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Shared decision-making in neuro-oncology: Existing practices and future steps

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"*It's about YOUR life, and of course, YOU should have a say in the decision.*" This statement was made by a patient with recurrent high-grade glioma concerning the decision-making about treatment for her recurrence.[1] While she deeply valued the expertise and experience of the neurosurgeon with whom she discussed the treatment options, it was crucial for her to feel actively involved in the decision-making and that her values and preferences were included and respected. This is the essence of shared decision-making (SDM).

As the example illustrates, sharing decisions requires attentiveness and interest in the patient's perspective and a willingness to accept that the best decision for the individual patient might not be identical to the decision the clinician would have made. On a more practical note, SDM entails making the patient and their family aware that there is a choice, providing them with evidence-based and tailored information about the options, eliciting and discussing the patient's preferences and values, and, finally, reaching a shared decision.[2]

The need to be involved in decisions regarding one's treatment and care is a shared priority for patients across diagnoses. Furthermore, there is solid evidence that involving patients in SDM increases their satisfaction with the decision while reducing feelings of uncertainty and decisional conflict.[3] Within neuro-oncology, SDM is still a relatively new area, with only a limited number of studies exploring its impact on patients with brain tumors.[4,5] However, the current knowledge suggests that similar to other patient populations, neuro-oncological patients prefer to be involved in decisions about their treatment and care. Moreover, involvement in SDM may enhance their emotional well-being and alleviate anxiety.[1,4]

Understanding the importance of patient involvement in decision-making, the paper by Bras et al.,[6] brought in this issue of *Neuro-Oncology Practice*, offers valuable insight into current decision-making practices in neuro-oncology. The paper: "A thematic analysis of shared decision-making in consultations with patients with a presumed brain tumor and neurosurgeons" presents a qualitative study in which the authors recorded and analyzed the decision-making during eleven neurosurgical consultations in the Netherlands. The authors found that the main focus of the consultations was on informed decision-making, in which the neurosurgeon guided the decision-making process, provided medical information about treatment options, and elicited informed consent. The involvement of patients and family members was typically limited to providing information about symptoms and asking follow-up questions about the medical information. Attention toward the values and goals of the individual patient was lacking, and personalization of the decision-making process was only occasionally encountered during the consultations.[6]

As demonstrated in the study by Bras et al.,[6] treatment decision-making often boils down to eliciting an anamnesis, providing information, and asking for informed consent for the suggested treatment plan. However, the importance of involving patients in SDM, beyond simply obtaining informed consent, is increasingly recognized and advocated by healthcare professionals, patient organizations, and policymakers. The significance of SDM is also emphasized in the 2024 ESMO practice guideline on communication and support of patients and caregivers in chronic cancer care.[7] In neuro-oncology, the interest in SDM has notably grown over the past five years, assessed by the rising number of published papers. In addition, an international SDM working group, organized within the European Association of Neuro-Oncology Nurses and Allied Health Professional Committee, was established in 2023. Hence, efforts are underway to strengthen awareness of SDM within the neuro-oncological community and support its integration into clinical practice. Future research in the field should be guided by the evidence on SDM from other patient populations and involve patients and families in developing the best decision support for patients with brain tumors.

A way to increase patient decision support is by implementing a decision-support intervention that facilitates

communication and SDM. A decision-support intervention can be applied either before the consultation to prepare for the decision-making or during the consultation to guide the decision-making process. The most commonly used decision-support interventions are patient decision aids, developed for many patient populations and proven to support patients during the decisional process.[3] At least two types of decision-support interventions have been developed and implemented in a brain tumor setting, both of which have been positively received by patients and clinicians.[8,9] In addition, the study by Bras et al.[6] is part of a larger project exploring how a symptom-tracking intervention might increase decision support and SDM.

Two essential aspects need to be articulated when discussing SDM in a neuro-oncology setting. One is the fact that many brain tumor patients experience cognitive impairments of varying degrees, which can impact their decision-making capacity.[10] Another concern is the accuracy of the patients' prognostic understanding. These aspects imply that SDM with brain tumor patients needs to be tailored to the patients' potentially impaired cognition and focus on increasing the patients' understanding and reasoning between the options. In addition, patients differ in their emotional state, health literacy, and information and involvement preferences, all of which influence their ability and desire to engage in SDM. The involvement of family members needs to be considered, as this is an important issue for both patients and families. Particularly in cases where the patient is severely emotionally or cognitively affected and relies on their family for support or decision-making.[1] All these factors underscore the importance of carefully assessing each patient's decision-making capacity and decisional needs and adjusting the information and decision support accordingly.

It would be easy to dismiss SDM as unsuitable in neuro-oncology due to the unique challenges of patients with brain tumors. However, SDM has been employed across various patient populations, including patients with low health literacy. It has demonstrated undeniable benefits such as increasing patients' knowledge, fostering accurate risk perceptions, and promoting a sense of being well-informed and aligned with their values.[3] This evidence suggests that cognitive impairments, diminished decision-making capacity, or limited prognostic awareness should not be viewed as barriers to decision support and SDM but rather as compelling reasons to prioritize it.

Authorship

The text is the sole product of the author and no third party had input or gave support to its writing.

Conflicts of interest statement

None declared.

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