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What it looks like to ‘mind the gaps’ in a Midwest survivorship clinic for childhood cancer survivors

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ABSTRACT

Background: As cancer prevalence increases and treatment improves, the population of childhood cancer survivors (CCS) will see remarkable growth. This population requires guideline-based survivorship care into adulthood; however, numerous gaps in care are common including record documentation, medical knowledge, and access to healthcare. Here we describe the patients seen in a US Midwest survivorship transition clinic (STC) and the aspects of the clinic designed to address the gaps in care this cohort faces.
Methods: After IRB approval, a retrospective chart review was completed for patients established in the STC between 2014 and 2022.
Results: A total of 261 patients were identified. The patients had an average age of 12 years at the time of cancer diagnosis and an average age of 28 years at clinic establishment. Patients presented from 9 states and 139 zip codes. We identified 42 different primary cancers with acute lymphoblastic leukemia (24.5%) and Hodgkin’s Lymphoma (19.2%) most common. We found that 244 (93.5%) received chemotherapy, 138 (52.9%) received radiation, and 41 (15.7%) underwent bone marrow transplant. Secondary malignancies were diagnosed in 29 (11.1%) patients with breast (23.3%) and thyroid (23.3%) malignancies most common.
Discussion: The clinical diversity, complex treatment history, and prevalence of secondary malignancies in this CCS population emphasizes the importance close follow-up and adherence to survivorship guidelines. Through strong local partnerships and a specialized nursing navigator this STC addresses care gaps common in this population. Although limitations persist, STCs are a strong model of care to address the unique care needs of this growing population of complex patients.

Introduction

As of January 1, 2022, more than 18 million Americans were living with a history of cancer.[1] As childhood cancer increases in prevalence and the survival rates continue to increase dramatically, the population of patients who survive cancer will see exponential growth in coming years.[1] Guideline based survivorship care is required to attend to this unique population’s needs in monitoring the risks of secondary malignancies and other late effects of treatment. Despite clear guidelines, these patients faces many barriers in the transition of their care from childhood to adulthood that range from emotional effects and self management skills to communication between healthcare systems and financial considerations.[2] This transition from childhood cancer survivors (CCS) to adulthood is a unique area that requires special attention and organization.[3]

The concept of organized survivorship care gained momentum with the publication of *From Cancer Patient to Survivor: Lost in Transition* in 2006.[4] A primary recommendation from this text described a “Survivorship Care Plan” (SCP) to be written by the provider who coordinated the patient’s oncology treatment with the goal of providing a comprehensive care summary and recommendations for follow up. SCPs are encouraged by many prominent oncology associations and the Commission on Cancer Mandate supported this idea with the goal of having SCPs for 25% of all CCS by 2016 and 100% of CCS by 2019. They are critical as research shows primary care providers (PCPs) are over 9 times more likely to discuss survivorship care if SCPs are provided.[5] Despite

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Abbreviations: CCS, childhood cancer survivor; SCP, survivorship care plan; STC, survivorship transition clinic.

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these endorsements and mandates as few as 5% of providers provide written SCPs to survivors[5,6] and PCPs report that they do not receive any form of a treatment summary up to 72% of the time.[7] Currently, use of SCPs are limited by acceptability, cost, and time and some studies present early questioning of their effect on outcomes.[8–10] However, communication of information between the time of treatment and survivorship care is vital and promotes intentional follow up for CCS.

Caring for CCS requires a specialized knowledge of the late effects of treatment and guidelines designed to address the long-term areas of vulnerability for these patients. Multiple sets of guidelines exist and their recommendations for follow up cover areas from cardiac toxicity to psychosocial late effects.[11–13] The extensive information and lack of standardized medical training in this area make it difficult for providers to appropriately care for CCS. A study surveying pediatric oncologists found that when presented with a case of a Hodgkin's lymphoma survivor 34% did not recommend appropriate breast cancer screening, 43% did not recommend appropriate cardiac monitoring, and 24% did not recommend appropriate thyroid function monitoring.[14] Further studies evaluating both family medicine physicians and general internists showed similar gaps in knowledge with even higher rates of incorrect recommendations.[7,15] While the lack of knowledge is concerning, it is not one that is fueled by blind confidence. Rather, these studies consistently show that providers across specialties are uncomfortable with the care of these patients and the overwhelming preference is to work in collaboration with a survivorship clinic.[7,14,15] CCS do not simply need long term follow up; they need follow up that specifically addresses the late effects of treatment.

Models of care for CCS is an area with significant interest in the literature due to the growing patient population, financial impact, and debate between specialist and non-specialist led follow up.[16–18] Oncologists address the early period of care during the first years following treatment and historically oncologists have been thought of as the main providers of survivorship care. However, it is well documented that a shortage of oncologists exists currently and is expected to worsen in the coming years.[19,20] Expecting oncologists to address the gap in provider care for long term management of these patients is unrealistic and inappropriate. One proposal to provide care for these patients is for patients to receive care from their primary practitioner which has been shown to be noninferior to specialist led follow up in randomized controlled trials and systematic reviews.[21–28] However, for this to be a realistic solution significant effort is needed to address the gaps in information and knowledge already discussed.

Another proposal to address this gap is dedicated primary care clinics with a focus in cancer survivorship – a survivorship transition clinic (STC). Within this model, PCP doctors with specific interest and continuing education training in cancer survivorship provide guideline-based survivorship care as well as primary care, to CCS within a certain catchment area. These clinics are designed with the intention to mind the gaps discussed above and have become a well-supported model of care across the world with clinics established in 18 different countries across five continents.[29–31] Although, these clinics provide a solution to the transition challenges that are present for CCS, they require resources that are not present in many communities. Across the United States only 75 of these survivorship clinics exist and 18 states simply do not have one.[32] This presents a challenge to rural communities who already encounter difficulties with access to care.

With awareness of these gaps and the challenge that rural communities face, we opened an internal medicine-based survivorship clinic in partnership with a regional pediatric survivorship clinic and our National Cancer Institute (NCI) designated comprehensive cancer center to support the adult CCS in our largely rural Midwest region. In 2014, this clinic was designed with the use of a regional needs assessment and thoughtful program implementation.[33] After years of experience in caring for these patients and navigating the challenges of survivorship care transitions this paper seeks describe the population of patients cared for in the SCT and to identify the strengths and weakness of the clinic in addressing the many gaps unique to the care of this patient population.

Methods

This STC was developed after identifying key stakeholders, establishing local relationships with pediatric healthcare systems, support from internal subspecialty groups, and the identification of a nurse navigator role. Information regarding the step-wise process to implement this SCT has previously been described in literature.[33] The clinic functions with a nurse navigator who works jointly with the local children's hospital and the health system associated with the SCT. The care for the patients is performed in a primary care clinic by a medical doctor with residency training in both pediatric and adult care. Care for patients is performed in correlation with clinical guidelines outlined by the Childrens Oncology Group and the American Society of Clinical Oncology.[34,35] Data for this study were collected for the purposes of quality improvement with the aim of determining the current reach of the STC in terms of the demographics of patients served as well as to evaluate the strengths and limitations of the clinic design for the care of CCS.

IRB approval

All study procedures were approved by the institutional IRB as a quality improvement project.

Data collection

A retrospective chart review was completed for all patients who had been seen in the survivorship transitions clinic since the clinic's opening in July, 2014 until the date of medical record abstraction in April 2022. All patients who attended the survivorship clinic were eligible for the study. Data was collected by a trained nurse navigator and de-identified for the purposes of research analysis.

Primary and secondary outcomes

Demographics

Participant demographics were abstracted from the patient's medical record, including patient sex (male, female), age at time of cancer diagnosis, and age at clinic establishment, and zip code of primary residence. Age at time of cancer diagnosis was primarily pulled from prior medical records or treatment summaries. Age at time of clinic establishment was calculated by subtracting participants' birth date from the date of their first survivorship clinic appointment. Finally, date of death was collected for patients who were deceased at the time of chart review.

Cancer and treatment history

Pediatric cancer diagnoses and treatment history were abstracted from the medical record, referencing prior medical records and/or treatment summaries as needed to verify this information. Treatment history was collected categorically by identifying whether patients had received chemotherapy, radiation, and/or bone marrow transplant. Secondary malignancies that had been diagnosed prior to the date of chart review (April 2022) were also collected via medical record abstraction.

Statistical analysis

Descriptive statistics were utilized to characterize the sample, including means, frequencies, and standard deviations. Analysis and calculations were performed using Microsoft Excel. Pivot tables were used to compile data regarding patient primary cancer diagnoses, locations of residence, and secondary malignancies. Analysis of the referral rate trends was performed using Microsoft Excel with Mann Kendall testing with an alpha of 0.05 and normal distribution.

Results

Demographics

A total of 261 patients were identified as established patients in the STC. Characteristics of this group are summarized in Table 1. In total, 150 (57%) of the patients were female, 111 (42%) were male, 223 (85%) were Caucasian, 11 (4%) were Black, 10 (4%) were Hispanic, and 4 (2%) were Asian. Among these patients, the average age at the time of cancer diagnosis was 12 years with a range of 2 months to 41 years. The average age at the time of clinic establishment was 28 years with a range of 18–61 years. In review of primary residence, it was found that the patients presented to the clinic from 9 different states, 47 counties, and 139 unique zip codes. In total, 254 (97%) of the patients were alive at the time of data analysis.

Prior cancers and treatments

A total of 42 unique cancer diagnoses were found among the 261 patients. The most common cancer diagnoses were Acute lymphocytic leukemia ($n = 64$ patients – 24.5%) and Hodgkin's Lymphoma ($n = 50$ patients – 19.2%). A full list of diagnoses is shown in Table 2. A total of 244 (93.5%) of the patients received chemotherapy for their cancer. In comparison, 138 (52.9%) received radiation and 41 (15.7%) received bone marrow transplant. Among the patients, 129 (46.4%) received a combination of chemotherapy and radiation therapy and 26 (10.0%) received a combination of chemotherapy, radiation therapy, and a bone marrow transplant.

Clinic referral

A total of 107 (41%) of patients were referred to the clinic by a local pediatric health system while 62 (24%) patients presented self-referred and 20 (8%) presented as external referrals. The number of patients referred each year from 2014 to 2021 by each type is shown in Fig. 1. Trends in referrals were analyzed using Mann Kendall tests as described in the methods. Trends in the rate of overall referral showed significant decrease from 2014 to 2021 (z-stat = −2.4; p-value = 0.017). Trends in the rate of self-referral showed significant decreased from 2014 to 2021 (z-stat = −2.1; p-value = 0.035). Otherwise, no significant trends were found among the rates of referrals. Notably, the rates of referrals showed no significant downtrend when years 2020 and 2021 were excluded from the analysis. In 2022, a total of 47 patients were referred to the clinic.

Table 1
Characteristics of childhood cancer survivors.

Characteristic	
	Age (Range)
Cancer Diagnosis Age	12 yr (2 m - 41 yr)
Clinic Establishment Age	28 yr (18–61 yr)
	No. of Pts. (%)
Female	150 (57)
Male	111 (43)
Caucasian	223 (85)
Black / African American	11 (4)
Hispanic	10 (4)
Asian	4 (2)
Other Race/Ethnicity	23 (9)
Kansas Residence	143 (55)
Missouri Residence	109 (42)
Other State Residence*	9 (3)
Received Chemotherapy	244 (94)
Received Radiation	138 (53)
Received Bone Marrow Transplant	41 (16)
Received Chemotherapy and Radiation	129 (49)
Secondary Malignancy	29 (11)
Alive	254 (97)

* Other states include: Arizona, Colorado, Illinois, Iowa, Minnesota, Nebraska, Texas.

Table 2
Primary malignancies of childhood cancer survivors.

Cancer Diagnosis	No. (%)
Acute lymphocytic leukemia	64 (24.5%)
Hodgkin's Lymphoma	50 (19.2%)
Ewings Sarcoma	14 (5.4%)
Non-Hodgkin's Lymphoma	14 (5.4%)
Wilm's Tumor	12 (4.6%)
Acute myeloid leukemia	11 (4.2%)
Osteosarcoma	11 (4.2%)
Medulloblastoma	10 (3.8%)
Astrocytoma	9 3.4%)
Germ cell tumor	9 (3.4%)
Neuroblastoma	8 (3.1%)
Rhabdosarcoma	7 (2.7%)
Aplastic Anemia	4 (1.5%)
Burkitts Lymphoma	4 (1.5%)
Ependymoma	4 (1.5%)
Testicular Cancer	4 (1.5%)
Desmoplastic small round cell	2 (0.7%)
Large B Cell Lymphoma	2 (0.7%)
Acute Biophenotypic Leukemia	1 (0.4%)
Adenocarcinoma of colon	1 (0.4%)
Atypical Teratoid Rhabdoid Tumor	1 (0.4%)
Breast cancer	1 (0.4%)
Chordoma	1 (0.4%)
Chronic myeloid leukemia	1 (0.4%)
Craniopharyngioma	1 (0.4%)
Dysgerminoma	1 (0.4%)
Eosinophilic gasteroenteritis	1 (0.4%)
Glioma	1 (0.4%)
Gorlin's Syndrome	1 (0.4%)
Grey-zone lymphoma	1 (0.4%)
Hemangiopericytoma	1 (0.4%)
Juvenile Myelomonocytic Leukemia	1 (0.4%)
Lymphoprolierative Disorder	1 (0.4%)
Melanoma	1 (0.4%)
Mixed Germ Cell Tumor with Choriocarcinoma	1 (0.4%)
Optic Nerve Glioma	1 (0.4%)
Pancreatic Neuroendocrine Tumor	1 (0.4%)
Peripheral Neuroepithelioma	1 (0.4%)
Small cell neuroendocrine carcinoma	1 (0.4%)
Synovial carcinoma	1 (0.4%)

Secondary malignancies

Throughout follow up of these patients, secondary cancers were diagnosed in 29 (11.1%) of the patients. The most common secondary cancers diagnosed were breast cancer ($n = 7$ patients – 2.7%) and thyroid cancer ($n = 7$ patients – 2.7%). A full list of secondary cancers found among the patents is shown in Table 3. Of the patients found to have secondary malignancies, 12 (41%) had Hodgkin's lymphoma as a prior cancer. Three of the patients in the cohort had two secondary malignancies identified. In total, 20 (69%) of the patients with secondary malignancies received combination therapy.

Discussion

In the context of a growing field of survivorship care, this project aimed to understand a specific group of patients cared for in a STC and provide lessons learned from over eight years of experience in minding the gaps and navigating the challenges of long term follow up for CCS. The population of patients cared for in this clinic are diverse in age, primary cancer, and prior treatment. At the time of clinic establishment, the range of patient age was broad with the average age of clinic establishment over 10 years after turning 18. In review of prior

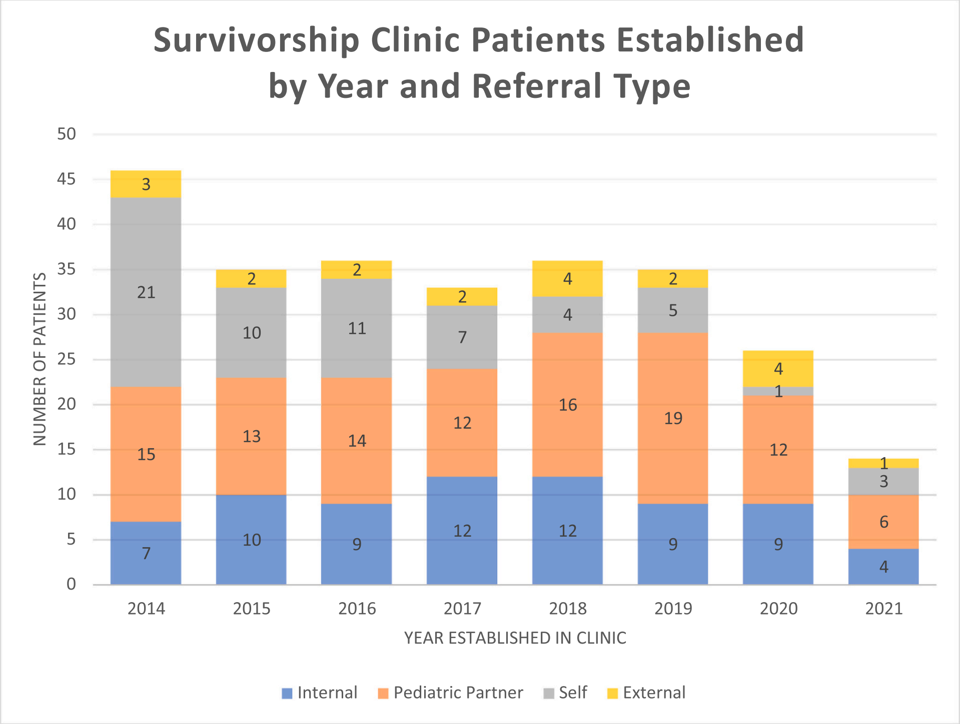

Fig. 1. Survivorship Clinic Patients Established by Year and Referral Type – *color preferred.*

Table 3
Secondary malignancies of childhood cancer survivors.

Secondary Malignancy	No. (%)
Breast Cancer	7 (2.6%)
Thyroid	7 (2.6%)
Basal Cell	7 (2.6%)
Glioblastoma	2 (0.7%)
Squamous cell carcinoma	2 (0.7%)
Melanoma	1 (0.4%)
Pancreatic	1 (0.4%)
Acute lymphocytic leukemia	1 (0.4%)
Renal cancer	1 (0.4%)
Adenocarcinoma	1 (0.4%)
Lung Cancer	1 (0.4%)
Fibrous histiocytoma	1 (0.4%)

treatments, nearly half of the patients received combination therapy and 1 in 10 patients received chemotherapy, radiation, and bone marrow transplant. As documented thoroughly in literature, this history of complex treatment for CCS leads to a higher incidence of malignancy.[36–38] In this specific group of patients, 11% were found to have secondary malignancies.

Given the known risks of secondary malignancies and other late effects of treatment, addressing the gaps of information, knowledge, and access to care was a critical part in the development and implementation of our SCT. Here we discuss the unique ways this was done in this clinic (shown in Fig. 2) and the challenges that we still face.

Record documentation

The transfer of information on arrival of a new patient often does not come in a succinct SCP as intended by the Commission on Cancer Mandate. Unfortunately, gathering information for a new patient can be hindered by the process of filtering through excessive records or on the other hand attempting to obtain any form of limited history available. In our STC this information gap is addressed by two important factors. First, in the development of this STC stakeholders were identified so that partnerships for CCS care were established prior to the implementation of the clinic. This allowed for an ongoing relationship with the local pediatric hospital who provides 41% of patient referrals. Through this partnership information sharing is a streamlined process of transitioning care. However, over half of the patients presenting to clinic do not arrive from the partnered hospital and therefore lack this benefit of information sharing. To address this, our STC has a dedicated nurse navigator to consolidate the extensive records from referrals into an efficient treatment summary. This nurse navigator plays a vital role in identifying the needs of each patient and providing the clinic with the necessary information to appropriately care for each survivor's unique requirements in long term follow up.

Medical knowledge

The early identification of secondary malignancies among our patient population is due to keen attention to guideline recommendations. In this clinic, the knowledge requirements to care for CCS are addressed by both a designated survivorship provider and the broad access to highly rated subspecialty care. As a clinic within a tertiary academic center, the clinic easily provides patients with access to subspecialties critical in their care including dermatology, endocrinology, and cardiology. In the development of this STC, relationships with these subspecialties were intentionally created in order to provide quick and meaningful referrals for the patients. In addition to these subspecialties, the medical field is rapidly recognizing the psychosocial needs of cancer survivors as literature has shown significant effects on quality of life and psychosocial impairment for these patients.[39–42] This need was quickly identified within the clinic patient population as it grew. To address this, the clinic partnered with a pediatric psychologist with doctoral training to provide patients with easy access to psychosocial support within the clinic itself. Finally, the provider in this clinic also works to empower the patients in ownership of their own care. With the development of a clear SCP by the clinic's nurse navigator, the patients have a greater ability to understand the structure and reasoning behind the different aspects of their care and necessary screenings.

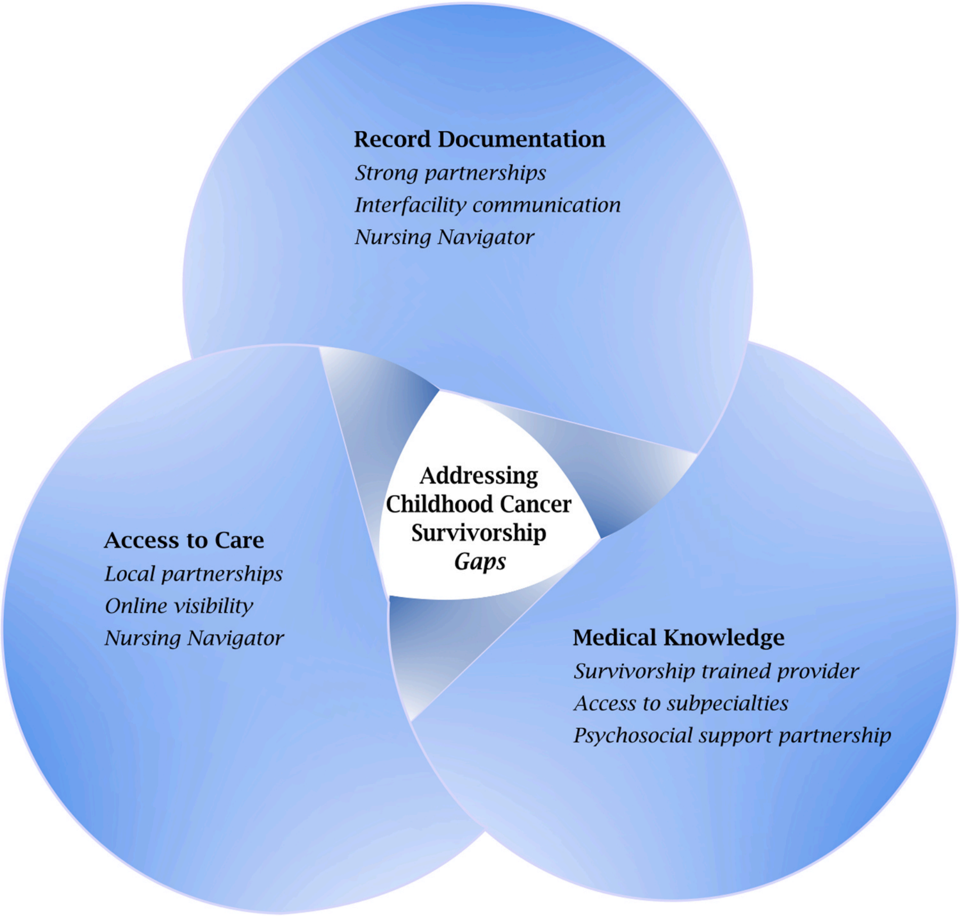

Fig. 2. Addressing Childhood Cancer Survivorship Gaps – *color preferred.*

Access to care

In a region of the country predominantly consisting of rural areas with historically difficult access to care, our clinic has been able to provide survivorship care to patients across 9 different states and 139 different zip codes. This was accomplished through three key aspects of the clinic. First, as already discussed, in the development of this STC a relationship was built with a local pediatrics hospital. This has led to improved information sharing and easy referral and transition of patients from pediatric care to adult survivorship care. This local pediatric hospital system referred 41% (107) of the patients currently in the STC. Second, the clinic has created strong visibility online. With a growing wealth of information online, cancer survivors often seek support and answers through the internet.[43–45] Furthermore, the clinic has partnered with local state based American Academy of Family Physicians, American College of Physicians, and American Academy of Pediatrics to give presentations on survivorship care. The strong online presence and activity in the community has led to 62 (24%) patients presenting to the clinic self-referred and 20 (8%) presenting as external referrals. Finally, the ability to provide care to a wide reach of patients relies heavily on the nurse navigator who communicates frequently with the patients and assists with scheduling needs.

Limitations and ongoing challenges

Despite the success of this STC, ongoing challenges remain. As the clinic develops, the growing needs of this patient population are recognized. The development of a multidisciplinary setting in which patients could see the survivorship provider, psychology, dietary, pharmacy, radiology services, and subspecialists all in the same day would bring significant benefits to these patients. Especially given that many patients travel large distances to reach the STC. As discussed, survivorship care can be linked to anxiety and increased stress for cancer survivors. Building a streamline multidisciplinary system for survivorship care should be a priority as this could have large effects on quality of life for these patients.

The changes in referral numbers and rates seen in 2020 and 2021 show the fragility of CCS access to care. Many factors likely contributed to these trends. The COVID-19 pandemic impacted the STC with a period of clinic closure in 2020 and likely increased patient hesitancy towards the healthcare system during this time. In review of local factors, marketing and media events have historically impacted self-referral rates. Notably, an annual event highlighting the clinic was stopped in 2020 and this likely influenced self-referral rates. Finally, it was discovered in 2022 that awareness of the STC was low and some referrals were being placed to the cancer center instead of the STC. Fortunately, the number of referrals in 2022 showed a significant increase compared to 2020 and 2021. These changes in referral rates and trends exemplify the need for awareness and advertisement of clinics STCs to ensure access to care for patients.

Another challenge seen in this clinic is the insurance coverage of survivorship care. As medical knowledge of late and long-term effects of cancer treatment grows, so to does the need for monitoring and treatment of these. Unfortunately, this expanding knowledge is not always met with financial support from insurance companies. Cancer survivors are at risk for significant financial hardships, particularly those who are young such as the CCS population.[46–48] Unfortunately, these financial hardships can lead to delayed medical care during cancer survivorship.[49] This is a systemic problem which has substantial effects on an individual level and must be a focus of ongoing survivorship care efforts.

In summary, we analyzed the patient population accumulated over 8 years of caring for CCS in a Midwest STC. We found that the patients we diverse in both their current age and their age at clinic establishment with some patients presenting to clinic a significant time after completion of prior treatments. In addition, we found that the patients were complex in their histories of prior treatments and over 1 in 10 were found to have secondary malignancies during follow up. We describe the key aspects to addressing the care gaps this group faces including strong partnerships with local children's health systems, partnerships with subspecialty care, and the use of the unique skills of a nurse navigator to coordinate the transition and follow up of these patients. Here we present the benefits and challenges of STCs; further research is needed to determine the most effective way to care for this complex and growing population.

Ethics approval and consent to participate

A proposal was submitted to the Kansas University Medical Center IRB and accepted under QI exemption.

Consent to participate

Not applicable.

Consent to publication

Not applicable.

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CRediT authorship contribution statement

BL and KA formulated the idea. BL and AK drafted IRB proposal. KA collected all data. SH performed formal analysis. SH and TA drafted the original manuscript. TA, KA, CB, BL assisted with manuscript editing.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Availability of data

The datasets for this manuscript are not publicly available as it contains patient health protected information. Requests for accessing the datasets should be directed to the corresponding author.

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