Between Two Worlds: The Challenges of Navigating New Primary Brain Tumor Diagnoses for Adolescents and Young Adults

by Rebecca Ripperton[1], Kelly Ground, MD[1]

1. School of Medicine, University of Colorado, Aurora, CO, USA.

Background: Adolescents and young adults (AYAs) aged 18–39 face unique challenges when navigating new primary brain tumor diagnoses. The robust pediatric oncology infrastructure is often inaccessible to this age group, while adult healthcare systems fail to address their distinct developmental and psychosocial needs. AYA patients must contend with a diverse spectrum of tumor types, limited standardized care protocols, disruptions to education and career progress, in addition to the psychological and relational burdens associated with their diagnosis. These challenges underscore the critical need for enhanced support systems and tailored interventions specific to this patient population.

Methods: A comprehensive literature review was conducted, synthesizing research from PubMed and Google Scholar, primarily between 2000–2024. Inclusion criteria focused on studies addressing AYA brain tumors, including topics such as tumor biology, treatment modalities, survivorship, and psychosocial outcomes. Qualitative and quantitative studies, clinical trials, and reviews were analyzed to identify gaps in knowledge and practice.

Results: AYA patients experience heightened challenges due to increased tumor heterogeneity, often encompassing both pediatric and adult classifications. Delayed diagnoses, fragmented care, and limited access to clinical trials exacerbate disparities. The absence of standardized services within the neuro-oncology sphere compounds difficulties in navigating the adult healthcare system, managing disability, and maintaining identity during critical developmental years. Furthermore, AYA patients encounter unique relational and psychosocial pressures, including disrupted family dynamics, peer isolation, and strained romantic relationships. Critical gaps in fertility preservation and end-of-life care further highlight the need for comprehensive, multidisciplinary support.

Discussion: Addressing the needs of AYA patients with brain tumors requires coordinated, patient-centered care. Tailored survivorship programs, age-appropriate healthcare infrastructure, and earlier integration of palliative care are

vital to improving outcomes. Increased inclusion of AYA patients in clinical trials and research focusing on tumor behavior and psychosocial impacts is also necessary. A multidisciplinary approach, involving oncologists, neurologists, reproductive specialists, mental health professionals, and social workers, is essential for holistic care delivery.

Conclusions: AYA patients with primary brain tumors face distinct challenges that necessitate targeted interventions. Enhanced awareness, research, and tailored support systems are critical to bridging gaps in care, improving survival rates, and supporting quality of life for this exceptionally vulnerable patient population.

Statement Concerning Conflicts of Interest: Rebecca Ripperton has no conflicts of interest to report; Dr. Kelly Ground has no conflicts of interest to report.