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# Wants and needs for involvement reported by relatives of patients with a malignant brain tumour: a scoping review

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## Abstract

**Objective:** This scoping review identifies and maps the breadth of available evidence on relatives' wants and needs for involvement throughout the course of the disease of patients with a malignant brain tumor.

**Introduction:** Patients diagnosed with a malignant brain tumor often have a poor prognosis, including a rapid progression of the disease, with changing physical, cognitive, and psychosocial symptoms. The caregiver burden is described as multifaceted, and relatives often neglect their own physical, emotional, and social needs.

**Inclusion criteria:** This review included studies that defined or assessed the wants and needs for involvement of relatives of patients with a malignant brain tumor throughout the disease and treatment trajectory. The populations were relatives of patients with a malignant brain tumor in various settings.

**Methods:** The JBI methodology for scoping reviews was employed in accordance with a previously published a priori protocol. An extensive search was conducted in the MEDLINE (PubMed), CINAHL (EBSCO) and Embase (Ovid). Gray literature was searched for using Grey Matters (CADTH) and BASE. The initial search was conducted in February 2020 and updated in March 2022. This review was limited to studies published since January 2010 in English, German, or Scandinavian languages. The data were extracted using a data extraction tool (authors, year of publication, country of origin, setting, study methods, and findings related to wants and needs for involvement) created by the authors. Textual data mapping of wants and needs for involvement were synthesized narratively using a basic qualitative content analysis. The review findings are reported in this paper as a descriptive summary, with tables and figures to support the data.

**Results:** The search identified 3830 studies, of which 10 were included. The studies were conducted in 6 countries and were published between 2010 and 2018. In total, 4 studies applied a qualitative study design that used semi-structured interviews, 2 studies applied a mix-method design that used questionnaires and semi-structured interviews, 1 study applied a multi-method design, and 3 studies used a quantitative survey. Research was conducted in a variety of settings, from an inpatient neurology center/neuro-oncology to post-bereavement. The findings showed that most of the relatives' needs were related to the caregiver role. The relatives were actively involved in the patients' disease and treatment trajectories. However, relatives were often required to adopt the caregiver role

and a large amount of responsibility at short notice. Thus, they expressed their need for a stronger connection with health care professionals because their needs changed as rapidly as the disease progressed. Relatives also had a need related to maintaining hope, which was essential for their involvement, and their wants for involvement in the patients' disease and treatment trajectories depended on a significant and timely amount of information.

**Conclusions:** The findings reveal that relatives are actively involved in the patients' disease and treatment trajectories. The relatives want and need support for their involvement, and these desires are related directly to the accessibility and availability of health care professionals, as the demands placed on them change rapidly throughout the progression of the disease. One way to address relatives' wants and needs might be to further strengthen the relationship between the relatives and health care professionals.

**Supplemental digital content:** A Danish-language version of the abstract of this review is available as Supplemental Digital Content [<http://links.lww.com/SRX/A26>].

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