



The impact of a high-grade glioma on everyday life: A systematic review from the patient's and caregiver's perspective

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A B S T R A C T

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Background: With poor prognosis and disabling symptomatology high-grade gliomas affect not only the patient but also the family.

Purpose: The aim of this systematic review is to explore the experiences and needs of patients with a high-grade glioma and their family caregivers.

Method: Based on literature search in six databases, sixteen qualitative studies, published between 2000 and 2010 and with mixed methodological quality, were included.

Results: For both patients and their caregivers the diagnosis is marked by shock and recognition of death. For patients, coping with restriction seems to be most difficult to deal with. Especially loss of autonomy is hard. For caregivers, neurocognitive symptoms and personality changes irreversibly change the relationship with the patient leading to caregivers expressing a sense of total responsibility. The experience of being a caregiver is described by positive as well as negative feelings. Both patients and caregivers describe the need for hope, support and information.

Conclusion: The review provides some relevant insight in the experiences and needs of patients with a high-grade glioma and their caregivers. The methodological limitations of the included studies, however, urge for more research to refine our understanding of patients' and caregivers' experiences and needs to better tune care to their needs.

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Introduction

With an age-adjusted incidence rate of 4.15 per 100,000 person years, high-grade gliomas represent 21.6% of all reported brain tumors in the US (CBTRUS, 2004–2007). The five year survival of a patient with a glioblastoma is 9.8% (6.4–14) and the median survival is 14.6 months (95% CI 13.2–16.8) (Stupp et al., 2009). Current therapy comprises surgery, radiotherapy and/or chemotherapy.

Symptoms mostly depend on the area of the central nervous system that is affected and fluctuate as the disease progresses. High-grade glioma patients may have, to a greater or lesser extent and depending on both tumor size and location, following symptoms: headache, seizures, cognitive changes, memory loss, motor impairment, speech disorder, visual problems, personality changes, disturbance of consciousness, nausea/vomiting, sensory problems and papilloedema (Chang et al., 2005). Brain tumors clinically

present with a symptomatology varying from grotesque disabilities to very subtle changes (Fox and Lantz, 1998).

A diagnosis of cancer and the effect of the extensive medical treatments have a great impact on life and quality of life. This is not different for brain tumor patients. Besides, a brain tumor has much in common with neurodegenerative disorders and can cause rapid physical, emotional and cognitive decline, ultimately evolving to the patients' death (Fox and Lantz, 1998). On top of this, brain tumors are associated with social stigmatization, like many other cognitive and neurological diseases, which may result in more isolation and discrimination than in other cancer patients (Fox and Lantz, 1998; Janda et al., 2006).

Obviously, a brain tumor affects not only the patient but also his social environment. It is a family disease (Fox and Lantz, 1998). Caregivers' distress is reflected in burden and depressive symptoms, both related to the reduced independence and neuropsychiatric symptoms of the patient (Sherwood et al., 2006, 2007). Compared with caregivers of other brain tumor patients, caregivers of patients with a glioblastoma have a worse quality of life (Janda

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et al., 2007) and may have more psychosocial needs because the disease process is faster and they have less time to adapt (Schubart et al., 2008). Arber et al. (2010a) report that emotional problems of caregivers of brain tumor patients are often not recognized.

Given the high levels of distress and burden of high-grade glioma patients and their caregivers, it is important to develop appropriate care services for these persons. Therefore specific information is required on their experiences and needs. The aim of this systematic review is to explore the experiences and the needs of patients with a high-grade glioma and their caregivers. The focus is twofold: How do patients with a high-grade glioma and their family caregivers experience the diagnosis, treatment, care and life with a brain tumor? And what are their needs with respect to care?

Method

Search strategy and article selection

Between April 2010 and January 2011 following databases were searched: Medline, Cochrane Library, Embase.com, PsycInfo, Web of Science and CINAHL. A combination of following keywords was used: brain tumor, high-grade glioma, glioma, brain neoplasms, brain tumor patients, caregivers, next of kin, family, coping, support needs, needs assessment, everyday living, activities of daily living and continuity of patient care. Two independent reviewers conducted the evaluation of the literature, first on title and abstract, next on full-text of the studies. In case of disagreement, a discussion was held between the two investigators and if necessary within the research team until consensus was reached. Appraisal of both eligibility and quality of the studies was not blinded. However, none of the authors were directly nor indirectly involved in the studies identified and evaluated.

Inclusion criteria were: (1) empirical, qualitative research, (2) on the illness experience and/or care needs, (3) of patients with a primary malignant brain tumor and patients with a high-grade glioma in particular, and/or their caregivers, (4) during any phase of the illness, (5) publications in English or Dutch, (6) studies published between January 2000 and December 2010. Limits regarding date of publication were prompted by the important evolution in therapeutic options for high-grade glioma patients in the last decade. Studies that reported to have recruited patients with cerebral metastases or only a clear minority of high-grade glioma patients (i.e. less than half of the patients in the sample) were systematically excluded, as were interventional studies, case studies and literature reviews. The references of traced reviews were accurately searched for additional papers meeting our inclusion criteria.

Qualitative data from the individual studies were extracted by one reviewer and discussed with two other reviewers. Topics that crossed the qualitative data were categorized into themes with higher level of abstraction and deepened by re-reading the original data. Finally, results of the review were discussed within the review team.

Critical appraisal of the quality of the papers

The quality of the eligible studies was assessed using the seven criteria for quality appraisal of qualitative studies of Mays and Pope (2000). Quality appraisal of the papers was performed by one reviewer and discussed with a second reviewer in case of doubt. The seven criteria were scored individually. '+' is used when the criterion is clearly met, '-' is used when the criterion is not met and '-/+' is used in case of unclear or lacking information on the criterion in the study report.

Results

Study selection and characteristics

Fig. 1 depicts the flow of the selection of articles. Combinations of the search terms revealed 998 papers. References yielded no additional papers. Based on title and abstract 33 papers were selected for closer, full-text evaluation. Finally sixteen articles were selected. In five of them the study samples fully reflect the target population of this review, namely high-grade glioma patients and/or their caregivers (Halkett et al., 2010; Lobb et al., 2010; McConigley et al., 2010; Salander and Spetz, 2002; Wideheim et al., 2002). The other eleven papers used more heterogeneous study samples of patients with different types of brain tumors and/or caregivers. Five of these reported a sufficient representation of the target population (Bradley et al., 2007; Molassiotis et al., 2010; Nixon and Narayanasamy, 2010; Schubart et al., 2008; Sherwood et al., 2004). Six studies reported unclearly about the representation of these criteria in the study sample (Adelbratt and Strang, 2000; Arber et al., 2010b; Rosenblum et al., 2009; Schmer et al., 2008; Strang, S. and Strang, P., 2001; Strang et al., 2001). In the interest of data thickness, these eleven papers were included. However, the study results were critically appraised and compared to the results of the papers with homogeneous and fully matching study samples.

Table 1 provides a summary of the sixteen papers. The appraisal of the methodological quality is presented in Table 2. Reflexivity of the account tends to be low. Reflexivity means sensitivity to the ways in which the researcher and the research process have shaped the collected data and study results (Mays and Pope, 2000). For example, Wideheim et al. (2002) report in detail on how the vulnerability of patients was reflected and managed in the design of the study method. Some papers do not clearly report about the context of the study and/or the study sample. For example Halkett et al. (2010) clearly discuss where the study was conducted. This allows to relate the findings to other settings.

Study results

In order to let both the patient and the caregiver perspective come to their own, they are discussed separately.

Patients' experiences

Experiences related to the diagnosis. The experience related to the diagnosis is marked by shock (Adelbratt and Strang, 2000; Lobb et al., 2010; Rosenblum et al., 2009; Wideheim et al., 2002), with reactions such as denial, lack of understanding, a sense of helplessness (Wideheim et al., 2002), anxiety (Adelbratt and Strang, 2000; Rosenblum et al., 2009; Wideheim et al., 2002), grief (Rosenblum et al., 2009; Wideheim et al., 2002) and disbelief (Lobb et al., 2010). Powerlessness and suffering dominate future perspectives (Wideheim et al., 2002). Uncertainty is mentioned in Halkett et al. (2010) and in Wideheim et al. (2002). Patients describe uncertainty about the effect the diagnosis would have on their quality of life and how their condition would affect their family and friends. Uncertainty can be experienced by treatment decisions, post-operative recovery, adjuvant treatment, disease progression and by thoughts of seizures, loss of vision or memory, speech difficulties, motor deficit, the ability to return to work and resumption of previous activities (Halkett et al., 2010).

Patients in Molassiotis et al. (2010) express anger and dissatisfaction about the way the diagnosis is delivered. Some patients tend to have misunderstood the terminal nature of their condition. It seems that the use of medical jargon and/or the shock of the diagnosis hinder the correct registration of information (Halkett

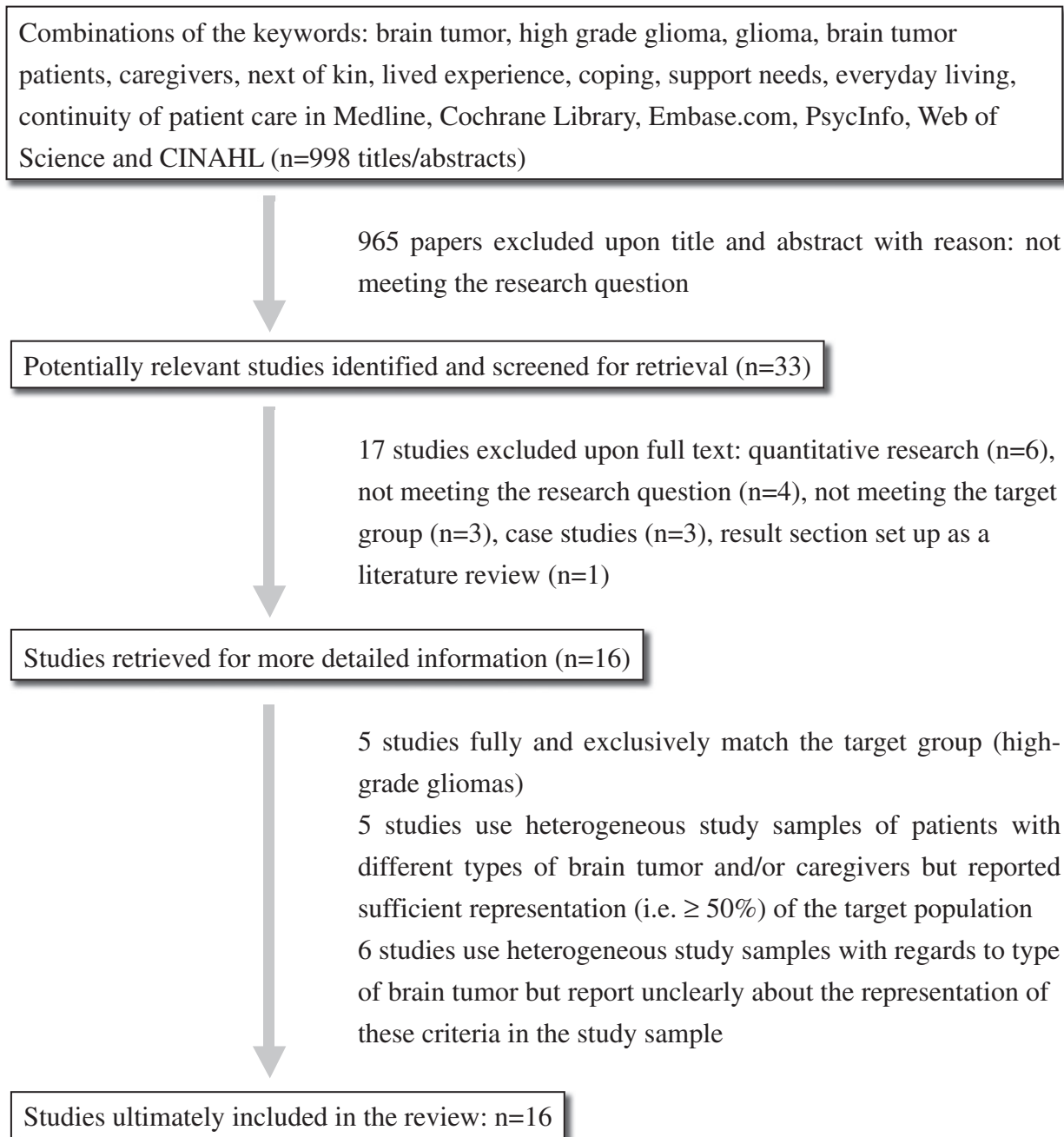


Fig. 1. Study flow diagram.

et al., 2010; Molassiotis et al., 2010). Moreover, they feel as if they were not given complete information. Therefore, prognosis is hard to estimate, and patients do not know what to expect from the future and cannot plan their life anymore (Halkett et al., 2010). Anger and dissatisfaction about this communication do not necessarily occur immediately after diagnosis, but arise when the fighting spirit, urged by the diagnosis, ceases and the real nature of the disease dawns (Molassiotis et al., 2010).

Dealing with the consequences of symptoms. Patients describe coping with restrictions as the major consequence of the disease (Adelbratt and Strang, 2000; Halkett et al., 2010; Molassiotis et al., 2010; Wideheim et al., 2002). The impact of symptoms on everyday life seems to be the most difficult to deal with (Adelbratt and

Strang, 2000; Halkett et al., 2010; Molassiotis et al., 2010; Strang, S. and Strang, P., 2001; Wideheim et al., 2002). Of the many symptoms they experience, patients in Molassiotis et al. (2010) find tiredness the most severe. They describe how this tiredness becomes more debilitating over time. It means more sleep, it limits social activities and contacts and causes frustration (Molassiotis et al., 2010). Above all, patients suffer from the loss of autonomy (Adelbratt and Strang, 2000; Halkett et al., 2010; Molassiotis et al., 2010). They report to lose their independence and ability to accomplish previous roles (Halkett et al., 2010). The prohibition to drive and the inability to go out are of most concern (Halkett et al., 2010; Molassiotis et al., 2010). This can lead to feelings of depression, restlessness, anxiety and can have severe repercussions on the patients' everyday life (Molassiotis et al., 2010). Loss of autonomy

Table 1
Studies included in the review.

Author	Object	Setting	Tumor type	Method	Phase in the disease trajectory, moment of the interviews	Method of sampling	Sample	Relevant patient selection criteria
Adelbratt and Strang, 2000	Explore whether and to what extent patients and their next of kin experience death anxiety and how this is expressed	Medical centre Sweden	Grade II–IV	Explorative and semi-structured interviews	Not specified	Purposive information-rich maximum variation sampling	<i>n</i> patients = 20 <i>n</i> relatives = 15 (1 daughter, 1 mother, 13 partners)	Functional and cognitive deficits
Arber et al., 2010b	To consider carers' access to information and information on managing the caring role	Hospital UK	Primary malignant brain tumour	Qualitative in depth interviews	Actively caring for a primary malignant brain tumor patient at the time of interview	Purposive sampling	<i>n</i> caregivers = 22 (17 partners, 3 children, 2 parents)	–
Bradley et al., 2007	Describe and evaluate the impact of costs	National support group USA	Primary malignant brain tumors: 25% Glioblastoma, 40% Astrocytoma I–III, 20% oligodendroglioma, 15% others	Interviews with open-ended questions	Within one year of diagnosis (85%)	Volunteer sampling Advertisement in a national support group newsletter	<i>n</i> patients in treatment = 20	Not specified
Halkett et al., 2010	Understand patients' experiences and identify and describe their information and support needs	Tertiary referral centre for neurological cancers Australia	High-grade gliomas	Semi-structured interviews	Different moments in the disease trajectory Within one year of diagnosis	First consecutive next purposive sampling	<i>n</i> patients = 19	Intellectual functioning
Lobb et al., 2010	Explore the perceptions of patients and their caregivers of how they were first told the diagnosis and prognosis	Tertiary referral centre for neurological cancers Australia	High-grade gliomas	Semi-structured interviews	Different moments in the disease trajectory Within one year of diagnosis	Purposive sampling	<i>n</i> caregivers = 21 (20 partners, 1 parent) <i>n</i> patients = 19	Intellectual functioning
McConigley et al., 2010	Articulate the experiences of family caregivers and describe their information and support needs	Tertiary referral centre for neurological cancers Australia	High-grade gliomas	Semi-structured interviews	Different moments in the disease trajectory Within one year of diagnosis	Purposive sampling	<i>n</i> caregivers = 21 (20 partners, 1 parent)	–
Molassiotis et al., 2010	To better understand the symptom experience of newly diagnosed patients with brain tumour over time and to explore the meaning and impact of those symptoms from the patients' perspective	Oncology centre UK	1 astrocytoma, 1 glioma, 7 glioblastoma	Semi-structured interviews	First interview: soon after diagnosis (9 patients) Second interview: 3 months after diagnosis (6 patients) Third interview: 6 months after diagnosis (5 patients) Fourth interview: 12 months (1 patient)	Sample method broad to include maximum variation	<i>n</i> patients = 9	Intellectual functioning
Nixon and Narayanasamy, 2010	To establish the spiritual needs of neuro-oncology patients from their perspective	Medical centre UK	19 grade III–IV, 1 anaplastic meningioma, 1 grade II	Highly structured interviews/questionnaires	Awareness of the diagnosis 3–5 months to a year or more	Convenience sample	<i>n</i> patients = 21	Emotional risk

Rosenblum et al., 2009	Explore the importance of hope, influencing factors, effects and identification of crisis moments	Brain tumor centrum USA	Malignant brain tumor	Structured telephone interviews	After the patient's death	Not specified	n = 14 patients or relatives (10 with patients, 4 with relatives of deceased patients)	Not specified
Salander and Spetz, 2002	Explore the communication between couples regard the fact that a family member is dying of cancer	Regional hospital Sweden	Malignant glioma grade III–IV	Interviews with structured questions and thematically structured interviews	First interview: after diagnosis and before radiotherapy (25 patients and 24 partners) Second interview: 2 months later at the end of the 6 weeks radiotherapy (24 patients, 23 partners) Third interview: 5 months later at home (17 patients and 15 partners) Fourth interview: 20 partners 1 month after decease	Consecutive sampling	n = 25 patients with spouse	Patient's performance status
Schmer et al., 2008	Explore the caregiver's perspective of providing care	Urban Mid-western city USA	Primary malignant brain tumor	Semi-structured interviews	During the first six months after the diagnosis, while the patient gets chemo as initial treatment	Convenience sample	n relatives = 10 (7 partners, 2 daughters, 1 son in law)	Emotional risk
Schubart et al., 2008	Explore the challenges of caregivers by providing care for a patient with a brain tumor	University neuro-oncologic centre USA	8/25 high-grade tumors (7 = GBM), 5/25 anaplastic oligoastrocytomas, 12/25 others	Semi-structured in-depth interviews	All phases of the illness trajectory are represented In 6 cases the patient was deceased	Purposeful and stratified sampling	n caregivers = 25 (18 partners, 4 parents, 2 children, 1 sibling),	–
Sherwood et al., 2004	Explore the positive and negative aspects of providing care	Support group USA	GBM 75%, grade I–III 15%, other 10%	Self-reported questionnaire (written)	Caregivers of deceased brain tumor patients	Volunteer sampling	n caregivers = 43 (27 partners, 8 children, 8 others)	–
Strang, S. and Strang, P., 2001	Explore the extent of coping, understanding and create a meaning or sense of coherence, explore the extent to which spirituality could give support or be a hindrance	Medical centre Sweden	Grade II–IV	Explorative and semi-structured interviews	Not specified	Purposive, information-rich maximum variation sampling	n patients = 20 n relatives = 16 (partners)	Functional and cognitive deficits
Strang et al., 2001	Describe opinions of patients and relatives about existential support	Universital hospital Sweden	Grade II, III, IV	Explorative and semi-structured interviews	Not specified	Maximum variation sampling	n patients = 20 n relatives = 16 (14 partners, 2 children)	Intellectual functioning
Wideheim et al., 2002	Describe what living with a highly malignant tumor is like from a family perspective	Neurology clinic Sweden	Highly malignant glioma	Qualitative interviews	First interview: 2–3 weeks after surgery Second interview: 3–6 months after diagnosis (drop-out 3 patients and 2 relatives)	Consecutive sampling	n = 3 families, 3 patients, 5 relatives (2 partners, 2 parents, 1 child)	Intellectual functioning

Table 2
Methodological quality assessment (Mays and Pope, 2000).

Author	Worth or relevance	Clarity of research question	Appropriateness of the design to the question	Context	Sampling	Data-collection and analysis	Reflexivity of the account
Adelbratt and Strang, 2000	+ ^a	+	+	-/+ ^b	-/+	+	-/+
Arber et al., 2010b	+	-/+	+	- ^c	-	-	-
Bradley et al., 2007	+	+	+	+	-/+	+	-
Halkett et al., 2010	+	+	+	+	+	+	-
Lobb et al., 2010	+	+	+	+	+	+	-
McConigley et al., 2010	+	+	+	+	+	+	-
Molassiotis et al., 2010	+	+	+	+	-/+	+	-
Nixon and Narayanasamy, 2010	-/+	+	+	-/+	-/+	+	-
Rosenblum et al., 2009	+	+	+	-	-	-	-
Salander and Spetz, 2002	-/+	-	+	+	+	+	-
Schmer et al., 2008	+	+	+	+	-/+	+	-/+
Schubart et al., 2008	+	+	+	+	-/+	+	-/+
Sherwood et al., 2004	+	+	-/+	+	-/+	-/+	+
Strang, S. and Strang, P., 2001	+	+	+	-/+	-/+	+	-/+
Strang et al., 2001	+	-/+	+	-/+	-	+	-
Wideheim et al., 2002	+	+	+	+	-/+	+	+

^a '+' is used when the criterion is clearly met.

^b '-/+' is used in case of uncertainty about the interpretation of the criterion.

^c '-' is used when the criterion is not met.

induces fear and is described as a central thought and a metaphor for dying (Adelbratt and Strang, 2000). It also can create feelings of meaninglessness. The feeling not to be recognized as a complete person feels humiliating and increases feelings of loneliness (Strang, S. and Strang, P., 2001). Losing independence also translates in increasing dependency on the caregivers (Halkett et al., 2010; Molassiotis et al., 2010). Some patients express difficulties with the loss of independence while others feel blessed with the support (Halkett et al., 2010).

Patients generally attempt to maintain an independent life. They balance between losing independence and trying to retain autonomy (Molassiotis et al., 2010; Wideheim et al., 2002). Patients describe how they try to hide their inabilities and undertake activities to be less dependent in order to experience meaning in their daily life. The fear of relatives is perceived as an irritation and an encroachment upon self-determination (Wideheim et al., 2002). After six months, patients in Molassiotis et al. (2010) start to organize their life more, accept their limitations and find ways to manage them.

Life near death. Recognition of death (Adelbratt and Strang, 2000; Strang, S. and Strang, P., 2001; Wideheim et al., 2002) can cause anxiety (Adelbratt and Strang, 2000; Strang, S. and Strang, P., 2001). Some patients express death anxiety that is triggered by hospital smell or headache. Others express an existential anxiety that they can not explain or that is caused by the thought of leaving close family members and friends behind. Not all patients feel anxiety about the thought of a near death (Adelbratt and Strang, 2000). Some even ascribe positive changes to the awareness of the inevitability of death: it renews their perspective in life and 'changes' them as a person (Molassiotis et al., 2010).

Some patients in Lobb et al. (2010) cope by believing that they are an exception to the rule. Molassiotis et al. (2010) describe how patients make fatalistic utterances as 'there is nothing to do about it' in talking about life near death. This fatalism seems necessary to cope with anxiety and fear (Molassiotis et al., 2010). Some patients eventually reach acceptance (Adelbratt and Strang, 2000; Molassiotis et al., 2010). This evolution is well described by patients in Molassiotis et al. (2010). The strong will to fight and overcome the disease, evoked by the initial diagnosis, eventually turns into a more time-conscious and time-awareness state of mind with awareness of the inevitability of death (Molassiotis et al., 2010). In the terminal phase of their illness some patients show some kind of acceptance of the fact that they are going to die. At this

point there is not so much anxiety, but rather sadness and an existential pain, facing the fact that life is coming to an end soon (Adelbratt and Strang, 2000).

Financial impact. In three studies patients mention how cost of their cancer care causes worry and contributes to fear and uncertainty (Bradley et al., 2007; Halkett et al., 2010; Strang, S. and Strang, P., 2001). This concern can be caused by loss of income, increased medical costs and the cost of disability. Whether to get financial benefits or reimbursements can cause appreciation or frustration (Bradley et al., 2007).

Patients' needs

Hope. Patients in Rosenblum et al. (2009) believe that hope helps them to live longer. Some declared this belief by the experience of less stress leading to better strength and ability to fight the disease. Even at relapse or progression there is still room for hope, namely a focus to maintain functions and hope for quality of life (Rosenblum et al., 2009).

The treatment enables a positive shift from despair to hope (Adelbratt and Strang, 2000; Rosenblum et al., 2009). The receipt of good news from imaging tests is a time of greatest hope. Furthermore, an important source of hope is talking, in local community organization or support groups, with patients who do it well or who have gone through the same (Rosenblum et al., 2009). Nevertheless, hope is particularly vulnerable and easily undermined (Lobb et al., 2010; Rosenblum et al., 2009). At four moments hope is particularly vulnerable: diagnosis, every new scan, treatment failure with terminal expectations and limited legacy (Rosenblum et al., 2009). Hearing the prognosis easily takes all hope away (Lobb et al., 2010). The word 'terminal' undermines hope, at least in terms of life expectancy (Rosenblum et al., 2009).

Support. Patients express the need for emotional and existential support. Close relations with children and family give meaning to life and strength to go on struggling (Adelbratt and Strang, 2000; Strang, S. and Strang, P., 2001).

Talking is an important source of emotional support. Patients are grateful with the opportunity to talk about personal and difficult topics (Nixon and Narayanasamy, 2010; Strang et al., 2001). Talking can help to reach a certain extent of acceptance (Strang et al., 2001). Talking with other cancer survivors about symptoms creates expectations and helps to cope with their situation. Experiences

from other patients help patients to put their own problems into context (Molassiotis et al., 2010). In Nixon and Narayanasamy (2010) patients express not only the need for connection but also the need for solitude, to deal with it on their own. Emotional support is also sought in professional caregivers. They value stability, thrust (Rosenblum et al., 2009); compassion, empathy (Lobb et al., 2010; Rosenblum et al., 2009) and a holistic view (Strang et al., 2001). Patients need to be seen and acknowledged by the health care professionals. When thoughts and feelings become too difficult, patients need rather presence than talking: just someone who is there (Strang, S. and Strang, P., 2001; Strang et al., 2001). Unfortunately, patients perceive communication problems and a lack of sensitivity in their relation with professionals (Molassiotis et al., 2010).

Information. Patients indicate the need for information about disease progression and symptomatic deterioration (Halkett et al., 2010). They also mention the need for practical information about treatment schedule, appointment times and about how they should live their everyday life (Salander and Spetz, 2002).

The sources where to get information (e.g. health care professionals, caregivers, books), the way to get it (verbal or written) and at what time differ among patients (Halkett et al., 2010). Patients in Halkett et al. (2010) report to need information around the time of diagnosis and they appreciate to gain information from and ask questions to the medical staff. They describe the importance of a contact person for questioning and of continuity in provision of information (Halkett et al., 2010). Rosenblum et al. (2009) note that patients, by diagnosis, prefer incremental doses of information that is adapted to their vulnerability and at the same time they have an urgent need for an effective treatment plan. Overall, patients tell that they want every possible information with an emphasis on the positive (Rosenblum et al., 2009). This is confirmed by patients in Lobb et al. (2010). They find it important that the prognosis contains a positive message.

Some patients comment that their relatives have other preferences concerning knowledge about their disease (Salander and Spetz, 2002). Nevertheless patients tend to rely also on their caregivers to gather additional information and make treatment decisions. Patients find it difficult to be actively involved in the decision-making process because of the feeling not having a choice and because of prognostic uncertainty (Halkett et al., 2010). Moreover, the need for and the interpretation of information is compromised by difficulties to understand certain terms (Wideheim et al., 2002) and by cognitive problems (Halkett et al., 2010).

A lack of information can lead to uncertainty and feelings of chaos and anxiety (Strang, S. and Strang, P., 2001).

Caregivers' experiences

Experiences related to the diagnosis. As for patients, learning the diagnosis is attended with shock (Lobb et al., 2010; McConigley et al., 2010; Rosenblum et al., 2009; Schmer et al., 2008; Schubart et al., 2008; Wideheim et al., 2002), related to the rapid progression of the disease (McConigley et al., 2010) and/or not expecting the possibility of a brain tumor (Schmer et al., 2008). It is described as a surreal feeling, the worst experience of their life (Wideheim et al., 2002) and is combined with disbelief (Lobb et al., 2010). Caregivers associate the diagnosis with a loss of safety in daily life. Suffering and powerlessness loom large as future perspectives (Wideheim et al., 2002). Feelings of being overwhelmed, denial, anger and isolation are described (Schubart et al., 2008).

In an attempt to cope with the diagnosis, caregivers take every day as it comes and do not want to plan ahead. They try to prepare themselves for the worst and want to be ready for when the patient deteriorates (Wideheim et al., 2002).

Telling third parties about the diagnosis is difficult, painful and emotional (Schmer et al., 2008). Parents ask themselves what to tell the children and when (Schubart et al., 2008).

Coping with symptoms. Neurocognitive symptoms and personality changes of the patient importantly mark the caregivers' experience (Schmer et al., 2008; Schubart et al., 2008; Sherwood et al., 2004; Strang, S. and Strang, P., 2001; Wideheim et al., 2002) and they feel inadequately prepared to manage these symptoms (Schubart et al., 2008; Sherwood et al., 2004).

Cognitive and neuropsychiatric symptoms are described as the greatest challenge to deal with (Schubart et al., 2008; Sherwood et al., 2004). Cognitive deficits and a lack of energy from the patient can cause burden (Wideheim et al., 2002). Personality changes and functional deficits can cause feelings of meaninglessness (Strang, S. and Strang, P., 2001). Caregivers describe the feeling of losing the patient (Schmer et al., 2008). Furthermore, the onset of mental changes is felt as a bending in their relationship with the patient, meaning that the relationship was better before these mental changes appeared (Sherwood et al., 2004).

The onset of new symptoms can cause anxiety because the doctor could bring bad news (Wideheim et al., 2002). Caregivers also express fear of seizures (McConigley et al., 2010). Side effects from treatment are experienced as a constant reminder of the illness (Wideheim et al., 2002).

Given the challenging task to deal with these many and drastic symptoms, caregivers feel inadequately prepared to do so (Schubart et al., 2008; Sherwood et al., 2004). Caregivers in Sherwood et al. (2004) describe how at times, professional caregivers perceive frightening symptoms as 'normal to the stage of disease' and how sometimes, these professionals struggle to cope with these symptoms themselves, therefore not being aware of the informal caregivers' need for guidance to manage these symptoms at home. Caregivers note that they learn by experience (McConigley et al., 2010; Schubart et al., 2008). They describe how understanding of neurocognitive changes, especially personality changes, is important to cope (Schubart et al., 2008; Strang, S. and Strang, P., 2001).

Role and responsibility changes. Several studies confirm that roles and responsibilities drastically change after the diagnosis (Adelbratt and Strang, 2000; McConigley et al., 2010; Schmer et al., 2008; Schubart et al., 2008; Sherwood et al., 2004; Strang, S. and Strang, P., 2001; Wideheim et al., 2002). Caregivers need to take a number of new roles together with their old ones (McConigley et al., 2010; Schmer et al., 2008; Schubart et al., 2008; Sherwood et al., 2004; Wideheim et al., 2002) and experience a sense of total responsibility (Schubart et al., 2008; Sherwood et al., 2004; Wideheim et al., 2002).

Caregivers in Schubart et al. (2008) describe the changes as subtle at the start, but more pronounced when there is tumor progression (Schubart et al., 2008). They are amazed about the quantity and size of the role changes (Schmer et al., 2008). New roles often compete with pre-existing roles (Schubart et al., 2008; Sherwood et al., 2004).

Many new roles are reported and associated with their caregiving task: assisting with activities of daily living (ADL) (Schmer et al., 2008; Schubart et al., 2008; Sherwood et al., 2004; Wideheim et al., 2002), being constantly available for the patient and protecting the patient from unnecessary information (Wideheim et al., 2002), managing finances, driving the patient to medical appointments, giving personal care, assuring medication intake, taking up the role of 'interpreter' and advocate when the patient cannot express his wishes anymore (McConigley et al., 2010), providing emotional support (Schubart et al., 2008; Sherwood et al., 2004), preventing social isolation, managing the

limitations of activity (Schubart et al., 2008), preventing that the patient is left home alone and trying to attend doctor's appointments (Schmer et al., 2008). They feel responsible for searching information about illness and treatment (Sherwood et al., 2004). During the terminal phase, physical and emotional comfort is given to allow the patient to die peacefully (Sherwood et al., 2004). The sense of total responsibility (Schubart et al., 2008; Sherwood et al., 2004; Wideheim et al., 2002) not only results from physical care, having to deal with neurological symptoms, and taking up new roles, but also from increased responsibility in terms of decision making. Caregivers have to make decisions on their own (Sherwood et al., 2004). Moreover, decisions are often to be made in emotionally difficult circumstances. Questions on the provided care and on quality of life weigh heavily: 'You have to make a decision whether you're going to extend life or extend death, oh no, prolong life or prolong death' (McConigley et al., 2010).

As caregivers pick up these new responsibilities, they have to assess and change expectations about what the patient can and cannot do (Schubart et al., 2008). In order not to feel guilty, caregivers place no demands on the patient. They find it difficult to balance between the wishes of the patient and their actual needs, for example the patient's wish to be independent and the caregiver's concern to prevent falls caused by possible epileptic insults. When they go out to work, they look for safety by keeping in touch with the patient by telephone (Wideheim et al., 2002). Caregivers feel reluctant to leave the patient, partly because of fear for seizures and partly because they feel reluctant to ask for help. At the same time however, they express the need for time away from the patient, both for practical matters as for a time out (McConigley et al., 2010).

Relatives feel badly prepared for the caregiving role (McConigley et al., 2010; Schubart et al., 2008). They need to pick up this role immediately after the operation and need to decide quickly if they can combine it with working (McConigley et al., 2010). Besides, the caregiving role has also a harmful effect on their own health (McConigley et al., 2010; Wideheim et al., 2002).

Being a caregiver. Caregivers ascribe different feelings to their role of caregiver. The caregiving role is stressful and relentless (McConigley et al., 2010) but it has also positive aspects (Adelbratt and Strang, 2000; Sherwood et al., 2004). Caregiving is sometimes described as physically and mentally exhausting (Schubart et al., 2008; Sherwood et al., 2004), but helping with ADL is not seen as a burden by caregivers in Schmer et al. (2008). In Sherwood et al. (2004) caregivers, who were asked about the positive aspects of caregiving, described being a caregiver as a gift and they felt grateful, blessed, proud and privileged to give care. Caregivers in Adelbratt and Strang (2000) describe mixed feelings: they talk about getting closer to each other, and at the same time they express anger directed to the patient. When caregivers lose their patience, they are feeling guilty (Sherwood et al., 2004).

Coping with (imminent) loss. Caregivers describe recognition of death (Adelbratt and Strang, 2000; Lobb et al., 2010; McConigley et al., 2010; Sherwood et al., 2004; Wideheim et al., 2002) and struggle to cope with this (Lobb et al., 2010; Sherwood et al., 2004; Wideheim et al., 2002). They describe how hearing the diagnosis creates fear and anxiety of losing the patient (Wideheim et al., 2002). As for patients, caregivers can experience death anxiety caused by different triggers (Adelbratt and Strang, 2000) and which can increase the feeling of meaninglessness when it is left unresolved (Strang, S. and Strang, P., 2001).

When prognosis is discussed shortly after the diagnosis, coping is complicated because they are still in shock (Lobb et al., 2010). Comments of professional health care workers that the patient has not long to live, are leaving deep and lasting feelings (Wideheim

et al., 2002). Caregivers try to cope with this information and to retain hope by believing that their patient is an exception to the rule (Lobb et al., 2010; Wideheim et al., 2002).

Caregivers in McConigley et al. (2010) reassess plans for the future and priorities. Other caregivers mention that they have no sense of security in their daily life and do not have the energy to do more than take each day as it comes. Security and relief can be received by hearing that the tumor has not grown (Wideheim et al., 2002). Caregivers in Sherwood et al. (2004) describe how their grieving process starts while the patient is still alive: 'I've lost him in stages, so our family's grief was in stages'. After the patient's death caregivers find it difficult to change from an active caregiver into a grieving relative: 'I had all these empty hours that used to be devoted to caring for him.' (Sherwood et al., 2004).

Impact on relations. The diagnosis of a brain tumor brings isolation and solitude (Schubart et al., 2008; Strang, S. and Strang, P., 2001; Wideheim et al., 2002). Feelings of isolation can be caused by the perception that everything is centered around the patient and that it is not easy for caregivers to get any attention (Strang, S. and Strang, P., 2001). Caregivers often take the burden of responsibilities alone, spend less time with friends and take time off at work. Because of this, caregivers feel isolated in their social network (Schubart et al., 2008; Wideheim et al., 2002). The relationship with family can get worse because caregivers do not want to alarm them (Wideheim et al., 2002).

Caregivers also express concerns about their relationship with the patient (Adelbratt and Strang, 2000; McConigley et al., 2010; Schmer et al., 2008; Schubart et al., 2008; Sherwood et al., 2004; Strang, S. and Strang, P., 2001; Wideheim et al., 2002). Partners describe an unequal marriage (Schmer et al., 2008; Strang, S. and Strang, P., 2001), experience a social death of the patient (Adelbratt and Strang, 2000) and they do not believe that the seriousness of the illness is seen by the patient (Wideheim et al., 2002). Caregivers often refer to the patient as someone else than the person they knew before. 'Sometimes it was like caring for a total stranger with only glimpses of the man he used to be' (Sherwood et al., 2004).

Financial impact. The impact of financial problems is mentioned in three studies (Schubart et al., 2008; Strang, S. and Strang, P., 2001; Wideheim et al., 2002). Issues around employment, understanding insurance, other benefits and approaching the family needs with a limited income are difficult. This financial impact is especially great when the patient is used to managing finances. Caregivers describe how they find patients not paying the bills because of the brain tumor (Schubart et al., 2008).

Caregivers' needs

Hope. As patients, caregivers describe the importance of hope. However the content is less clearly described.

The patients' hope is of great influence to the contact between patient and family. When the patient appears to feel better, the caregiver feels better too and gains a sense of assurance (Wideheim et al., 2002). Assurance that the patient gets the best treatment and that everything will be done for the patient is an important source of hope for caregivers (Lobb et al., 2010; Wideheim et al., 2002). As for patients, prognosis and communication about it can easily take away hope. At the same time, communication about prognosis can be a source of hope when it contains a positive message (Lobb et al., 2010; Wideheim et al., 2002).

Support. Caregivers and patients share expectations about their relationship with professional caregivers: compassion and empathy (Lobb et al., 2010), as well as stability and trust (Rosenblum et al., 2009) and a holistic view (Strang et al., 2001). They express the need for a dedicated contact person (Schubart

et al., 2008; Wideheim et al., 2002). Caregivers mention that a lack of conversation on life and death can cause feelings of depression (Strang et al., 2001). As patients, caregivers find that the communication with professionals needs to be better and clearer (Lobb et al., 2010; Sherwood et al., 2004). It is not always easy for caregivers to get emotional support, because everything is centered around the patient and because of a lack of formal structures (Schubart et al., 2008; Strang, S. and Strang, P., 2001).

Caregivers need guidance to manage symptoms and side effects at home as well as practical, physical support (Sherwood et al., 2004). While they state to be present at hospital stays and visits, caregivers report a general lack of coordination from the formal health care system in terms of communication and education on how to care for the patient (Schubart et al., 2008). Sharing experiences with other caregivers through support groups and with friends and family who had similar experiences, is a source of emotional support (Sherwood et al., 2004). Family and friends are important in providing practical support (e.g. laundry, cooking, changing diapers) as well as emotional support and the absence can cause frustration (Sherwood et al., 2004). Asking for help, unless for practical tasks, is difficult and when help is given, they describe feeling guilty about it (Sherwood et al., 2004).

Caregivers report that it is difficult to know where to find support (McConigley et al., 2010; Sherwood et al., 2004). On the one hand caregivers stress the importance of getting formal support on time (Schubart et al., 2008), on the other formal respite services and community services are not often used (McConigley et al., 2010; Schubart et al., 2008; Sherwood et al., 2004). Reasons for this can be the limited availability of the services as well as unfulfilled patient criteria. Caregivers who do use hospice services seem to appreciate it (Sherwood et al., 2004).

Information. Information about the future is perceived as very important (McConigley et al., 2010; Rosenblum et al., 2009; Salander and Spetz, 2002; Schubart et al., 2008). Caregivers want to know what happens following diagnosis, treatment (Arber et al., 2010b), symptoms (Schubart et al., 2008; Strang et al., 2001) and want accounts of how people had survived the illness (Wideheim et al., 2002). They want information about neurocognitive symptoms, home care after discharge and health care systems (Schubart et al., 2008), and how to provide care (McConigley et al., 2010). Such information helps them to make new plans and reorganize their life. Because of the fear for seizures and the feeling of inadequate preparation, caregivers actively search for more information on this matter (McConigley et al., 2010).

A lack of information is reported about combining employment and caring, managing finances and benefits, locating support groups, what to expect following neurosurgery and managing medication (Arber et al., 2010b), about how to provide daily care and to manage psychoses and neuropsychiatric problems at home (Sherwood et al., 2004). Yet, even when this information is given, caregivers still feel unprepared to encounter these problems: *'Even though I was fully aware of what to expect by way of changes as (her husband's) tumor progressed, I was still not prepared when those changes began to manifest'* (Sherwood et al., 2004).

The need for information is the largest at the moment of diagnosis (Schubart et al., 2008) and they need an immediate access to information (McConigley et al., 2010). Information is difficult to obtain because they do not know which questions to ask and where to find information (McConigley et al., 2010). The doctor is seen as the key figure and most important source of information (Schubart et al., 2008).

As patients, caregivers have difficulties to understand certain medical terms (Wideheim et al., 2002). A lack of information can lead to uncertainty and feelings of chaos and anxiety (Strang, S. and Strang, P., 2001). Anxiety and worry make it difficult to retain information (Arber et al., 2010b).

Discussion

This review is based on 16 qualitative studies. Five studies use mixed samples regarding the type of brain tumor (Bradley et al., 2007; Molassiotis et al., 2010; Nixon and Narayanasamy, 2010; Schubart et al., 2008; Sherwood et al., 2004). Six studies are unclear on the characteristics of their study sample (Adelbratt and Strang, 2000; Arber et al., 2010b; Rosenblum et al., 2009; Schmer et al., 2008; Strang, S. and Strang, P., 2001; Strang et al., 2001). Though tumor classification is likely to influence the perception of the illness trajectory, these eleven studies have no conflicting results. Some topics were only superficially described by the five studies that fully match the inclusion criteria, but were deepened by the other studies. Therefore, it is considered justified to include these studies in the review.

Studies in the review have several methodological limitations. Some studies using data from both patients and caregivers failed to report whether results were about patients or caregivers (Lobb et al., 2010; Rosenblum et al., 2009; Strang, S. and Strang, P., 2001). Ten studies (Adelbratt and Strang, 2000; Arber et al., 2010b; Bradley et al., 2007; Halkett et al., 2010; Lobb et al., 2010; McConigley et al., 2010; Nixon and Narayanasamy, 2010; Schubart et al., 2008; Strang, S. and Strang, P., 2001; Strang et al., 2001) are vague about the studied time frame of the illness trajectory, although it seems plausible that every phase is marked by different experiences and needs. Three papers (Molassiotis et al., 2010; Salander and Spetz, 2002; Wideheim et al., 2002) conducted follow-up interviews and faced a significant drop-out of patients and/or their next of kin. The main reasons for the patients drop-out were health issues and death (Molassiotis et al., 2010; Wideheim et al., 2002). The next of kin was no longer able to participate mainly because of under too much pressure (Wideheim et al., 2002). Salander and Spetz (2002) give no reasons for the drop-out. Besides this, sampling methods of several studies imply an important risk of selection bias. Obviously, recruitment from support groups (Bradley et al., 2007; Sherwood et al., 2004) means an undeniable threat to the validity of the study results. This is confirmed by Madsen and Poulsen (2011), who state that support groups can be a valuable source of hope and information and that partners participating in a support group show less anxiety and less depressions. A second source of selection bias arises from the exclusion of patients with a cognitive deficit and/or their caregivers (Adelbratt and Strang, 2000; Halkett et al., 2010; Lobb et al., 2010; Nixon and Narayanasamy, 2010; Salander and Spetz, 2002; Strang, S. and Strang, P., 2001; Strang et al., 2001; Wideheim et al., 2002). This is remarkable since neurocognitive and functional changes are not only highly prevalent in this population but also importantly mark both patients' and caregivers' experience (Adelbratt and Strang, 2000; Halkett et al., 2010; Molassiotis et al., 2010; Schubart et al., 2008; Schmer et al., 2008; Sherwood et al., 2004; Strang, S. and Strang, P., 2001; Wideheim et al., 2002).

Next to the methodological bottlenecks of the individual studies included in these review, the review process itself may imply risk of bias. The study selection and critical appraisal were not blinded. However, it was performed by two independent reviewers and carefully supervised by the research team. Qualitative data extraction was performed by one researcher but the results were closely reflected and discussed by three reviewers.

Reflection on the results

Despite the parallels between the two perspectives (e.g. shock by diagnosis, recognition of death, the needs for hope and support) deeper understanding of the major themes reveals sometimes subtle, but important differences in their meaning for both perspectives. Approving care for both patients and caregivers

implies acknowledgement and understanding of the parallels as well as the differences.

For both patients and their caregivers the diagnosis comes as a shock. This experience of shock after the diagnosis is well known and described in other cancer settings (Clemmens et al., 2008; Docherty et al., 2007; Griffiths et al., 2008; Maliski et al., 2002). As in other cancer patients (Drageset et al., 2010; Maliski et al., 2002) and their caregivers, the diagnosis also means recognition of death which creates death anxiety. Patients describe how their initial reaction of fight later turns into a more realistic awareness of the inevitability of death. This is well confirmed in the study of Molassiotis et al. (2010). Concerning information around the diagnosis, patients in Molassiotis et al. (2010) are dissatisfied that communication hampers awareness of the terminal nature of the disease. There is a thin line between wanting full information and wanting to keep hope. Caregivers describe anxiety about losing the patient. Yet, at the same time they say that this feeling of loss begins long before the patient's death. From diagnosis on, caregivers report isolation and solitude. A sense of isolation is also described by caregivers of patients with other neurodegenerative diseases and can be explained by the role of caregiving as well as by the patients' cognitive impairment (Galvin et al., 2010; Sanders et al., 2008). Indeed, caregivers of patients with a high-grade glioma perceive the onset of mental changes as a turning point in the relationship, they feel totally and solely responsible for many new as well as former roles and they struggle to get social time for themselves.

Patients describe their symptoms in terms of negative experiences such as loss and restrictions. Deficits mean not only loss of independency but also loss of meaning. Patients deal with this by attempting to maintain an independent life, hide deficits and undertake activities. Some reach acceptance of the limitations and find ways to manage them. Some patients find it difficult to get support, others feel blessed to get some. The patient's neuro-cognitive symptoms and personality changes are perceived as most burdensome by the caregivers. As for patients, this may induce a sense of meaninglessness. While caregiver's behavior is often directed by concern and a sense of total responsibility, patients experience it as a source of irritation and as a violation to their right of self-determination. In a study with glioblastoma and other brain tumor patients, Kaplan and Miner (2000) describe that 64% of the married patients report marital problems and that these are significantly related to the overprotection by the partners.

The experience of being a caregiver is ambivalent, with positive and negative aspects. Keir et al. (2009) find that caregiver appraisal is related to various domains of patients' quality of life, such as social and functional well-being. Blum and Sherman (2010) raise the importance of realistic expectations among caregivers, in that the burden and the satisfaction of caregiving is a dynamic experience with the balance changing day to day. Besides, this study mentions that an honest assessment of strengths and both internal and community resources as well as actual help in recruiting those resources may support and develop more positive caregiver experiences. Indeed, that caregivers feel insufficiently assisted in their tasks, is confirmed in this literature review. They express the importance of help and support, but lack access to it or are reluctant to ask for it. The problem of limited availability of home care support in this patient group has been raised (Faithfull et al., 2005). Moreover, the services needed for high-grade glioma patients and their caregivers seem little understood. Prospective research on this topic is necessary (Faithfull et al., 2005; Lidstone et al., 2003). Five studies from Australia, Sweden and the US report on financial concerns. However, this theme lacks in-depth information and is not mentioned in 11 of the 16 included studies.

The needs experienced by patients and caregivers are mainly hope, support and information. Pace et al. (2010) describe that the

psychosocial needs of brain tumor patients have not been studied well. Hope is an important need, but is easily undermined and vulnerable. It is difficult to draw the exact meaning of hope from these papers. Though hope is an often reported concept in cancer research, Chi (2007) questions whether its meaning varies among cancer types and stages.

The need for support is also frequently reported. However it is less deepened for the patients' perspective. Both patients and caregivers have a need for emotional, instrumental and informational support and find it important to talk about difficult and personal topics. Asking for help is difficult for both however getting help is felt as a blessing. Both patients and caregivers express the need for a contact person and continuity of care. Patients and caregivers both have high information needs. Information about diagnosis and prognosis is often dissatisfying, because a positive message is lacking. Caregivers experience a lack of information about practical matters and they feel inadequately prepared to deal with neuropsychiatric symptoms and to give care. Dalton et al. (2009) state that the need for information is often not satisfied because of the urgent treatment. Patients report that the feeling of urge and haste should be decreased (Lepola et al., 2001).

Implications for further research

In the last decade, several studies of high-grade glioma patients and their caregivers have provided relevant data and a clearer understanding of the experiences and needs during the disease trajectory. However, the needs for hope, support and information of both patients and caregivers should be explored in further research. Also the impact on relationships as perceived by patients deserves further exploration. This information is necessary to improve care for high-grade glioma patients and their caregivers.

Validity was unsure in several of the included studies. It is therefore recommended that future research takes following criteria into account: inclusion of patients with cognitive problems and their caregivers, clear outline of the type of brain tumor, clear documentation on the phase the participants are interviewed about and a clear description whether results are about patients or caregivers.

Conclusion

The aim of this review was to explore the experiences and needs of patients with a high-grade glioma and their caregivers. Sixteen qualitative studies with mixed quality were included.

The diagnosis of a high-grade glioma creates shock and a confrontation with the end of life, which is difficult to cope with. For patients, symptoms mean loss of autonomy and meaning. For caregivers, the burden is characterized by a sense of total responsibility. Moreover, neurobehavioral symptoms and personality changes irreversibly change their relationship with the patient. Both patients and caregivers report many emotional, instrumental and informational needs. Yet, they report dissatisfaction about received support or lack of adequate support.

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Conflict of interest statement

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