**Intervention Strategies to Reduce the Most Common Barriers to Care Among Adolescent and Young Adult Oncology Patients**

Christina Miller, MS, LCPC, Meghan van der Eijk, MSW, LICSW, Samantha Horn, MA, Megan Solinger, MHS, MA, Alexandra Gubin, MSW, LCSW-C, Nicole Sanchez Herrera, BA, Francesca Music

**Category**: Category II: Care Coordination/Care Transitions

**Background**: Approximately 72,000 adolescents and young adults (AYA), defined by the National Comprehensive Cancer Network (2017) as ages 15-39, are diagnosed with cancer each year. A cancer diagnosis during this life stage generates unique medical and psychosocial needs as developmental milestones are simultaneously impacted (Institute of Medicine, 2013). Social isolation and alienation are commonly reported among AYA patients and survivors (Zebrack, Hamilton, & Wilder-Smith, 2009). Even after treatment ends, survivors continue to express concerns about finances and job discrimination (Roberts et al., 1997). The Ulman Cancer Fund for Young Adults (UCF) addresses these issues by employing AYA patient navigators.

**Objective**: The purpose of this multisite study was to 1. Identify common barriers for AYA patients across treatment sites and 2. Demonstrate intervention strategies used to reduce these barriers. In order to measure and improve the quality AYA oncology patient navigation, programs must use standardized metrics and focus on evidence-based practice.

**Methods**: The study took place January 1, 2017 through June 30, 2018. A total of 561 unique patients were included in the data collection, which tracked patients from five large cancer centers in the Baltimore/DC region. A Google Form was used to gather data, with each AYA patient navigator entering information for each patient they supported, on a monthly basis. This study tracked the variation in barriers and the intervention strategies used to address them.

**Results**: Of the 561 unique patients tracked, the most common diagnoses were breast cancer (14%), acute lymphocytic leukemia (12%), Hodgkin lymphoma (10%), and brain cancers (8%). The median patient age was 28, with racial distributions of 56% white, 27% black, 8% Hispanic, 7% Asian, 2% mixed/other. Gender was nearly equally distributed. In order of highest count, the most commonly cited issues that AYAs faced were social isolation, limited support, side effects and late effects, general financial need, adjusting to illness and/or hospitalization, dealing with work or school, mental health, understanding diagnosis and treatment, communication with medical team, and fertility. The most commonly cited interventions, in order of highest count, were one on one emotional support, encouragement, UCF program referrals, routine check-ins, logistical support, referral to social or educational activities, resources related to coping with diagnosis, treatment and side effects, referral to other staff or hospital resource, facilitation of communication/coordination among medical team, and fertility preservation education.

**Conclusions**: In addition to their unique medical needs, AYAs have informational and psychosocial needs that most programs do not address (Institute of Medicine, 2013). They include information about diagnosis, age-specific support groups, and fertility preservation, as well as financial, practical, and peer support. Optimal quality care was described as including awareness among providers of the unique psychosocial context for AYA growth and development and referral to age-appropriate resources during treatment. This is precisely what the UCF AYA Patient Navigation model aims to do. The current study highlights the age-specific resources and referrals AYA patient navigators rely upon in order to help patients overcome the most common barriers they face (social isolation, financial need, fertility, etc.).

**References**

Institute of Medicine (2013). Workshop summary. *In Identifying and addressing the needs of adolescents and young adults with cancer* (Introduction). Retrieved from http://www.nap.edu/read/18547/chapter/2#introx-ch1.

National Comprehensive Cancer Network. (2017). But I’m too young to have cancer! *In Guidelines for Patients - Adolescent and Young Adults with Cancer* (1). Retrieved from https://www.nccn.org/patients/guidelines/aya/files/assets/basic-html/page-10.html

Roberts, C.S., Severinsen, C., Carraway, C., Clark, D.A., Freeman, M., & Daniel, P. (1997). Life changes and problems experienced by young adults with cancer. *Journal of Psychosocial Oncology, 15*(1), 15-25.

Zebrack, B., Hamilton, R., & Wilder-Smith, A. (2009). Psychosocial outcomes and service use among young adults with cancer. *Seminars in Oncology, 36*(5), 468-477.