

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



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## Background

- Adolescents and young adults (AYAs) aged 18–39 are a distinct, medically atypical, and understudied population within the field of neuro-oncology.
- AYA patients often fall between pediatric and adult healthcare systems, receiving care that fails to adequately address their developmental needs.
- These patients experience a broader range of tumor types, including both pediatric and adult classifications, with tumor biology that frequently behaves atypically and is historically under-researched.

## Project Objectives

- To identify and synthesize the unique medical, psychosocial, and systemic challenges faced by adolescents and young adult patients with new primary brain tumor diagnoses.
- To highlight critical gaps in care that can inform future research, clinical interventions, and age-appropriate healthcare infrastructure for this vulnerable patient population.

## Methods

- A comprehensive literature review was conducted using PubMed and Google Scholar, focusing on literature published between 2000 and 2024.
- Quantitative and qualitative studies, clinical trials, reviews, and expert opinions were included.
- Pediatric and adult literature was reviewed for comparison when AYA-specific data were limited.
- Thematic analysis was used to identify common trends, challenges, and gaps in the literature.

#### Results

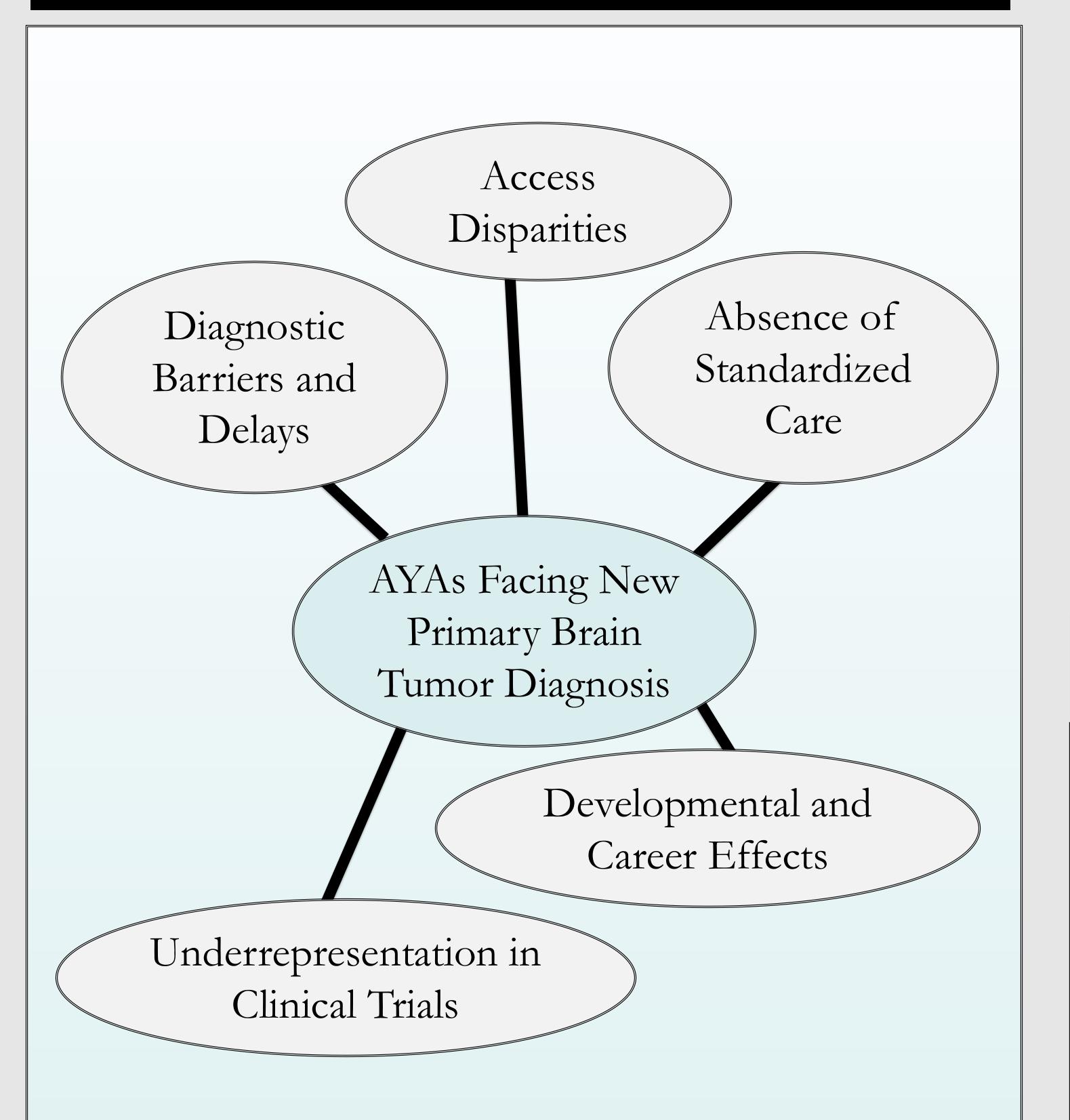


Figure 1. Key Challenges Faced by AYA Patients with Brain Tumors.

This diagram illustrates the major challenges encountered by adolescent and young adult (AYA) patients with brain tumors. These include diagnostic barriers and delays, absence of standardized care, developmental and career disruptions, underrepresentation in clinical trials, and disparities in access to care. Moreover, each factor is interconnected, contributing to the complexity of managing brain tumors in this population.

### Discussion

- •AYA patients with brain tumors face complex, multifactorial challenges that extend beyond medical treatment.
- Transitioning into adult care systems adds logistical and emotional burdens during a critical developmental period.
- Disruptions to education, careers, and relationships exacerbate stress and can lead to lasting psychosocial consequences.
- Palliative care is often introduced too late or not at all, limiting opportunities for symptom management and support.
- System-wide awareness and targeted interventions are necessary to close existing gaps in care.

## Next Steps

- Develop standardized guidelines for managing AYA brain tumors, integrating both clinical and psychosocial care
- Increase AYA representation in clinical trials to generate more age-specific data and improve outcomes.
- Design age-appropriate survivorship programs addressing education, employment, and fertility.
- Expand access to early palliative care, with services tailored to younger adults.
- Foster interprofessional collaboration to create comprehensive, developmentally informed care teams.
- Advocate for healthcare policy changes that support transitions between pediatric and adult systems.

### Disclosures

The authors have no disclosures or conflicts of interest to report.