

Treatment Decision-Making Involvement in Adolescents and Young Adults With Cancer

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PROBLEM IDENTIFICATION: Involvement in treatment decision making (TDM) is considered a key element of patient- and family-centered care and positively affects outcomes. However, for adolescents and young adults (AYAs) with cancer, little is known about the current state of knowledge about their perspective on and involvement in TDM or the factors influencing AYAs' TDM involvement.

LITERATURE SEARCH: Integrative review focused on AYAs aged 15–21 years, their involvement in TDM, and factors influencing their involvement using the MEDLINE®, PsycINFO®, CINAHL®, and Web of Science databases.

DATA EVALUATION: 4,047 articles were identified; 21 met inclusion criteria.

SYNTHESIS: Five factors were identified: AYAs' preferred, actual, and perceived involvement; age and cognitive maturity; disease and illness factors; information and communication; and relationships, roles, and perspectives of parents and healthcare providers. AYA involvement in TDM varies depending on the magnitude and timing of the decision. AYAs' role in decision making is situational and may evolve with time.

IMPLICATIONS FOR RESEARCH: Research is needed to understand AYAs' preferences for TDM, the type and degree of their involvement, and the interactions between factors that contribute to or impede TDM.

KEYWORDS adolescent and young adult; pediatric oncology; decision making; patient participation

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Although cancer survival rates generally have improved for pediatric and adult patients, survival rates for adolescents and young adults (AYAs) with cancer have not kept pace. This lack of progress is most evident for those aged 15–25 years (Albritton et al., 2006; Bleyer, Ulrich, & Martin, 2012), who are confronted not just by cancer, but also by normal developmental challenges, the progression of which is affected by dependence on family and healthcare providers (HCPs), and by parental protectiveness (Coyné & Gallagher, 2011).

An important reason for the poorer outcomes in this age group is nonadherence to cancer treatment. Nonadherence rates as high as 60% have been reported (Alsous et al., 2017; Bhatia et al., 2014; Smith, Rosen, Trueworthy, & Lowman, 1979), which can lead to cancer relapse (Bhatia et al., 2015; Butow et al., 2010). Participation of AYAs in treatment decision making (TDM) may support adherence to medical treatment (Butow et al., 2010).

A core principle of patient- and family-centered care is empowering patients and families and building their confidence so they can make decisions about their health care (American Academy of Pediatrics, 2012). AYAs with cancer are increasingly encouraged to be involved in TDM by organizations such as the National Comprehensive Cancer Network (Coccia et al., 2014). Professional organizations, government agencies, and ethical and legal perspectives promote the inclusion of children and adolescents in TDM. However, guidelines about when and how to involve children and adolescents in TDM are mostly opinion-based, with little empirical support, and evidence suggests they are infrequently followed (Unguru, Sill, & Kamani, 2010).

Understanding AYAs' preferences is key to changing healthcare delivery to improve participation in decision making, satisfaction with the process of