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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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ABSTRACT

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.

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 papiloedema (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 tell 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