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The Creation of a Comprehensive Adolescent and Young Adult Cancer Survivorship Program: "Lost in Transition" No More

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Purpose: The Reid R. Sacco AYA Cancer Program set out to improve survivorship care for AYA-aged patients (15–39 years) of pediatric or AYA cancer. This article discusses the steps in establishing the clinic, including the creation of a database on cancer history, exposures, and attendant risks of late effects. Results from the database tell the broader story of AYAs who seek care within a dedicated survivorship clinic.
Methods: The database was created with REDCap® (Research Electronic Data Capture), a secure web-based, HIPAA compliant application for research and clinical study data. Data were abstracted and analyzed by trained members of the program team.
Results: A total of 144 patients were seen for their initial survivorship visit between January 2013 and September 2019. Regarding physical health, two-thirds of the patients presented with an established late effect, one third with an established medical comorbidity, and 11% ($n=16$) with secondary cancer related to their oncologic treatment. In assessing mental health, a significant cohort reported a known affective disorder (32%, $n=46$) with one quarter already taking a psychotropic medication. Despite the transient nature of AYAs, 85% of patients remained in care within the long-term follow-up clinical model.
Conclusions: Data presented illustrate how multilayered and complex survivorship care needs can be, as patients enter the clinic with complicated pre-existing psychosocial issues, significant late effects, and co-morbidities. This study reinforces the value of a clinical database to better understand AYA survivors with the ultimate goal of optimizing and coordinating care.

Keywords: survivorship, late effects, care continuum, health-related quality of life

Introduction

Landmark recommendations for survivorship care were published in the 2006 report, *From Cancer Patient to Cancer Survivor: Lost in Transition.*[1] Essential components of care included prevention and detection of new cancers, surveillance for recurrence, intervention for consequences of cancer and its treatment, and coordination among specialists and primary care providers (PCPs) to ensure that all health care needs are met. Although the last decade and a half has brought progress, survivorship care continues to be broad, fragmented, and unintegrated into mainstream oncology.[2]

Furthermore, with the variability of survivorship programs and the heterogeneity of providers, settings, diagnoses, and goals of care, there is limited research to support the optimal models of survivorship care or to target clinical outcomes.[3,4] The majority of adolescents and young adults (AYAs) will likely become long-term survivors[5] and face a unique set of needs due to increased risk for late effects, secondary malignancies, and premature morbidity and mortality.[6] Survivorship care is important for the nearly two million cancer survivors in the United States, who have been diagnosed as AYAs, with this number only expected to increase.[7]

The Reid R. Sacco AYA Cancer Program at Tufts Medical Center (Tufts MC), established in 2013, aims to provide survivorship care for AYA-aged patients (15–39 years) of pediatric or AYA cancer, regardless of disease, treating

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institution, time since completion of treatment, or current health status. The program is composed of four components: clinical care; training future providers; health-related quality-of-life (HRQL) care delivery research; and education and outreach. This article discusses establishing the clinic, as well as the development of a clinical database to understand better the patients served. Through the data collected, a broader story unfolds about the AYAs who receive care within a survivorship clinic.

AYA survivors

AYA survivors report a lack of knowledge regarding their cancer, treatment received, and potential for treatment-related late effects.[8–10] This is disconcerting, given that childhood cancer survivors, from whom information regarding AYA-aged survivors has been extrapolated, experience deficits in general health, mental health, and functional status.[11] Research also indicates that the vast majority of survivors diagnosed at a young age will experience a serious/disabling or life-threatening chronic health condition by the age of 50.[5]

Within the psychosocial domain, many survivors experience mental health challenges, neurocognitive deficits, and poor social outcomes secondary to their cancer experience. Many have increased rates of anxiety, depression, and somatization compared to their siblings.[12,13] Research by Parsons et al.[14] reported that more than 50% of individuals expressed problems at work and school, such as chronically ''forgetting'' or difficulty ''keeping up.'' This may factor into higher unemployment, lower occupational attainment, and more dependent living seen within this cohort.[15–17] AYAs also participate in risky health behaviors, such as the use of alcohol, tobacco, illicit drugs, and sexual behaviors at the same rate as their siblings,[18] which is more concerning for those already at risk for long-term organ dysfunction, secondary cancers, and increased late mortality.

A comprehensive survivorship clinic

The Reid R. Sacco AYA Cancer Program's survivorship clinic can best be defined as a comprehensive, academic, longitudinal model.[4,19] Set up with philanthropic funds and with support of hospital leadership, it was created to provide care to 18–39 year olds with a history of cancer, regardless of their age at diagnosis. Long-term follow-up care is based on individual treatment exposures and guideline-based associated risks, which creates the flexibility to see patients with both hematologic and solid tumor malignancies. Patients are scheduled on an as needed, quarterly, biannual, or annual basis, with appointments billed as outpatient specialty visits.

Tufts MC with its full-service pediatric Floating Hospital for Children is a tertiary referral center for the greater Boston area, caring for patients with many complex and rare diseases. The AYA clinic resides within the Tufts MC Division of Adult Hematology/Oncology. This decision was not without debate or ''turf wars,''[20] as stakeholders within the adult and pediatric divisions were concerned regarding staffing and potential revenue flow. A compromise was reached in which the AYA clinic would focus on patients 18 years of age and older, accepting patients as young as 15 years on a case-by-case basis. The placement of the clinic within adult-based oncology was deliberate to help younger AYAs transition from pediatric to adult-based health care; address the critical shift from active treatment to long-term survivorship care;[21,22] and foster closer care coordination among adult primary and specialty providers who help manage treatment-related health consequences.

Recommendations for best practices in AYA clinic models include a designated clinic space that is both developmentally and age appropriate.[23,24] Securing protected space was important to the philanthropic donors as their son had been diagnosed as an older teen and often felt out of place during his treatment. This sentiment has been referred to as the ''no-man's land''[24] that AYAs often experience when straddling care between pediatric and adult oncology. The waiting area and examination rooms utilized are not shared during AYA clinic blocks. To enhance this space, new signage, artwork, and population-specific reading material were added.

Clinic team

It was important to establish a multidisciplinary team who understood AYA concerns and were committed to providing developmentally appropriate care.[23] The clinicians include one pediatric and one adult-trained hematologist/oncologist, and one neuro-oncology trained nurse practitioner. In 2016, the team added an adult-trained cardio-oncologist, who specializes in the acute and long-term effects of treatment exposures to the cardiovascular system. Another key component of the team is a full-time program manager who oversees complex care coordination, scheduling, and outreach. She receives all incoming phone calls (vs. a general call center) and meets patients in the clinic. This consistent voice and face of the program support the continuity of care and the ability to build trusting relationships with patients. The clinic also has access to a designated oncology social worker for ongoing psychosocial consultation.

The national call for AYA and survivorship-specific education for medical professionals has increased.[25–29] Training future providers has been a core feature of the program, since its inception. The clinic team has trained over 25 medical students, primarily from Tufts MC's affiliated Tufts University School of Medicine, who join as part of their selective or elective rotations. Undergraduate student volunteers have also participated in the program. The program also provides young adults, who are interested in learning about AYA cancer survivorship, an endowed Summer Scholar position. Composed primarily of rising second-year medical students, Summer Scholars join the team for an 8-week immersion to participate in clinical and research activities.

Methods

Data collection

Analysis began in 2019 following the determination by the Tufts MC/Tufts University Health Sciences Institutional Review Board that this retrospective review study was exempt. Data collection occurs at each clinic visit. Patients complete a health questionnaire and the Patient-Reported Outcomes Measurement Information System (PROMIS®) Global Health Scale,[30] which are reviewed by the provider before seeing the patient.

The health questionnaire, partially adapted from publicly available surveys, has been routinely administered to patients since the clinic opened. It includes demographic information (e.g., occupation and insurance source) and a review of systems, interval medical problems, and health behaviors (e.g., exercise and tobacco use), and usually takes 10 minutes to complete. Patients who are seen more than annually are provided with an abbreviated form. To reduce a potential delay, the questionnaire is sent to the patient before the visit. Patients who do not complete the questionnaire at home are provided with a hard copy upon arrival. This document is scanned into the patient's record after the visit.

PROMIS global health measure

PROMIS, a system of validated HRQL measures for physical, mental, and social well-being, developed as part of a trans-National Institute of Health initiative to improve the patient-reported tools of clinical research,[30] has been collected at each visit since March 2015. Patients complete the 10-item measure by rating their health using a five-point Likert scale. This measure usually takes less than 2 minutes to complete. Responses are entered into a secure database and scored in real time using established algorithms. The measure yields a total score for physical and mental health with a standardized mean of 50 (and a standard deviation of 10). A score of five or more points below the mean (e.g., <45) is considered to be clinically meaningful. Scores are recorded in the visit note. Patients under legal guardianship and/or those who had significant cognitive deficits are not asked to complete the measure.

Survivorship care plan

Research has demonstrated that knowledge increases after a dedicated visit to a survivorship clinic to discuss late effects.[8] Each AYA visit is guided by the patient's Survivorship Care Plan (SCP), which is created and subsequently updated by a member of the clinic team, and is embedded within the visit note. The SCP includes a cumulative treatment summary, outlining the chemotherapy, radiation, surgery, and/or transplant exposures, and a detailed care plan.[31] The care plan is guided by Children's Oncology Group Guidelines and other professional societies.[32–36] It is organized by organ system and includes recommended surveillance and testing based upon prior treatment exposure, time interval, date of completion, and the responsible provider.

Established late effects and/or comorbidities

The National Cancer Institute's Common Terminology Criteria for Adverse Events scoring system was used to document established late effects and/or comorbidities.[37] These were graded as severe/disabling or life-threatening, and analyzed. This grading system was utilized by the Childhood Cancer Survivor Study when assessing chronic conditions in adult survivors of childhood cancers.[38] Late effects were defined as medical conditions commonly associated with cancer treatments including cardiomyopathy, hypogonadism, or neurocognitive impairment. Established medical comorbidities were classified as chronic conditions if they were not related to oncologic treatment, were present before the initial survivorship visit, and/or required medical management. Examples included idiopathic hypertension, hypercholesterolemia, or diabetes. Consistent with other comorbidity scales, affective disorders were recorded separately.

Development of a database

The database, developed in 2016, includes demographic information, as well as health characteristics related to the patient's diagnosis and treatment. It is managed in REDCap™ (Research Electronic Data Capture), a secure web-based, HIPAA-compliant application for research and clinical study data.[39,40] The program's medical director and a dedicated data manager oversee access to the database. Data abstraction from clinic-generated documents, which has taken ~20 minutes, is completed by members of the program team, including medical student trainees, and validated as needed by a provider.

Results

We report on 144 patients seen for their initial survivorship visit between January 2013 and September 2019. To prevent inadvertent breach of confidentiality, data categories were merged whenever small cell sizes were encountered (i.e., less than 5 patients per category).

Patient characteristics

The median age of patients was 26 years (range 15–64) upon entry into the clinic. The majority of patients were AYAs (15–39 years at initial visit) diagnosed as children (0–14 years, $n = 92$, 64%) or as AYAs (15–38 years, $n = 35$, 24%). Time since completion of initial therapy ranged from 0 to 33 years, reflecting the adaptability of the care model to accommodate both short- and long-term survivors. Patients who required surveillance were also seen by their treating oncologist until the care team agreed to a full transition to the survivorship clinic. A third group emerged of adult-aged patients aged 40+, who had been diagnosed as children or AYAs (8–39 years, $n = 15$), (Table 1). The adult-aged group transitioned into survivorship care following treatment for a secondary cancer or referred by their oncologist, given the complexity of their cancer-related sequelae. These patients were seen on a separate day from AYA-aged patients.

Demographic information is detailed in Table 2. Slightly more than half of the patients were female (55%, $n = 79$) and 84% ($n = 121$) identified their race as white. Patients of other racial and ethnic backgrounds (16%, $n = 23$) were collapsed into one category to include non-white or Hispanic. Most patients had private insurance (69%, $n = 100$) with plans secured through their employer, school, parents, or spouse. Of those privately insured, the largest cohort obtained coverage through their employer (44%, $n = 44$), followed by coverage through their parents (39%, $n = 39$) or coverage from their school or spouse (17% $n = 17$). Private plans varied in coverage and financial exposure to the patient. The remainder of the patients (31%, $n = 44$) carried insurance through government plans ranging from the health exchanges, MassHealth/Medicaid, Social Security Disability, or government-subsidized private insurance.

Seventy percent ($n = 101$) of patients reported being employed. Half were living on their own (54%, $n = 78$), independent from parents/guardian. Regarding higher education attainment, patients reported some college (18%, $n = 26$), a college degree (32%, $n = 46$), or a post-graduate degree (19%, $n = 27$). Demonstrating they had yet to complete their highest level of education, 35% ($n = 51$) reported still being a student.

Table 1. Comparison of Patient Cohorts, by Age at Initial Survivorship Visit and Age at Diagnosis

	All patients (n=*144*)	*Age at initial visit (median, range)*	*Age at time of diagnosis (median, range)*	*Years since completed initial therapy (median, range)*
AYA-aged survivors of pediatric cancer	92 (64%)	24 (15–39)	5 (0–14)	18 (2–33)
AYA-aged survivors of AYA cancer	35 (24%)	28 (20–39)	21 (15–38)	5 (0–21)
Adult-aged *(≥40 y)* survivors of pediatric or AYA cancer[a]	17 (12%)	49 (41–64)	28 (8–39)	23 (3–47)

[a] Two patients were diagnosed as pediatric patients.
AYA-aged defined as 15–39 years old.

Health characteristics

As noted in Table 3, 62% of patients had hematological diagnoses while 34% had peripheral or central solid tumors. Overall, 21% (*n*=30) of patients had a history of relapse, including seven who relapsed during initial therapy. More than half, 63% (*n*=91), of patients presented to the clinic with an established late effect, of which 49% were severe/disabling or life-threatening. Sixteen of these patients (11%) had developed a secondary cancer related to their treatment with median of a 14-year onset after their initial therapy. Of note, 29% (*n*=42) of patients presented with established comorbidities, and of these, 15 were severe/disabling or life-threatening.

Mental health considerations were assessed, as described in Table 3. Patients presented to the clinic with a known affective disorder (32%, *n*=46), already taking a psychotropic medication (25%, *n*=35), and/or actively seeing a psychosocial provider (15%, *n*=21). Following the initial clinic visit, 30% (*n*=43) patients were encouraged to continue or reestablish care with their current psychosocial provider, or referred to a new provider.

As shown in Table 4, 85 patients completed the PROMIS measure during their initial visit. While many patients rated their physical and mental health above the population norm, 59% (*n*=50) and 76% (*n*=65), respectively, a sizeable subset, had scores more than a half standard deviation below the mean (41%, *n*=35 physical and 24%, *n*=20 mental). This was most notably seen in adult-aged patients' physical health scores (82%, *n*=14).

Table 2. Patient Characteristics (*N*=144)

	N
Age (in years) at initial appointment, median (range)	26 (15–64)
Gender (Female)	79 (55%)
Race/ethnicity	
White	121 (84%)
Non-white or Hispanic	23 (16%)
Insurance	
Private only	100 (69%)
Government	43 (30%)
Other[a]	1 (<1%)
Currently employed	
Yes	101 (70%)
Living status	
Living on own	78 (54%)
Living with family member	63 (44%)
Other	3 (2%)
Education level	
Less than or equal to high school	35 (24%)
Some college	26 (18%)
College graduate	46 (32%)
Post-graduate	27 (19%)
Other or indeterminate	10 (7%)
Currently a student	
Yes	51 (35%)

[a] Foreign government support.

Table 3. Initial Disease and Health at Initial Visit Characteristics (*N*=144)

	N
Initial diagnosis	
Lymphoma	46 (32%)
Acute leukemia/myelodysplastic syndrome	43 (30%)
Peripheral Solid tumor	41 (28%)
Other[a]	14 (10%)
History of relapse	
Yes	30 (21%)
Relapsed during initial therapy	7 (5%)
Established late effects	
Yes	91 (63%)
Severe, disabling, life-threatening	49 (34%)
Therapy-related Second cancer (e.g., non-melanoma skin, breast, and thyroid cancer)	16 (11%)
Heart disease	12 (8%)
Other	26 (18%)
Established comorbidities	
Yes	42 (29%)
Severe, disabling, life-threatening	15 (10%)
Known affective disorder	
Affective disorder mentioned in 1st note	46 (32%)
Patient taking psychotropic medication	36 (25%)
Patient seeing psychosocial provider	21 (15%)
No known affective disorder	89 (62%)
Patient encouraged to pursue psychosocial care	43 (30%)
Patient encouraged to continue/reestablish care with existing/previous provider	25 (17%)
Patient referred to a new provider	18 (13%)

[a] To prevent inadvertent breach of confidentiality, data categories were merged whenever small cell sizes were encountered. "Other" refers to central nervous system tumors or other hematologic disorders, excluding benign hematologic disorders unless those patients received a hematopoietic stem cell transplant.

Table 4. PROMIS Scores, Comparison of Patient Cohorts

	Total administered at initial visit, since March 2015 (n = 85)	*AYA-aged survivors of pediatric cancer (n = 40)*	*AYA-aged survivors of AYA cancer (n = 28)*	*Adult-aged (≥40 y) survivors of pediatric or AYA cancer[a] (n = 17)*
Global physical health				
At or above population norm (45+)	50 (59%)	29 (72.5%)	18 (64%)	3 (18%)
Below population norm (<45)	35 (41%)	11 (27.5%)	10 (36%)	14 (82%)
Global mental health				
At or above population norm (45+)	65 (76%)	30 (75%)	22 (79%)	13 (76%)
Below population norm (<45)	20 (24%)	10 (25%)	6 (21%)	4 (24%)

[a] Two patients were diagnosed as pediatric patients.

AYA-aged defined as 15–39 years old.

Patients' care-seeking behaviors are detailed in Table 5. A goal of survivorship care is to work in partnership with the patients' other providers, specifically their PCP. While 93% (*n* = 134) of patients reported having a PCP, only 51% (*n* = 69) had been seen within the past 2 years. A majority of patients (78%, *n* = 112) had a cancer-related follow-up appointment within the prior year, most often with their primary oncologist, 66% (*n* = 95). The clinic averages ∼20–25 new patients per year (range 13–29). The initial group of patients was primarily referred from pediatric hematology/oncology. Over time, adult provider and self-referrals have increased as a result of presentations, complex care discussions between providers, and patient word of mouth.

Clinic retention

Despite the transient nature of AYAs, 85% of patients remain in care within this long-term follow-up model. Patients (*n* = 20) chose to discontinue care or became ineligible for reasons including insurance-related barriers, a permanent relocation out of state, or due to changes in disease status (e.g., recurrence).

Discussion

The Reid R. Sacco AYA Cancer Program's comprehensive, longitudinal model helps to eliminate barriers to survivorship care. In addition to the challenge of transitioning from on-treatment to long-term follow-up, many AYA survivors must also learn to navigate adult-based medicine.[41] AYA-aged survivors of pediatric or AYA cancer, as well as older individuals diagnosed with cancer as AYAs, were welcomed into the clinic regardless of their diagnosis or current health status. With this large scope of eligibility, results demonstrated that a significant number of patients entered the clinic with pre-established late effects and/or comorbidities.

Within oncology circles, there is ongoing debate regarding the best way to deliver survivorship care. Grunfeld recommends that SCPs should be ''Studied within a model of care that supports their implementation and within an environment that can provide the resources and services recommended,'' as to understand the ''real-life'' challenges and successes of delivering care to these complex patients.[42] The AYA clinic team has established a model of care to not only identify and track medical complexity but also to provide structured,

Table 5. Care-Seeking Behaviors

	All (n = 144)	*AYA-aged survivors of pediatric cancer (n = 92)*	*AYA-aged survivors of AYA cancer (n = 35)*	*Adult-aged (≥40 y) survivors of pediatric or AYA cancer[a] (n = 17)*
Primary care provider (PCP) identified				
Yes	134 (93%)	88 (96%)	29 (83%)	17 (100%)
Active patient, seen within 2 years	69 (51%)	39 (44%)	19 (66%)	11 (65%)
Last known cancer-related follow-up				
Previous cancer-related follow-up ≤1 year	112 (78%)	68 (74%)	28 (80%)	16 (94%)
Type				
Primary oncologist	95 (66%)	59 (64%)	25 (71%)	11 (65%)
Survivorship specialist	30 (21%)	24 (26%)	4 (11%)	2 (12%)
PCP	9 (6%)	4 (4%)	2 (6%)	3 (18%)
Other	10 (7%)	5 (5%)	4 (11%)	1 (6%)
Referral source				
Pediatric Hematology/Oncology[a]	71 (49%)	62 (67%)	9 (26%)	0 (0%)
Adult Hematology/Oncology[a]	34 (24%)	10 (11%)	12 (34%	12 (71%)
Self-referred	25 (17%)	10 (11%)	12 (34%)	3 (18%)
Other (e.g., PCP and other specialist)[b]	14 (10%)	10 (11%)	2 (6%)	2 (12%)

[a] Providers within the medical center.

[b] Providers within and outside the medical center.

AYA-aged defined as 15–39 years old.

comprehensive, and meaningful intervention. This has been accomplished, in part, by a network of relationships with specialty providers, which has been strengthened over time, as well as with PCPs, who report being unfamiliar with late effects and surveillance guidelines, and, thus, prefer to share care for this reason.[43]

This emphasis on care coordination has led to vast information sharing and a more organized referral and transition process. A notable example of this comprehensive approach is an emphasis on mental health, supported by the implementation of the PROMIS measure. As reported, nearly one third of patients presented at their initial visit with a previously diagnosed affective disorder. The providers realized that many patients were experiencing psychological sequelae from their cancer experience and had difficulty obtaining psychological services. The team utilized their connection with psychosocial providers, so that they could not only identify mental health distress but also make timely referrals to provide ongoing clinical assessment and support.

Limitations to this study include a small sample within one urban-based survivorship clinic, which may not be generalizable to other patient populations. Second, data were reported on patients currently in survivorship care without a comparison of AYAs who are not in such care. Further studies should analyze these groups side by side to determine how patients who seek and remain in care differ from those who do not.

Our next steps will be to continue to expand the database with a plan to analyze associated treatment consequences and risks to better understand this patient population, optimize care, and provide early intervention. Patients' completion of recommended specialty referrals and follow-up testing will also be examined. In addition, while the goal of the program continues to be focused on survivorship care, we look forward to extending our outreach efforts to define and meet the needs of newly diagnosed AYA patients. We share our evolving model as an effective strategy to build knowledge and expand this new frontier of AYA survivorship care.

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Author Disclosure Statement

No competing financial interests exist.

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