Experiences of Adolescents and Young Adults Living With Advanced Cancer: An Integrative Review

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Evidence suggests that people are living longer with advanced cancer as a result of improved screening, early detection, and treatment advances (American Cancer Society, 2019; Kamal et al., 2011; Salakari, Surakka, Nurminen, & Pyllikkiänen, 2015). Most individuals with advanced cancer face psychological, physical, social, emotional, and spiritual issues related to their diagnosis (Kamal et al., 2011; Meier & Beresford, 2008). Some individuals with advanced cancer may experience accumulating symptom burden and deterioration of function, whereas others may remain relatively independent and functional for longer periods of time. In addition, although some individuals living with advanced cancer may experience a steady decline in function, others may retain a moderately high level of performance (Lunney, Lynn, Foley, Lipson, & Guralnik, 2003). Studies have described individuals living with advanced cancer as feeling forgotten and alone, with persistent unrecognized and unmet needs (Haylock, 2010a, 2010b; Lynn, 2005; Singer et al., 2015).

The adolescent and young adult (AYA) cohort is made up of individuals aged 15–39 years (National Cancer Institute, 2018). Cancer is the leading cause of death among this age group when accidental deaths are excluded (Siegel, Miller, & Jemal, 2016). Diagnosis occurs at a time when these individuals are developing identities, finding their places in the world, establishing careers, creating relationships, and building families (Chen, Parmar, & Gartshore, 2014; Cleeland et al., 2014; Shaha & Bauer-Wu, 2009). Overall, there is limited understanding of the biologic, genetic, epidemiologic, and psychosocial factors of, as well as the quality-of-life implications for, this group. Physical and functional challenges may exacerbate emotional burdens that accompany the disease and its treatment.

It is well established that more research with this population is needed across all stages of disease (DeRouen et al., 2015; National Cancer Institute, 2018).