Improving the Quality of Care Transitions and Care Access for Adult Survivors of Childhood Cancer through Patient-Centered Care

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Background

Comprehensive care for childhood cancer survivors (CCS) is imperative. With improving survival rates in the treatment of childhood cancer this is a growing population of patients.

Studies evaluating the knowledge and comfort of primary care providers and oncology providers have found limitations in provider knowledge of long term follow-up guidelines and expressed discomfort with providing survivorship care for these patients. Most providers express a desire to work together with a survivorship or long term follow-up clinic.

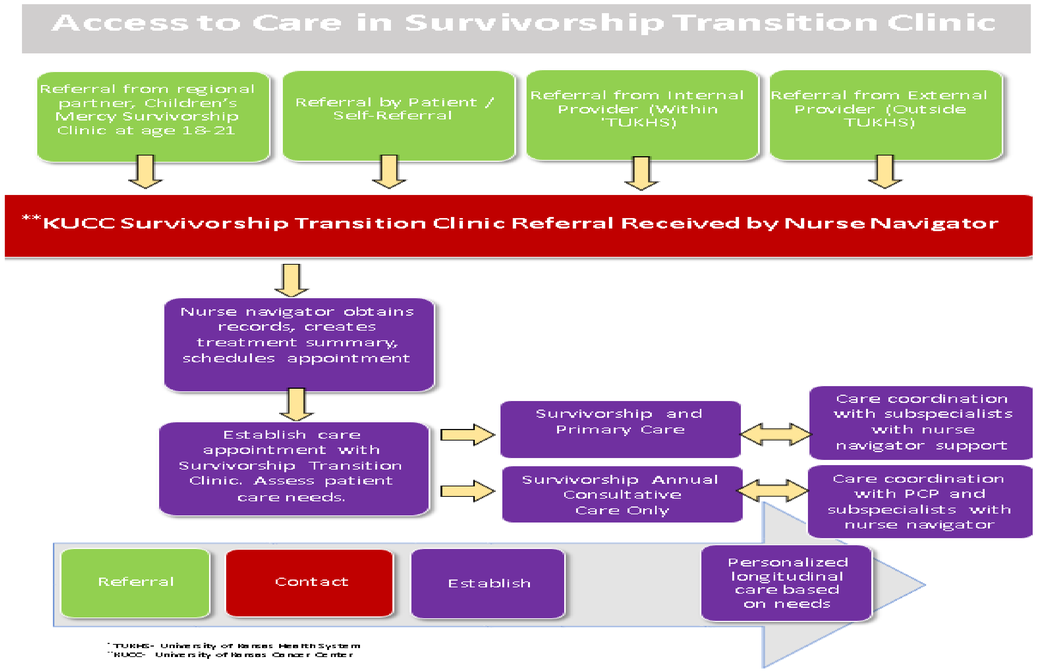
Less information is available around processes of transition and access to care needs including primary care gaps and subspecialty referral trends for CCS. Literature describes the concept of an onco-generalist, subspecialty providers, and nurse navigation of care as crucial in the development of a survivorship clinic. Patient-centered care is key to providing high quality care and understanding care needs for these complex patients.

Aim

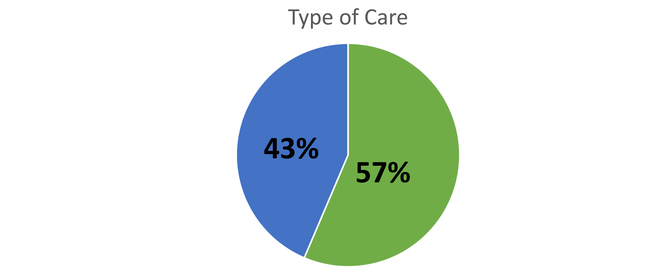
Develop a process map for care delivery for childhood cancer survivors transitioning to an adult survivorship clinics. Develop a process for tracking the primary and subspecialty care needs of the adult survivors of childhood cancer being seen in the Survivorship Transition Clinic (STC).

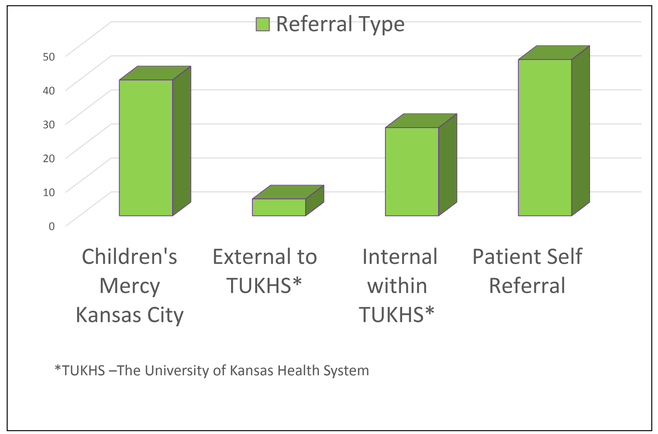
Process

- Developed regional partners to coordinate care transitions with a local children's hospital. Determined a process for referral types received from children's hospital, self referrals, external referrals, and internal referrals.
- Primary care determination: Upon arrival, the primary care physician (PCP) care needs were determined. Patients with an established relationship with a PCP were enrolled in survivorship consultation care only. Patients without a PCP were enrolled for both survivorship and PCP care.
- Retrospective chart review was completed on 117 adult CCS from the Kansas University Cancer Center (KUCC) Survivorship Transition Clinic (STC) between 2014-2017.
- Subspecialty referral needs identification: Retrospective chart review and electronic medical record referral query were analyzed to determine five most frequent referrals for patients in the STC. Duplicate referrals on the same patient were not counted more than once.
- A dedicated nurse navigator supported patient scheduling in the process of establishing care with the STC and with subspecialty providers.



Subspecialty	Number of patients	Percent of Total
Psychology/ Psychiatry	46	39%
Dermatology	44	38%
Fertility	29	25%
Hematology / Oncology / BMT	22	19%
Cardiology	20	17%





Results

- Despite their complex medical history and the importance of maintaining enrollment with a medical care team, over half of our childhood cancer survivors arrived to STC without an established PCP.
- The largest number of clinic referrals were initiated by patients as self-referrals.
- The need for mental health referral echoed the well described impact that cancer diagnosis and treatment has on CCS overall health.
- Referral to subspecialty trends reflected common late effect manifestations of chemotherapy, therapeutic radiation or both highlighting dermatologic screenings, fertility / reproduction, cardiac health, secondary malignancy and/or post-transplant monitoring.
- Given the care complexity for this patient population, a dedicated nurse navigator is essential in supporting patient scheduling in both establishing survivorship care and completing referrals to subspecialty providers

Conclusions

- Having a clear process map for referrals is important for high quality care transitions and ensuring patient access needs are addressed.
- Analyzing care patterns is useful for adapting care delivery and ensuring adequate resources are available.

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