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# Patient and carer involvement in the formulation of research questions: findings from the Italian guideline on palliative care in adults with glioma

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## Abstract

**Background:** In 2017, the European Association for Neuro-Oncology (EANO) published the guideline for palliative care (PC) in adults with glioma. The Italian Society of Neurology (SIN), the Italian Association for Neuro-Oncology (AINO), and the Italian Society for Palliative Care (SICP) joined forces to update and adapt this guideline to the Italian context and aimed to involve patients and carers in

the formulation of the clinical questions.

**Methods:** During semi-structured interviews with glioma patients and focus group meetings (FGMs) with family carers of deceased patients, participants rated the importance of a set of pre-specified intervention topics, shared their experience, and suggested additional topics. Interviews and FGMs were audio-recorded, transcribed, coded, and analyzed (framework and content analysis).

**Results:** We held 20 interviews and five FGMs (28 carers). Both parties considered the pre-specified topics as important, chiefly information/communication, psychological support, symptoms management, and rehabilitation. Patients aired the impact of focal neurological and cognitive deficits. Carers reported difficulties in dealing with patient's behavior and personality changes and appreciated the preservation of patient's functioning via rehabilitation. Both affirmed the importance of a dedicated healthcare path and patient's involvement in the decision-making process. Carers expressed the need to be educated and supported in their caregiving role.

**Conclusions:** Interviews and FGMs were well informative and emotionally challenging. Both parties confirmed the importance of the pre-specified topics, and carers suggested one additional topic: education/support to caregivers. Our findings strengthen the importance of a comprehensive care approach and of addressing the needs of both patients and their family carers.

**Keywords:** Brain tumors; Consumer involvement; Gliomas; Palliative care; Practice guideline; Qualitative study.

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