
Survivorship Care Preferences

A pilot study of young adults with cancer

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BACKGROUND: Adolescents and young adults (AYAs) face increased risk for physical, social, and cognitive late complications of cancer therapy. Strategies are needed to better engage AYAs in survivorship research.

OBJECTIVES: This study aimed to determine the feasibility of enrolling AYAs within six months of diagnosis to a survivorship study and assess their health concerns and survivorship care preferences.

METHODS: Patients aged 15–34 years who were diagnosed with leukemia, lymphoma, or sarcoma at three Connecticut hospitals from 2008–2011 were identified and recruited by mail. Participants and their physicians received a survivorship care plan. Participants completed surveys at 6 months and 18 months after diagnosis.

FINDINGS: Recruiting AYAs to survivorship research remains challenging, even when approaching them soon after diagnosis. Novel strategies are needed for nurses and other healthcare team members to engage AYAs in survivorship care and research.

KEYWORDS

survivorship; psychosocial; epidemiology; late effects; young adult

DIGITAL OBJECT IDENTIFIER

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ATTEMPTS HAVE BEEN MADE TO RAISE AWARENESS of adolescent and young adult (AYA) patients aged 15–39 years diagnosed with cancer because of their unique health issues (Smith et al., 2016). AYA patients experience cancer-related health disparities in terms of lagging survival rates for common cancers (Kent et al., 2015; Smith et al., 2016), underrepresentation on therapeutic trials (Freyer & Seibel, 2015; Harlan et al., 2011), and heightened risk for comorbid conditions (Nass et al., 2015). The survivorship period, after therapy ends, brings new challenges because of the late complications caused by previous curative chemotherapy and radiation therapy. These include infertility (Cardonick, 2016), second cancers (Nass et al., 2015; Smith et al., 2016), cardiovascular disease (Chao et al., 2016), musculoskeletal problems (Daniel et al., 2015), psychosocial distress (Tai et al., 2014), and cognitive difficulties (John, Sender, & Bota, 2016). Because AYA survivors are at a particularly critical juncture in their lives, impairment of cognitive function and medical interruptions can have devastating effects on these patients' education (Parsons et al., 2012; Patterson, McDonald, Zebrack, & Medlow, 2015; Tai et al., 2012), attainment of employment (Parsons et al., 2012; Patterson et al., 2015; Tai et al., 2012), and ability to start a family (Bellizzi et al., 2012; Smith et al., 2016). Although AYA survivors deserve focused attention, this group is challenging to recruit and retain in research because of members' geographic mobility, transition from pediatric to adult specialty and primary care providers, and hesitancy to have regular contact with the healthcare system because of under-insurance and out-of-pocket costs (Clinton-McHarg, Carey, Sanson-Fisher, & Tracey, 2011).

Participation rates in research studies among AYAs are notoriously low, with rates as low as 1.5% (Rabin, Horowitz, & Marcus, 2013) and most under 50% (Clinton-McHarg et al., 2011; Harlan et al., 2011; Hendricks-Ferguson et al., 2013; Link et al., 2009). Only one study was identified with a participation rate of 61%, but this was after multiple mailings and telephone calls that added up to a substantial recruitment cost per patient that could be cost prohibitive for many studies (Richards et al., 2010). Low rates of AYA participation in research have been attributed, in part, to loss to follow-up and to challenges connecting with socially and geographically mobile patients (Harlan et al., 2011; Nass et al., 2015). Historically, recruitment of AYAs has been conducted one or more years