

Survivorship Disparities in Pediatric, Adolescent, and Young Adult Cancer Patients

Pediatric cancer survivors are those diagnosed with any cancer between ages less than one year to 14 years, while adolescent and young adults (AYA) are ages 15 to 39 years. With tremendous advances in treatments, 85 percent of AYA and pediatric survivors are alive at least five years after diagnosis in 2019 compared to only 58 percent of pediatric and 68 percent of adolescent survivors 40 years ago. Unique challenges faced by these groups include greater risk of late-term side effects, employment difficulties, financial toxicities, psychological challenges, secondary cancers, and reduced quality of life. These challenges are further compounded if children/AYA belong to a racial or ethnic minority or a medically underserved group. To improve long-term follow-up care and optimize quality of life it is essential to understand how disease burden differs by race/ethnicity, sexual orientation and gender identity, and geographic location.



Quality of Life

The disruptive nature of a cancer diagnosis on social development, psychological health, career development, and finances results in a lower reported quality of life among AYA cancer survivors compared to those who have never received a cancer diagnosis.

Financial Toxicity

Due to younger age at diagnosis, rising costs of health care, and lower enrollment in insurance, AYA cancer survivors are at a greater risk of experiencing financial toxicity compared to survivors over the age of 40 years old, who have had more time to establish a career and build financial assets. Poverty in AYA survivors was associated with worse survival while racial and ethnic minorities reported experiencing financial toxicity more often than Whites.

Palliative Care

Assessment of the multifactorial impact of cancer treatments on the psychosocial, physical, and financial challenges faced by AYA groups is important to identify areas of intervention. The unique needs of AYA cancer survivors come from their early stage of life and social development compared to older survivors, and present challenges for patient and provider.

Determinants of end-of-life care include many interrelated factors that are determined by location (treatment center, local resources, provider characteristics, and patient/caregiver preferences) and treatment (intensity of intervention, pain control, and timely referral), which contribute to patient well-being. One study that looked specifically at treatment intensity found that in AYA cancer patients, there was increased frequency of intense interventions, such as the use of mechanical ventilation or admittance to intensive care units, in racial minorities compared to non-Hispanic Whites. Current guidelines during end-of-life care favor highest quality of life over intense treatment interventions, which can be aggressive, invasive, and expensive, so understanding why these groups receive this type of care needs to be assessed to enhance quality of life and reduce overtreatment.

Side Effects

Experiencing cancer therapies early in life increases the likelihood of survivors developing late-term side effects including stroke, secondary cancers, neurodegenerative defects, cardiovascular disease, diabetes, and other pulmonary diseases compared to those without a cancer diagnosis. In a study examining childhood cancers, compared to non-Hispanic White patients, non-Hispanic Black and Hispanic patients had higher prevalence of obesity and diabetes, although these risks were not significant after adjusting for socioeconomic status and other factors. Studies such as this demonstrate how the social determinants of health impact survivors and influence different experiences of side effects.

Follow-Up Care

After conclusion of treatment, continuing to screen for subsequent cancers, managing side effects, and maintaining healthy behaviors like not smoking and staying physically fit, are important for health and well-being among survivors. There are differences in follow-up and long-term care observed depending on race/ethnicity. For instance in AYA cancer survivors, Black women are more likely to have a Pap smear and breast self-exam compared to White women, while Hispanic women were less likely to have a Pap smear even when adjusting for income, education, and health insurance status. Data also indicate that both Black and Hispanic adult survivors of pediatric cancer are less likely to smoke, and Black survivors are less likely to binge drink than their White counterparts.

An important component to accurate follow-up care and continuity of care is having a comprehensive knowledge regarding previous care. Survivors of childhood cancers who had less than a high school education were 6.7-fold less likely to accurately report their diagnosis or treatment. This deficit reduces a survivor's ability to seek and receive appropriate follow-up care and highlights the need for long-term solutions. For instance, the national implementation of an electronic health record is a secure way for a patient's medical history to be accessed by a qualified health care professional throughout the life of a survivor and reduces the risk of lost health data.