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EDITORIAL (BY INVITATION)

True shared decision-making in neurosurgical oncology: does it really exist?

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Recent years have shown a shift in consent for surgery away from medical paternalism—often referred to as shared decision-making (SDM). This ethical approach of informed consent might create a patient–physician relationship that is based on partnership. SDM has been defined in literature as "an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences" [11]. In this way, the consent process becomes a more dynamic process instead of a signature on an informed consent form [15] and might improve health outcomes and increase patient satisfaction [6, 9].

Leu et al. [18] are the first to study both patient and staff satisfaction with SDM in a neurosurgical oncology practice before and after SDM training and the introduction of decision grids. The individualized decision grids were developed for three types of brain tumors (low-grade and high-grade glioma and brain metastases) and showed the three most reasonable treatment options including the best medical care next to each other, to help to structure the treatment option conversation. The team training in SDM and the decision grids increased the staff satisfaction with the SDM process, and patients showed a non-significant increase in the already high level of patient satisfaction. However, one might ask if the training and decision grids resulted in true SDM, which requires that both patient and physician need to be informed equally, both educationally and emotionally.

Emotions affect perception, processing, presentation, and decision-making [25]. The patient and physician can also influence each other's emotions, which is referred to as emotional contagion. For example, the optimism or pessimism of a physician about a particular treatment option during an SDM conversation can turn a patient's fear into hope and vice versa [25]. Complex decisions, including decisions about oncology treatment, require substantive processing, giving emotions more opportunity to influence decisions [25]. SDM makes the assumption that patients can process complex information from the physician at the most vulnerable and emotional time in their lives and use that information to make a rational decision about their treatment options [24, 25]. A paper by Akinsanya et al. [1] described both patients' and doctors' perspectives on assessing the capacity to consent for thrombolysis. The patient suffering from a stroke with mild expressive dysphasia and right hemiplegia described the following about the consent conversation with the physician: "It is extremely difficult to take in all the information that is being given to you and in my case, this was made even harder because of the difficulty expressing myself clearly. Furthermore because of the thoughts that are going through your mind as a patient in these particular circumstances, such as the prospect of serious disability which will have a major impact on your family, career, personal independence, or indeed death, one clearly misses important information being imparted under the requirements of the act" [1].

Although simple tests of cognitive functions might be normal, sickness can result in impaired thinking, especially proportion and risk tasks which are important concepts in SMD [5]. For brain tumor patients, this becomes even more relevant as the disease can be inherent to a deficit in cognition or a disturbed mental status, impacting the capacity to be involved in SDM [26]. Hewins et al. [13] concluded that brain tumor patients need additional assessment of cognitive functions to test the ability to give informed consent for treatments. For these patients, the involvement of relatives is important, even though they are often, just as the patients, confused by hope and fear, unprepared, and unable to understand all the information given. Relatives can be confronted

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with dilemmas about treatment unaware about the preferences of the patient [21, 27].

An important incentive of the SDM model is that what is considered important for a patient to make a decision might be different from what the physician considered relevant. A review of SDM in surgery showed a discrepancy in the perception of SDM in the surgery consultation by the patient and physician; 29.3% of the patients and 43.6% of the surgeons experienced that the consultation was performed in an SDM approach [8]. The most ideal situation for SDM is where both the patient and the physician agree that there is a situation where options that are in balance in terms of attractiveness or equally (un)desirable outcome need to be deliberated, referred to as dual equipoise [10]. However, in medicine, situations exist where dual equipoise does not exist, and the physician believes that the scientific evidence for benefit outweighs the harm [10]. Patients frequently want more information and more involvement in decision-making than physicians think [7, 17, 19].

Although patients often want more information, a study by Krupp et al. [16] found that patients undergoing neurosurgical procedures recalled less than one-fifth of the information presented during the informed consent process regardless of their age. Some of the proposed reasons for recall failure of risks are that patients might feel that they are less vulnerable to the risks than other patients [15, 28], or they might be blocking out the most serious risk to protect themselves psychologically [15]. During the SDM process, patients can identify their illness as a greater threat to mortality and morbidity than the risks of a particular treatment [15, 20]. In addition, one might question if you can really understand what it means to be hemiplegic after a tumor resection while you are sitting in a doctor's room without any symptoms at this moment, able to walk out of the door any moment. People change their perspective of what is acceptable during life and learn to live with deficits while still enjoying life although they previously judged these deficits as unacceptable [3]. Physicians also have to recognize that an unacceptable outcome in their opinion might not be an unacceptable outcome for the patient [27].

However, SDM in neuro-oncology can still be a useful approach. The use of decision aids might help the physician to be aware of the abovementioned critical notes and optimize the SDM process. If offered the option, patients will take an active role in decision-making if the relevant information is provided in a clear and understandable way [29]. Decision aids make treatment, care, and support options explicit by providing evidence-based information about the associated benefits and harms and help patients to consider what matters most to them in relation to the possible outcomes [4]. It has already been shown to achieve and improve SDM in neurocritical care [2, 12, 14, 22], although there is a relative lack of SDM and validated decisional aids in literature for neurosurgery including neuro-oncology [6, 23]. For glioblastoma patients, SDM provided a model for the empowerment of patients, improved patient-physician communication, and reduced anxiety in patients and caregivers [23]. Leu et al. [18] provided both SDM training and decision grids resulting in increased satisfaction for both patients and physicians. For future investigation, it would be interesting to see what the patient recall of information after the use of these decision grids.

In conclusion, SDM is a potentially beneficial approach of consent in neuro-oncology, although one might question if true SDM is possible in neuro-oncology due to the educational and emotional gap that exists between the physician and patient. The study by Leu et al. [18] showed that SDM and the use of decision grids and SDM training improved staff and patient satisfaction. These decision grids are a tool to implement SDM in the standard neuro-oncology practice.

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