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A thematic analysis of shared decision-making in consultations with patients with a presumed brain tumor and neurosurgeons

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Abstract

Background. Patients with brain tumors, family members, and healthcare professionals face complex healthcare decisions that can significantly impact everyday life. Engaging in shared decision-making (SDM) can help ensure treatment decisions align with patients' preferences and goals. Little is known about the decision-making process in neurosurgical consultations. This study aims to qualitatively explore and describe the SDM process during neurosurgical consultations for patients with a presumed brain tumor.

Methods. The first consultation between patients with presumed glioma or meningioma and their neurosurgeons was audio-recorded and transcribed. Decision-making models were used as sensitization concepts, with coding carried out inductively. We employed a reflexive thematic analysis to develop themes and subthemes until saturation was beginning to emerge.

Results. Analyzing eleven consultations, we developed three main themes and twelve subthemes. The results depict decision-making guided by neurosurgeons (theme 1), with varying degrees of engagement from patients and family members (theme 2) and personalization of the decision-making process based on the medical situation and everyday life priorities (theme 3). The consultations lacked specific attention to the everyday life priorities of the patients.

Conclusions. The decision-making processes seemed to focus primarily on medically informing patients with a presumed brain tumor, in line with informed decision-making. However, less emphasis was placed on learning more about the patient's everyday life and preferences to integrate into the decision-making process, which is key to SDM. Incorporating patient goals may lead to greater personalization and decisions that align with both the patient's medical situation and their goals.

Key Points

1. The decision-making process was mostly conducted in line with informed decision-making.
2. Less attention was given to the patient's everyday life, goals, and preferences.
3. Integrating patient goals may enhance the personalization of the decision-making process.

Importance of the Study

This study qualitatively explores and describes the shared decision-making (SDM) process during neurosurgical consultations for patients with presumed brain tumors, highlighting its critical role in enhancing patient-centered practices. The findings suggest that the current decision-making processes primarily focused on medically informing patients, in line with informed decision-making. However, there was insufficient emphasis on understanding patients' everyday lives and preferences, which are considered key elements for SDM. By addressing this gap, the study not only contributes to existing literature by analyzing the intricacies of the decision-making process but also lays the groundwork for future research on optimizing SDM practices. This research has the potential to transform how healthcare professionals engage patients in critical treatment decisions, ultimately improving patient outcomes and satisfaction.

Patients with a presumed brain tumor, family members, and healthcare professionals (HCPs) face complex healthcare decisions that can significantly impact everyday life.[1,2] The aims of the available treatment options have traditionally mainly been focused on stabilizing and limiting the progression of the disease for as long as possible. However, both the brain tumor and its treatment can profoundly impact cognitive functioning, psychological well-being, symptoms, and role functioning.[3–6] It is therefore essential to weigh the potential benefits of treatment against their possible risks, disadvantages, and consequences for individual patients' quality of life.[4,5,7] The weight attributed to the benefits and risks of treatment can only truly be determined by involving the patient and family members in the decision-making process.[1,4,8] Family members play an indispensable role in supporting the patient in this regard.[1] Accordingly, it is important for patients with a brain tumor, family members, and HCPs to engage in shared decision-making (SDM).[2,7]

Roughly there are three different approaches to making decisions in clinical practice.[9,10] In paternalistic decision-making (PDM), the HCP weighs up the advantages and disadvantages for the patient and decides what is best following evidence-based medicine or clinical experience, and asks the patient for consent.[9,10] Informed decision-making (IDM) entails informing the patient medically on alternative treatment options, their advantages and disadvantages, and asking the patient to decide between options.[10] However, IDM is generally discouraged to prevent the patient from feeling alone or overburdened when making decisions.[11] Instead, SDM is advocated as the preferred method of involving patients in healthcare decisions whenever possible.[9–11] By tailoring the decision-making process to the specific patient, SDM goes beyond only informing the patient medically on options.[9,10,12] It includes integrating the patient's preferences for how decisions are made, and moreover their preferences for treatment outcomes.[8,13] Even though there is no consensus on what constitutes the ideal SDM process, 4 key elements can be distinguished in most influential SDM models, namely (1) fostering choice awareness: patients need to be aware that there is a decision to be made; (2) discussing relevant treatment options including advantages and disadvantages; (3) discussing patient preferences and supporting their deliberation process; and (4) making a decision about treatment or follow-up care.[9,14] Recent models additionally suggest patient goals as a fundamental part of SDM, to align treatment and treatment outcomes with what matters to patients in everyday life.[12,15]

Satisfactory involvement of patients in decision-making can have beneficial effects on patient-centered outcomes,[2] such as reduced decisional uncertainty and improved social and emotional well-being.[16,17] A recent qualitative study using semi-structured interviews with patients with a primary malignant brain tumor reported that, in hindsight, patients felt they had little choice regarding treatment. For surgery, this was mainly due to the shock and urgency of treatment.[18] Most studies to date have investigated reported outcomes of SDM after consultations.[2,7] However, to the best of our knowledge, no studies have evaluated the actual neurosurgical decision-making process for patients with a brain tumor.[2,7] Existing SDM measures to quantitatively rate behaviors might fail to capture the intricacies of the decision-making process.[19] Therefore, we chose to qualitatively explore and describe the SDM process during neurosurgical consultations for patients with a presumed brain tumor.

Methodology

Study Design

Data were collected as part of a mixed-method, quasi-experimental, non-parallel 2-group study undertaken at the departments of Neurosurgery and Neurology of the Elisabeth-TweeSteden Hospital in Tilburg, the Netherlands. The main aim of the parent study was to evaluate the effects of a patient life goal and symptom-tracking intervention (the Goings-On app®[20]) on SDM, compared to an observational group. The results of the parent study will be published separately.

The current analysis only used the audio recordings of the observational group. This qualitative study used reflexive thematic analysis as a method.[21,22] It involved observing and describing the SDM process, without extensive interpretation of latent meaning or theory development. The current study is reported following the Standards for Reporting Qualitative Research.[23]

Ethical Considerations

The Medical Ethics Committee (METC) Brabant determined that the study did not fall within the scope of the Medical

Research Involving Human Subjects Act (WMO).[24] Ethical approval was obtained from the Ethics Review Board of the School of Social and Behavioral Science of Tilburg University (RP398). The study used procedures in accordance with the Declaration of Helsinki. Personal data were processed in line with the EU General Data Protection Regulation and the Dutch Act on Implementation of General Data Protection Regulation.

Population

Patients of 18 years or older with a presumed diagnosis of low- or high-grade glioma, or meningioma (including multiple differential diagnoses such as high-grade glioma and brain metastasis), based on MRI, who had a scheduled first extensive consultation with a neurosurgeon in the outpatient clinic were considered eligible. Patients were excluded if (1) the appointment with the neurosurgeon was scheduled in a different hospital, (2) patients had already received treatment for their brain tumor, (3) stereotactic radiosurgery was the only recommended line of treatment, (4) patients were participating in another study that would interfere with this study, (5) patients would not be cognitively or physically able to complete study procedures, (6) patients had a psychiatric disorder that was explicitly mentioned in the multidisciplinary neuro-oncology meeting, or (7) patients had a presumed diagnosis of midline glioma, brain stem glioma, nervus opticus sheath meningioma, or infratentorial meningioma due to different ensuing treatment trajectories.

Data Collection and Sampling

Fifteen neurosurgeons working at the Elisabeth-TweeSteden Hospital, a tertiary referral center for neurosurgery with a catchment area of 2.3 million people, were asked to participate in the parent study during a staff meeting and sign an informed consent for participation. A neurosurgeon or neurosurgeon in training identified eligible patients during weekly multidisciplinary neuro-oncology meetings. Patients were asked for permission to be approached by the researcher through the Neurosurgery secretary or physician assistant. With verbal consent, the researcher contacted the patient by telephone, explained the study procedures, and provided an information letter. After consideration time, patients could sign a digital or paper informed consent form. All participating patients provided written consent before the consultation. Accompanying family members provided verbal consent (audio-recorded) for the audio recordings.

Neurosurgeons were asked to conduct the consultation as usual. The researcher was not present during the consultations. Audio recordings were made by the neurosurgeon with a voice recorder (Olympus, WS-311M). The audio recordings were first transcribed by automatic transcription software, AmberScript,[25] and then corrected by the coders (IB and IV). Identifying characteristics were removed from the transcripts.

For the current qualitative study, we analyzed a subset of the 66 audio recordings of the observational group. Purposeful sampling was employed chronologically to ensure a balanced representation of patients with glioma or meningioma and a good representation of neurosurgeons and patient age groups. The audio recordings included in the sample were made in January and February 2021.

Data Analysis

The audio recordings were analyzed thematically, focusing on semantic descriptions rather than latent meaning, following the reflexive thematic analysis framework of Braun and Clarke (Figure 1).[21,26] The decision-making models (PDM, IDM, and SDM[10]), the key elements of SDM,[9,14] and patient goals[12,15] described in the introduction were used as sensitization concepts providing the lens through which we analyzed and interpreted the data. However, considering the explorative nature of the research question, the sensitization concepts were not used as predefined themes. Instead, themes describing SDM were developed through reflexive practices with the data.[12,14,19] The coders in this study were a neuropsychologist with research and clinical experience in cognitive neuroscience and neuropsychology (IB) and a nurse practitioner working at the inpatient neurosurgical clinic (IV). First, to develop themes the coders familiarized themselves with the audio recordings by correcting the initial transcripts while noting behaviors that stood out. Second, both coders independently and inductively coded, in an unstructured and organic manner, 2 transcripts to code any behavior related to SDM. Coding was conducted in ATLAS.ti Windows version 9.1.7.[27] The codes were discussed and merged to enrich the eventual interpretation of data. Third, using these codes, IB alone continued the analysis process, including further adaptations and additions of codes, grouping codes in clusters, and creating candidate themes through visual mapping. Through visual mapping, it became clear that the parties involved in the decision-making process were central to answering the research question and the decision was made to cluster codes around their behaviors, such as how HCPs verbally elicited, responded to, or used information provided by patients and family members. Fourth, themes were named and defined, and the results were written up. This process was conducted recursively. The research team's discussions throughout the analysis helped refine the research question, resolve emerging issues, and develop and review themes and subthemes until saturation was beginning to emerge.[22] We determined that saturation was beginning to emerge when additional data analysis no longer led to the development of new themes, and the insights gathered were effectively reiterating existing themes. Our decision to conclude the analysis phase was based on having developed a rich and comprehensive narrative of the SDM process. This judgment was made through thorough discussions within the research team, ensuring that we had captured the depth and breadth of the developed themes. References to treatment options in this text include tumor treatment, nonsurgical approaches like wait-and-scan, and diagnostic procedures like biopsy. The research team may share the codebook upon reasonable request.

Results

Participants

Saturation was beginning to emerge after analyzing eleven consultations. Until the sample of eleven for this study was definite, 23 eligible patients were approached. Nine patients declined participation or were ultimately

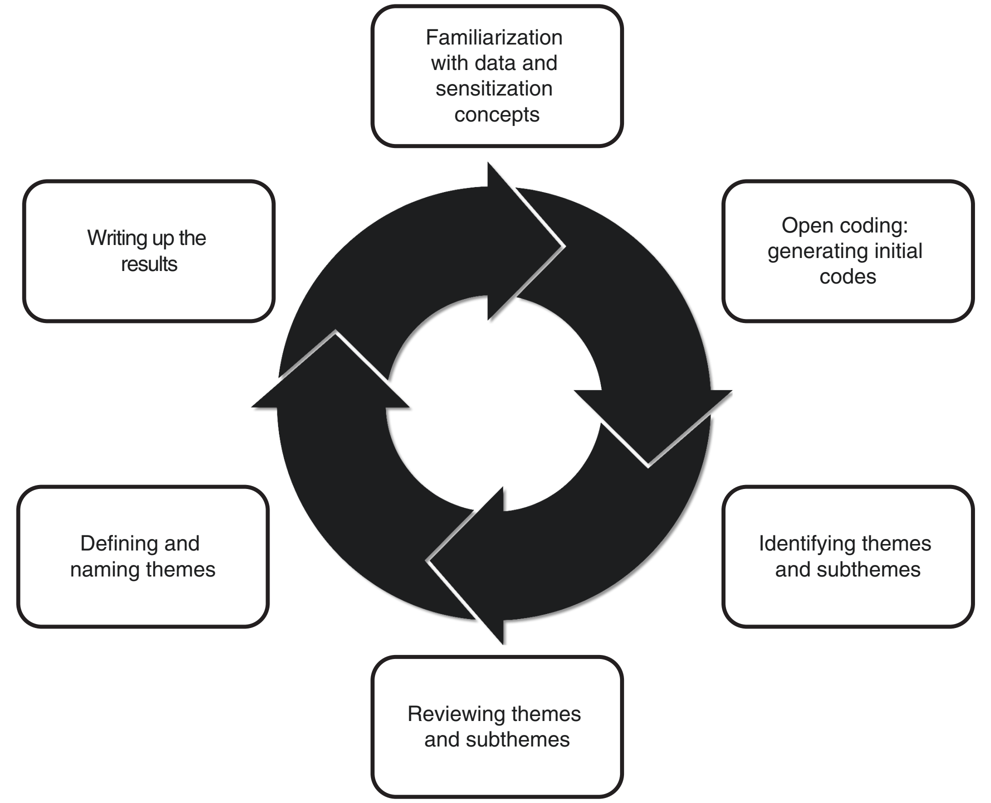

Figure 1. Depiction of reflexive thematic analysis process.[21,22]

excluded for various reasons: too burdensome (5), too unwell/deceased (2), not interested (1), not reached (1), and unclear (1). Two audio recordings were not selected due to purposeful sampling based on patients' diagnoses. The average age of patients was 61 (range 29–84) years. The sample included 7 males and 4 females. Five patients had higher education, 4 middle, 1 low, and 1 had missing data. See Table 1 for individual patient and consultation characteristics. All neurosurgeons agreed to participate in the baseline group, with no dropouts. The neurosurgeons held diverse experience levels working with brain tumor patients, ranging from experienced to highly seasoned practitioners. Nine of the ten neurosurgeons in this sample were male. The mean duration of the audio recordings was 36 (±11) minutes.

Themes

We developed 3 themes and 12 subthemes (Figure 2). Quotations in Dutch and translations in English can be found in Supplementary Material.

Theme 1: The Neurosurgeon Guiding the Decision-Making Process

Neurosurgeons guided decision-making by inviting patients to participate in decision-making, introducing conversation topics, and providing information. Five subthemes were developed on how neurosurgeons involved patients in the decision-making process.

Inviting patients to participate in decision-making.— Neurosurgeons invited patients to participate in decision-making. In some cases, this was done explicitly, by emphasizing to patients in the consultation that their perspective, opinion, or thoughts matter and that the next step is something to discuss. In this example, the neurosurgeon posed a direct question to the patient about their thoughts on the presented treatment options:

> ***Neurosurgeon:*** *So like, you are in a bit of a grey area. And then it becomes very important how you feel about it yourself. I get the impression that you've thought about things thoroughly.*
> ***Patient:*** *Absolutely.*
> ***Neurosurgeon:*** *So I am curious, what your own thoughts were about it?*
> Patient 3, 80+, meningioma, partner present, treatment modalities discussed: surgery, radiation: Gamma Knife, not-taking-action.

In other cases, patients were implicitly invited to participate by starting the consultation with a review of the patient's symptoms from the medical file or by asking how well-informed the patient was about their situation. For instance, some neurosurgeons started the consultation by asking patients what they already understood about the diagnosis

Table 1 Individual Patient Characteristics and Details of the Consultation

Patient number	Neuro-surgeon number	Age range of patient (in years)	Differential diagnoses based on MRI [a]	Family member present	Treatment modalities discussed during the consultation [b]	Duration of recorded consultation (min) [c]
1	1	20–39	Glioma (low-grade)	Mother	• Wait-and-scan • Biopsy • Surgery • Awake surgery (decision)	43
2	2	60–79	Glioma (low-grade)	Partner (and 2 children on the phone)	• Not taking action • Biopsy • Surgery (decision)	28
3	3	80+	Meningioma	Partner	• Surgery • Radiation: Gamma Knife (decision) • Not taking action (not presented by HCP, but family member asked about not-taking-action)	35
4	4	60–79	Glioma (high-grade) or brain metastasis	Partner	• Surgery (decision) • Biopsy (not presented by HCP, but patient asked a question about biopsy) • Not taking action	27
5	5	60–79	Meningioma	Partner	• Surgery (decision) • *Not taking action (discussed as not a viable option in in the long-term)*	28
6	6	60–79	Meningioma	Partner	• Biopsy • Surgery • Wait-and-scan (decision)	23
7	7	20–39	Glioma (high-grade)	Partner	(patient initially lists options, except for awake surgery, HCP elaborates) • Wait-and-scan • Biopsy • Surgery • Awake surgery (decision)	55 [d]
8	7	60–79	Glioma (high-grade)	Daughter	• Biopsy • Surgery • Awake surgery (decision)	57
9	8	60–79	Glioma (high-grade) or brain lymphoma	Partner	• Biopsy (decision) • *Surgery* *(discussed as not a viable option)* • Not taking action	37
10	9	40–59	Meningioma	Daughter	• Wait-and-scan • *Radiation (discussed as not a viable option)* • Surgery (decision)	36
11	10	60–79	Meningioma	Daughter	• Surgery (decision) • *Radiation: Gamma Knife* *(discussed as not a viable option)*	29

[a] As set prior to the consultations in a multidisciplinary meeting with, for example, radiologists, neurosurgeons, neurologists, radiotherapists, oncologists, and nurse-practitioners.

[b] In the order in which treatment modalities were addressed during the consultation. Not all discussed treatment modalities were necessarily discussed extensively. The treatment modality wait-and-scan is listed as such if a follow-up scan was mentioned.

[c] Duration of consultation is an approximation of the consultation time based on recording time. Recording was trimmed to exclude permission for the audio-recording given by the attendees.

[d] Recording was erroneously stopped mid-consultation when neurosurgeon left the consultation room. Recording was started again upon return of the neurosurgeon. Patient and family member spoke to neurosurgical assistant in absence of the neurosurgeon.

and options, allowing them to tailor the discussion to the patient's specific information needs.

> ***Neurosurgeon:*** *I have had a little look in your [medical] file, so I know why you are with me today. But I always like to get a sense of what you already know, and who has already told you something. So I always let you start, to just tell me about what has already been explained to you, then I know where to start my story.*
> Patient 10, 40-59, meningioma, daughter present, treatment modalities discussed: wait-and-scan, radiation, surgery.

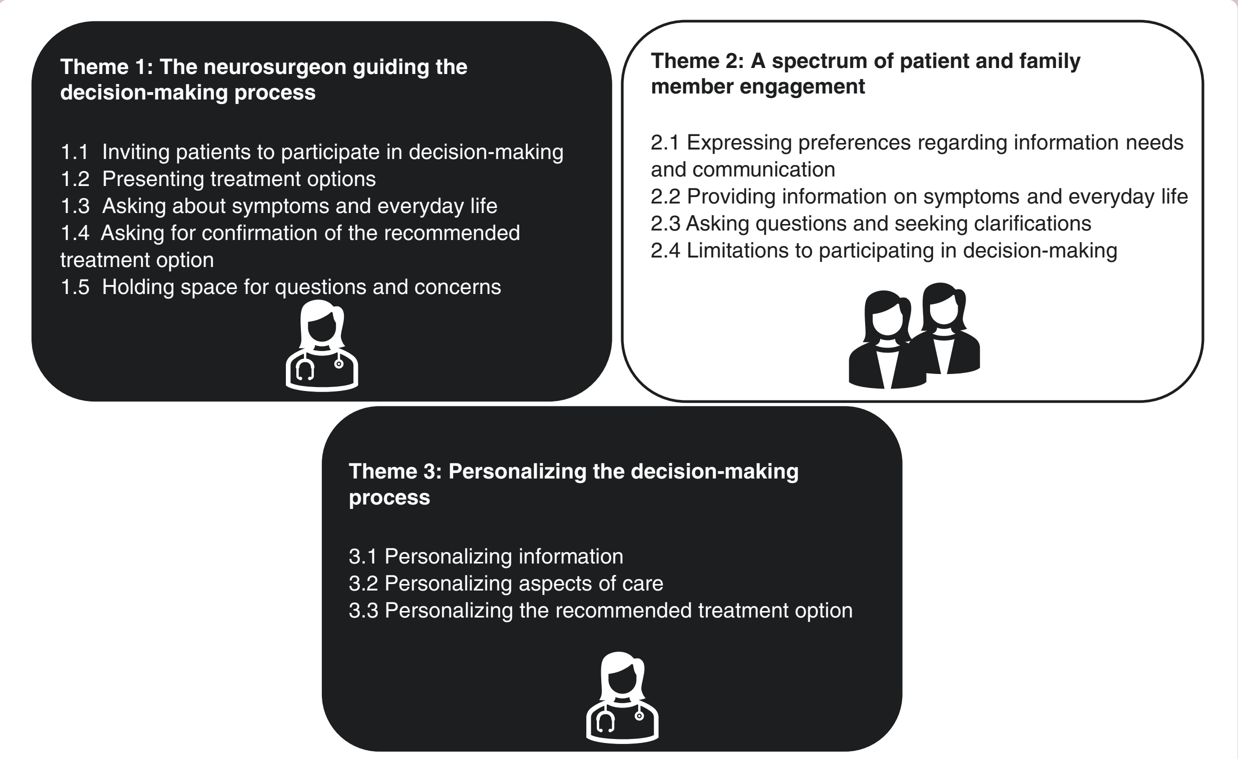

Figure 2. Overview of three themes with twelve subthemes concerning shared decision-making during neurosurgical consultations with patients with a presumed brain tumor.

Furthermore, in many consultations, neurosurgeons used the word "we" when discussing decision-making to involve the patient in the process. Simultaneously, they emphasized that the final treatment decision was ultimately up to the patient.

> ***Neurosurgeon:*** *But that does not mean that we have to decide right now. [. . .] But we can. Medically speaking, from our perspective, there is no rush to make a decision. But somewhere in the near future you will have to make a decision about what is best ...*
> ***Patient****: Yes.*
> ***Neurosurgeon****: ... and what to do.*
> Patient 7, 20-39, high-grade glioma, partner present, treatment modalities discussed: wait-and-scan, biopsy, surgery, awake surgery.

The neurosurgeons positioned themselves as guides in the decision-making process by involving the patient in the conversation about treatment and assigning themselves the task of informing the patient well.

> ***Neurosurgeon:*** *So, there are two things to choose from. And that is a good thing but can also make it [the decision] a bit more complicated. It is up to me to provide some nuances, of one thing or another.*
> Patient 3, 80+, meningioma, partner present, treatment modalities discussed: surgery, radiation: Gamma Knife, not-taking-action.

Presenting treatment options.—In all consultations, neurosurgeons presented treatment options. However, the depth of discussion around options varied. In some cases, treatment modalities were discussed even when they were not medically viable for the patient. For instance, if a tumor was too large for stereotactic radiosurgery alone, the neurosurgeon would explain why this approach was not feasible in that specific scenario. Additionally, surgical treatment was typically explored in greater detail than the option of not undergoing surgery. While the latter was mentioned in most consultations, it was often framed as wait-and-scan or not taking action.

> ***Neurosurgeon:*** *You can, of course, also say, we're not doing any of that [biopsy]. [. . .] But that is a lot more complicated, because then you actually do not know what you are treating and then you actually decide to not undergo treatment. But yeah, then you actually do not know what the alternative is.*
> Patient 9, 60-79, high-grade glioma or brain lymphoma, partner present, treatment modalities discussed: biopsy, surgery, not-taking-action.

Neurosurgeons often communicated why they favored one treatment option, such as a biopsy or a wait-and-scan approach, over another. During consultations, they frequently deliberated about the feasibility of surgical treatment, considering factors like the tumor's location and whether it allowed for safe resection. They also discussed the necessity of intervention to reduce symptoms like epilepsy, decrease tumor mass for oncological or functional purposes, or obtain a more accurate diagnosis through tumor tissue analysis. Additionally, they assessed the patient's ability to withstand the burden of a specific option, such as undergoing anesthesia.

> **Neurosurgeon**: *When we see that something [the brain tumor] is causing symptoms, then we think we should consider doing something about that. [. . .] In the past there was always one option, which was surgery. Nowadays, we have an alternative on hand. And you are a bit on the borderline of whether we should or should not be thinking about that.*
> Patient 3, 80+, meningioma, partner present, treatment modalities discussed: surgery, radiation: Gamma Knife, not-taking-action.

Asking about symptoms and everyday life.— Neurosurgeons asked about symptoms throughout the consultation. Most often these were questions about the onset, the duration, the frequency, and the experience of symptoms. Sometimes, inquiries about the interference of symptoms in everyday life were also made.

> **Neurosurgeon**: *And now, looking back, have you ever noticed any other symptoms? Lately, did everything go well at work and well [. . .] in terms of being able to do things and …*
> Patient 7, 20-39, high-grade glioma, partner present, treatment modalities discussed: wait-and-scan, biopsy, surgery, awake surgery.

Furthermore, neurosurgeons inquired about everyday life to learn about a patient's profession and family. Yet this did not happen throughout all consultations, and if it happened, this was more often discussed toward the end, usually when the treatment decision had already been made.

> **Neurosurgeon**: *What did you actually do in your daily life? Or what do you do in daily life? I haven't even asked that yet.*
> Patient 8, 60-79, high-grade glioma, daughter present, treatment modalities discussed: biopsy, surgery, awake surgery.

Notably, only once did a neurosurgeon explicitly ask about a patient's goal near the beginning of the consultation to understand what mattered most to the patient and the patient clearly expressed what was important to him regarding the treatment outcomes.

> **Neurosurgeon**: *There are roughly three things that we discussed last time as options. But before [deciding], it is very important, how you feel about it [. . .]. What do you find important, what is your goal, so to say?*
> ***Patient:*** *Well, if it is possible, my goal would be, to come out of this and suffer as little as possible [. . .] and that I can just continue to live. Yes, without too many, like now, I have regular epileptic seizures.*
> Patient 1, 20-39, low-grade glioma, mother present, treatment modalities discussed: wait-and-scan, biopsy, surgery, awake surgery.

Asking for confirmation of the recommended treatment option.— Usually near the end of the consultation, neurosurgeons guide patients in the decision-making process by asking for confirmation of the recommended option. Neurosurgeons mostly asked closed questions or repeated a treatment recommendation that was previously given. They also cited cases of patients choosing options not in line with treatment recommendations. The reason why patients expressed a preference for a treatment was usually not explored further.

> ***Neurosurgeon:*** *I saw that when you walked in, that you entered with that expectation, and that is also how we feel about it, so in that sense we are on the same wavelength.*
> ***Daughter patient:*** *We are a 100 percent set on the surgery.*
> ***Patient****:Yes, yes.*
> ***Neurosurgeon****. Yes. That is a good fit, makes my job a little easier today. Then from now on, we can discuss the surgery itself a bit more.*

Patient 10, 40–59, meningioma, daughter present, treatment modalities discussed: wait-and-scan, radiation, surgery.

Holding space for questions and concerns.— In most consultations, the neurosurgeons offered ample room for questions and concerns, usually near the end of the consultation. They would ask questions such as: "Are there any other questions?" or "Is everything clear?"

Theme 2: A Spectrum of Patient and Family Member Engagement

We observed varying levels of patient and family member engagement in the decision-making process, ranging from passive reception of information to active expression of needs, preferences, and concerns.

Expressing preferences regarding information needs and communication.— There were some examples of patients expressing preferences regarding information needs and communication, such as what information they would like to receive and their preferred communication style. Several patients requested to see or photograph their MRI scans, while others explicitly asked not to have them shown. One patient stressed the importance of straightforward, honest communication:

> ***Patient:*** *I think that that is very honest. And that is what I want in conversations, or when undergoing treatment.*
> ***Neurosurgeon:*** *Exactly.*
> ***Patient:*** *Just open, honest. When something is up, don't spare me.*
> ***Neurosurgeon:*** *Right.*
> ***Patient:*** *That won't get us any further.*
> ***Neurosurgeon:*** *That's right.*
> ***Patient:*** *It is good that the risks are mentioned.*
> Patient 4, 60-79, high-grade glioma or brain metastasis, partner present, treatment modalities discussed: surgery, biopsy, not-taking-action.

Providing information on symptoms and everyday life.—Patients, with the help of family members, provided information about their symptoms and everyday life. Specifically detailing the presence, onset, and course of their symptoms. The impact of the brain tumor on everyday life was only rarely discussed, though it was sometimes mentioned spontaneously by patients or family members. Examples of topics covered were work, hobbies, social role functioning, and driving. While restrictions on driving were discussed in detail during several consultations, the impact on alternative modes of transportation was also discussed.

> ***Patient:*** *I notice when I am cycling, which I am currently not doing, because ...*
> ***Neurosurgeon:*** *It is wobbly.*
> ***Patient:*** *Your stability when getting on and off [the bike], yes, that ...*
> ***Partner patient:*** *That is more ...*
> ***Patient:*** *That is risky.*
> Patient 3, 80+, meningioma, partner present, treatment modalities discussed: surgery, radiation: Gamma Knife, not-taking-action.

The consultations provided only glimpses into the deliberation process of patients and family members on what is important to them regarding treatment and treatment outcomes. One patient expressed feeling pressure to make a decision as quickly as possible. Patients occasionally expressed statements about surgery that suggest they may not fully grasp its potential outcomes, such as implying surgery can stop the tumor from growing. One patient clearly prioritized living longer above functioning, while others emphasized the importance of preserving functioning to do certain activities such as theater, sports, or running their own company.

> ***Patient:*** *I also run my own company. I think that when you are [states own age], yes, then I suppose that you actually have a whole life ahead of you. And if you then ...*
> ***Neurosurgeon:*** *Absolutely.*
> ***Patient:*** *... go downhill very much, that does not seem very wise to me either.*
> Patient 1, 20-39, low-grade glioma, mother present, treatment modalities discussed: wait-and-scan, biopsy, surgery, awake surgery.

Family circumstances were also occasionally tied into the treatment decision. One patient explained she was scared to undergo surgery. However, she wanted to do everything she could for her grandchildren and children. Another patient wanted to continue being a caregiver to their partner:

> ***Patient:*** *Well, I am happy that there is a second option.*
> ***Neurosurgeon:*** *Yes.*
> ***Patient:*** *Cause we are currently caregivers for one another [. . .]. That is something that I definitely wanted to consider in the decision that we will be taking today.*
> Patient 3, 80+, meningioma, partner present, treatment modalities discussed: surgery, radiation: Gamma Knife, not-taking-action.

Interestingly, the patient who was asked once relatively at the beginning of the consultation about their goal repeatedly mentioned things that were important to them throughout the consultation without further prompting.

> ***Patient:*** *But what if later, I will have a conversation with someone, then I do want to be able to express myself normally. Then I want ...*
> ***Neurosurgeon:*** *Yes.*
> ***Patient:*** *At least, yes, I would mind that very much if later, I don't know, won't be able to express myself or something ...*
> ***Neurosurgeon:*** *Yes.*
> ***Patient:*** *... those kind of things. That is very important to me.*
> Patient 1, 20-39, low-grade glioma, mother present, treatment modalities discussed: wait-and-scan, biopsy, surgery, awake surgery.

Asking questions and seeking clarifications.—Patients and family members asked questions and sought clarifications throughout the consultation. The questions usually concerned the tumor's characteristics, treatment goals and risks, expected symptom burden, and potential disease progression. They also inquired about when surgical treatment would be scheduled, the procedure itself, and the next steps of care following a surgical procedure.

> ***Partner patient:*** *So radiation could make it [the brain tumor] a bit smaller?*
> ***Neurosurgeon:*** *No.*
> ***Partner patient:*** *Oh, what?*
> ***Neurosurgeon:*** *The goal of radiation is to stop the growth [of the brain tumor]. But it does not become smaller [with radiation].*
> ***Partner patient:*** *Oh, but, if it [radiation] goes well it will not grow bigger?*
> Patient 3, 80+, meningioma, partner present, treatment modalities discussed: surgery, radiation: Gamma Knife, not-taking-action.

Rarely did patients or family members ask questions about the impact of treatment on everyday life activities; however, there are a few exceptions of people asking about whether they could continue their hobbies or daily routines.

> ***Neurosurgeon:*** *People who for instance work or exercise, we say to them that it's better not to do that the first couple of weeks [after surgery]. [. . .]*
> ***Partner patient:*** *But taking the dog around the block, that's okay.*
> ***Neurosurgeon:*** *It is possible, in the ideal situation everything will just keep functioning as it is functioning. But it is possible that you will be held back by certain symptoms.*
> Patient 2, 60-79, low-grade glioma, partner present, treatment modalities discussed: not-taking-action, biopsy, surgery.

Limitations to participating in decision-making.—Patients could be limited in their participation in the decision-making process by their symptoms. For instance, one patient had severe speech-induced epilepsy, and the daughter stepped in to largely conduct the consultation.

> ***Daughter patient:*** *I try to speak as much as possible, on behalf of [refers to patient] of course, but we have noticed that since two days ago there have been focal [epileptic] seizures again and that they are triggered by talking. So today thankfully has gone well up until now, but we are consciously trying to ensure that [patient] says as few unnecessary things as possible.*
> ***Neurosurgeon:*** *I understand.*
> Patient 8, 60-79, high-grade glioma, daughter present, treatment modalities discussed: biopsy, surgery, awake surgery.

Theme 3: Personalizing the Decision-Making Process

There were several ways in which neurosurgeons personalized the decision-making process. That is, by tailoring the provided information to the medical or personal situation of the patient, integrating preferences regarding aspects of care and personalizing the treatment recommendation.

Personalizing Information.—There were numerous examples of neurosurgeons personalizing information. Neurosurgeons tailor information to inform a specific patient about the advantages or disadvantages of a particular treatment option. Questions by patients and family members led neurosurgeons to explain certain details about a procedure or setting expectations about recovery that were not discussed in every consultation. Most expectations were set for the short term, such as what to expect directly following surgical treatment. Expectations for the long-term following treatment, such as the likelihood of returning to everyday life, were rarely discussed. Personalization of information frequently happens based on the medical situation of the patient, such as their current condition, age, the severity of symptoms, the location of the tumor, and the certainty regarding the type of brain tumor. In all consultations, symptom burden was discussed, and neurosurgeons often explained the symptoms by relating them to the characteristics of the tumor. Personalization of information rarely happened in light of what matters to the patient in everyday life, but was occasionally observed:

> ***Neurosurgeon****: So there could be a small risk that when we are operating on this thing [the brain tumor], the speech part will function a little less well. But, because you are righthanded, that risk is not very high. [. . .]*
> ***Patient:*** *Okay, I do have to be able to act.*
> ***Daughter patient:*** *Yes.*
> ***Patient:*** *I do have to be able to speak. [. . .]*
> ***Neurosurgeon:*** *Okay, look, is that a hobby of yours?*
> ***Patient:*** *Yes [gives information on acting group].*
> ***Neurosurgeon:*** *Amazing hobby. [. . .] I am hopeful that you will be able to do that again.*
> ***Patient:*** *Well, I am going to try to do everything I can to do that again.*
> ***Neurosurgeon:*** *We will work on it together.*
> Patient 11, 60-79, meningioma, daughter present, treatment modalities discussed: surgery, radatiation: Gamma Knife.

Personalizing aspects of care.—The preferences voiced by patients or family members resulted in personalization of aspects of care. Preferences that were expressed concerning aspects of care sometimes influenced or altered standard care procedures, such as the frequency of MRI scans:

> ***Patient:*** *Do I have to go through the MRI scanner a lot then?*
> ***Neurosurgeon:*** *Ah, yes, the day before surgery we will make a beautiful MRI-Scan*
> ***Patient****: [laughs] well, okay.*
> ***Neurosurgeon:*** *A lot of people hate it very much. One in six people would rather not go in [the scanner].*
> ***Patient****: No, me neither. [. . .]*
> ***Neurosurgeon:*** *well, the MRI. Let's see. Well, actually I don't need a new MRI. No need for a new MRI. Cancel it with the secretary. [. . .]*
> Patient 11, 60-79, meningioma, daughter present, treatment modalities discussed: surgery, radatiation: Gamma Knife.

Furthermore, there were frequent discussions regarding preferences for surgical treatment strategy, particularly in the context of awake surgery. The discussion revolved around whether to operate more aggressively (ie, to remove as much tumor as possible) or more conservatively (ie, removing less tumor) to preserve cognitive or motor functioning:

> ***Neurosurgeon:*** *And that agrees with what you're saying actually …*
> ***Patient:*** *Yes.*
> ***Neurosurgeon****: … I want to preserve functioning, and look, that can interfere with removing epilepsy, because we know that the more [tumor tissue] we remove, the higher the chances are that the epilepsy goes away. [. . .]*
> ***Patient****: No, yes, I'd rather suffer from epileptic seizures, than to suffer failure of function, for instance. But …*
> ***Neurosurgeon****: But well, then we have a very clear idea of what the goal should be.*
> Patient 1, 20-39, low-grade glioma, mother present, treatment modalities discussed: wait-and-scan, biopsy, surgery, awake surgery.

Personalizing the recommended treatment option.—In several instances, the information shared by the patient on symptoms or everyday life was used to personalize the recommended treatment option made by the neurosurgeon. In other words, the information provided mostly spontaneously by patients and family members could influence the treatment recommendation, such as high expected treatment burden or everyday life priorities.

> ***Neurosurgeon****: And since you're saying, I am currently in a position at home where we are taking*

> *care of each other, I really cannot afford to be on the bench right now.*
> ***Partner patient**: And vice versa.*
> ***Neurosurgeon**: [. . .] And that is why you prefer the least strenuous treatment option [radiation: Gamma Knife].*
> Patient 3, 80+, meningioma, partner present, treatment modalities discussed: surgery, radiation: Gamma Knife, not-taking-action.

Discussion

This study aimed to qualitatively explore and describe the SDM process during neurosurgical consultations for patients with a presumed brain tumor. The majority of neurosurgeons guided the decision-making process (Theme 1: **The neurosurgeon guiding the decision-making process**), by presenting treatment options and explaining their rationale, with limited discussion about patients' priorities. Questions about everyday life were rare and usually occurred after decisions had been made, reducing their impact on the decision-making process. Most patients and family members contributed to the decision-making process by explaining symptoms or asking questions (Theme 2: **A spectrum of patient and family member engagement**). The consultations only provided glimpses into the deliberation process of patients on what is important to them regarding treatment and treatment outcomes. Occasionally personal information was spontaneously discussed and integrated into the process (Theme 3: **Personalizing the decision-making process**). It allowed for more tailored information, personalized care procedures, and patient-centered decisions. However, the analyzed consultations showed that while patients' everyday life priorities and preferences were occasionally considered, the process primarily focused on providing medical information.

Several insights emerge when evaluating the findings in light of the sensitization concepts used, decision-making models (PDM, IDM, and SDM[10]), the key elements of SDM,[9,14] and patient goals.[12,15] For the analyzed consultations, the decision-making process was not conducted paternalistically, where the HCP solely dictates actions.[9,10] Instead, an effort was made to involve patients by informing them of treatment options and requesting confirmation of a proposed option. Most consultations reflected the elements: (1) fostering choice awareness, (2) discussing relevant options, including advantages and disadvantages, and (4) making a decision.[9,14,19] However, the consultations lacked specific attention to the everyday life priorities of the patients, which can be considered part of element (3) discussing patient preferences and supporting the deliberation process, the key element distinguishing IDM from SDM.[9,10,12,14,19]

The neurosurgical context and current levels of understanding of SDM may account for our findings. It should be noted that in most neurosurgical consultations the available options are not comparable in terms of oncological outcomes, with surgery providing the most optimal oncological strategy.[4] Neurosurgeons may perceive the decision-making context for patients with a presumed brain tumor at this stage of the disease as less suitable for SDM. Additionally, while there is increasing attention to the impact of treatment on daily life,[3–6,28] much remains unknown about how different treatment options affect individual patients, such as their ability to return to work or experiences of fatigue. Therefore, HCPs may be reluctant to explore patient preferences and everyday life to personalize the decision-making process, as they may feel ill-equipped to advise patients on these aspects.[29,30] Additionally, many HCPs have not received formal training on conducting SDM.[30] Moreover, even the literature on SDM tends to emphasize providing patients with medical information, while paying less attention to patient involvement.[2,19] For instance, a review of SDM behavioral coding schemes ($k = 12$) showed that most items measure information provision, such as explaining treatment advantages and disadvantages and respective probabilities, with fewer items measuring patient involvement, such as discussing patient preferences.[19] Information provision has received more attention in research and implementation and may even have led HCPs to misinterpret IDM as SDM.[19,30]

SDM could potentially improve the quality of care, including less misaligned treatment, better adherence, and improved patient satisfaction.[8,18] Recent SDM models suggest incorporating patient goals into the decision-making process to facilitate a greater emphasis on patient preferences.[12,15] Vermunt and colleagues provide a comprehensible framework for categorizing patient goals into 3 levels: symptom- and disease, functional, and fundamental goals.[31] The latter relates to patients' life priorities, values, and core relationships. HCPs can then tailor the discussion of the advantages and disadvantages of options based on the patient's goals and align the treatment plan with patient preferences for treatment outcomes.[12,13,15] In our consultations, there was one example of a neurosurgeon explicitly asking an open question about a patient's goal, and the patient subsequently mentioned a symptom goal (reducing epilepsy), a functional goal (having to be able to speak), and fundamental goals (running his own company, doing sports). The neurosurgeon and patient ultimately reached a consensus and explicitly prioritized functional and fundamental goals over the symptom goal, deciding on awake surgery. A previous study on SDM regarding palliative chemotherapy in an advanced cancer population suggests that probing questions by the HCP, as exhibited in this example, are likely to trigger more preference-related talk.[32]

This study provides a unique and detailed insight into SDM during neurosurgical consultations with a heterogeneous group in terms of presumed brain tumor diagnoses and age. However, there are some potential limitations associated with our study. The decision-making process in the first neurosurgical consultation of the Elisabeth-TweeSteden Hospital may provide a unique setting. The qualitative research methodology precludes analysis of behavioral frequencies for generalizing findings. Our findings might not apply to decision-making processes later in the disease trajectory, at other neurosurgical centers, or in different cultures.[33,34] Also, exploring patient characteristics that may influence the decision-making process such as cognitive functioning or sociodemographic status,[35] were beyond the scope of this study. Furthermore, the observational design only allowed for an analysis of behavior during the consultation. Future research should explore HCPs' motivations and experiences in decision-making, providing further insight into the prevalence of PDM, IDM, and SDM in clinical practice. Additionally, it should identify the support HCPs need and examine the implications for patient outcomes. Finally, the fact that participants were aware of the audio recording and the study's focus on SDM may have influenced their behavior. We tried to minimize this effect by making an audio recording rather than a video recording, which is considered less invasive.[36] To reduce the impact on neurosurgeons' behavior, they were not yet informed about the future implementation of the Goings-On app, with which patients share their goals, and how it would facilitate them in SDM, during data collection of the observational group.

Conclusions

The decision-making processes seemed to focus primarily on medically informing patients with a presumed brain tumor, in line with IDM. However, less emphasis was placed on learning more about the patient's everyday life and preferences to integrate into the decision-making process, which is key to SDM. Incorporating patient goals may lead to greater personalization and decisions that align with both the patient's medical situation and their goals.

Supplementary material

Supplementary material is available online at *Neuro-Oncology Practice* (https://academic.oup.com/nop/).

Keywords

neurosurgery | patients with a brain tumor | reflexive thematic analysis | shared decision-making

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Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work; I.J.M.B.; M.C.W.J.; G.-J.M.R.; I.J.M.V.; M.M.S.; F.W.B.; P.H.; and K.G. Drafting the work or reviewing it critically for important intellectual content; I.J.M.B.; M.C.W.J.; G.-J.M.R.; M.M.S.; F.W.B.; P.H.; and K.G. Final approval of the version to be published; I.J.M.B.; M.C.W.J.; G.-J.M.R.; I.J.M.V.; M.M.S.; F.W.B.; P.H.; and K.G. Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved; I.J.M.B.; M.C.W.J.; G.-J.M.R.; I.J.M.V.; M.M.S.; F.W.B.; P.H.; and K.G.

Conflict of interest statement

None declared.

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