

A Qualitative Systematic Review of the Experiences and Needs of Patients With Gliomas

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PROBLEM IDENTIFICATION: With poor prognosis and debilitating symptoms, gliomas affect not only patients' physical health, but also their psychological well-being. A systematic review was conducted to explore the experiences, needs, and coping mechanisms of adult patients with gliomas.

LITERATURE SEARCH: A literature search was performed in Cochrane Library, PubMed®, Embase®, MEDLINE®, Scopus®, PsycINFO®, CINAHL®, CNKI, and Wan Fang for studies published from January 1999 to December 2019.

DATA EVALUATION: The selected studies were assessed by two independent reviewers to determine methodologic quality. Meta-aggregation was used to synthesize the findings.

SYNTHESIS: Three overarching themes were developed: (a) the impact of gliomas on daily life, (b) emotional changes, and (c) the recognized need to move on. Findings from each study were categorized into 12 subthemes.

IMPLICATIONS FOR PRACTICE: The findings from this systematic review provide data related to the experiences of patients with gliomas, which can inform practice changes and interventions aimed at enhancing patients' quality of life.

KEYWORDS gliomas; living experiences; quality of life; symptom burden; qualitative research

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Gliomas are the most common form of primary intracranial tumors, representing 81% of malignant brain tumors. Although relatively rare, gliomas are a life-threatening tumor, with five-year survival rates ranging from 0.05% to 4.7% (Ostrom et al., 2014). Gliomas differ from other types of brain tumors because of the high rate of recurrence (Felsberg et al., 2017) and the severe symptom burden caused by invasive growth into the surrounding brain tissue (Piil et al., 2019). Symptoms, which can vary depending on the tumor's size, location, and classification (Hricik et al., 2011), can be physical (e.g., headaches, hemiparesis, aphasia, seizures), psychosocial (e.g., stress, anxiety, depression), or cognitive (e.g., personality changes, concentration problems, reduced attention span, short-term memory loss) (Piil et al., 2015). According to the World Health Organization's grading of selected central nervous system tumors, gliomas can be divided into four grades based on their histology and isocitrate dehydrogenase status (Louis et al., 2016). Treatment for gliomas mainly includes surgery, radiation therapy, chemotherapy, pharmacotherapy, and tumor treatment field therapy (National Comprehensive Cancer Network [NCCN], 2020).

Throughout disease progression and treatment, patients with gliomas can be highly affected by the diagnosis, various and increasingly severe symptoms (e.g., fatigue, aphasia, hemiplegia, headaches, reduced consciousness), and treatment complications (Flechl et al., 2013). Cognitive functioning can deteriorate as a result of gliomas, as well as from subsequent treatment by means of surgery, radiation therapy, or chemotherapy, with or without concomitant medication. In addition, patients often experience emotional distress (Klein et al., 2002; Taphoorn & Klein, 2004). Although results from previous studies vary, 21%–39% of patients with gliomas suffer from clinically significant symptoms of depression (Rooney et al., 2014;

Zhang et al., 2019). As a result, the physical and neurocognitive effects of gliomas and treatment can compromise a patient's ability to maintain relationships, perform social roles, and stay engaged in valued social activities. These side effects put patients at risk of social isolation and loneliness, which have been associated with reduced psychological and physical health (Klein et al., 2001).

Therefore, it is important to gain a better understanding of how patients experience and cope with a glioma diagnosis, as well as its effects on associated life experiences and personal and social adjustment, and the information support needed by patients. Previous studies have explored the experiences of patients receiving treatment for different types and grades of glioma (Bennett et al., 2016; Cavers et al., 2013; Vedelø et al., 2018), but these studies examined the patient experience from different perspectives and did not provide a comprehensive understanding of the unique experiences and needs of patients with gliomas. Sterckx et al. (2013) conducted a systematic review of the effects of high-grade gliomas (HGG) on everyday life from the perspectives of patients and caregivers, but the review primarily focused on the feelings and the needs of patients and caregivers and did not include coping strategies that patients could apply in the future. Patients with low-grade gliomas (LGG) have better outcomes compared to those with HGG, but their quality of life is often affected by a variety of symptoms to the same extent as those experienced by patients with HGG (Moore et al., 2013).

There is a lack of empirical evidence on the needs and experiences of patients with gliomas and strategies to help them achieve a better quality of life. This article aimed to systematically review, appraise, and synthesize the evidence on the experiences (emotional, suffering, and coping) of patients with gliomas and provide a set of practical implications to assist healthcare providers in supporting these patients.

Methods

Design

This systematic review was designed as a qualitative meta-synthesis based on guidelines from the Joanna Briggs Institute (JBI) (Lockwood et al., 2017). The Cochrane Library, PubMed®, Embase®, MEDLINE®, Scopus®, PsycINFO®, CINAHL®, CNKI, and Wan Fang databases were searched to identify qualitative studies that explored the lived experiences and information needs of patients with gliomas. All included studies were critically appraised using the standard JBI Critical Appraisal Checklist for Qualitative Research.

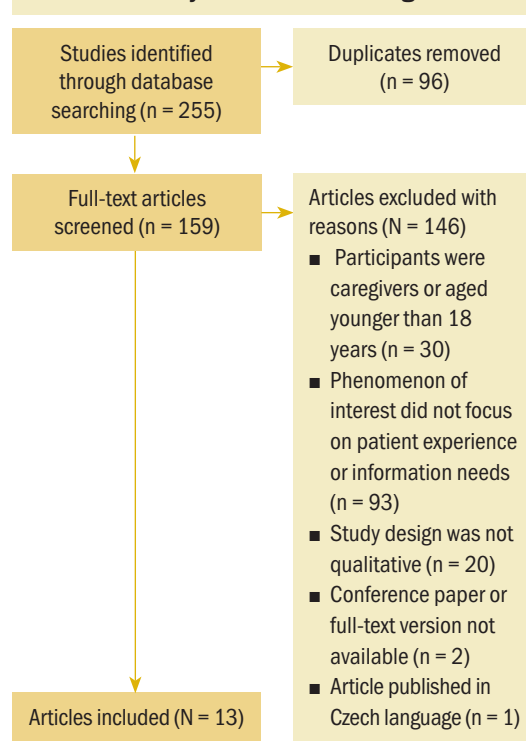
A meta-aggregative approach was used to synthesize the qualitative evidence extracted from the studies.

Meta-aggregation, which originated from the transcendental phenomenology of the interpretive philosophical perspective of Husserlian phenomenology (Hannes & Lockwood, 2011), was used to systematically identify and assimilate all relevant qualitative research exploring the topic. Meta-aggregation aims to examine the essence of texts in a valid manner by maintaining the original meaning and avoiding reviewers' influence on the text. This approach allows for a review of qualitative evidence across different studies (Paterson, 2012), produces a generalizable statement to inform health policymakers and practitioners, and is sensitive to the nature and traditions of qualitative research (Pearson, 2004). Compared to other qualitative approaches, meta-aggregation focuses on the practicality and usability of the primary research findings and does not seek to reinterpret those findings (Lockwood et al., 2017).

Inclusion and Exclusion Criteria

Studies were included if they (a) consisted of male or female patients diagnosed with gliomas and aged 18 years or older; (b) focused on patients'

FIGURE 1. Study Selection Flow Diagram



experiences, including needs, emotional experiences, disease experiences, and coping strategies; (c) took place in any setting, such as inpatient or outpatient departments, meeting rooms, patients' homes, or in an outdoor setting; and (d) used a qualitative research design, including, but not limited to phenomenology, grounded theory, ethnography, and narrative approaches. Studies that included patients and caregivers were considered if their experiences were reported separately. Mixed-methods studies were also considered if qualitative findings were reported separately. Duplicate studies, abstracts, and studies published in languages other than Chinese or English were excluded.

Search Strategy

Publication dates ranged from January 1999 to December 2019. An initial limited search was conducted using PubMed, followed by analyses of the titles, abstracts, and index terms used to describe each study. This informed the development of a search strategy, which was then tailored for each database. Search terms included *glioma, neuroglioma, neurospingioma, quality of life, health-related quality of*

life, experiences, living, well-being, information, information need, psychology, stress, psychological, psychology, empirical research, qualitative research, grounded theory, hermeneutics, and interpretive. Boolean operators and various combinations were used to search the full extent of the literature.

Following the database search, all identified studies were collated and uploaded into EndNote X7, and duplicates were removed. Titles and abstracts were screened by two independent reviewers to assess eligibility according to inclusion and exclusion criteria. A total of 255 studies were identified. After screening, 13 studies were included in the final review. The study selection process is detailed in Figure 1.

Quality Appraisal of Selected Studies

The JBI Critical Appraisal Checklist for Qualitative Research was used to assess the methodologic quality of the studies (Lockwood et al., 2017). The appraisal process was conducted by two independent reviewers who had completed evidence-based nursing training, and any differences of opinion were resolved through discussions. The results of the critical appraisal of the

TABLE 1. Quality Appraisal of Selected Studies

Study	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Score
Amano & Suzuki, 2019	U	U	U	U	U	U	U	U	U	U	10
Bennett et al., 2016	U	U	U	U	U	C	C	U	U	U	9
Cavers et al., 2012	U	U	U	U	U	US	C	U	U	U	8.5
Cavers et al., 2013	U	U	U	U	U	US	C	U	U	U	8.5
Edvardsson & Ahlström, 2005	U	U	U	U	U	US	US	U	U	U	8
Fahrenholtz et al., 2019	U	U	U	U	U	C	U	U	U	U	9.5
Halkett et al., 2010	U	U	U	U	U	US	U	U	U	U	9
Hayhurst et al., 2011	U	U	U	U	U	US	US	U	U	U	8
Lobb et al., 2011	U	U	U	U	U	US	U	U	U	U	9
Philip et al., 2014	U	U	U	U	U	US	C	U	U	U	8.5
Sterckx et al., 2015	U	U	U	U	U	US	US	U	U	U	8
Vedelø et al., 2018	U	U	U	U	U	US	U	U	U	U	9
Yuqin et al., 2018	U	U	U	U	U	U	US	U	US	U	8

C—credible; Q—question; U—unequivocal; US—unsupported

Note. Based on the Joanna Briggs Institute Critical Appraisal Checklist for Qualitative Research (Lockwood et al., 2017). For each question, studies received a score of 0 (findings not supported by the data), 0.5 (findings lack a clear association with the data), or 1 (findings are beyond a reasonable doubt), with a total higher score indicating a lower risk of bias.

TABLE 2. Study Characteristics

Study	Methodologic Approach, Participants, and Setting	Phenomenon of Interest	Findings
Amano & Suzuki, 2019	A grounded theory study of 10 participants using semistructured interviews in a private room in Japan	The process of life adjustment in patients who continuously receive oral anticancer drugs	Seeking information on the life-threatening disease; imagining the uncertainty of life following diagnosis and resulting symptoms; conducting repeated trial and error to establish coping methods based on ability; losing self-confidence because of unexpected limitations; feeling resigned to the unchangeable reality; feeling enhanced motivation to recover based on functional improvement; fulfilling wishes within a limited lifespan
Bennett et al., 2016	A thematic analysis of 14 patients using face-to-face semistructured interviews in a cancer center department in the United Kingdom	The impact of headaches on quality of life	Underlying determination and positivity; headaches that subsequently affected social situations; headaches that acted as a psychological springboard for negative thoughts about the patient's condition or the future
Cavers et al., 2012, 2013	A grounded theory study of 26 participants (n = 2 with HGG and n = 2 with LGG; the grade of glioma was unknown for 22 participants) using in-depth qualitative interviews in the home or hospital setting in the United Kingdom	Patients' and their families' emotional experiences of illness, information and support needs, and their impact on adjustment from diagnosis to bereavement	Distress, anxiety, and worry prior to and following diagnosis; variations and timing of information preferences; the importance of reassurance, support, and hope; dynamic physical trajectory; dynamic social trajectory; dynamic psychological trajectory: uncertainty, concerns about life expectancy, and anxiety; dynamic existential trajectory: adjust priorities, have a firm faith in God, and prepare for and accept the possibility of dying
Edvardsson & Ahlström, 2005	A content analysis of 39 patients with LGG using semistructured interviews in the home, work, or hospital setting in Sweden	Describe perceived illness-related problems in patients with LGG and the coping used in everyday living	Perceived illness-related physical, psychological, and communication issues; coping strategies
Fahrenholtz et al., 2019	A phenomenologic study of 5 participants using semistructured interviews in the home, work, or hospital setting in Denmark	The experience of patients recently diagnosed with a life-threatening disease in a rehabilitation program using coping and motivational theories	Coping with a new life situation; motivating self and maintaining life; experiencing benefits from rehabilitation programs
Halkett et al., 2010; Lobb et al., 2011	A grounded theory study of 19 patients with HGG using semistructured interviews at home or in another location in Australia	Patients' information and support needs during the course of their disease	Feelings of uncertainty; the need for information; dependence on caregiver; communication with healthcare professionals; shock at hearing the diagnosis; trying to understand and process information on prognosis while in shock; loss of hope; individualizing prognostic information; clinicians' communication skills
Hayhurst et al., 2011	A grounded theory study and thematic analysis of 24 patients with LGG using semistructured interviews held in a private room in Canada	Impact of a diagnosis from the patients' perspective to understand the physical and emotional burdens of a long-term disease without cure	Experiences of initial devastation followed by acceptance and decreased anxiety; absence of symptoms decreases anxiety about the possibility of progression; preference to defer surgery until there is progression or a change in quality of life; anxiety is reduced by trust in the physician; quality of life is not affected by the diagnosis because fear of morbidity is greater than fear of uncertainty.

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TABLE 2. Study Characteristics (Continued)

Study	Methodologic Approach, Participants, and Setting	Phenomenon of Interest	Findings
Philip et al., 2014	An exploratory qualitative analysis of 10 patients with HGG using in-depth interviews in the home, hospital, or hospice setting in Australia	Understanding patients' experiences at the end of life and documenting their support and palliative care needs	Impending loss and decline; loneliness and isolation; coping day to day; perceived focus of healthcare professionals; waiting and uncertainty
Sterckx et al., 2015	A grounded theory study of 17 patients with HGG using semistructured interviews in the hospital or home in Belgium	Patients' experiences with life and their professional care needs	Shock at diagnosis; uncertainty and anxiety; fear of leaving relatives; feelings of disregard; staying optimistic; hearing positive, hopeful, and encouraging words from caregivers
Vedelø et al., 2018	A hermeneutic phenomenologic case study of 4 patients using structured interviews, informal conversational interviews, and direct observations in the hospital setting in Denmark	Patients' experiences and care needs throughout the diagnostic phase of an integrated brain cancer treatment pathway	Information needs; balancing hope and reality while trying to perceive the unknown reality of cancer; not knowing what to expect; perceptions of the relationship with healthcare providers
Yuqin et al., 2018	A qualitative study of 8 patients with HGG using semistructured interviews in the hospital setting in China	The postoperative disease experiences of patients with glioblastoma multiforme	Lack of confidence in treatment; fear of separation from relatives; changes in social adaptability and reluctance to communicate with others; hope and acceptance of the poor prognosis; desire for survival and realization of self-worth

HGG—high-grade glioma; LGG—low-grade glioma

selected studies are presented in Table 1. All studies assessed achieved scores of 8 or higher, indicating a low risk of bias (Lockwood et al., 2017).

Data Extraction

The JBI Qualitative Assessment and Review Instrument was used to extract information from the studies. The extracted data included specific details about geographic location, context, phenomenon of interest, methodologic approach, data collection method, and participants. Two independent reviewers read all studies several times to obtain a clear overall understanding of each study. Because two studies included the same participants with the same methodologic approach (Cavers et al., 2012, 2013), the data were merged into a single set of information in the synthesis table, similar to two additional studies by Halkett et al. (2010) and Lobb et al. (2011). Sixty individual findings were identified from the selected studies, and level of credibility was allocated based on the perception of the degree of support each study offered for the specific finding with which it was associated. A summary of study

characteristics and findings for each study are presented in Table 2.

Data Synthesis

The findings were pooled using the JBI System for the Unified Management of the Assessment and Review of Information, with a meta-aggregation approach being used to integrate the findings. This involved synthesizing the findings to generate a set of statements that represented the aggregation. Findings were assembled and rated according to their quality and categorized according to similarities in meaning. The categories were subjected to a meta-synthesis to produce a single comprehensive set of synthesized findings that could be used for evidence-based practice. At each stage of the process, the authors returned to the original literature and compared their understanding and interpretation of the data, resulting in the establishment of overarching themes and subthemes based on the original study context and study results. The understanding of each finding was based on the participants' own words to ensure the reliability of the synthesis.

Findings

Findings from the selected studies were aggregated into 3 overarching themes and 12 subthemes that reflected similar meanings and dimensions of the experiences of patients with gliomas (see Figure 2). The three overarching themes were (a) the impact of gliomas on daily life, (b) emotional changes, and (c) the recognized need to move on.

Theme 1: The Impact of Gliomas on Daily Life

A series of symptoms among patients with gliomas were observed, such as headaches, memory deterioration, and movement limitations. These unexpected symptom experiences required patients to adjust their priorities and react accordingly to the effects of the illness on their social life.

The impact of symptoms: The most common symptoms that affected patients' lives were headaches, memory loss, seizures, and cognitive decline. These symptoms, particularly headaches and seizures, were a source of anxiety in daily lives of patients and also affected patients' sleep: "They may possibly have been part of the reason that I wasn't sleeping properly because they were part of the reason I wasn't feeling great" (Bennett et al., 2016, p. 5). The severity of symptoms also affected patients' emotions, with some patients correlating the symptoms with disease severity and being vigilant about every symptom they felt: "I worry that it's changed, but I focus more on the symptoms" (Hayhurst et al., 2011, p. 258). Cognitive symptoms can have a substantial impact on patients' strength, mobility, communication, understanding, behavior, and appearance, and problems with memory, speech, and language were particularly distressing: "I can see you being annoyed with the situation intensely because you can't think of the right word" (Cavers et al., 2012, p. E376). Symptoms, such as fatigue, imbalance, memory loss, and cognitive decline tended to increase in frequency and severity over time, causing patients to lose their self-care ability (Cavers et al., 2012).

The impact on social life: Although patients wanted to return to normal life, diagnosis, treatment, and rehabilitation substantially disrupted their lives, and the effort of socializing posed a barrier. In a study by Cavers et al. (2012), one participant said, "We stopped doing that because it's . . . like, the pubs and all that sort of stuff, just gave up that because you cannot really get into that at all" (p. E376). Unpredictable symptoms can be detrimental to patients' self-esteem in social situations because they do not want others

to worry too much. For example, some patients in the studies reviewed complained of the effects of unexpected headaches and fatigue on their social life: "You kind of feel like you're a bit disconnected, like you can't think properly, and it's hurting" (Bennett et al., 2016, p. 4).

Theme 2: Emotional Changes

Patients with gliomas experienced considerable emotional mood swings and negative psychological changes from the time of diagnosis to end of life. Fear and loss of hope were the most evident psychological issues reported by patients.

Fear: Patients expressed feelings of fear when they realized the seriousness of the disease. After seeking information about gliomas, patients became extremely scared by this life-threatening illness, with one participant in a study by Amano and Suzuki (2019) describing his experience as follows: "At first, I could not understand the disease, and I was optimistic about it. . . . Recently, I was able to look it up on the internet, et cetera, and I found that the disease is very serious" (p. 136). Sometimes, patients feared the symptoms of the disease more than the disease itself:

It felt to me almost [as] if I was having the start of a seizure . . . just a bit of a shuddering in my head and wanting to just be lying down, but never ever lost consciousness or anything like that. . . . I was scared; I was very scared. (Cavers et al., 2012, p. E376)

FIGURE 2. Themes and Subthemes Developed From Selected Studies

The Impact of Gliomas on Daily Life

- The impact of symptoms
- The impact on social life

Emotional Changes

- Fear
- Uncertainty and anxiety
- Shock
- Loneliness
- Experience of life ending
- Loss of hope

The Recognized Need to Move On

- Caring needs
- Information needs
- Personal inner influence
- Perceived influence from physicians and caregivers

Uncertainty and anxiety: Uncertainty and anxiety were prominent psychological characteristics among patients with gliomas. The sources of anxiety and uncertainty included unknown disease diagnosis, prognosis, physical condition and symptoms, and possible influence of the disease on one's future. In a study by Philip et al. (2014), one patient expressed a constant sense of waiting from the time of diagnosis to the time of death: "I feel like I'm just sort of waiting, and so, I'm a bit anxious, and I'm depressed. I'm anchored here, dependent on everyone else . . . so, I feel disempowered. It's not a nice feeling" (p. 394). In addition, feelings of anxiety and uncertainty tended to be compounded, leaving the patients physically and psychologically exhausted as described by one patient in a study by Cavers et al. (2013):

Sheer and utter panic and very, very stressful. I can't describe it any other way. There's obviously lots of negative thoughts going through your head and . . . morbid, lots of morbid thoughts going through my head, you know? (p. 1,301)

Shock: Shock is the most common response to a diagnosis of cancer, regardless of the type (Butow et al., 1996), and a glioma diagnosis is no exception. The shock experienced by patients with gliomas can be exacerbated by a better knowledge of the disease or a poor prognosis. Patients may also struggle to fully grasp the meaning of the diagnosis. Some patients attribute this surreal feeling to the abruptness of the diagnosis in the absence of symptoms: "In the beginning, you don't believe it [the diagnosis] because you don't feel sick. You don't know it. It is later that you come to realize, much later" (Sterckx et al., 2015, p. 385).

Loneliness: Because patients with gliomas may have no visible signs of disease, changes in cognition, vision, behavior, and mental suffering may be difficult for others to understand, which may be a source of loneliness: "People look at me and can't tell any difference. I look normal even now. And yet, I can hardly see and can hardly walk. Like, even my brother . . . he doesn't even know where my vision is" (Philip et al., 2014, p. 392). Some patients also felt that they were disregarded by their family caregivers, who deprived them of their freedom to decide how to proceed with treatment: "I find it terrible that I cannot do something about it. I'm used to helping myself a little and in this case I can't" (Sterckx et al., 2015, p. 386).

Experience of life ending: Patients were concerned about disease, side effects following the glioma

diagnosis, and death. Many faced the reality that they could not solve these issues by themselves, and they then accepted the situation: "Worrying is a waste of time. Suffering from this disease is unfortunate for me, but I cannot do anything about it. . . . Maybe it is better to focus on positive things and just do the best that I can" (Amano & Suzuki, 2019, p. 137). After reflecting on the past, patients often tried to live freely and rationally for the remainder of their lives and fulfilled their desires. In addition, patients reported that they were more afraid of leaving relatives than death itself:

Everything [the people] you have to leave behind because you are never going to see them anymore, the bond gets broken. And that will be the worst part, I think. If I cry at that moment, that will be the reason. (Sterckx et al., 2015, p. 385)

Loss of hope: Prognosis was closely related to patients' loss of hope in the reviewed studies. Many patients reported feeling that hope was being taken away when they were informed of the prognosis: "One day, we did have a family meeting with some doctor. . . . She looked like this and just said, 'There's no hope, no hope.' More or less, he's going to go home and die. Get over it" (Lobb et al., 2011, p. 319). Patients also reported feeling overwhelmed with despair until they received magnetic resonance imaging results and were relieved from their anxiety and uncertainty: "After the first year . . . I saw it wasn't changed. I relaxed, and now, I don't think about it anymore" (Hayhurst et al., 2011, p. 258).

Theme 3: The Recognized Need to Move On

Although patients with gliomas suffered considerable physical impairment, psychological distress, and cognitive decline, they continued to go on with their lives. They had different information and care needs. Internal and external influences motivated them to move on.

Caring needs: Patients in the reviewed studies described care needs throughout the course of their illness. Some patients felt unable to fulfill their previous roles, and they became more dependent on their caregivers: "I just left everything up to her. . . . I mean, I'm totally dependent on her" (Halkett et al., 2010, p. 116). Patients not only needed care from caregivers, but also from physicians. Establishing good communication with the doctor helped to provide patients with a greater sense of security regarding their disease. In a study by Vedelø et al. (2018), one patient described his experience with his doctor as follows:

“It was a good conversation. He is a pleasant doctor; he was nice and made me calm” (p. 3,051). When patients focused on the care provided by family caregivers and physicians, their feelings of anxiety and depression were considerably reduced.

Information needs: Many patients described the lack of clear clinical information they received during the early stages of their illness, and having appropriate information reduced anxiety for many of these patients: “I like to know. Information, for me, is the best because you can be afraid of what you don’t know” (Cavers et al., 2013, p. 1,302). Patients preferred verbal repetition and access to healthcare professionals to obtain specific information. The following example showed that a patient was unable to recall the details concerning his diagnosis or prognosis, and he decided not to seek further information: “The information I’ve got is basically what they’ve told me—that it’s the most aggressive one around, and what more information do I need?” (Lobb et al., 2011, p. 319).

Personal inner influence: Managing symptoms or regaining the ability to participate in certain activities can be important sources of strength for patients. Although uncertainty and anxiety were common and the process of rehabilitation was extremely difficult, many patients managed to maintain hope and found it important to stay optimistic because this bolstered their ability to bear the burden of the disease with more confidence. In the study by Amano and Suzuki (2019), one patient shared her experience as follows:

Although my walking was unstable, I am able to walk smoothly now. The distance I can walk has increased little by little, which made me extremely happy just after being discharged. I’m thankful to even be able to do trivial things. (p. 138)

Coping with the disease through acceptance also helped patients with gliomas to remind themselves of the positive aspects of life despite illness. Focusing on the meaning of life and having faith and trust in the future were significant. In addition, religious beliefs comforted patients as the illness progressed: “I believe there’s life after death . . . so that way I’m not frightened of dying. . . . It calms me down” (Cavers et al., 2012, p. E378).

Perceived influence from physicians and caregivers: Supportive relationships and communication, which enabled patients to maintain hope over time, were critical factors. Most patients valued the support they received from family and friends, particularly in the early stages of disease. In the study by Cavers

KNOWLEDGE TRANSLATION

- Based on the qualitative articles reviewed, adult patients with gliomas have unique experiences and needs, which require tailored coping mechanisms.
 - Three themes were identified that described the experiences of patients with gliomas: (a) the impact of gliomas on daily life, (b) emotional changes, and (c) the recognized need to move on.
 - Healthcare professionals can apply these findings by critically reflecting on their work and developing individual nursing plans to manage patients with gliomas.
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et al. (2013), one patient described the tremendous support she received from her children: “I couldn’t imagine doing this without my children. They have been fantastic. . . . It’s making me more positive, more determined” (p. 1,302). Patients also received reassurance from their physician about the prognosis of LGG: “I had reassurance that it was likely benign, so I just carried on with life” (Hayhurst et al., 2011, p. 258). Studies have shown that patients prefer to hear positive, hopeful, and encouraging words from their professional caregivers (Sterckx et al., 2015). Patients also felt motivated and supported when other patients were involved in the rehabilitation process: “The good thing about the training was, like, you have an agreement. . . . It just helps” (Fahrenholtz et al., 2019, p. 5).

Discussion

This systematic review identified 13 studies that examined the impact of gliomas on patients’ daily life, emotional changes experienced by patients following the diagnosis, and the recognized need of patients to cope with the illness. Seven studies focused on care and information needs for patients with gliomas (Cavers et al., 2012, 2013; Halkett et al., 2010; Lobb et al., 2011; Philip et al., 2014; Sterckx et al., 2015; Vedelø et al., 2018), three studies reported on patients’ emotional burden (Cavers et al. 2012, 2013; Hayhurst et al., 2011), and six studies evaluated patients’ experiences of living with gliomas (Cavers et al., 2012, 2013; Philip et al., 2014; Sterckx et al., 2015; Vedelø et al., 2018; Yuqin et al., 2018). All studies were strictly screened according to the inclusion and the exclusion criteria, particularly in terms of the phenomenon of interest and study participants. The studies in which participants were caregivers or pediatric patients and the phenomena of interest were unrelated to the patient’s life experiences, needs, or quality of life were excluded, ensuring the homogeneity of the included

studies. According to Petticrew et al. (2008), qualitative research is as likely to remain unpublished as quantitative research. To minimize publication bias, the authors conducted a comprehensive search of multiple databases for studies in which the titles and abstracts fulfilled the inclusion criteria.

A study by Edvardsson and Ahlström (2005) presented an elaborate description on illness-related issues concerning various physical, psychological, and communication functions, as well as the social life of patients with LGG, and summarized many psychological coping strategies, which cannot comprehensively reflect the results of synthesis. In a study by Fahrenholtz et al. (2019), coping and motivational theories used in the rehabilitation process were discussed, which emphasized the importance of a rehabilitation program aimed to improve quality of life of patients with gliomas. Although perspectives varied across the studies reviewed, the interpretation of the findings was based mainly on the experiences of patients. Similarities in the experiences of patients with gliomas were found in all studies; therefore, the authors of the current study synthesized those experiences and needs from different perspectives to obtain a more comprehensive understanding of the patients' feelings, needs, and coping strategies.

Limitations

The literature search did not include gray literature (i.e., written material that was not commercially published or easily accessible), leading to a likelihood of some bias in the integration of findings. Second, the authors of the selected studies were from different countries with different cultural backgrounds, which may have led to a bias in the interpretation of patients' experiences. In addition, three of the studies (Amano & Suzuki, 2019; Bennett et al., 2016; Vedelø et al., 2018) did not report on the grade of the glioma, and two studies (Cavers et al., 2012, 2013) provided an incomplete classification of the participants, which may have limited the accuracy of the synthesis of the integrated findings based on the grade of glioma.

Implications for Nursing and Research

In the literature reviewed, patients with gliomas described their symptoms in terms of terrible experiences, such as seizures, headaches, and cognitive decline. Physical and cognitive symptoms tended to increase in number and severity over time, with a substantial impact on patients' strength, mobility, communication, understanding, behavior, and appearance. Consequently, these symptoms not only

resulted in anxiety and depression, but also reduced patients' quality of life. Therefore, more attention should be paid to the management of glioma symptoms and their effects on patients. Using screening instruments that include patient-reported outcomes has been identified as a possible solution for meeting the needs of patients with gliomas and improving their quality of life (Boele et al., 2014).

The negative emotional changes caused by the illness or diagnosis led to signs of distress or depression, which is common and understandable following a diagnosis of a serious illness (Boele et al., 2014). According to Kübler-Ross (1969), the loss of one's health leads to the five following stages of grief: denial, anger, bargaining, depression, and acceptance. However, when an individual does not reach the acceptance stage and instead continues to struggle with feelings of depression for a prolonged period, a major depressive disorder can occur (Boele et al., 2014). Therefore, more targeted psychological care measures, companionship, and support should be offered to help patients cope throughout this difficult period. Depression and anxiety screening should be routinely completed. If screening for mood alterations indicates anxiety or depression, nonpharmacologic interventions, such as cognitive behavioral therapy, mindfulness-based stress reduction, and psychoeducational interventions, are recommended (Oncology Nursing Society, 2019). In addition, NCCN guidelines recommend that pharmacologic interventions can be used carefully with consideration to potential side effects for the patient (NCCN, 2020).

The findings of this review indicate that internal and external influences can encourage patients with gliomas to continue living their life. Encouragement and care received from relatives and healthcare professionals can give patients hope for survival. However, patients' internal influences also play an important role in their lives. Nurses can actively help patients to find beliefs that can motivate them to survive, such as providing rehabilitation plans that promote functional improvements and seeking social support for these patients. Positive communication from healthcare workers can also contribute toward enhancing patients' feelings of security and decreasing levels of anxiety.

Several studies have found that patients with gliomas, which are associated with high rates of recurrence and mortality, reported a significant sense of fear and uncertainty (Amano & Suzuki, 2019; Cavers et al., 2012, 2013; Halkett et al., 2010; Sterckx et al., 2015). There is a lack of empirical evidence on how

to reduce the psychological distress caused by glioma symptoms. It is important to conduct research on how a glioma diagnosis affects patients and how to reduce the psychological effects that the diagnosis can have on patients. In addition, patients may have different degrees of understanding based on the times at which they receive information, so discussing when and how to present information about the diagnosis and prognosis to patients is necessary.

Conclusion

This systematic review integrated the experiences and needs of patients with gliomas. The studies reviewed revealed that patients with gliomas experience emotional changes caused by the symptoms of the disease, and patients often require support from family caregivers and healthcare professionals to help them to cope with the diagnosis. Additional studies of the management of common symptoms experienced by patients with gliomas are warranted. Healthcare professionals should assess patients for symptoms and potential psychosocial effects from gliomas to enhance quality of life.

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REFERENCES

Amano, K., & Suzuki, K. (2019). The process of life adjustment in patients at onset of glioma who are receiving continuous oral

- anticancer drug: A qualitative descriptive study. *International Journal of Nursing Science*, 6(2), 134–140. <https://doi.org/10.1016/j.ijnss.2018.12.009>
- Bennett, S.R., Cruickshank, G., Lindenmeyer, A., & Morris, S.R. (2016). Investigating the impact of headaches on the quality of life of patients with glioblastoma multiforme: A qualitative study. *BMJ Open*, 6(11), e011616. <https://doi.org/10.1136/bmjopen-2016-011616>
- Boele, F.W., Klein, M., Reijneveld, J.C., Verdonck-de Leeuw, I.M., & Heimans, J.J. (2014). Symptom management and quality of life in glioma patients. *CNS Oncology*, 3(1), 37–47.
- Butow, P.N., Kazemi, J.N., Beeney, L.J., Griffin, A.M., Dunn, S.M., & Tattersall, M.H. (1996). When the diagnosis is cancer: Patient communication experiences and preferences. *Cancer*, 77(12), 2630–2637.
- Cavers, D., Hacking, B., Erridge, S.C., Morris, P.G., Kendall, M., & Murray, S.A. (2013). Adjustment and support needs of glioma patients and their relatives: Serial interviews. *Psycho-Oncology*, 22(6), 1299–1305. <https://doi.org/10.1002/pon.3136>
- Cavers, D., Hacking, B., Erridge, S.E., Kendall, M., Morris, P.G., & Murray, S.A. (2012). Social, psychological and existential well-being in patients with glioma and their caregivers: A qualitative study. *Canadian Medical Association Journal*, 184(7), E373–E382. <https://doi.org/10.1503/cmaj.111622>
- Edvardsson, T., & Alström, G. (2005). Illness-related problems and coping among persons with low-grade glioma. *Psycho-Oncology*, 14(9), 728–737. <https://doi.org/10.1002/pon.898>
- Fahrenholtz, M.L., Hansen, A., Sogaard, K., & Andersen, L.N. (2019). Finding ‘the inner drive’ for a rehabilitation process: A small-scale qualitative investigation among male patients with primary glioma. *BMJ Open*, 9(12), e031665. <https://doi.org/10.1136/bmjopen-2019-031665>
- Felsberg, J., Hentschel, B., Kaulich, K., Gramatzki, D., Zacher, A., Malzkorn, B., . . . Weller, M. (2017). Epidermal growth factor receptor variant III (EGFRvIII) positivity in EGFR-amplified glioblastomas: Prognostic role and comparison between primary and recurrent tumors. *Clinical Cancer Research*, 23(22), 6846–6855. <https://doi.org/10.1158/1078-0432.CCR-17-0890>
- Flechl, B., Ackerl, M., Sax, C., Oberndorfer, S., Calabek, B., Sizoo, E., . . . Marosi, C. (2013). The caregivers’ perspective on the end-of-life phase of glioblastoma patients. *Journal of Neuro-Oncology*, 112(3), 403–411. <https://doi.org/10.1007/s11060-013-1069-7>
- Halkett, G.K.B., Lobb, E.A., Oldham, L., & Nowak, A.K. (2010). The information and support needs of patients diagnosed with high grade glioma. *Patient Education and Counseling*, 79(1), 112–119.
- Hannes, K., & Lockwood, C. (2011). Pragmatism as the philosophical foundation for the Joanna Briggs meta-aggregative approach to qualitative evidence synthesis. *Journal of Advanced Nursing*, 67(7), 1632–1642.
- Hayhurst, C., Mendelsohn, D., & Bernstein, M. (2011). Low grade glioma: A qualitative study of the wait and see approach. *Cana-*

- dian Journal of Neurological Sciences, 38(2), 256–261. <https://doi.org/10.1017/S0317167100011434>
- Hricik, A., Donovan, H., Bradley, S.E., Given, B.A., Bender, C.M., Newberry, A., . . . Sherwood, P. (2011). Changes in caregiver perceptions over time in response to providing care for a loved one with a primary malignant brain tumor. *Oncology Nursing Forum*, 38(2), 149–155. <https://doi.org/10.1188/11.ONF.149-155>
- Klein, M., Heimans, J.J., Aaronson, N.K., van der Ploeg, H.M., Grit, J., Muller, M., . . . Taphoorn, M.J.B. (2002). Effect of radiotherapy and other treatment-related factors on mid-term to long-term cognitive sequelae in low-grade gliomas: A comparative study. *Lancet*, 360(9343), 1361–1368.
- Klein, M., Taphoorn, M.J.B., Heimans, J.J., van der Ploeg, H.M., Vandertop, W.P., Smit, E.F., . . . Aaronson, N.K. (2001). Neurobehavioral status and health-related quality of life in newly diagnosed high-grade glioma patients. *Journal of Clinical Oncology*, 19(20), 4037–4047.
- Kübler-Ross, K. (1969). *On death and dying*. Macmillan.
- Lobb, E.A., Halkett, G.K.B., & Nowak, A.K. (2011). Patient and caregiver perceptions of communication of prognosis in high grade glioma. *Journal of Neuro-Oncology*, 104(1), 315–322.
- Lockwood, C., Porritt, K., Munn, Z., Rittenmeyer, L., Salmond, S., Bjerrum, M., . . . Stannard, D. (2017). Chapter 2: Systematic reviews of qualitative evidence. In E. Aromataris & Z. Munn (Eds.), *JBİ manual for evidence synthesis*. Joanna Briggs Institute.
- Louis, D.N., Perry, A., Reifenberger, G., von Deimling, A., Figarella-Branger, D., Cavenee, W.K., . . . Ellison, D.W. (2016). The 2016 World Health Organization classification of tumors of the central nervous system: A summary. *Acta Neuropathologica*, 131(6), 803–820. <https://doi.org/10.1007/s00401-016-1545-1>
- Moore, G., Collins, A., Brand, C., Gold, M., Lethborg, C., Murphy, M., . . . Philip, J. (2013). Palliative and supportive care needs of patients with high-grade glioma and their carers: A systematic review of qualitative literature. *Patient Education and Counseling*, 91(2), 141–153. <https://doi.org/10.1016/j.pec.2012.11.002>
- National Comprehensive Cancer Network. (2020). *NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®): Central nervous system cancers* [v.1.2020]. https://www.nccn.org/professionals/physician_gls/pdf/cns.pdf
- Oncology Nursing Society. (2019). *Depression*. <https://www.ons.org/pep/depression>
- Ostrom, Q.T., Bauchet, L., Davis, F.G., Deltour, I., Fisher, J.L., Langer, C.E., . . . Barnholtz-Sloan, J.S. (2014). The epidemiology of glioma in adults: A “state of the science” review. *Neuro-Oncology*, 16(7), 896–913. <https://doi.org/10.1093/neuonc/nou087>
- Paterson, B.L. (2012). “It looks great but how do I know if it fits?”: An introduction to meta-synthesis research. In K. Hannes & C. Lockwood (Eds.), *Synthesizing qualitative research: Choosing the right approach*. John Wiley & Sons. <https://doi.org/10.1002/9781119959847.ch1>
- Pearson, A. (2004). Balancing the evidence: Incorporating the synthesis of qualitative data into systematic reviews. *JBİ Reports*, 2(2), 45–64. <https://doi.org/10.1111/j.1479-6988.2004.00008.x>
- Petticrew, M., Egan, M., Thomson, H., Hamilton, V., Kunkler, R., & Roberts, H. (2008). Publication bias in qualitative research: What becomes of qualitative research presented at conferences? *Journal of Epidemiology and Community Health*, 62(6), 552–554. <https://doi.org/10.1136/jech.2006.059394>
- Philip, J., Collins, A., Brand, C.A., Moore, G., Lethborg, C., Sundararajan, V., . . . Gold, M. (2014). “I’m just waiting . . .”: An exploration of the experience of living and dying with primary malignant glioma. *Supportive Care in Cancer*, 22(2), 389–397.
- Piil, K., Jakobsen, J., Christensen, K.B., Juhler, M., & Jarden, M. (2015). Health-related quality of life in patients with high-grade gliomas: A quantitative longitudinal study. *Journal of Neuro-Oncology*, 124(2), 185–195. <https://doi.org/10.1007/s11060-015-1821-2>
- Piil, K., Nordentoft, S., Larsen, A., & Jarden, M. (2019). Bereaved caregivers of patients with high-grade glioma: A systematic review. *BMJ Supportive and Palliative Care*, 9(1), 26–33. <https://doi.org/10.1136/bmjspcare-2017-001386>
- Rooney, A.G., Brown, P.D., Reijneveld, J.C., & Grant, R. (2014). Depression in glioma: A primer for clinicians and researchers. *Journal of Neurology, Neurosurgery, and Psychiatry*, 85(2), 230–235. <https://doi.org/10.1136/jnnp-2013-306497>
- Sterckx, W., Coolbrandt, A., Clement, P., Borgenon, S., Decruyenaere, M., De Vleeschouwer, S., . . . Dierckx de Casterlé, B. (2015). Living with a high-grade glioma: A qualitative study of patients’ experiences and care needs. *European Journal of Oncology Nursing*, 19(4), 383–390. <https://doi.org/10.1016/j.ejon.2015.01.003>
- Sterckx, W., Coolbrandt, A., Dierckx de Casterlé, B., Van den Heede, K., Decruyenaere, M., Borgenon, S., . . . Clement, P. (2013). The impact of a high-grade glioma on everyday life: A systematic review from the patient’s and caregiver’s perspective. *European Journal of Oncology Nursing*, 17(1), 107–117. <https://doi.org/10.1016/j.ejon.2012.04.006>
- Taphoorn, M.J.B., & Klein, M. (2004). Cognitive deficits in adult patients with brain tumours. *Lancet Neurology*, 3(3), 159–168. [https://doi.org/10.1016/S1474-4422\(04\)00680-5](https://doi.org/10.1016/S1474-4422(04)00680-5)
- Vedelø, T.W., Sørensen, J.C.H., & Delmar, C. (2018). Patients’ experiences and care needs during the diagnostic phase of an integrated brain cancer pathway: A case study. *Journal of Clinical Nursing*, 27(15–16), 3044–3055. <https://doi.org/10.1111/jocn.14372>
- Yuqin, Z., Xiao, Z., Jing, Z., & Dongming, Y. (2018). A qualitative study on postoperative disease experience in patients with glioblastoma multiforme. *Chinese Journal of Modern Nursing*, 24(16), 1900–1903. <https://doi.org/10.3760/cma.j.issn.1674-2907.2018.16.010>
- Zhang, X., Yang, B., Shao, D., Zhao, Y., Sun, J., Li, J., . . . Cao, F. (2019). Longitudinal association of subjective prospective and retrospective memory and depression among patients with glioma. *European Journal of Oncology Nursing*, 42, 1–6.