



# A Collaborative Step-Wise Process to Implementing an Innovative Clinic for Adult Survivors of Childhood Cancer

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With a 5 year survival rate of approximately 80%, there is an increasing number of childhood cancer survivors in the United States. Childhood cancer survivors are at an increased risk for physical and psychosocial health problems many years after treatment. Long-term follow-up care should include education, development of individualized follow up plans and screening for health problems in accordance with the Children's Oncology Group survivor guidelines. Due to survivor, provider and healthcare system related barriers, adult survivors of childhood cancer (ASCC) infrequently are receiving care in accordance to these guidelines. In this paper we describe the stepwise process and collaboration between a children's hospital and an adult academic medical center that was implemented to develop the Survivorship Transition Clinic and address the needs of ASCC in our region. In the clinic model that we designed ASCC follow-up with a primary care physician in the adult setting who is knowledgeable about late effects of childhood cancer treatment and are provided transition support and education by a transition nurse navigator.

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## Background

### Rationale for Establishing a Transition Clinic for Adult Survivors of Childhood Cancer

SIGNIFICANT ADVANCES IN the treatment of childhood cancer have led to a 5-year survival rate of approximately 80% and an increasing number of long-term survivors with unique

health needs. Currently there are an estimated 375,000 childhood cancer survivors in the United States (Howlander et al., 2014). However, childhood cancer survivors are at an increased risk of developing acute or chronic health conditions (known as "late effects") long after treatment ends (Mertens et al., 2001; Seehusen, Baird, & Bode, 2010; Suh et al., 2014). The risk of developing late effects increases with age and is influenced by both modifiable and non-modifiable risk factors including, but not limited to, age at diagnosis, cancer diagnosis,

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genetics, treatment received and lifestyle choices (Kopp, Gupta, Pelayo-Katsanis, Wittman, & Katsanis, 2012). The Childhood Cancer Survivor Study (CCSS) reports that two out of three survivors will develop a chronic health condition and more than one third will develop a life threatening condition (Oeffinger & Wallace, 2006). When compared to age-matched and sex-matched siblings, CCSS found survivors were eight times more likely to develop a life-threatening condition (Oeffinger & Wallace, 2006).

Late effects of cancer treatment have the potential to impact any organ system and the risk of developing a complication increases as survivors age (Oeffinger & Wallace, 2006). Examples of physical late effects include, but are not limited to, cardiovascular disease, pulmonary dysfunction, endocrinopathies, secondary malignancy, fertility issues, neurocognitive dysfunction and hearing loss. A report from the St. Jude Life Cohort Study found 98% of adult childhood cancer survivors had at least one chronic health condition and 67.6% had a severe or life threatening condition (Hudson et al., 2013). Specific examples of health conditions identified in this study include abnormal pulmonary function, heart valve disorders, dyslipidemia, and kidney dysfunction. The average length of time from cancer diagnosis was 26.3 years and the average age of the cohort was 32 years (Hudson et al., 2013).

In addition to the myriad of physical late effects, survivors are also at risk for developing symptoms of emotional distress which may be influenced by the development of late effects rather than the actual diagnosis and treatment of cancer (Oancea et al., 2014). One study from the CCSS found that there is a subset of survivors who experience emotional distress and low health related quality of life (HRQOL) (Zeltzer et al., 2009). Survivors are also twice as likely to report emotional distress when compared to their health siblings (Zeltzer et al., 2009).

A subgroup of survivors, primarily those with a history of central nervous system (CNS) directed therapy, are at risk for developing neurocognitive dysfunction. Neurocognitive dysfunction develops over time and often becomes apparent when a survivor is not meeting developmental milestones or acquiring knowledge at the same rate as their peers (Kurt et al., 2008). Neurocognitive dysfunction may be further complicated by the development of neurosensory deficits, which may not appear until years after completion of treatment (Kurt et al., 2008).

In 2003, the Institute of Medicine (IOM) recommended life-long, risk-based health care for childhood cancer survivors to help prevent, identify and manage late effects that may occur. The plan of care should include specific recommendations based on an individual's previous cancer, treatment, genetic predisposition and co-morbidities (Hewitt, Weiner, & Simone, 2003). The Children's Oncology Group (COG) survivorship guidelines are evidence- and consensus-based guidelines that provide standardized recommendations based on exposure to specific treatments with an emphasis on the history and physical as the primary assessment tools to

screen for potential late effects (Landier et al., 2004; Suh et al., 2014). The American College of Surgeons (ACoS) Commission on Cancer program standards require all accredited cancer programs to incorporate treatment summaries and follow-up plans into the care of survivors starting in 2015 with full implementation by 2019 (Commission on Cancer, 2014). A treatment summary includes demographics, past medical history prior to cancer, cancer diagnosis details, date of diagnosis and treatment completion, chemotherapy with cumulative doses, radiation therapy, surgical summary, significant events or complications and any known late effects (Landier, 2007).

Long-term follow-up programs are being developed and implemented to provide up-to-date information about late effects, educate survivors about their diagnosis and treatment history, develop and implement personalized follow-up plans and assist with the transition from pediatric care to the adult medical community (Aziz, Oeffinger, Brooks, & Turoff, 2006; Prasad, Bowles, & Friedman, 2010; Tonorezos & Oeffinger, 2008). In 2009, Children's Mercy Hospital developed the Survive & Thrive Clinic to better meet the needs of childhood cancer survivors. The clinic is a comprehensive clinic with each survivor meeting with an oncologist or nurse practitioner, nurse coordinator, social worker and dietitian. The clinic follows the COG guidelines to screen for both physical and psychosocial late effects of treatment. Survivors are provided with their treatment summary along with individualized recommendations for screening and preventing late effects. Referrals are made to subspecialists if a late effect is identified during the visit. Survivors are followed annually until 21 years of age, at which time their care is transitioned to an adult provider, typically the primary care provider who may not have adequate education regarding how to care for childhood cancer survivors.

There are clear guidelines and recommendations for the lifelong care of childhood cancer survivors; however barriers to a successful transition of care from pediatric-centered to adult-centered care still exist. The barriers can be categorized into three groups: provider related barriers, patient and family related barriers and health care system or institutional barriers (Henderson, Friedman, & Meadows, 2010; Oeffinger, 2003).

Provider related barriers can be further sub-divided to acknowledge barriers associated with the pediatric oncologists and with the adult providers who will care for the survivors as they age. As many as 50–60% of children with cancer are treated in cancer centers, but only 40–45% receive their follow-up care in these specialized clinics (Oeffinger, 2003). Eshelman-Kent et al. (2011) report 35% of COG institutions follow adult survivors indefinitely without transition to adult providers. In another study, only 33% of pediatric oncologists identified appropriate follow up care based on the COG guidelines when presented with a case scenario of a childhood cancer survivor (Henderson, Hlubocky, Wroblewski, Diller, & Daugherty, 2010). This

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