunities for networking, outreach and education to assist patients in becoming autonomous in their comprehensive care and survivorship. The purpose of this article is to share our experiences with the implementation of this program, offer information on how to build a similar model in institutions caring for childhood cancer patients and adult survivors of childhood cancer.

**Keywords:** Pediatrics; Late effects; Survivorship; Cancer care continuum

## Background and Significance

Over the past decade, research in pediatric oncology has found children and adolescents surviving their disease to be 1) at risk for an increasing incidence of chronic medical conditions related to their disease/treatment 25 years after diagnosis and with this incidence increasing over time [1,2], 2) aging out of the pediatric realm of medicine but requiring Long-Term Follow-Up (LTFU) care [3] and 3) transitioning back to community-based providers who may have limited knowledge about specialized LTFU care [4]. When adult survivors of childhood cancer are followed in a pediatric oncology setting their care can be fragmented, leading to barriers for both the providers and the patients [5]. For example, as childhood cancer patients become adults they develop medical issues that are often outside the scope of care for pediatric oncologists and pediatric nurse practitioners (e.g. hyperlipidemia, hypertension, thyroid disorders etc.) [5]. As medical issues arise, survivors may require care from specialists who treat adults with complex medical issues (e.g. cardiology). Information such as diagnostic tests completed, results, and treatment plans needs to be communicated back to the pediatric oncologist. If this does not routinely occur, patient care can be adversely affected due to a lack of care coordination.

Approximately 15 years ago oncology nurses and physicians at Children's Memorial Hospital in Chicago, Illinois (now called the Ann and Robert H. Lurie Children's Hospital of Chicago, or Lurie Children's), recognized the need for an adult based, LTFU survivorship program for a growing number of childhood cancer survivors reaching young adulthood. The pediatric survivorship clinic at Lurie Children's had an existing affiliation with an adult medical facility and cancer center (Northwestern Medical Faculty Foundation, NMFF and The Robert

H. Lurie Comprehensive Cancer Center of Northwestern University, RHLCCC). This existing collaboration provided a framework on which to establish a LTFU program in an adult setting. In June of 2001, the first long-term childhood cancer survivors were seen at Northwestern by a multidisciplinary team including an internist (medical director), pediatric Clinical Nurse Specialist (CNS) and clinical psychologist. Shortly after the first clinic the program was named "The STAR Program" (Survivors Taking Action & Responsibility) which has three main components: clinical care, education and research.

## Clinical Care

### Referral process and patient clinical treatment summary

To date, 65% of the 326 patients followed in the adult STAR Program at Northwestern are referred from Lurie Children's Hospital. The remaining 35% are referred from other pediatric cancer clinics, by physicians, or self-referral. NMFF is the outpatient facility that houses RHLCCC clinical programs and the STAR Program. NMFF accepts a wide variety of insurance plans including most PPO's, several HMO's and Medicare/Medicaid. Upon referral, patients send their medical

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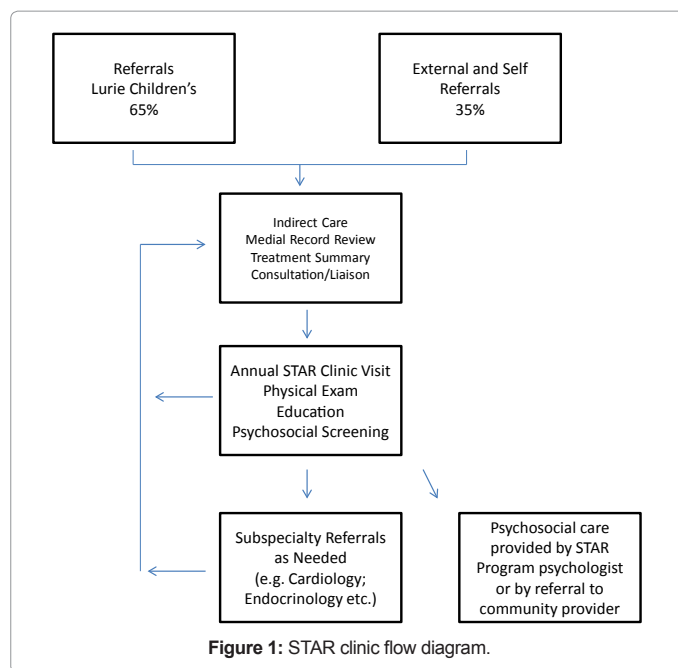
records to the STAR Program Clinical Nurse Specialist who closely reviews them and compiles records into a personalized “STAR Clinical Summary”. This treatment summary includes the patient’s diagnosis and staging; age at diagnosis; treatment protocol; list of surgeries; important complications; names of all chemotherapy agents (cumulative doses for agents such as anthracyclines and Bleomycin); radiation doses/sites; past medical, surgical and family history; as well as transfusion history. Patients receive a copy of their STAR Clinical Summary at each clinic visit. Information related to labs and diagnostic test results are updated annually within the summary prior to each patient’s annual visit. A copy is maintained in the patient’s electronic medical record affording accessibility to medical providers within the institution and a copy is included with any referrals to external providers.

### Description of clinical population

Table 1 describes the demographic and disease characteristics of our patient cohort (N=326). The STAR Program provides care to patients ≥ 18 years of age, ≥ 5 years post diagnosis and diagnosed with cancer at 21 years of age or younger. The current age range of participants is 19-60 years old (mean = 33.0 yrs) and the range of time since diagnosis is 6-52 years (mean=23.2 yrs). Cancer survivors of any diagnosis are accepted including CNS tumors, survivors who had a stem cell transplant, or persons treated with chemotherapy for a non-oncologic disease such as Histiocytosis. There is no upper age limit for entry into the STAR Program. The most prevalent late effects among our STAR Program

Gender	N=326	Percent
Female	178	54.6
Male	148	45.4
Race Ethnicity		
Caucasian (non-Hispanic)	273	83.7
Hispanic	25	7.7
Black	16	4.9
Other	8	2.5
Asian	2	0.6
Multi racial	2	0.6
Diagnosis Category		
Acute Lymphoblastic Leukemia	103	31.60
Hodgkin's Disease	68	20.86
Non-Hodgkin's Lymphoma	31	9.51
Wilm's Tumor	28	8.59
Osteosarcoma	19	5.83
Brain Tumor	14	4.29
Rhabdomyosarcoma	14	4.29
Acute Myelogenous Leukemia	12	3.68
Neuroblastoma	10	3.07
Other	8	2.45
Chronic Myelogenous Leukemia	3	1.84
Ovarian Germ Cell	3	0.92
Sarcoma	6	0.92
Retinoblastoma	2	0.61
Langerhans Cell Histiocytosis	1	0.31
PNET	1	0.31
Neurofibromatosis	1	0.31
Yolk Sac Tumor	1	0.31
Craniopharyngioma	1	0.31
	Mean (SD)	Range
Diagnosis age, years	9.6 (6.9)	(<1-21)
Time since diagnosis, years	23.2 (13.5)	(6-52)
Current age, years	33.0	(19-60)

**Table 1:** STAR Program cohort demographics.



cohort include endocrinopathy (44.2%), musculoskeletal dysfunction (23.3%), secondary malignancy (15.3%), and cardiac dysfunction (14.1%). There are 203 patients (62.3%) with at least one documented medical late effect.

### Clinic flow and scheduling

A typical annual clinic visit in the STAR clinic has four components, 1) a pre-clinic visit review of medical records by the CNS and ordering/scheduling of tests prior to the appointment, 2) a comprehensive medical history and physical exam performed by the medical director, 3) education provided by the medical director and CNS emphasizing health promotion and potential/actual late effects based on the patient’s prior exposures to chemotherapy, radiation and surgery, and 4) brief psychosocial screening conducted by the program’s clinical health psychologist (Figure 1). The STAR clinic is held in a NMFF clinical cancer center outpatient facility. Patients are referred as needed to the adult cancer center’s on-site multidisciplinary Supportive Oncology team which includes social workers, psychiatrists, dietitians, a fertility navigator and a medical librarian.

The STAR clinic currently runs one half day, twice monthly. On average 6 patients are seen per clinic session with two patients scheduled concurrently. Each visit is scheduled for one hour. Blood draws and laboratory based analyses are conducted either early in the morning for fasting studies or after the appointment. Diagnostic testing procedures are conducted based on patient risk factors for late effects and according to the Children’s Oncology Group LTFU Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers (found at <http://www.survivorshipguidelines.org>) [6]. When possible, tests are scheduled on the same day as the initial or follow-up visits. This coordinated approach tends to minimize patient burden and increase adherence with recommended tests. Annual visits are recommended and some patients are seen in the medical director’s General Internal Medicine clinic for interval visits, short term follow-up of medical conditions or other general health maintenance (i.e. pap smears, immunizations etc.). STAR Program patients may choose the medical director to be their primary care physician (PCP) while others maintain

care with another PCP and return to the STAR Program for their annual LTFU evaluation.

### Psychosocial assessment and intervention

The importance of providing psychosocial care for survivors of childhood and adult malignancies has increasingly been recognized [7]. The Childhood Cancer Survivor Study (CCSS) has evaluated large samples of childhood cancer survivors and siblings. Survivors of leukemia and lymphoma demonstrated an increased risk of depression and somatic distress [8]. CCSS survivors of brain tumors had elevated distress compared to siblings, though the rate of clinically significant distress (11%) was similar to the general population [9]. Distress appeared to be related to diminished social functioning. CCSS survivors demonstrated a fourfold greater risk of post-traumatic stress disorder compared to siblings [10]. Recent CCSS research has also documented post-traumatic growth among survivors, indicating that some survivors perceive positive outcomes from their cancer experience [11].

Every STAR patient meets with the program psychologist during initial and annual visits. The psychosocial assessment consists of a semi-structured interview to review symptoms of mood and anxiety disorders (including health-related anxieties), health behaviors (e.g. exercise, substance use), and psychosocial concerns (e.g. vocational/academic performance). Common symptoms, including fatigue, pain, cognitive impairments and sleep difficulties are also assessed. For patients whom psychosocial intervention is indicated or who request additional psychosocial care schedule a follow-up outpatient appointment with the STAR Program psychologist or are referred for psychosocial care proximal to their residence.

### Subspecialty referrals

One of the most important aspects of the STAR Program is the ease and availability of subspecialty referrals. As mentioned previously, 62.3% of our cohort has at least one documented medical late effect of which many require specialty care. The STAR team has developed relationships with physicians in numerous specialty areas (e.g. endocrinology, dermatology, neuro-oncology, cardiology, pulmonary, rehab medicine etc.). To foster these relationships we alert these practitioners to newly published articles related to their specialty and childhood cancer, and have invited them to present at patient and professional education symposiums. The established relationships with these specialists and the use of our electronic medical record facilitate communication and referrals. This also allows STAR staff to review the patient's encounters and learn the intended plan of care set up by the specialists, update their STAR Clinical Summary with test results and notes, and set our plan of care. Table 2 describes the number of specialist visits/diagnostic tests that the STAR patient cohort had in a two year period. This table can also demonstrate some of the "downstream" revenue that was generated in different departments within our institution. While the exact revenue numbers have not been calculated, it is worthwhile to note this as a potential source of income for institutions considering implementing such a model.

### Patient and Family Education and Outreach

One-on-one patient education is routinely provided during clinic visits. Formal education venues tailored for the unique needs of cancer survivors is a combined effort by the STAR Program staff, STAR patient advisory board, and the staff of the RHLCCC Office of Community Affairs. Previous educational symposiums have included programs for STAR patients and their families; support groups; social events; and cancer survivor related CME events for professionals. Feedback

	Patient Count
Patients who <b>visited</b> SPCC*	268
<b>New</b> patients having their first SPCC visit	59
STAR patients seeing Dr. Aarati Didwania at the SPCC	351
STAR patients seeing Dr. Aarati Didwania in GIM **	90
STAR Patients seeing other GIM physicians for acute medical issues	89
Number of STAR Patients with visits to following Specialty Departments:	
<i>Cardiology</i>	118
<i>Dermatology</i>	107
<i>Endocrinology</i>	61
<i>Neuro-Oncology</i>	58
<i>Pulmonary</i>	19
STAR Patients receiving Echocardiograms	167
STAR Patients receiving DEXA*** scans	79

\*SPCC=STAR Program Cancer Center \*\*GIM=General Internal Medicine \*\*\*Dual energy X-ray absorptiometry

**Table 2:** Summary of STAR Program Clinical Activity over 2 year period: Sept. 2009-2011.

from evaluations from these events has been overwhelming positive. Funding for these events is secured primarily from outside the cancer center through acquisition of grants and gifts in coordination with RHLCCC education programs.

## Research and Administration

### STAR program research

Patients are presented with a consent form at their first clinic visit (approved by the Northwestern Institutional Review Board) to provide consent to enroll into a STAR Program patient registry, which allows staff to approach patients regarding participation in research studies. Participation in future research is voluntary and medical care is not affected if they decline. Demographic and medical information including documented late effects are entered into a database maintained by the CNS. Our current patient volume is not conducive to large-scale studies, such as those conducted by the CCSS. We have found STAR Program patients to be enthusiastic about participating in research studies. We have observed a high level of participation on studies that require significant time from participants (e.g. focus groups) and that have required participants to disclose information on sensitive and personal topics. We have leveraged this resource, the group of engaged childhood cancer survivors who are receptive to research studies, to conduct exploratory and qualitative studies which provide a foundation on which to build follow-up larger investigations. For example, our qualitative research with STAR Program patients documented the significant prevalence of concerns related to fertility among young adults and provided an empirical foundation to support the establishing of the Oncofertility Consortium of Northwestern University. Publications over the past 5 years are presented in Table 3.

### Administration and billing

One of the most challenging pieces of implementing and maintaining a program such as the STAR Program is the financial cost to the institution. Much of the time and effort that goes into the patient visit is completed by the CNS prior to the visit and is not covered by insurance. This critical pre-visit work includes the medical record review, compiling and updating the patient's clinical summary, and the scheduling of tests in coordination with the annual clinic visit. Follow-up after the visit also requires dedicated staff effort and is not



Title	Journal/Book	Description
Scarring, Disfigurement, and Quality of Life in Long-Term Survivors of Childhood Cancer: A Report from the Childhood Cancer Survivor Study	<i>Journal of Clinical Oncology</i> , 30 (20), 2466-2474.2012.	A pilot STAR study (Dermatologic issues in adult survivors of childhood cancer) led to the development of this Childhood Cancer Survivor Study concept and study.
An Exploration of the Attitudes, Preferences and Concerns about Fertility Preservation among Adult Male Survivors of Childhood Cancer	<i>Psycho-Oncology</i> , 21 (S1), 26. 2012.	Qualitative, exploratory study consisted of five focus groups with 15 adult male survivors of childhood cancer (diagnosed 10-20 years old) and 7 of their parents. Groups included a semi-structured guide to elicit short and long-term attitudes, preferences and concerns about fertility preservation. An analytic approach was used to identify relevant themes within and across groups.
Dermatologic issues in adult survivors of childhood cancer	<i>Journal of Cancer Survivorship</i> , 3 (3), 158-163. 2009.	78 STAR patients completed this descriptive study consisting of an 8 item self-reported questionnaire about the incidence of, treatment for and resolution of 13 common dermatologic conditions.
Adult Survivors of Childhood Cancer and Their Parents: Experiences with Survivorship and Long-term Follow-up	<i>Journal of Pediatric Hematology Oncology</i> , 30(9), 651-658. 2008.	In-depth telephone interview study with 54 STAR patients and 43 of their parents to examine the communication practices of long term pediatric cancer survivors and their parents as they continue to interact about their cancer experiences.
Beyond the Crisis: Communication between Parents and Children who Survived Cancer	In F. Dickson & L. Webb (Eds.) <i>Communication for Families in Crisis: Theories, Research, Strategies</i> . Peter Lang Publishing, New York. 2012.	Data from the above study
Quality of Life in Adult Survivors of Childhood Cancer	<i>Journal of Pediatric Oncology Nursing</i> , 24 (4), 220-226. 2007.	In a cross-sectional design, 70 of 100 eligible survivors from the STAR Program completed a QOL and depression symptom measure. Medical information was abstracted from charts. Analysis revealed that survivors with elevated depressive symptoms had significantly lower QOL across all domains than those with lower levels of depressive symptoms.
Fertility Preservation and Adolescent Cancer Patients: Lessons from Adult Survivors of Childhood Cancer and their Parents	In T. Woodruff & K.A. Snyder (Eds.) <i>Oncofertility: Fertility Preservation for Cancer Survivors</i> . Springer Publishing Company, New York. 2007.	Qualitative, exploratory study consisted of four focus groups of adult women treated during ages 13-21 for cancer and their parents. Patients were either in ovarian failure or were at risk for infertility due to treatment. The purpose of the study was to explore and compare the attitudes towards fertility and fertility preservation among and between survivors and parents.

**Table 3:** Research and Publications resulting from the STAR Program.

a covered service with regard to insurance benefits. We are fortunate to have RHLCCC institutional support for the STAR Program. The continuous operation of our program is supported by RHLCCC through philanthropic support, to manage the gap between operational expenses and revenue generated from patient visits and lab billing. The medical director is an internist and bills at a CPT 99214 level 4/moderate complexity decision making (CPT 99214) for return patients or level 5/high complexity decision making (CPT 99215) for new patients [12]. This billing practice is consistent with other pediatric cancer survivor programs' visits reported through a recent Children's Oncology Group (COG) survey of late effects service practices [4]. The clinical psychologist's evaluation is supported, in part, through philanthropic support. This allows the STAR Program psychologist to meet with every STAR patient during their annual visit to assess psychosocial needs. For patients who request an in-depth evaluation or who request ongoing psychosocial care outside of their annual STAR Program visit, billing under Health and Behavior Codes (CPT 96150-96155) using the patient's medical diagnosis is typically the most appropriate approach because for the majority of STAR Program patients psychosocial concerns are directly related to cancer history or current late effects. The implementation of procedures for billing for psychosocial care is essential to promote sustainability of this service over time and reflects our program's philosophy that managing psychosocial late effects is an integral component of the STAR Program.

## Conclusion and Limitations

Advances in the treatment of childhood cancer have improved the overall estimated 5-year survival rate to 80% and there are now over 300,000 childhood cancer survivors in the United States [13,14]. The need for LTFU programs and late effects monitoring for pediatric, adolescent and young adult cancer survivors is being discussed by pediatric and adult oncologists, nurses and social workers nationwide. A recent paper by Eshelmen-Kent et al. [4] reported on late effects

services in 179 of 220 Children's Oncology Group member institutions (81% response rate). Of the 179 institutions, 87% reported providing late effects services to survivors and 59% of institutions reported providing that care in a specialized late effects program by designated late effects providers. Information obtained regarding models of care utilized for *adult survivors* of childhood cancer (161 responses) showed 44% utilizing a "Cancer Center-Based Model without Community Referral". In this model, survivors are kept indefinitely at the treating pediatric institution for cancer related care and generally both adult and children surviving pediatric cancers are cared for by the same providers. The Eshelmen-Kent study describes the top barrier pediatric oncology providers report when transitioning their survivors outside the pediatric setting is a "lack of knowledge about late effects by the clinician being referred to" which is consistent with transition barriers previously reported [4,15]. The literature on the topic of models of care for adult survivors of childhood cancer and long-term follow-up care is abundant and will inevitably evolve. It is important to note that there is currently no "standard of care" or "best practice" for these survivor programs [16].

Implementing comprehensive long-term follow-up programs in the pediatric and adult settings is expensive, resource intensive and can exceed resources available in most health care systems [17]. The care provided must not only include risk-based medical care (based on the survivors' past treatment and toxicities) but also ideally include components of health promotion, psychosocial care, patient education and assistance with insurance, advocacy and financial challenges [16,18,19]. Taking the first step to start a program like STAR can be overwhelming. The advice given to us by Dr. Kevin Oeffinger in 2000 "Start slow, but start" helped us build this program, one patient at a time, while learning from our mistakes and expanding on our successes.

Several limitations to this report are noted. First, documentation of late effects can be vulnerable to reporting bias, as it is measured via

a combination of chart review, clinician exam, and patient self-report. Chart review data may be obtained from internal and/or external institutions and therefore lacks standardization. Second, while research within the cohort has been ongoing, we recognize that additional outcomes data will need to be collected and presented in future manuscripts. Finally, the STAR Program has not tracked “downstream” revenue generated by referrals to the various professionals involved in this comprehensive surveillance approach. Collection of this data would be important for programs attempting to generate enough clinical revenue to survive without philanthropic and/or institutional support.

We are extremely grateful for the support of the STAR Program from the RHLCCC of Northwestern University. We continue to strive to provide excellent, comprehensive medical and psychological LTFU care to the survivors enrolled in the program as well as survivors we will meet in the future. We also continue to support other institutions through sharing our experiences with those who are trying to implement a similar model of care for this growing population of childhood cancer survivors. We will continue to work toward our ultimate goal of improving the health and quality of life of all adult survivors of childhood cancer.

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Assuring quality of care for cancer survivors: The survivorship care plan. Cancer survivorship: Cardiovascular and respiratory issues. Cancer-related fatigue: Treatment. The Childhood Cancer Survivor Study (CCSS) is the largest cohort of childhood and adolescent cancer survivors in North America, with 25 participating institutions and 14,054 survivors diagnosed under the age of 21, a majority of whom have been assessed as AYAs [30]. The CCSS has found that poor mental health is reported by 30 percent of those who are on average over 20 years after a diagnosis of cancer [31].

PHYSICAL ISSUES

As with adults, cancer treatment can result in long-term issues in adolescent and young adult (AYA) cancer survivors. These include the following

Journal of Integrative Oncology. Cancer Survivorship Care for Adult Survivors of Childhood Cancer: An Adult Based Model Facilitating Multi-Disciplinary Long-Term Follow-Up Care, Educa. Journal of Palliative Care & Medicine. Childhood cancer survivors, in particular, need comprehensive long-term follow-up care to thrive. One way this can be accomplished is through continuous follow-up care with a primary care physician that is trained to identify possible late effects from previous treatments and therapies.[32]. The Children's Oncology Group (COG) has designed a set of survivorship guidelines that hope to aid both health care professionals and survivors themselves, in both the intricacies and basics of long-term follow-up care. Models of cancer survivorship care for adolescents and young adults. Seminars in Oncology Nursing January 1, 2015. Kinahan KE, Sanford S, Sadak KT, Salsman JM, Danner-Koptik K, Didwania A (2015). Models of cancer survivorship care for adolescents and young adults. Seminars in Oncology Nursing. 31: 251-259.

Cancer Survivorship Care for Adult Survivors of Childhood Cancer: An Adult Based Model Facilitating Multi-Disciplinary Long-Term Follow-Up Care, Education and Research. Journal of Integrative Oncology. 2: 106. January 1, 2013. Other authors. Longitudinal prospective assessment of sleep quality: Before, during and after adjuvant chemotherapy for breast cancer. Supportive Care in Cancer. 21(4), 959-967. January 1, 2013. Other authors.