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Associates of Engagement in Adult-Oriented Follow-Up Care for Childhood Cancer Survivors

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ABSTRACT

Purpose: Understanding how to predict appropriate uptake of adult-oriented medical care is important for adult patients with pediatric-onset chronic health conditions with continued health vulnerability. We examined associates of engagement in adult survivors of childhood cancer following transfer to adult-oriented care.
Methods: Adult survivors of childhood cancer (N = 80), within 1–5 years post transfer from pediatric to adult-oriented follow-up care, completed assessments of engagement with recommended adult-oriented follow-up care and psychosocial and transition readiness measures. Measures were validated with adolescent and young adults and/or intended to measure readiness to transition to adult care.
Results: Earlier age at diagnosis, parental involvement in health care decision-making, higher motivation, and increased comfort speaking to providers about health concerns were significantly associated with attendance at adult-oriented follow-up care visits.
Conclusions: Associates of engagement in adult care are complex, representing social-ecological variables. Current measures of transition readiness or adolescent and young adult health-related measures may not adequately capture the associates of engagement in care or identify targets of intervention to promote successful transfer of care. Identifying patients at risk for loss to follow-up will be useful to design interventions for young adult survivors of childhood cancer and other young adults with pediatric-onset chronic conditions who require ongoing adult-oriented care.

IMPLICATIONS AND CONTRIBUTION

Understanding associates of engagement with adult-oriented follow-up care is important for adults with pediatric-onset chronic conditions. Modifiable associates of engagement in care should be considered and addressed throughout the transition process and transfer.

The number of youth with special health care needs surviving to adulthood has increased in recent decades, prompting attention to transition from pediatric to adult-oriented health care [1,2]. To date, transition planning and engagement with adult-oriented care have been suboptimal for patients with pediatric-onset chronic conditions, leading to gaps in care [3–5]. To address this disparity, the Society of Adolescent Health and Medicine, the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians have endorsed guidelines for clinical best practices regarding transition from pediatric to adult-oriented

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health care and call for additional research to focus on describing and improving transition outcomes [6–8]. With implementation of clinical guidelines, patients are increasingly receiving a formal transfer of care whereby a handoff is made between a pediatric and adult provider. However, our understanding of associates of engagement in adult care remains elusive given limited research, limited validated transition measures, and lack of theory-informed approaches. This hinders the ability to identify and intervene during the transition process with youth at higher risk for disengaging from care after a transfer. Thus, there is a need for theoretically informed studies of associates of engagement in adult-oriented care following a formal transfer of care.

Survivors of childhood cancer are an exemplar group with which to study predictors of engagement in adult-oriented care. Their current and/or potential risk for late effects of cancer treatment, usually resulting from the toxicity of treatment, cover a wide range of impairments, resulting in a variety of chronic health conditions [9]. Given the variation of cancer diagnoses and treatment (types and doses) used over time, young adult survivors lie on a spectrum from healthy individuals requiring surveillance for conditions or second cancers that may emerge in adulthood to those with severe and life-altering symptoms, chronic illness, and disability making transition to adult care complex [10]. Guidelines recommend, at minimum, annual lifelong follow-up care, yet only 20%–40% access appropriate medical care related to their prior cancer [5]. Even in our setting with formal transition practices and transfer of care, up to 40% of survivors do not report a cancer-related follow-up visit in the prior year within 5 years after transfer [11].

Prior studies have suggested that disease, treatment, and demographic variables are associated with follow-up care [12–15]. Furthermore, qualitative studies of survivors and other young adults with chronic illness indicate that transition is multifaceted and many psychosocial and demographic variables relate to the process [16,17]. However, few quantitative studies have examined psychosocial associates of engagement in adult-oriented cancer-related follow-up care. To provide a framework accounting for the complexity of transition and to facilitate research and measurement development related to transition readiness, the Social-ecological Model of Adolescent and Young Adult Readiness to Transition (SMART) was developed and validated with childhood cancer survivors, parents, and providers and has been applied to other chronic health conditions [18–21]. Understanding the role of such modifiable variables is important for targeting youth at risk for poor engagement after transfer.

To advance the science and practice of transition, several gaps in the literature must be addressed including: (1) identifying theoretically informed associates of engagement in adult follow-up care after transfer for young adults with pediatric chronic health conditions and (2) testing whether or not current measures of transition readiness and related constructs are actually associated with engagement in care post transfer. Thus, the aim of the study is to determine, as informed by prior research and the SMART model; demographic, disease/treatment-related, and psychosocial variables related to uptake of care after transfer to adult care for adult survivors of childhood cancer.

Methods

Descriptions about the cohort and rates of engagement in follow-up care after transfer were previously reported (Szalda et al. [11]) and briefly summarized below.

Study population

Eligible participants were young adult survivors (YAS) over 18 years of age and greater than 5 years from treatment who were cognitively able to complete measures and transferred from the Cancer Survivorship Program at The Children's Hospital of Philadelphia to adult-oriented follow-up care in the past 1–5 years. At our center, patients are generally transferred to adult care in their early 20s, often by age at 22 years of age, though adjustments have been made for transfer between 18 and 26 years based on individual circumstances. Transition practices include identification of an adult provider, education on cancer history, and need for follow-up care as a young adult and provision of a treatment summary and last clinic letter with individualized care plan to both the patient and accepting provider. One hundred eighteen potential participants were contacted, 99 of whom consented to participate and 80 of whom completed all measures for a response rate of 68%. Reasons for refusal included being too busy or cognitive limitations (reported by parent).

Procedures

The study was approved by the institutional review board at Children's Hospital of Philadelphia. Participants completed online measures assessing health care utilization, transition readiness, and other psychosocial measures, via Redcap [22]. Patients were compensated $25.

Measures

Uptake of adult-oriented care (primary outcome). To assess engagement in adult-oriented follow-up care, YAS identified the type of provider(s) (subspecialist or primary care) who manage their cancer-related follow-up care and reported whether or not they saw that provider in the past year.

Demographics, disease, and treatment-related variables. Demographics were self-reported and included age, gender, race, ethnicity, education, marital status, and insurance status. Cancer diagnosis, date of diagnosis, and age at diagnosis were abstracted from the electronic health record. Intensity of treatment rating was assigned as 1 (least intense) to 4 (most intense) therapy based on the intensity of treatment rating 3 [23]. Perceived severity of late effects was self-reported by YAS as minimal or greater than minimal.

Psychosocial/transition readiness variables. Potential psychosocial associates were guided by prior findings and the SMART model. SMART purports that, psychosocial variables, in addition to demographic and treatment/disease variables commonly studied as associates of engagement of follow-up or adult care are important to transition (Figure 1) [18]. Specifically, disease knowledge, beliefs and expectations of transition and health status, a future goal-orientation, positive communication and relationships with providers, and emotional well-being have been reported by stakeholders (patients, parents, and providers) to be important associates of transition readiness and engagement in care. While no published measure exists to assess this multifaceted conceptualization of transition readiness [24], we have established initial content validity of an item pool of SMART-informed transition readiness items [25]. For the current study, psychosocial components of SMART were measured by