



## Living with a high-grade glioma: A qualitative study of patients' experiences and care needs



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### A B S T R A C T

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**Purpose:** Patients with high-grade glioma (HGG) face debilitating symptoms and a poor prognosis. The aims of this study were to better understand how patients with HGG experience life with a brain tumor, and to explore their professional care needs.

**Methods:** We conducted a qualitative research of HGG patients' experiences using semi-structured interviews and using a Grounded Theory approach. Participants were recruited during patients' hospital visits for treatment or follow-up at the University Hospitals Leuven, Belgium. Seventeen HGG patients were interviewed for the study.

**Results:** Interviews showed that HGG diagnosis left patients feeling like everything was surreal. From that point on, their life was marked by loss. HGG patients sometimes felt disregarded by family caregivers, professional caregivers, and the health care system. They felt as if they were on the "sidelines" of their own life. Despite the devastating experience of living with this type of brain tumor, HGG patients also expressed great inner strength, and they tried to maintain hope. Their pivotal professional care needs concerned information, communication, and accessibility.

**Conclusions:** Diagnosis of HGG changes life drastically. Our results highlight the need for professional caregivers to be more considerate and supportive of patients with this life-changing diagnosis. Additionally, professional caregivers need to acknowledge these patients as persons and strive to empower them in order to bolster their personal strength.

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### Introduction

The World Health Organization (WHO) classifies gliomas into four grades, with grade III and IV being high-grade gliomas (HGG) (Louis et al., 2007). In the case of the best state-of-the-art therapy, the five-year survival rate for glioblastoma, the most common HGG, is 9.8% and the median survival time is 14.6 months (95% CI 13.2–16.8) (Stupp et al., 2009, 2005). HGG is an extremely difficult diagnosis for patients. Besides the poor prognosis, HGG is associated with severe, debilitating symptoms that often limit patients' activities and opportunities in daily life. Depending on tumor size

and location, the most common symptoms are: 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). Dealing with these symptoms and their impact on daily life has been described as the most difficult to deal with (Adelbratt and Strang, 2000; Halkett et al., 2010; Molassiotis et al., 2010; Strang and Strang, 2001; Wideheim et al., 2002). Symptoms represent loss of independence and previous roles and this can create feelings of meaninglessness. Besides, the shock of the diagnosis (Adelbratt and Strang, 2000; Lobb et al., 2011; Rosenblum et al., 2009; Wideheim et al., 2002), permanent uncertainty (Halkett et al., 2010; Wideheim et al., 2002) and recognition of death (Adelbratt and Strang, 2000; Strang and Strang, 2001; Wideheim et al., 2002) contribute to the burden of living with a high-grade glioma.

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Unfortunately, many qualitative studies have included mixed samples of patients with different types of brain tumors, have excluded patients with cognitive problems or have other sources of selection bias (Sterckx et al., 2013). Further research in this patient group is needed in order to adequately tune care to the specific experience and needs of high-grade glioma patients. This qualitative study focused on following research questions: how do patients with a high-grade glioma experience living with HGG, and what are their needs related to professional care?

## Methods

### Design

We used a Grounded Theory approach (Glaser and Strauss, 1967) in order to generate a rich, in-depth understanding of the experiences and needs of HGG patients (Maso and Smaling, 2004). Grounded Theory is a qualitative research approach that facilitates exploration of emergent themes of the subjects' experiences as well as the interconnections of these themes. Thus, this design enables a better understanding of the process as a whole (Corbin, 2008); in this case, how patients with an HGG experience life with a brain tumor.

### Sampling

#### Setting

Patients were recruited at the oncology wards of the University Hospitals Leuven, Belgium, during two separate periods between February 2011 and July 2011, and between April 2012 and November 2012. Interruption of the recruitment period was due to practical reasons only.

#### Selection of participants

Eligible patients were diagnosed with an HGG and were treated with chemotherapy and/or radiotherapy, or were in follow-up after such treatment. Additional inclusion criteria were the following: being capable of being interviewed, being able to give informed consent, and being able to speak Dutch. Patients who were physically, mentally or emotionally unable to participate – according to the judgment of the physician or head nurse – were not invited to participate, or were invited later, when they were judged capable.

Initially, we collected data using purposive sampling, which was later superseded by theoretical sampling in order to confirm, deepen, assay, or refute concepts emerging during the analysis (Glaser and Strauss, 1967). Recruitment proceeded until data saturation was reached, i.e., when the data were rich, full, and complete, and new data failed to reveal any further insights into the core concepts of the study (Maso and Smaling, 2004; Morse, 1995). Patients were given oral and written study information.

#### Data collection

Single, semi-structured interviews were conducted. The topics, e.g. diagnosis, symptoms and functioning, family relationships and communication with professional caregivers, were chosen on the basis of results of a systematic review (Sterckx et al., 2013). These were revised and supplemented as often as needed in light of interim analyses of participants' experiences. Interviews took place in the hospital or in the patient's home, according to the patient's preference. All interviews were audiotaped and transcribed verbatim.

### Data analysis

Three researchers analyzed the data, guided by the Qualitative Analysis Guide of Leuven (QUAGOL) (Dierckx de Casterle et al., 2012). Our independent reading and re-reading of every interview yielded an initial, provisional understanding of the key concepts of the patient's experience. Next, each researcher's understanding of the individual interviews was discussed during several meetings, enriching our understanding of the patient experience. When new concepts emerged in later interviews, they were actively explored in a re-reading of the earlier interviews. This cyclical approach of data collection and analysis is characteristic of the Grounded Theory approach.

Across-interview analysis and discussions among the researchers enabled us to identify key concepts throughout all the interviews. Detailed coding using QSR Nvivo 9 software (QSR International (UK) Limited, Daresbury, Cheshire, UK) for qualitative research helped us to clarify and empirically support the meaning of every major theme that emerged. After thirteen interviews, we consulted with five experts in a peer debriefing to get their views on our preliminary results (Boeije, 2005; Maso and Smaling, 2004). All peer debriefers had expertise in neuro-oncology or oncology nursing and/or in qualitative research. As a result, some themes (e.g., anxiety, patients' strength, professional care needs) were further explored in a re-reading of the interviews and during four additional interviews. Because of restrictions in the budget and timing of the project, we were unable to expand our study and understanding of the key concepts with a full examination of the interconnection between the themes. Therefore, we do not present a conceptual framework of our study results.

### Research ethics

This study was approved by the Research Ethics Board of UZ Leuven (NCT01638130) and written informed consent was obtained from all participants.

## Results

### Participants

Fig. 1 describes how we recruited and selected patients. Finally, 17 patients participated in our study. Participant characteristics are listed in Table 1. The mean duration of the interviews was 50.6 min (range: 22–97 min). A family caregiver was present at six of the interviews. Nine interviews were held in a quiet, private room at the hospital; eight were held in patients' homes. Two patients participated in a follow-up interview: one because of unclear data from the first interview, the second because of disease progression and end of treatment shortly after the first interview.

### Experiences of patients

First, we will describe the experience of patients, followed by their needs related to professional care. We illustrate our study results with exemplifying interview excerpts.

#### Devastating experience of living with HGG

The diagnosis of HGG comes as a *shock* to patients, resulting in frightening and surreal feelings. Patients experience the diagnosis as something unreal. This feeling persists long after receiving the bad news of the diagnosis. They 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, whereas

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