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"Aiming at a moving target"—The daily life experiences of adolescents and young adults with a low-grade glioma

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Abstract

Background. Low-grade gliomas (LGG) are among the most frequently occurring tumors in adolescent and young adult (AYA) patients (aged 18–39 years old at primary diagnosis). These tumors have a variable prognosis, presenting challenges for patients in shaping their future. This study aimed to identify the age-specific experiences and needs of AYA patients with LGG in their daily lives.

Methods. In-depth interviews were conducted with AYA patients diagnosed with LGG. Thematic analysis was performed to derive the age-specific codes, looking for overarching themes and sub-themes.

Results. Sixteen patients participated in this study. The cognitive symptoms of the disease (including difficulty concentrating, memory issues, and speech problems) are invisible to others but caused significant disruptions in many domains that were particularly important to AYA patients (eg, employment, family life, and autonomy). Additionally, the uncertainty regarding their life expectancy led to difficulties in making decisions about the future. They also perceived a lack of control over their future and the time they had left.

Conclusions. LGG have a significant impact on AYA patients. However, this impact is not fully understood by others close to them. The results highlight the importance of providing these patients with appropriate peer support, interventions tailored to both their disease and life phase, utilizing a multidisciplinary approach, and maintaining a focus on long-term support for these patients. It is crucial to provide AYA care for these patients within the neurology department, as LGG involve both tumor- and age-specific problems.

Keywords

adolescent and young adult oncology | daily life challenges | low grade glioma

The third most common type of cancer among adolescents and young adults (AYAs—defined as individuals 18–39 years old at primary diagnosis) is central nervous system (CNS) tumors. Despite improvements in surgical management and better outcomes with the addition of chemotherapy to radiotherapy, there is no curative treatment for most patients.[1–4] CNS tumors among AYA patients are distinctive and have different epidemiology (the frequency of the most common subtypes), tumor biology, and tumor location compared to pediatric or older adult patients.[1] Low-grade gliomas (LGG) are among the most frequently occurring CNS tumors in AYA patients,[5] and almost all grade II LGG present with an Isocitrate Dehydrogenase (IDH1 or IDH2) mutation. This mutation causes these tumors to progress gradually into an aggressive disease[6,7]; however, it is also associated with a relatively favorable impact on survival.[8–10]

Treatment options for LGG are primarily based on age, histopathological diagnosis, performance status, tumor location, residual tumor, molecular profile, and the patient's preference.[11,12] The primary treatment is surgical resection to safely

remove as much of the tumor as possible. Patients are often stratified into risk groups, with AYA patients who undergo gross-total resection primarily identified as low-risk due to their age. Generally, low-risk patients are managed with a wait-and-scan policy after resection.[11] For patients with residual tumors or tumor growth post-surgery, radiotherapy with chemotherapy is the mainstay of further treatment. A recent randomized phase 3 study with vorasidenib, targeting the IDH1 or IDH2 mutation, showed a prolongation of progression-free survival and time to the next intervention compared to placebo.[7]

Patients with LGG have a life expectancy of 5 to 15 years, resulting in significant uncertainty about their future.[13] Our previous analysis for the INVAYA study reported that living with an uncertain or poor cancer prognosis (UPCP) causes an ongoing confrontation with the disease and premature death among AYA patients, but also feelings of loneliness, a sense of grief about life, a loss of control over the future, and feeling inferior to others and self (no longer achieving things, not feeling useful, being dependent on other).[14] Normative milestones can no longer be met with certainty. Additionally, questions arise about how to spend the remaining time of one's life, as the future is limited but not necessarily short-term, and may sometimes be longer than expected.[13] The literature shows that illness insecurity (regarding prognosis, which results in a lack of structure) led to a reduced quality of life (QoL) and more psychological complaints among older, advanced cancer patients, as symptoms of anxiety, distress, and lower emotional functioning often develop.[15] Longitudinal studies have reported a low health-related quality of life among patients with LGG throughout the disease trajectory due to symptom burden, cognitive, psychological and social impairment, perceived health status, and reduced vitality.[5] Furthermore, the majority of patients with LGG experience epileptic seizures, which, if uncontrolled, significantly decrease their QoL.[16] Moreover, the majority of brain tumor patients suffer from death anxiety—more than those with other types of advanced cancer. Potential contributors to this include the decline these patients will experience, as well as the certainty of tumor progression.[17]

LGG are often accompanied by cognitive decline, which can be related to various factors, such as tumor location, comorbidities, fatigue, or the use of anti-epileptics. These factors can either cause or worsen these symptoms.[18,19] Epileptic seizures are common among patients with LGG, affecting at least 80% of them, and can lead to cognitive impairment. Optimal seizure management can be difficult to establish.[20] Anti-epileptics can cause a patient to gain weight, experience depressive symptoms or agitation, feel drowsy, or have difficulty concentrating.[12] Additionally, therapy modalities for LGG can be associated with cognitive impairment. Surgical treatment, for instance, is associated with motor problems, trouble speaking, behavioral alterations, or sensory issues. Radiotherapy can, in the long term, cause cognitive decline, as well as hearing and vision problems.[21] Cognitive problems, such as impairment in communication, attention, processing speed, or executive functioning, can result in reduced health-related quality of life and negatively impact daily functioning.[13,18]

The impact of LGG may be different for AYA patients, as the diagnosis can disrupt many domains of life that are important at the AYA age (eg, self-esteem, peer relationships, and future plans).[1] As cognitive impairment occurs during a crucial period of life when young people are shaping their future—building careers, romantic relationships, and families—it is important to identify the age-specific impact of LGG. This study aimed to provide insight into the challenges, experiences, and needs of AYA patients with LGG.

Methods

The Consolidation Criteria for Reporting Qualitative Studies Guideline was followed to ensure quality and transparency of reporting.[22] This study constitutes a secondary analysis of data derived from the INVAYA study, which has been reported previously.[14] INVAYA aimed to qualitatively examine the challenges, coping styles, and healthcare needs among AYA patients with a UPCP. These patients are diagnosed with advanced cancer and are likely to die prematurely from their disease; however, they do not face an immediate likelihood of death.[13] As INVAYA focused on all AYA patients with UPCP, the factors that may specifically impact patients with LGG did not prominently emerge from the results. For this reason, a sub-analysis was conducted, focusing specifically on patients with LGG. Ethics approval was obtained by the Institutional Review Board of The Netherlands Cancer Institute (IRBd20-205).

Sample

In-depth, semi-structured interviews were conducted among AYA patients with WHO grade II LGG. Two patients who were diagnosed with a high-grade glioma at the time of the interview were included. Their data were utilized as they were initially diagnosed with LGG, which had progressed to grade 3 or 4 by the time of the interview. Moreover, these AYA patients had lived with their tumors for several years. Participants were recruited from 4 Dutch University Medical Centers: Erasmus University Medical Center, Amsterdam University Medical Center, Maastricht University Medical Center, and Leiden University Medical Center. They were also recruited from the Netherlands Cancer Institute-Antoni van Leeuwenhoek, a comprehensive cancer center, and Haaglanden Medical Center, a nonacademic teaching hospital. Eligible patients were between 18 and 39 years old at diagnosis and were recruited via their healthcare professionals (HCP), who shared the study information with them. Participants signed an informed consent form, after which the interviews were scheduled.

Data Analysis

The interviews were conducted by a female psychologist and researcher (VB) and were audiotaped and transcribed verbatim in Dutch. A second researcher (MR) analyzed the interviews using QSR NVIVO software.[23] The analysis was based on the bottom-up thematic analysis from Braun and Clarke.[24] First, all interviews were reviewed twice,

and all textual information describing any type of impact, challenge, or need was highlighted (open coding). Two researchers (MR, WG) then reviewed the codes to consider which ones were AYA-specific until they reached a consensus. This was conducted by deciding which codes were age-specific and which factors would have a greater impact on AYA patients, given their young age and developmental phase of life. To clarify, excluded codes were (1) getting emotional when someone asks how I am doing, (2) others do not want to talk about death, (3) feeling let down by my body, and (4) I am getting used to the new situation. These were not age-specific and can be applicable to all (advanced) cancer patients. A subsequent analysis of the AYA-specific codes was conducted to identify overarching themes and sub-themes (axial coding). During the process of writing, the Dutch codes and quotes were translated into English (MR) and checked by the other authors. Descriptive statistics were used to determine the sociodemographic data, which was performed using SPSS version 29.0.

Results

Sixteen AYA patients with LGG were interviewed. Their characteristics are displayed in Table 1. Fourteen patients were diagnosed with an astrocytoma and 2 patients were diagnosed with an oligodendroglioma. Most patients were not receiving treatment at the time of the study and were on a "wait-and-scan" policy. Five themes were derived from the data. Quotes from the AYA patients with LGG that support the data are reported in Supplementary Material. The high-impact issues are represented in Figure 1.

Functional and Cognitive Impact of the Disease

Cognitive symptoms.—Cognitive symptoms and complaints interfering with daily life were reported by AYA patients with LGG. Patients noted that the tumor made them more blunt, less tidy, disorganized, and caused slower speech. Additionally, they reported concentration problems, particularly in social settings, which led to reading problems and fatigue. Patients also experienced word-finding problems and speech errors, which occurred more frequently when patients had been focusing for a long time. They tended to be forgetful, had memory issues, difficulty with numeracy, and struggled with multi-tasking. Other symptoms included hearing impairment and emotional volatility. Upon experiencing these symptoms without a clear explanation, patients had to adjust their mindset after learning that these symptoms were caused by a brain tumor (1.1.1). They also found it emotionally challenging to compare their current abilities to their pre-disease functioning, thus realizing the extent of their impairments (1.1.2).

Epilepsy.—Epilepsy primarily affected patients' independence and resulted in more cognitive complaints. The fear of seizures led to dependency on others, as patients were reluctant to leave the house and were not allowed or afraid to drive a car. Patients also feared having seizures in front

Table 1. Sociodemographic Characteristics of AYA Cancer Patients With LGG

	N (%)
Mean age at diagnosis	29.4 (SD 5.6) Range 20–39
Mean age at study	33.2 (SD 5.6) Range 23–43
Sex	
Male	9 (56.3)
Female	7 (43.7)
Marital status	
Single	2 (12.5)
With partner	14 (87.5)
Employment status	
Unemployed	1 (6.3)
Full-time employed	6 (37.5)
Parttime employed	4 (25.0)
On sick leave	3 (18.7)
Work disability	2 (12.5)
Living situation	
With partner	6 (37.5)
Partner and children	8 (50.0)
Alone	1 (6.3)
With parents	1 (6.3)
Educational level	
No education or primary education	2 (12.5)
Secondary (vocational) education	7 (43.7)
Higher (vocational) education	5 (31.3)
University	2 (12.5)
Diagnosis	
Astrocytoma	14 (87.5)
Oligodendroglioma	2 (12.5)
WHO grade	
1	0 (0.0)
2	14 (87.4)
3	1 (6.3)
4	1 (6.3)
IDH-mutation	
Yes	15 (93.7)
No	1 (6.3)
Primary treatment*	
Resection	16 (100)
Radiotherapy	6 (37.5)
Photon therapy	3 (18.7)
Proton therapy	3 (18.7)
Chemotherapy	6 (37.5)
Re-resection	4 (25.0)
Wait and scan	2 (12.5)
Treatment at time of study*	
Experimental targeted therapy	1 (6.3)

Table 1. Continued

	N (%)
Chemotherapy	4 (25.0)
Wait and scan	10 (62.5)
Radiotherapy	1 (6.3)
No treatment	1 (6.3)
Treatment goal according to patients*	
Prolong my life (keep disease under control)	16 (100)
Curation	3 (18.7)
Treatment goal according to the physician*	
Prolonging life (keep disease under control)	15 (93.8)
Symptom management	3 (18.7)
Curation	0 (0.0)
Years post-diagnosis	Median 27 months
<1 year	4 (25.0)
1–5 years	8 (50.0)
5–10 years	4 (25.0)

*Participants were allowed to select multiple answers.

of others. The decision to not have children was influenced by epilepsy, as it felt unsafe to take care of a baby while dealing with seizures (1.2). Others were unable to work due to this condition, as it could cause dangerous situations. Anti-epileptics caused mood swings, agitation, and anger, as well as fatigue. Due to the medication, patients were advised to avoid alcohol.

Feeling dependent on others.—The disease reduced patients' ability to undertake activities independently and left them reliant on others, resulting in a reduced sense of control over their lives. It appeared to be emotionally difficult at this young age to be dependent on the care of others and to be monitored by them, as finishing tasks was more complicated due to the cognitive symptoms (1.3). Also, partners often had to create daily routines for the patients. They relied on others for transportation, which affected their ability to engage in activities like sports or picking up their children. Patients who were still allowed to drive found the annual examinations for their driving licenses very stressful, as the results could significantly impact their autonomy. The isolation caused by their diminished social and work life led to feelings of irritability and loneliness.

Physical changes.—The physical symptoms caused by the disease complicated daily and social activities. Patients' reduced energy levels led to anxiety and uncertainty about the future improvement of these symptoms (1.4), often necessitating the discontinuation of work and interruption of previously enjoyed activities (eg, seeing friends). Treatment sometimes resulted in weight gain. Physical discomfort frequently caused patients to express frustration towards family members, which they later regretted. Additionally, some patients experienced motor function disorders.

Dealing With a Changed Future

Changed future for patients.—The disease and its prognosis limited the future that AYA patients had planned for themselves before their diagnoses. The lack of a gradual progression into an incurable disease phase could be emotionally jarring. One patient described the immediate challenge of facing mortality, causing life to come to a sudden halt. Chemotherapy-induced infertility and treatment advice from HCP made starting or extending a family less likely (2.1). Patients were unable to pursue their desired careers, secure permanent job contracts, change jobs, or start businesses. Daily life often revolved around household tasks and medication schedules. The uncertain prognosis prevented participants from obtaining mortgages and buying houses, while income loss hindered home renovations.

Changed future for a partner.—Partners of AYA patients with LGG faced additional challenges and changes in their future because of the disease. An unequal relationship developed, where the patient required care, and dependency on their partner would only increase. Partners had to determine their caregiving capacity, facing long-term, significant burden. Decisions about starting their own family (2.2) and managing life after the patient's death were necessary. Partners needed to balance caregiving tasks alongside their busy family lives and careers, and deal with the financial burden and consequences after bereavement.

Uncertainty about the future.—AYA patients found it challenging to make future decisions due to the uncertainty of their prognosis. They knew their life would likely be limited by the disease but hoped for new treatments that might extend their life expectancy. Patients hoped to grow old and questioned if they would really die prematurely. However, dreaming about the future was hard, as most patients were facing the reality of premature death. The long prognosis (2.3.1) and the term "incurable illness" were burdensome. Although these patients might feel well for a long time, a negative scan could abruptly confront them with their disease, treatments, side effects, and prognosis. Patients also struggled with the prospect of physical and cognitive decline, unsure when it would occur and how severe the impact would be. They faced the ethical dilemma of whether to have children (2.3.2), considering how their premature death could impact their families. Patients reported reduced work hours to spend more time with family; however, being employed was also necessary for financial considerations. At the same time, being employed was a type of daytime activity and part of living a normal life. Additionally, the uncertain prognosis made decisions like pursuing education more challenging, as, with a normative life expectancy, they would have been eager to take the opportunity but had to re-evaluate their priorities for spending their time in the face of a shortened life span.

Social Impact

Family life.—These issues were mainly related to continuing family life and involving the children. Parental

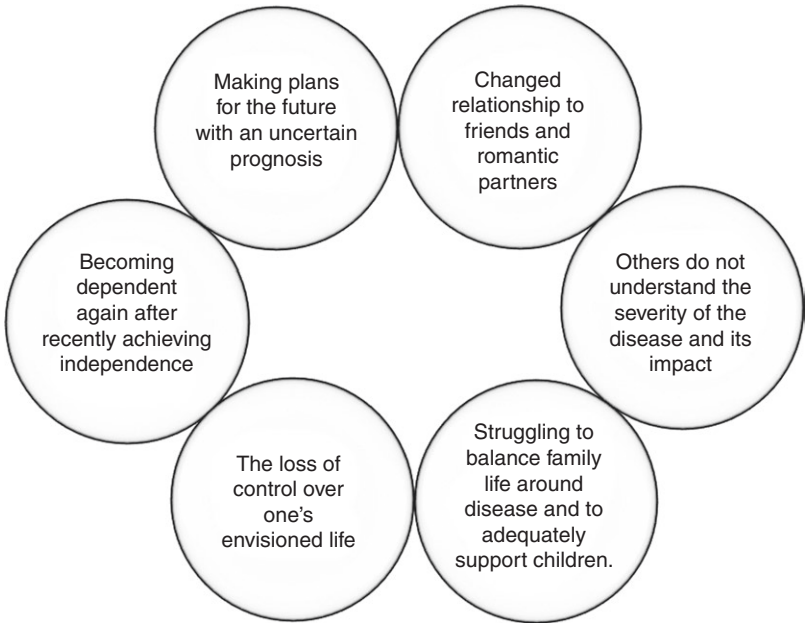

Figure 1. High-impact issues for AYA patients with LGG.

responsibilities often required patients to prioritize these duties over their own physical symptoms, such as fatigue, which became especially difficult when caring for young children (3.1). Integrating treatment schedules and coping with side effects posed significant concerns for patients, with one mentioning the need to coordinate treatment around their partner's pregnancy and childbirth.

Employment.—Most AYA patients with LGG in this study remained employed (Table 1). Sometimes, it was difficult to continue working post-treatment and participating in a re-integration program could be necessary. When these programs were unavailable, patients had to arrange them independently, which could be exhausting. For instance, one patient, eager to prove his work capabilities despite his disease, pushed himself upon returning to work. Participants were forced to accept positions below their skill level, with no opportunity for promotion. One patient even declined treatment to avoid cognitive side effects, prioritizing work. Changing jobs was often impossible due to difficulty learning new tasks, and some patients had to leave work because of severe cognitive symptoms and task management issues. Others could not return to work due to their treatment schedule or physical symptoms (3.2), leading to contract termination.

Romantic relationships.—Patients in romantic relationships were worried about the impact of the disease on their partner. Relationships in the early stages did not always withstand the impact of the disease and sometimes ended. One AYA patient felt that multiple partners were unable to handle the situation, causing him to end those relationships (3.3). Other AYA patients mentioned that their relationships with their partners had strengthened because of the disease. Patients without partners wondered what dating would be like in this new situation, worried about what to disclose to potential new partners and when to tell them about their disease.

Relationship to parents.—AYA patients with LGG often had different coping styles than their parents. They felt that their parents were overly concerned, making them feel less like adults. Furthermore, AYA patients indicated that their parents were more emotional, leading to conflicts as the patients were less focused on end-of-life issues. Patients were agitated when parents wanted to discuss different topics during consultations (eg, alternative treatments) or interfered in conversations with physicians (3.4). One AYA patient reported that their in-laws appeared more concerned with the experience of the patient's spouse and care partner, rather than the patient's own well-being. Patients were hesitant to share their emotions with their parents to avoid burdening them and withheld information. They mentioned that their parents provided financial support, helped them to avoid overstimulation, and assisted with household tasks.

Relationship to peers.—Friends often did not understand the impact of the disease because the patient looked well, and also did not comprehend the severity of the health situation until progression occurred. They perceived the disease as intangible and had not been through a similar situation. AYA patients sometimes felt isolated, as they no longer felt like the same person, and not everyone was understanding (3.5.1). Cognitive complaints, such as handling noises and large crowds, complicated socializing with

their friends. Slower speech also affected their ability to interact with others at the same level and speed. Patients' reduced energy was difficult for others to understand, especially since friends preferred evening meetups when patients were often too tired. However, canceling plans was burdensome, making patients feel like they were letting their friends down. It was difficult for AYA patients to accept that they were not able to do as much as their peers (3.5.2). Their social life decreased because some patients were no longer able to work or play sports, leading to feelings of loneliness. It was helpful to share experiences with others, but many support groups included older patients who were in a different life phase. One patient suggested that young patients with other neurodegenerative disorders could be appropriate peers but were often overlooked.

Difficulty Regarding End-of-Life

Treatment decisions.—Patients found it difficult to determine how long to continue treatment. Treatment options vary, requiring frequent decisions to be made throughout their long disease trajectory. Due to their young age, patients often wanted to prolong treatment to maximize their life expectancy and to feel like they had tried everything possible. Patients with children, in particular, wanted to extend treatment to see their children grow up, remarking that they might have declined treatment sooner if they did not have children (4.1). Having a family often led patients to start treatment earlier, instead of waiting for tumor progression. Thus, social circumstances significantly impacted treatment decisions.

Fulfillment of Life

Patients reported enjoying the remaining time more consciously, aware of their shortened life expectancy. They were less likely to procrastinate, prioritizing activities they enjoyed and achieving certain milestones (eg, traveling with their family). They often expressed gratitude for the time they had left. In contrast, some AYA patients reported feelings of a lack of accomplishment and maturity compared to their peers due to missing key milestones (4.2). Their prognosis created a sense of urgency, prompting patients to experience as much as possible. One patient, despite aiming for the maximum life expectancy, felt like there was still too little time to do everything they wanted. Additionally, patients mentioned difficulty in accepting their premature mortality.

Taking control by anticipating the future.—AYA patients sometimes focus on arranging matters (eg, their funeral) to regain control of their situation. This was burdensome due to their young age (for example, having to arrange euthanasia or discuss death-related topics with their young partners). AYA patients often offered their partner a way out after diagnosis (4.3), allowing the partner to live their lives and possibly start a family with someone else. Patients were concerned with ensuring their partners and children were taken care of after their death. They also thought about how they would be remembered and created video footage (for example, by participating in a television program).

Children.—Having young children increased the impact of an uncertain prognosis for AYA patients. They found it burdensome not to see their children grow older and worried their children might not remember them. Patients also struggled with their children witnessing their physical and cognitive decline (4.4.1). It was challenging to cope with their children's worries, fear of losing the patient, and anxiety about the scan results, while also dealing with their own emotions. At times, their children refrained from expressing their worries to avoid burdening the patient any further. Determining how much information to share with their children was challenging, as patients wanted to avoid upsetting them (4.4.2). In addition, AYA patients often focus on the future of their families.

Healthcare Needs

AYA patients with LGG expressed varying healthcare needs, which also changed throughout their disease trajectory. They sought support for their children (5.1) and specialized AYA care, which they felt should be offered more frequently. Patients also wanted support for cognitive decline, guidance on fertility, and decisions about pregnancy. They indicated it would be helpful to have a case manager available for discussions and practical support upon the patient's request. Psycho-education for loved ones was deemed essential to manage their understanding and expectations of the patient. AYA patients sometimes utilized oncological rehabilitation, but this was not universally available. However, it was perceived as beneficial for energy management, reducing overstimulation, post-surgery support, and addressing the needs of young patients with LGG. Patients appreciated rehabilitation as it considered both cognitive function training and physical recovery after surgery.

Discussion

The impact of LGG and their treatment on AYA patients is significant. Cognitive symptoms often disrupt crucial life aspects: necessitating adjustments or discontinuation of employment, changes in the relationship with partners, and caring for children can be challenging. Moreover, some patients decided against having children due to their prognosis or comorbidities. The cognitive symptoms are often inadequately recognized by others, leaving the AYA patient to suffer from this "invisible impact" on their own. The uncertain prognosis of LGG complicates future decision-making and induces feelings of losing control over their life. Patients also indicated a lack of support for age-specific issues, cognitive symptoms, rehabilitation, and care for their family members. Many of these themes are common among AYA patients with UPCP, as observed in the INVAYA study. The cognitive impact and decline are

more specific to patients with LGG and require a distinct approach to support these patients.[14]

Cognitive impairment significantly impacts these young patients, which is similar to those of early-onset dementia (EOD) and young-onset Parkinson's Disease (YOPD). These patients, typically older than AYA patients, reported that the disease threatened their identity, autonomy, professional role, relationships with loved ones, and sense of self. Being dependent on others was also perceived as challenging, as they had to burden their informal caregivers.[25,26]Therefore, it is recommended to identify a patient's fears before acute treatment. Social support for patients with brain tumors mainly revolves around experiencing a similar impact of the disease, regardless of the underlying condition.[27] AYA patients with LGG could benefit from being paired with patients who have other neurodegenerative diseases. Well-functioning support groups provide information, resources, and psychological support.[28,29] HCP treating young patients with LGG, as well as those treating young patients with neurodegenerative disease, could strive to identify mutual challenges in both patient groups to deliver appropriate healthcare and support.

Aside from the cognitive impact, a focus on age-specific needs is crucial as the disease affects many aspects of life during a key developmental phase.[1,30] However, AYA patients are less familiar with the healthcare system. It is therefore advised to train one or more neurology nurse specialists to develop AYA expertise and provide specialized care, addressing disruptions in patients' employment, education, family, and social life. Neurologists and neurology nurse specialists doubt their capabilities to support these patients throughout their long disease trajectory, and education can equip them with the necessary communicative and psychosocial knowledge and skills.[31] Since patients with LGG are often treated in neurology rather than medical oncology departments, AYA-specific care should be tailored to the neuro-oncology setting to ensure they receive appropriate attention and care.

There are various interventions, some tailored for AYA patients, addressing themes encountered by participants in this study: treatment preferences, support, future planning, spirituality, and legacy considerations by loved ones.[32–34] For example, managing cancer and living meaningfully (CALM) has been shown to be adequate, acceptable, and useful for lowering death anxiety in patients with brain tumors.[34,35] Cognitive rehabilitation was mentioned as helpful, and was proven effective in improving attention, memory, as well as QoL. However, it was not available to all patients.[36,37] A focus on self-management could be applicable, to help patients adjust to their situation and to feel able to deal with psychological issues and cognitive impairment.[38] EOD literature indicates that there should be support focused on family, addressing the financial, psychological, and social needs of informal caregivers, partners, and children.[39] HCP could be informed on how to refer patients to social services for benefits and job opportunities.[40] It is important to tailor support to the individual, as the severity of symptoms may vary between individuals, but may also change over time.[38]

To provide comprehensive care and referrals, it is advised to enhance connections between disciplines (including nurse specialists, medical specialists including the general practitioner (GP), psychosocial support, and palliative care professionals) as this addresses the physical, social, emotional, and practical needs. Literature on adolescent-onset epilepsy emphasizes the importance of this multidisciplinary focus, also involving informal caregivers, the educational system, and society. This causes patients to feel empowered and understood beyond their disease-related issues.[29] GPs could continuously manage the psychosocial and general physical symptoms of patients with prolonged, incurable cancer, with additional education to adequately support these patients.[41] Integrating standard care with early palliative care can enhance QoL and functional capabilities. However, as patients may live long and may have very few symptoms, it can be a challenging decision when to initiate this care.[42,43] The Dutch Neuro-Oncology Society Investigators created information and recommendations for symptom management for patients with brain tumors during the end-of-life phase. This could be a first step in informing the network of the patients, such as their informal caregivers or the GP.[44]

This study qualitatively examined the daily life impact of LGG on AYA patients, analyzing affected aspects without making any prior assumptions. However, patients may be unaware of the impact of their diagnosis due to the gradual nature of changes in their health or cognitive impairment. Partners often provide more accurate insights during consultations, as they may take over tasks from the patient, leading to uncertainty about the extent of the patient's impairment. Therefore, assessing the impact solely from the patient's perspective can be challenging. Future studies should incorporate partners' perspectives to identify additional challenges and evaluate the support available for loved ones. The erratic course of the diseases, seizure occurrence and management, the received treatments, and the degree of cognitive impairment should be examined in follow-up studies, using larger samples, to identify group differences. In addition, since only Dutch patients were interviewed, the results—especially those regarding healthcare, and financial and social support—may not be fully generalized to other national populations.

Conclusion

This study shows a significant impact of LGG on the daily lives of AYA patients. The disease affects multiple domains, including physical, cognitive, psychological, and social aspects. There should be a greater focus in healthcare for AYA patients on recognizing age-specific elements, providing timely support across all affected domains, and offering guidance through the often-prolonged disease trajectory marked by decline. Additionally, within existing AYA care, a distinct emphasis should be placed on patients with LGG, given their unique disease trajectory compared to AYA patients with other tumor types. AYA healthcare providers may benefit from specialized training to improve healthcare for this group, and could also consider the impact of other young patients with neurodegenerative diseases for peer support initiatives. Moreover, it may be important to support patients' loved ones and provide them with psycho-education, as they

are an essential source of support for patients but may sometimes lack understanding of the impact of the disease on their loved ones.

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We report no conflict of interest for all authors.

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