Journal of Pediatric Nursing (2015) **30**, 724–731

Development of a Primary Care-Based Clinic to Support Adults With a History of Childhood Cancer: The Tactic Clinic

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Received 17 March 2015; revised 28 May 2015; accepted 29 May 2015

Key words:
Pediatric cancer survivorship;
Pediatric to adult care transition;
Primary care;
Chronic disease management;
Survivorship care planning

Purpose Describe the development and evolution of a primary-care-based, multidisciplinary clinic to support the ongoing care of adult survivors of childhood cancer.

Methods: A consultative clinic for adult survivors of childhood cancer has been developed that is located in an adult, academic internal medicine setting and is based on a long-term follow-up clinic model available at Children's Hospital Colorado.

Results: The clinic opened in July 2008. One hundred thirty-five patients have been seen as of April 2014. Referrals and clinic capacity have gradually increased over time, and a template has been developed in the electronic medical record to help facilitate completion of individualized care plan letters.

Conclusions: A primary care-based, multidisciplinary consultative clinic for adults with a history of childhood cancer survivor is feasible and actively engages adult primary care resources to provide risk-based care for long-term pediatric cancer survivors. This model of care planning can help support adult survivors of pediatric cancer and their primary care providers in non-academic, community settings as well.

THE OVERALL SURVIVAL rate of cancer diagnosed in children and adolescents under age 20 has been increasing steadily and is now close to 84% (Howlader et al., 2013). As a result of this success, there are currently over 375,000 childhood and adolescent cancer survivors living in the United States (using International Classification of Childhood Cancer criteria) (Howlader et al., 2013). Though pediatric cancer survivors make up only 1% the entire cancer survivor population (Anonymous, 2011) it is estimated that 1 in every 750 adults is a survivor of childhood cancer and this number is projected to increase (Robison & Hudson, 2014). This is significant because we know that childhood cancer and its treatment often come with side effects, many of which can persist over time or may not become apparent until well into adulthood. Childhood cancer survivors are at risk for

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http://dx.doi.org/10.1016/j.pedn.2015.05.023

premature morbidity (Hudson et al., 2003, 2013; Oeffinger et al., 2006). Treatment-related health risks include important cardiac, pulmonary, endocrine, neurocognitive and other late and long-term effects (Diller et al., 2009; Hudson et al., 2009, 2013; Lipshultz et al., 2013; Oeffinger et al., 2003, 2006; Robison & Hudson, 2014), as well as a significant excess risk of death from secondary cancers, cardiac and pulmonary causes (Armstrong et al., 2009; Mertens et al., 2001, 2008; Yeh et al., 2010). Recent evidence suggests that this disparity in health risks persists as individuals age (Armstrong et al., 2014). Individuals with childhood cancer treatment exposures often require additional surveillance and appropriate follow-up to ensure that the unique health risks associated with treatment are identified and treated in a timely, proactive manner. Such an approach is risk-based (Oeffinger, 2003), as opposed to care that is delivered reactively once symptoms or problems appear.

Because of the comprehensive nature of the health care needs of these individuals as adults, there is a need to ensure a seamless transition from the pediatric oncology setting to the adult primary care setting (Freyer, 2010) but also to provide a suitable resource for those long-term survivors who have already transitioned out of the pediatric oncology setting or may never have been seen in a pediatric long-term follow up clinic. Once cancer cure has been achieved, less than 25% of these survivors as adults continue to obtain follow up by specialized cancer centers, which decreases the likelihood of receiving survivorship-focused care (Nathan et al., 2008; Oeffinger et al., 2004) and surveillance for late effects (Cox et al., 2009). Even for adults that were seen in pediatric cancer long-term follow up, they may not have received detailed information regarding their treatment and follow up recommendations. In pediatric cancer settings that are part of the children's oncology group (COG) network only 68% of institutions responding to a 2011 survey reported routinely providing survivors with a copy of a treatment summary and survivorship care plan (Eshelman-Kent et al., 2011). In this same survey of COG institutions, the mostly commonly cited barrier to transition to adult services was a perceived lack of knowledge on the part of the receiving clinician about late effects (Eshelman-Kent et al., 2011); this provider-level barrier was cited more often than any patient-related barrier. Perceived discrepancies between COG recommendations for ongoing care and adult provider recommendations were also cited as barriers (Eshelman-Kent et al., 2011).

Other documented barriers to receiving appropriate medical care include lack of knowledge about treatment-related health risks or specific knowledge of cancer treatment information (Mertens et al., 2004), a historical lack of knowledge outside of pediatric oncology regarding the unique needs of this population (Mertens et al., 2004; Zebrack et al., 2004), financial and insurance concerns (Zebrack et al., 2004), lack of formal processes to transfer care or communicate with the adult primary care or community setting (Aziz et al., 2006; Mertens et al., 2004; Oeffinger et al., 2004) and significant and often under-recognized long-term psychosocial sequelae of treatment. Long after active treatment is completed, anxiety, fear and post-traumatic stress reactions associated with the trauma of past cancer treatment may lead to avoidance of future medical visits (Granek et al., 2012; Mertens et al., 2004; Zebrack et al., 2004), compounding the general lack of focus and attention on preventive care often observed in young adults. Psychosocial sequelae have been cited as possible barriers affecting participation in studies evaluating survivorship care for this population (Blaauwbroek et al., 2012; Cox et al., 2009; Kazak et al., 2010; Stuber et al., 2011; Zebrack et al., 2015). Post-traumatic stress symptoms for those who go through cancer treatment as children can influence health behaviors in many ways: avoidance of hospitals and medical visits, engaging in high risk health behaviors, excessive vigilance or worry about symptoms or even physical symptoms when confronted with reminders of cancer treatments (i.e., palpitations) (Rourke et al., 1999).

The opportunity to receive recommended survivorship care exists. Over 80% of individuals with a history of childhood cancer report receiving general medical care or visits in the previous 2 years from community, primary care settings (Nathan et al., 2008; Oeffinger et al., 2004). It is imperative that the adult health care workforce who will be seeing these patients, many times through acute care visits, become knowledgeable about risk for treatment-related future health problems and starts to take a more participatory role in risk assessment and care planning. Developing primary care-based clinical resources to pick up where pediatric oncology resources end is crucial and fosters adult health care provider skills, familiarity with and expertise in long-term risk-based care for adults with a history of childhood cancer.

The Institute of Medicine issued a report in 2003 on childhood cancer survivorship care, describing the importance of designing minimum standards for comprehensive follow-up care and a recommendation to "…evaluate alternate models of the delivery of this care" (Hewitt et al., 2003). A recurring theme within the literature is the need for a multidisciplinary approach to treatment with an emphasis on proactive care (Oeffinger, 2003), and the need to address communication with primary care providers (Aziz et al., 2006). In order to fill this need, we developed a multidisciplinary, primary care-based clinic, the TACTIC (Thriving After Cancer Treatment is Complete) clinic, that provides comprehensive consultations for adult survivors of pediatric cancer. The TACTIC clinic was developed to provide a local/regional primary care-based resource that extends beyond what is available for children and adolescents in the pediatric oncology setting.

Aim

The primary goals of this report are to describe: 1) the development and characteristics of this primary care-based clinic; and 2) the evolution of clinic growth over time with plans for next steps.

Methods

Setting

The TACTIC clinic opened in July of 2008. TACTIC is held as a monthly ½-day clinic housed in the General Internal