

BMJ Support Palliat Care. 2024 Oct 1:spcare-2023-004659. doi: 10.1136/spcare-2023-004659.  
Online ahead of print.

# Patient experiences in high-grade gliomas: from symptoms to radiotherapy

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PMID: 39353720 DOI: [10.1136/spcare-2023-004659](https://doi.org/10.1136/spcare-2023-004659)

## Abstract

**Objectives:** Little is known in the literature about felt experience and supportive care needs of patients with new diagnosis of adult-type diffuse gliomas Central Nervous System WHO grades 3 and 4. The purpose of this study is to influence clinicians' attitudes and facilitate the referral process and the development of support services by better understanding the patient's journey.

**Methods:** Adult patients with a new histopathological diagnosis of high-grade glioma, who underwent radiotherapy, participated in a semistructured, face-to-face interview. Different segments of the patient's journey were explored focusing on patient's emotions, interactions with healthcare providers, satisfaction during the process and access to supports. Descriptive thematic analysis in the tradition of grounded theory was performed.

**Results:** Fifteen patients were interviewed, and four themes were emerged from the analysis. First, information conveyed by the medical team was frequently disconnected from patients' understanding regarding diagnosis and treatment. Second, specific events created a lasting impression that the medical system, and at times medical care providers, lacked empathy. Third, patients' perceptions of shortcomings within the medical system led to decreased trust, particularly regarding the follow-up process. Finally, although respondents identified multiple inadequacies during their journey, they nonetheless acknowledged the great support and quality of services they received.

**Conclusions:** This study provides insight into patients' experiences and perceived shortcomings of the medical system, from the time of presentation until the end of radiotherapy treatment in patients with new diagnosis of high-grade glioma. These findings should influence clinicians' attitudes and guide systematic changes including delivery of information and the referral process.

**Keywords:** Brain; Neurological conditions; Psychological care; Quality of life.

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