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REVIEW OPEN ACCESS

What are the Gaps in the Tools/Services for Adolescent and Young Adult High Grade Gliomas Patients?

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Abstract

Introduction: High-grade gliomas (HGGs) in adolescents and young adults (AYAs; 15–39 years) straddle pediatric and adult disease biology. Yet, current care systems are optimized for neither group. Fragmented services, delayed diagnosis, limited access to research and targeted therapies, and profound psychosocial disruption suggest current models are poorly aligned with AYA needs. This review synthesizes service gaps across the AYA HGG care continuum.

Methods: PubMed, Cochrane Library, and Web of Science were searched using glioma, AYA age, and service-gap terms. Selected publications reported data or structured syntheses relevant to healthcare delivery, access, supportive care, or outcomes in AYAs with HGG. Drug-efficacy trials without service data, single case reports, and non–data-driven commentaries were excluded. Study quality and applicability to AYA care were appraised; findings were narratively integrated across predefined domains.

Results: Clinical trial eligibility criteria were often restrictive or age-ambiguous. Treatment access was constrained by AYA underrepresentation in targeted (IDH-, histone-directed) studies, financial barriers and poorly structured pediatric–adult transitions. Diagnosis was frequently delayed by nonspecific early symptoms and specialist scarcity, while the absence of validated AYA-specific molecular markers and limited advanced testing impeded risk stratification. Psychosocial support was also inadequate, with notable deficiencies in peer programs, psychoeducation, fertility counseling, and vocational resources. Regarding clinical presentation, AYAs experienced substantial neurocognitive burden, fatigue, visual change, and motor deficits that disrupted school and work.

Discussion: Improving outcomes for AYA with HGG requires coordinated, developmentally aligned reform. Key strategies include age-inclusive, molecularly stratified trial designs with harmonized eligibility, automated multidisciplinary referral, patient-centered consent, and routine tissue banking. Supportive services, financial navigation, transportation aid and adherence coaching can boost enrollment and retention. Clinically, structured pediatric–adult transition pathways and early palliative integration should be standard. Routine neurocognitive surveillance linked to scalable rehabilitation, academic accommodations, and return-to-work planning preserves function. AYA-specific peer networks, staged psychoeducation, and proactive fertility and life-planning counseling reduce isolation and strengthen engagement across care and research. Ultimately, this integrated model can guide evidence-based improvement.

Conclusion: System-wide redesign grounded in longitudinal, AYA-focused research is essential to improve outcomes and quality of life for young people living with high-grade gliomas.

Keywords: high grade gliomas; adolescents; young adults; supportive care; clinical trials; psychosocial support; treatment gap

Introduction

High-grade gliomas (HGGs), including glioblastoma (grade IV) and anaplastic gliomas (grade III), are aggressive brain tumors accounting for the majority of malignant primary brain tumors [1–3]. Despite the aggressiveness, non-specific early symptoms and high heterogenicity among patients and within individual tumor, make diagnosis of HGG complex and challenging and typically require biopsy for definite diagnosis [4, 5]. HGGs grow rapidly and infiltrate surrounding brain tissues, making complete surgical removal difficult [6, 7]. Other standard treatments, including radiation and chemotherapy, only slow the disease progression but rarely lead to complete remission [6]. The presence of the blood-brain barrier (BBB) limits the effectiveness of many drugs [8]. In addition, novel, targeted therapies are still in experimental and early clinical trial phase, making the 5-year survival rate of glioblastoma (grade IV) 5-10% and anaplastic gliomas (grade III) approximately 25-30% under 44 years old [8, 9].

These tumors are particularly devastating for adolescents and young adults (AYA, 15–39 years), among whom gliomas constitute approximately 29–35% of CNS tumors, with about one-third being high-grade (III or IV) [10, 11]. However, the diagnosis and management of HGGs in this age group are particularly complex due to their intermediate position between pediatric and adult glioma subtypes [12, 13]. Although gadolinium-enhanced MRI is routinely used for tumor visualization and biopsy planning, definitive diagnosis necessitates histopathological and molecular analyses [11, 14]. AYA gliomas often exhibit overlapping histological and molecular characteristics from both pediatric (e.g., H3 mutations) and adult (e.g., IDH mutations, EGFR amplification) tumor profiles, complicating accurate classification and personalized treatment decisions [12, 15].

The transition between pediatric and adult oncology services often results in fragmented care, which can delay critical diagnoses and treatment initiation [15, 16] . This delay is concerning due to the aggressive nature of HGGs, where prompt intervention is crucial for improving outcomes. Furthermore, the relative rarity and complexity of certain HGG subtypes can limit the availability of specialized neuro-oncology clinics and expert neurosurgeons at high-volume centers, which are essential for providing accurate diagnoses and advanced treatment options tailored to the unique needs of adolescents and young adults [17].

Psychosocial considerations are particularly critical for AYAs diagnosed with cancer, as they experience unique developmental disruptions distinct from those faced by younger children or older adults. AYAs often encounter profound isolation during their diagnosis and treatment journeys, disrupting essential developmental milestones such as identity formation, educational achievement, career progression, and establishing independent social relationships [17, 18]. These disruptions could severely impact their autonomy, self-identity, and future orientation, complicating their transition to independent adulthood [19]. “Financial toxicity” further compounds these psychological burdens, with over half of AYA survivors reporting heightened medical debt and employment instability, factors that exacerbate stress, negatively influence quality of life, and may hinder adherence to treatment regimens [20].

Given the intersecting challenges of diagnostic ambiguity, fragmented care pathways, and severe psychosocial and financial burdens, AYAs with HGGs are at high risk of receiving suboptimal care. Therefore, evaluating the effectiveness of current healthcare services is critically important. This study aims to identify gaps in the tools and services available to adolescent and young adult patients with high-grade gliomas.

Methods

A systematic literature search was conducted using three databases: PubMed, Cochrane Library, and Web of Science. PubMed and Cochrane Library primarily cover peer-reviewed journals in the fields of biomedicine and life sciences. The Web of Science database serves as an interdisciplinary resource, ensuring the inclusion of literature potentially missed by the first two databases. The search strategy incorporated combinations of keywords and their synonyms using Boolean operators. Keywords included terms such as "glioma," "glioblastoma," "anaplastic gliomas," "gaps," "lack," "resources," "support," and "programs."

Pre-defined eligible criteria were used to select articles for this review. To be included in the review, articles had to specifically focus on the AYA patient population and thoroughly discuss at least one of the identified gaps. Articles are limited to peer-reviewed publications written in English, published between 1980 and 2025, to ensure comprehensive quality (Table 1).

Exclusion criteria included publications lacking original or synthesized data, such as conference abstracts, research protocols and commentaries. Single case reports were excluded due to their limited generalizability. In addition, studies focused primarily on genetic mutations were excluded as they did not align with the review's objective. Clinical trials were also excluded because they are conducted in controlled environments that often provide protocol-specific resources and support systems not reflective of standard clinical practice. In addition, primary focuses of clinical trials are on treatment efficacy and safety, not service gaps.

Duplicates identified from database searches were removed prior to screening titles and abstracts. Two reviewers independently screened titles and abstracts, followed by a full-text review of potentially relevant articles to determine final inclusion. The quality assessment of selected articles involved evaluating potential biases, adequacy of sample size, reliability and robustness of methodologies used, and the generalizability and applicability of the findings.

Table 1. Inclusion Criteria Used for Selecting Relevant Literature

Criterion	Specification
Year of publication	1980 – 2025
Article Type	Books and Documents, Clinical Study, Comparative Study, Corrected and Republished Article, Government Publication, Meta-Analysis, Multicenter Study, Network Meta-Analysis, Review, Systematic Review and Validation Study
Language	English

Results

Clinical Presentation

AYAs with HGG frequently experience significant disease-related neurocognitive impairments, which can be present at diagnosis. These deficits, distinct from the side effects of therapy, are caused by the tumor itself and manifest primarily as diminished academic and vocational attainments [21, 22]. Currently, systematic monitoring and tailored cognitive rehabilitation programs such as computer-based training and pharmacological interventions are lacking, despite clear evidence of cognitive deficits significantly affecting quality of life [21].

Common clinical symptoms in AYAs with HGG include persistent fatigue, cognitive deficits, visual impairments, and muscle weakness [22]. These symptoms profoundly disrupt patients' educational pursuits, career progression, and the ability to achieve personal life goals. Further, AYAs report insufficient academic and social support systems, necessitating substantial time away from educational and professional activities, thus exacerbating social isolation and psychological distress [22]. Moreover, AYA patients lack support to transit back to work post-treatment as well as support for long-term planning discussions [22].

Diagnosis and Prognosis

The challenge in diagnosing AYA HGG lies in their biological position on a spectrum between pediatric and adult diseases. These tumors include pediatric-type subtypes (40%, mainly H3-mutants) as well as various adult subtypes. The heterogeneous nature of the disease necessitates specialized expertise for accurate diagnosis, which is often lacking. Consequently, diagnostic delays are common and are further exacerbated by nonspecific early symptoms [23, 24, 25]. These delays frequently cause disease progression that makes patients ineligible for clinical trials, ultimately limiting therapeutic options and adversely affecting prognosis [21].

Diagnostic delays are common, driven by nonspecific early symptoms and a lack of specialized clinical expertise [23, 24, 26]. Diagnostic delays frequently result in patients becoming ineligible for clinical trials due to disease progression or metastasis, limiting therapeutic options and adversely affecting prognosis [27]. Emerging data suggest that GBM in AYAs may differ biologically from GBM in patients over 40, although specific markers have yet to be identified [26]. Rare GBM subsets with specific driver mutations and gene fusions are potentially targetable, but no immunohistochemistry or advanced molecular testing are unavailable despite the common drivers like IDH, and histone mutations are lacking [26].

Additionally, the prognosis for AYAs is complicated by the absence of age-specific molecular prognostic markers, with available prognostication largely derived from adult data [27]. Furthermore, AYAs at both ends of the age spectrum experience distinct clinical and prognostic trajectories, necessitating specialized assessment [24].

Treatments

The treatment landscape for AYAs with HGG is complex, with notable deficiencies in targeted therapies, particularly immunotherapies for pediatric-type HGGs, such as diffuse midline gliomas (DMGs) and diffuse hemispheric gliomas with histone mutations (e.g., H3K27M) [21, 23, 24, 28]. The promise of targeted strategies is often limited by the distinct tumor biology of the AYA population. For instance, AYA glioma subtypes may have a lower incidence of the mutations targeted in critical trials like INDIGO (examining IDH inhibition), leading to their biological ineligibility or underrepresentation [23]. Compounding this, adjuvant therapies proven effective in adults often lack AYA-specific clinical data, hindering their application to this group [24]. Moreover, treatment challenges extend beyond drug availability to practical concerns, such as limited private drug insurance coverage restricting access to medications not reimbursed by public insurance [28].

Care transitions pose substantial challenges for AYAs, particularly the transition from pediatric to adult care or community-based primary care and supportive services [21]. This fragmentation can lead to disruptions in continuity of care, delays in treatment initiation, and compromised treatment adherence [21]. Furthermore, no developmental or tailored interventions exist to facilitate effective transitions, exacerbating the psychosocial and clinical management difficulties [29].

Palliative care services with HGG are severely limited, reflecting a lack of universal guidelines and variability in institution-specific provisions [29]. Delayed referrals to palliative care services are frequently observed due to clinicians' discomfort or lack of confidence in operationalizing referrals. Additionally, specialized adolescent-focused palliative care is insufficient, and the infrastructure to support end-of-life care, particularly at home, is inadequate [29]. These deficiencies can significantly increase stress levels among patients and their families, diminishing overall quality of life during advanced disease stages [22].

Clinical Trials

Participation of AYA patients with HGG in clinical trials is notably limited and multifaceted [21, 25, 27]. From a patient perspective, this is often the result of stringent eligibility criteria, mostly related to age restrictions and the severity of disease progression [21, 27]. For instance, a study conducted by Mojica et al. in a multidisciplinary AYA neuro-oncology clinic in 2025 reported that only 3 out of 100 AYA patients with HGG met eligibility criteria for clinical trial enrollment [25]. Patients also face significant barriers to accessing novel targeted therapies, primarily due to prohibitive costs and restricted availability from pharmaceutical companies [23].

From the healthcare providers' perspective, systemic issues further restrict clinical trial participation. This is often driven by low clinician referral rates, which reflects a broader lack of awareness and education on the critical importance of enrolling AYA patients in research and the need to design trials that account for their distinct biological and psychosocial needs [21, 27]. Additionally, inconsistent and inadequate systematic referral mechanisms exacerbate these gaps [21, 27]. Physician expertise can also limit enrollment, as failure to adjust radiation dosage or frequency according to patient age may render AYAs ineligible for later trial enrollment [27].

AYA patients may be perceived as noncompliant due to barriers such as transportation difficulties, financial challenges, and psychosocial factors. In some instances, AYAs deliberately deviate from trial protocols to retain a sense of normalcy in their daily lives [27]. Attitudes towards healthcare systems, such as fear of physicians, lack of trust in the health system, or perceptions that clinical trials are excessively time-consuming, may also hinder trial engagement [26]. Unique challenges also include the process of consent, as many AYAs struggle with parental relationships or lack comprehensive understanding of trial implications despite making the final enrollment decision [27].

From the clinical research infrastructure standpoint, critical limitations hinder progress. A primary issue is the insufficient access to tumor tissue samples, as many clinical trials do not routinely collect adequate biopsies for comprehensive molecular profiling [27]. Furthermore, this challenge is compounded by a structural fragmentation of research. Without dedicated AYA-centric locations, studies are often siloed between pediatric and adult institutions [21]. This dual challenge of scarce biological data and a disjointed research environment significantly slow the advancement of personalized therapeutic strategies for AYA patients.

Psychosocial Consequences

Psychosocial impacts on AYAs with HGG are profound, characterized by significant disruptions in identity formation, autonomy, independence, and social competency deficits [21, 22, 25]. There are no published guidelines directing psychiatric care for AYAs regarding functional assessment, and developmental or psychoeducational interventions designed to enhance coping skills and social interactions are limited [21].

Opportunities for AYAs to connect with peers undergoing similar experiences, which could substantially alleviate feelings of isolation, foster identity formation, and enhance social integration, remain scarce [22, 25]. Additionally, structured peer interactions such as organized activity packages or safe at-home engagement suggestions, which could help AYAs maintain a sense of normalcy, mitigate social competency deficits, and encourage meaningful interpersonal connections, are largely absent or underdeveloped [22].

Furthermore, essential topics such as fertility preservation and family planning are frequently overlooked or inadequately addressed, further complicating psychosocial adaptation and negatively impacting long-term well-being [22, 27].

Discussion

This review has identified critical gaps in healthcare services and supportive care for adolescents and young adults diagnosed with high-grade gliomas. These shortcomings exist across continuum of care, from clinical research and diagnostics to long-term survivorship. Addressing these deficiencies requires targeted, evidence-based interventions tailored to the unique developmental and clinical needs of this vulnerable population.

One of the most profound areas of unmet need involves the management of the complex physical and neurocognitive sequelae of the disease and its treatment. Implementing structured training programs to enhance clinician awareness and expertise in identifying early, non-specific signs of HGGs among AYAs can speed up diagnosing [27, 29]. Multidisciplinary diagnostic teams equipped with advanced imaging and molecular diagnostics should become standard practice to ensure prompt and accurate tumor characterization [21, 23, 26]. Together, these measures would not only accelerate the diagnostic timeline but also ensure a more comprehensive tumor characterization, which is foundational for selecting optimal therapeutic strategies and mitigating the patient's disease burden. Additionally, developing age-specific prognostic biomarkers through expanded research and molecular profiling could substantially improve personalized prognostic assessments and therapeutic decision-making [26]. Care fragmentation at the pediatric–adult interface is a recurrent threat to timely and continuous therapy, necessitating dedicated transition clinics or nurse-led navigation services that proactively manage patient transfers between services [21]. Such services are crucial for ensuring therapeutic continuity and preventing critical delays in care that can arise when patients move between different healthcare systems. Implementing routine neurocognitive screening at diagnosis and throughout the treatment continuum is critical for preserving the functional independence and quality of life of AYA patients [21, 22]. To address the cognitive impairments that arise from both the disease and its treatments, rehabilitation strategies, including evidence-based computer-assisted cognitive training and targeted pharmacological interventions, could offer significant therapeutic benefit [21, 22, 25]. Similarly, debilitating physical symptoms such as fatigue, visual changes, and motor weakness, which disrupt education and employment, require proactive management. Interdisciplinary symptom management clinics that integrate physiatry, occupational therapy, low-vision services, and mental health support could reduce functional decline [22]. By combining early neurocognitive screening with integrated symptom management, clinicians can more effectively

alleviate the patient's symptom burden and mitigate the cascading functional deficits associated with the disease, thereby improving long-term quality of life. Structured educational and vocational support systems, including academic accommodations and return-to-work planning, could significantly reduce educational disruptions facilitate smoother reintegration post-treatment [21, 22].

These patient-level challenges are compounded by systemic deficiencies within the clinical and research infrastructure that governs how AYA patients are diagnosed and treated. Improving clinical trial access for AYAs requires two different approaches. First, eligibility criteria for broader, adult-focused trials should be reformed to explicitly include AYAs as an eligible cohort, thereby eliminating ambiguity and improving enrollment in existing studies [21]. Second, it is critical to design and launch new trials dedicated specifically to the AYA population. These AYA-centric trials should investigate promising therapies targeting the unique molecular features of their tumors, such as IDH inhibitors and histone-targeted immunotherapies [22]. Successfully launching such AYA-centric trials, however, is a significant undertaking that would necessitate parallel efforts in systematic clinician education and training to ensure awareness and drive referrals [21, 22]. Furthermore, standardized referral pathways with clear guidelines and integrated multidisciplinary tumor boards are essential to facilitate timely and consistent clinical trial referrals [21, 22]. Therefore, a commitment to AYA inclusion at both the individual clinician and broader health-system levels is required to expand the portfolio of available clinical trials and, consequently, future treatment options. Policy changes advocating for improved private and public insurance coverage of novel therapies are also crucial to ensure equitable access to innovative treatments regardless of financial background [26]. Regarding research infrastructure, enhanced collection and banking protocols for tumor tissue samples are necessary to advance molecular profiling and targeted treatment approaches [21]. Such protocols are essential for enabling more comprehensive, larger-scale studies that can provide crucial insights into disease mechanisms and facilitate the identification of novel therapeutic targets. Ultimately, a multifaceted approach that reforms trial design, streamlines diagnostic pathways, and removes financial barriers is essential to bridge clinical diagnosis and advanced therapeutic options for AYA HGG patients.

Finally, the unique psychosocial and developmental needs of AYAs are insufficiently addressed by current care models. Specialized training for clinicians and care coordinators in adolescent health and development could significantly improve communication and the care quality during critical transition periods [29]. Establishing AYA-specific peer support groups, along with psychoeducational interventions tailored to enhancing coping skills, emotional regulation, and social interaction, should become standard components of comprehensive supportive care [22, 25]. Addressing the psychological needs of AYA patients is not only crucial for their well-being but may also yield direct clinical benefits, including improved treatment adherence and greater participation in clinical trials. In addition to peer support, educational materials that teach self-management strategies for common symptoms may reduce perceived dependence and improve psychological coping [22]. Furthermore, discussions on fertility preservation and family planning should be routinely integrated into clinical pathways, supported by clear guidelines and counseling protocols [22, 25]. Proactively initiating these discussions is essential, as it can alleviate significant anxiety for patients and their families and address critical concerns that patients themselves may feel hesitant to raise during diagnosis or treatment. A comprehensive care model must extend beyond medical treatment to include structured psychosocial, developmental, and survivorship support that addresses the whole person and their future.

The selected papers for this review present several inherent limitations. Many studies exhibited small sample sizes and single-center designs, reducing the generalizability of findings. Longitudinal follow-up was uncommon, impeding insight into late effects, survivorship needs, and durability of interventions. Several reviewed papers lacked robust methodological rigor, specifically in clearly defined control groups or randomized designs, further complicating efforts to draw definitive conclusions about intervention efficacy. Importantly, few studies stratified outcomes across the broad AYA age span, obscuring developmental gradients in need and response. Finally, a potential limitation is that the challenges identified may not be exclusive to HGG. Many of the issues discussed, including care fragmentation, unmet psychosocial needs, and barriers to clinical trial access, are likely endemic to the broader AYA oncology population.

Conclusions

This current review synthesizes critical insights into gaps and potential solutions for AYAs with HGG, offering a structured framework for future clinical practice and research. However, limitations exist, the broad focus of this review on multiple care domains may limit in-depth exploration of specific areas, suggesting a need for more specialized reviews focusing on individual elements like clinical trials or psychosocial support. The review primarily integrates cross-sectional data, limiting insights into long-term outcomes and effectiveness of proposed interventions over extended periods.

Future research could prioritize longitudinal studies that evaluate the effectiveness of tailored cognitive rehabilitation, psychosocial support, transitional care models, and palliative services for adolescents and young adults with high-grade gliomas. These studies are essential for understanding how early, developmentally appropriate interventions impact long-term functional outcomes and quality of life. More research dedicated to AYA could potentially lead to

developmentally integrated, age-appropriate strategies that address the clinical, biological, and psychosocial gaps identified in the care of AYAs with high-grade gliomas.

List of Abbreviations
AYA: adolescents and young adults (15-39 years old)
BBB: blood-brain barrier
CNS: central nervous system
DMG: diffuse midline gliomas
GBM: glioblastomas
HGG: high-grade gliomas
IDH: isocitrate dehydrogenase
MRI: magnetic resonance imaging

Conflicts of Interest
The author declares that they have no conflict of interests.

Ethics Approval and/or Participant Consent
This study is a literature review that synthesizes data from previously published sources from scientific paper databases. It did not involve the collection of new data from human participants or animals. Ethics approval and participant consent were not required.

Authors' Contributions
JG: contributed to all aspects of this literature review, including the conception and design of the review, acquisition and interpretation of data from published literature, drafting and revising the manuscript, and approving the final version for publication.

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