Development of a Connectedness with Healthcare Providers Scale for Adolescents and Young Adults with Cancer

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Dates of Support: 09/01/2012– 02/28/2016 Total Award Amount: $34,664

Funding Agency: Alex’s Lemonade Foundation

Abstract:

Adolescents and young adults with cancer (AYA) are a vulnerable and underserved population to the extent that several organizations, including the National Cancer Institute and the Lance Armstrong Foundation, have set AYA research as a priority to find ways to better meet their specific health care needs and improve their outcomes. AYA survivorship is complicated by physical and psychosocial late effects and higher participation in risky lifestyle behaviors. These complications increase AYA risk for subsequent cancers and other chronic illnesses. To help minimize long-term late effects and engage in healthy lifestyle behaviors, AYA must establish and maintain a good relationship with their healthcare providers for long-term follow-up. The willingness of AYA to engage in long-term follow-up is influenced by their experiences of connectedness with healthcare providers across the cancer continuum (from diagnosis to survivorship). In an effort to better understand how AYA connectedness with their healthcare providers occurs, the influence of connectedness on AYA survivorship outcomes, and to help prevent disconnectedness from healthcare providers in survivorship, an instrument to measure connectedness with healthcare providers needs to be developed and evaluated. Following the National Quality Forum’s priority to better understand the experiences that foster or interfere with patients’ engagement in health care, we will develop an instrument to measure AYA connectedness with healthcare providers. The purposes of this study are to: (1) develop a patient-reported measure of connectedness with healthcare providers for AYA and (2) evaluate the psychometric properties of the instrument. In Phase 1, items will be generated and evaluated by two expert panels (an AYA panel and clinician panel) for content validity. Phase 2 will involve pretesting the instrument with a small sample of AYA (N = 10) to determine if items need revising prior to pilot testing. In Phase III, the psychometric properties of the instrument (dimensionality, internal consistency reliability, and construct validity) will be evaluated in a sample of AYA (N = 100). Findings from this study will contribute to an ongoing program of research focusing on the development of interventions to establish and maintain AYA connectedness with healthcare providers that will ultimately influence the survivorship outcomes of AYA.