Poster: INNV-23

Understanding the burden of mIDH1/2 diffuse glioma and the complexity of navigating the patient pathway: insights from patients and caregivers

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KEY MESSAGES

- The pathway for patients with mutations in isocitrate dehydrogenase 1 or 2 (mIDH1/2) diffuse glioma is heterogeneous and complex. This pathway and the management options for mIDH1/2 diffuse glioma (active observation and radiotherapy/chemotherapy [RT/CT]) are associated with substantial physical, emotional and socioeconomic impact.
- Improved patient and caregiver education, as well as facilitating early navigation and prioritizing shared decision-making along the disease pathway, will better support people living with mIDH1/2 diffuse glioma.
- mIDH1/2 diffuse glioma is a substantial burden on the health and quality of life (QoL) of patients, and active observation and RT/CT do not address all these issues. Ultimately, the patient experience requires improvements that maintain QoL while controlling disease progression.

PATIENT SUMMARY

- Patients with mIDH1/2 diffuse glioma experience a slow-growing disease, but one which can have a profound impact on their daily life and survival outcomes.
- QoL is one of the most important considerations for patients with gliomas when making decisions about their treatment.[4]
- We wanted to better understand the experience of being diagnosed with and treated for glioma, and how this impacts QoL from the viewpoint of the patient and their caregivers.
- We held interviews with patients, caregivers and patient association groups, and asked patients to complete online exercises to describe their own experiences.
- We found that the pathway from the first symptoms through diagnosis, surgery and treatment was complicated and highly varied.
- Throughout the pathway, patients and caregivers reported emotional and practical burdens with physical impacts of disease.
- Active observation and RT/CT were considered to have their own burdens, demonstrating that the patient experience requires improvements that maintain QoL while managing the disease.
- We show that there is a need to help educate patients and their caregivers so that they can be more involved in decisions about managing their disease, and to provide more support to patients throughout their unique journey with glioma.

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INTRODUCTION

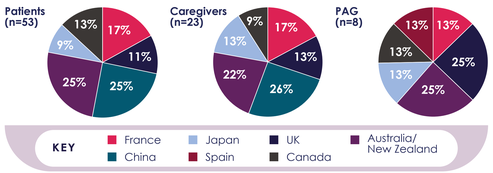
- Diffuse gliomas with mIDH1/2 are characterized by a slow-progressing yet life-limiting disease with median ages at diagnosis of 37 (astrocytoma) and 44 (oligodendroglioma) in young people.[1,2]
- Patients view QoL concerns as the most important consideration behind making decisions about treatment; balancing the potential benefits and risks of therapy is a critical consideration in the treatment of mIDH1/2 diffuse gliomas.[3,4]
- Herein, we report final findings from a qualitative study to describe the mIDH1/2 diffuse glioma patient pathway, experience of the disease, and perceptions of treatment

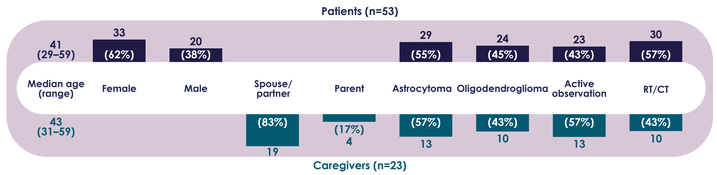
METHODS

- Participating patients were aged ≥12 years with grade 2 or 3 mIDH1/2 glioma and last resection ≥6 months before enrollment, either undergoing active observation or receiving RT/CT. Caregivers were living with the patient. Patient advocacy group (PAG) representatives were active members of a brain tumor PAG.
- Patients completed online exercises comprising a step-by-step description of the clinical pathway (developed for this study in collaboration with the International Brain Tumour Alliance), along with the 12-item Short Form Survey Version 2 (SF-12v2).
- Patients, caregivers and PAG representatives participated in interviews conducted via Zoom, which were expected to last 60 minutes for patients and 45 minutes for caregivers and PAG representatives. Interviews were audio/video recorded, translated into English (if required), and transcribed.

RESULTS AND INTERPRETATION

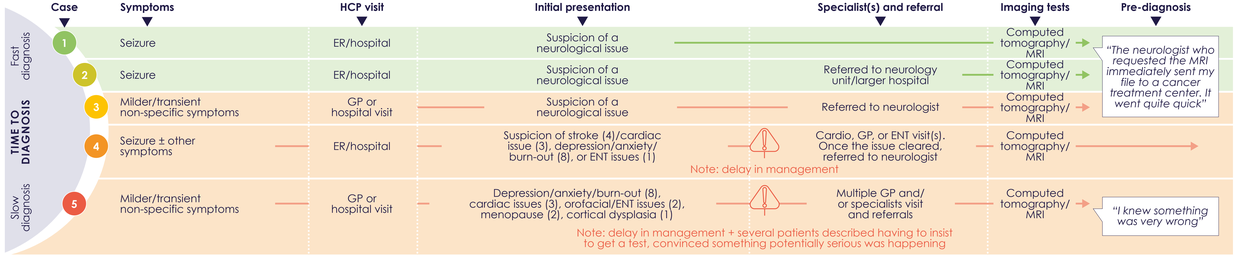
Between November 2023 and April 2024, 53 patients, 23 caregivers and eight PAGs participated





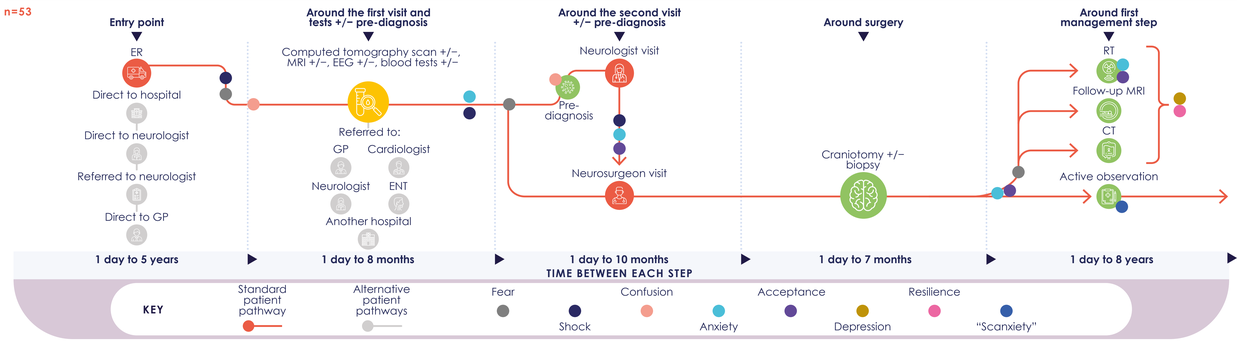
- The median age of patients was 41 years. Of 53 patients, 29 (55%) had astrocytoma and 24 (45%) had oligodendroglioma.
- A general clinical and emotional pathway from the patient's perspective was elucidated from the online exercises and interviews.
- The specifics of the patient pathway, including presentation, access to care and the ability to navigate healthcare systems, varied between patients and within countries.

The steps leading to a diagnosis varied between patients; however, five main scenarios were identified



ENT, ear nose throat; ER, emergency room; GP, general practitioner; HCP, healthcare professional; MRI, magnetic resonance imaging.

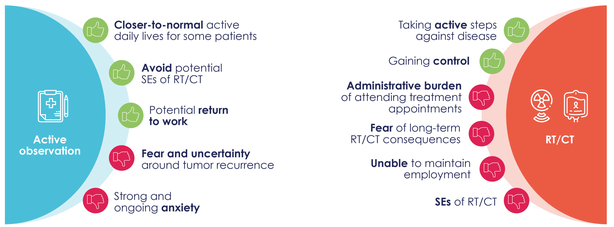
The glioma patient pathway is complex, and each step is associated with different emotions



EEG, electroencephalogram.

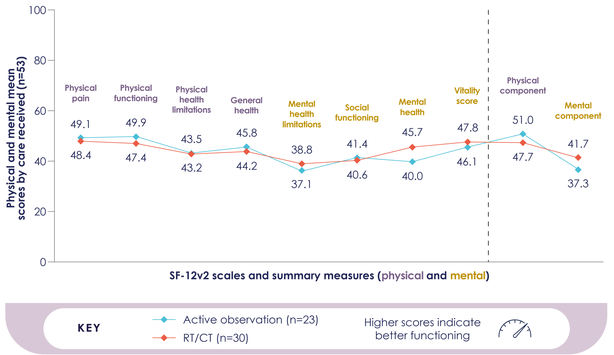
- Several needs relating to the pathway were identified in PAG interviews, including a need for better communication between patients/caregivers and their healthcare teams, patient-friendly information to support shared decision-making, and increased help in navigating patients' respective healthcare systems.
- Surgical resection was perceived as a pivotal therapeutic step in the clinical pathway. Of the patients who specified the type of resection they received, most (n=26) had a partial resection, while others (n=11) underwent total resection.

Both active observation and RT/CT are associated with ongoing burdens for patients

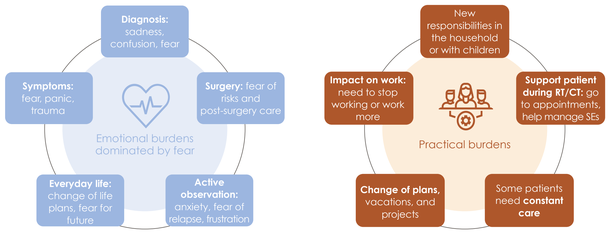


SE, side effects.

Patients undergoing active observation had higher SF-12v2 scores for the physical component than patients undergoing RT/CT, indicating better physical function



Caregivers reported experiencing emotional and practical burdens



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