Social, psychological and existential well-being in patients with glioma and their caregivers: a qualitative study.

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Abstract

BACKGROUND: Cerebral glioma has a devastating impact on cognitive, physical, social, psychological and spiritual well-being. We sought to understand the multidimensional experience of patients with this form of cancer as they progressed from receiving a diagnosis to the terminal phase of the disease.

METHODS: We recruited patients with a suspected brain tumour from a tertiary referral centre in the United Kingdom. We interviewed patients and their caregivers at key stages of the illness: before receiving a formal diagnosis, at the start of initial treatment, after initial treatment was completed and at six months’ follow-up; caregivers were also interviewed post bereavement. We interviewed the patients’ general practitioners once, after treatment had been completed. We transcribed the interviews and analyzed them thematically using the constant comparative method of a grounded theory approach.

RESULTS: We conducted in-depth interviews with 26 patients, 23 of their relatives and 19 general practitioners. We saw evidence of physical, social, psychological and existential distress even before a diagnosis was confirmed. Social decline followed a similar trajectory to that of physical decline, whereas psychological and existential distress were typically acute around diagnosis and again after initial treatment. Each patient’s individual course varied according to other factors including the availability of support and individual and family resources (e.g., personal resilience and emotional support).

INTERPRETATION: There are practical ways that clinicians can care for patients with glioma and their caregivers, starting from before a diagnosis is confirmed. Understanding the trajectories of physical, social, psychological and existential well-being for these patients allows health care professionals to predict their patients' likely needs so they can provide appropriate support and sensitive and effective communication.

PMID: 22431898 [PubMed - as supplied by publisher]  Free full text

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