

# Finding patients' perception and attitudes to neurosurgery: A qualitative approach

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## Research Article

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# Abstract

**Objective:** Undergoing a neurosurgical procedure is thought to be traumatic and anxiety provoking which can affect treatment decisions. This study aims to explore the attitude and perception of neurosurgery.

**Method:** Eight semi-structured open-ended questions were administered to 47 patients who underwent neurosurgery from 2018 October to 2019 April. Two questions which were common to pre and post-operative conditions explored the patients' emotional responses before and after the surgery. The two other questions explored the communication between the patient and the doctor. To determine the moderating factors responsible for the attitude-change, two additional questions were administered postoperatively. The patients were interviewed a week before and two days after the surgery. The patient responses in verbatim were recorded and were subjected to open and axial coding.

**Results:** After thematic analysis the emerging themes were noted. The overarching themes were 1) The patients experience worry before the surgery. 2) The patients are comfortable in their communication with the doctor before getting operated. 3) Post-surgery, the patients experience a dip in their worry. 4) A significant percentage of patients is happy with the information received from their doctor. 5) Majority of the patients reports satisfaction with the communication between them and the doctor. 6) There is a section of patients who are not comfortable despite the information they have received.

**Conclusion:** The patients experience anxiety before and after the surgery and have concerns about the future. The communication skills of the treating doctor have a moderating effect on the patients' perception of neurosurgery.

# Introduction

Reporting an attitude involves deciding on liking versus disliking or favouring versus disfavoring an attitude object [1]. The attitude to neurosurgery is often that of a disfavoring one. The patients scheduled for neurosurgery often voice that it is risky to be subjected to the surgery. A patient's perception of and attitude towards the neurosurgery may influence his or her experience and anticipated outcomes. A small number of patients back off from the surgery because of their perception of undertaking a huge risk. Though the risks associated with neurosurgery is almost equal to the risks posed by any other major surgeries, patients are often very vocal about and afraid of the prospect of being disabled. Patients who are to undergo neurosurgery often express worries about the possible associated morbidity. This fear stops at least some of them from obtaining timely treatment. The hesitations often cost them their health and wellbeing. In this background, this study aims to explore the attitude to and perception of neurosurgery.

# Methods

This was a prospective qualitative study where ethnographic and grounded theory research methodologies, were followed. Participants were selected on a purposive basis. The study was conducted

in a quaternary care hospital. Forty-seven native Malayalam speaking patients who underwent neurosurgery from 2018 October to 2019 April were included. Out of the sample, 17 patients underwent an awake procedure. All the patients had a chance to talk directly with their doctor. Patients with frank psychiatric symptoms, severe speech and comprehension difficulty, severe sensory and cognitive deficits, and below the age of 18 were excluded. The questionnaire and methodology for this study was approved by the Institutional Ethics Committee of the hospital. Informed consent for participation and publication of the results of the study was obtained from all the individual participants included in the study.

It was decided to continue with the data collection till no fresh themes emerged, and hence the sample size was not estimated. "Saturation" is a concept in qualitative research describing the situation in which no new concepts arise during successive interviews [2].

Eight semi-structured open-ended questions were administered to the patients who met with the inclusion criteria. Two dedicated psychologists interviewed the patients. The same interviewer conducted the interview in the preoperative and postoperative setting for a given patient. The interviews happened in a one-on-one situation. At no point, the telephonic interview was done. An information schedule captured the sociodemographic features of age, gender, education, marital status and occupation. Tumour characteristics of laterality, grade, and histopathological diagnosis were obtained from the electronic medical records. Responses of the patients who underwent the awake procedure were also separately noted.

Patients were interviewed a week before the surgery and later two days after surgery once they were stabilized and were out of the surgical ICU. The patients were informed about the purpose of the interview following which informed consent was obtained. Two questions were common to both pre and post-operative conditions that explored the patients' emotional response to the surgery and on the retrospective perception on the same. Two other questions asked during pre-op condition explored the communication between the patient and the doctor.

- *What specifically are you afraid of?*
- *Did you communicate your fear to the doctor? If no, why?*
- *Did you communicate your fear to the doctor? If no, why?*
- *Did the communication with your doctor reassure you sufficiently? If no why?*

Postoperatively two additional questions were asked to find the moderating factors of the changes in the attitude if any.

- *Are you scared/worried now?*
- *If yes, what are you scared/anxious of?*
- *Do you think all the necessary information regarding the treatment was imparted?*
- *In your opinion, what more can be done from the doctor's side to put you at ease?*

Patient responses verbatim were recorded.

The collected responses were tabulated under preoperative and postoperative headings side by side, and they were subjected to thematic analysis, where open, axial, and selective coding was done. Open coding is the first level where the researcher identifies distinct concepts and themes for categorization [3]. Axial coding is a way to construct linkages between data [4, 5]. Selective coding enables the researcher to select and integrate categories of organized data from axial coding in a cohesive and meaning-filled manner [3].

## Results

All 47 patients were interviewed. The sociodemographic details of the participants and the tumour related variables are presented in Table 1 and 2.

**Table 1 Patient demographics**

<b>Age in years</b>	<b>Number of patients</b>
20-30	9
31-40	13
41-50	10
51-60	6
61-70	7
<70	2
<b>Gender</b>	
Male	27
Female	20
<b>Marital Status</b>	
Single	10
Married	36
Separated	1
<b>Education</b>	
College	29
School	18

**Table 2 Tumor details**

<b>Tumor Types</b>	<b>Number of patients</b>
Vestibular Schwannoma	3
Diffuse astrocytoma	4
Anaplastic Oligodendroglioma	3
Glioblastoma Multiforme	9
Oligodendroglioma	3
Diffuse glioma	5
Meningioma	11
Cavernoma	1
Xanthoastrocytoma	1
Ependymoma	1
Pilocytic astrocytoma	1
Third ventricular colloid cyst	1
Others*	4

\*Left proximal Internal carotid artery stenosis, Sellar supra sellar lesion-Silent corticotroph adenoma, Posterior falcine metastasis KCO Renal Cell Carcinoma s/p excision of cerebellar metastasis, Extensive necrosis with features of vasculitis and perivascular and intramural mixed chronic inflammatory infiltrates

The overarching themes that emerged in the preoperative phase were presence or absence of worry and communication quality with the doctor. Worry about the diagnosis, treatment and cure was reported by 53.19%, while 46.80% reported an absence of worry. Communication with the doctor about their worries, fears and concerns was done by 65.95%. Followed by the communication with the doctor, 61.70% reported being reassured, while 17.02% reported that they were not reassured despite the communication that has happened. Nineteen percentage decided not to communicate about their worries and concerns to the doctors. Of the forty-seven cases, there were 16 cases of awake surgeries, where 4.25% reported concerns about the procedure. Of the total, four cases were recurrences. While three of them (6.38%) expressed worry at having to undergo the procedure again, one person was stoic about the same.

The overarching themes of the post-operative scenario were the presence or absence of worry and the perception about the communication between the doctor and the patient. After the operation, 70.21% reported no worry about the surgery, while 27.65% reported worry after the procedure. There was a group which was not worried at the outset but was worried after the surgery. This constituted 10.63%. All the necessary information was perceived to be communicated by the doctor to the patients by 85.10%, while

12.76% felt the doctors did not pass all the relevant information to them. A subset of the patients (25.53%) was not convinced about the information passed on to them by their doctor.

The preoperative concerns centred on the operation itself (14.89%), loss of functionality and mobility (12.76%), the outcome of the surgery and aesthetic concerns (10.63%), family concerns (12.76%) and possibility of being confined to home (4.25%). The other preoperative concerns voiced by 2.12% were on probable inability to attain the life goals, the diagnosis itself, being in coma, future, sense of doom, tolerate uncertainty, and personality changes.

The post-operative concerns were about the biopsy result (8.51%), difficult post-operative period and infections (6.3%), unspecific worries (6.3%), functionality (2.12%), family concerns (2.12%), and further treatment (2.12%).

The group which was not worried initially started to worry after the surgery due to factors such as family's overprotection and apparent show of undue concern, the experience of pain which triggered anxiety, post-operative speech difficulty, sleeplessness and periorbital edema.

### ***Thematic Analysis***

The analysis revealed the following overarching themes which are described and illustrated using the verbatim responses of the patients.

Almost half of the patient sample experienced worry before the surgery. Their worry was about their loss of functionality and mobility, the prospect of becoming dependent on others, and about the probable personality change.

'I am worried that I may lose my mobility.'

'I am upset at the possibility of losing my functionality. I am also concerned that my personality may change after the surgery.'

'No matter what, there are chances of losing my mobility and functionality. I find it very hard not to worry about it.'

'I wonder whether I will be as functional as I am now after the surgery. Hope I will not become bedbound or dependent on others'

Most of the worry was about the procedure itself rather than about the diagnosis.

'What if something goes wrong during the procedure? I am scared that my children will be badly affected if something goes wrong.'

'I have undergone the same procedure before. So I know what to expect and it worries me.'

'I am scared the surgery may render me unable to realize my goals in life.'

'This is not like any other surgery.... This is brain surgery. The very idea scares me.'

'The surgery may cause another insult to my already compromised brain.'

Patients are comfortable in their communication with the doctor before getting operated. No matter what nature of the worry is, talking with their doctor seems to help. Many patients reported easing of their worry and fear after communicating with their doctor.

'I was very much concerned about losing my hair as an aftermath of the surgery. I also had this constant fear that I may go into coma. The doctor spent some time with me and cleared my worries.'

'Who will not be worried before surgery? However, my doctor has explained everything in detail. I trust my doctor completely.'

'My doctor has supported me emotionally and has educated me on what to expect during the awake bit. Talking with the doctor really helped.'

'To begin with, I am an anxious person. After listening to the doctor, I am relatively calm and feel that I am in good hands.'

'I am anxious and worried about the side effects of the surgery. I talked about this to the doctor. He then cleared my concerns.'

Post-surgery, the patients experience a dip in their worry, especially those who had reported anxiety and worry before the surgery.

'Nothing happened as bad as I feared. There are no side effects except for the occasional pain. All my worries are now gone.'

'As I feared, they did not shave off my hair. I can now move and talk like before. It is not a worry for me anymore.'

'The awake procedure went well. Surprisingly I can remember all of that happened when I was awake. I sang a lot during the procedure. I have no worries now; I am happy.'

'I was very anxious earlier. Now, I am calm. I am happy that doctors continue to communicate things to me.'

'After the procedure, I feel there was really nothing to be so worried about'.

A significant percentage of patients is happy with the information they have received from their doctor.

'I am happy that doctors are available for communication and they take time to talk.'

'Doctors have given me all the necessary information I need regarding the post-surgery care and about the next steps.'

'I felt at ease because of the willingness of the doctors to communicate despite their busy schedule'.

There is also a sizeable chunk of patients who are not convinced, despite their perception of having received all the information.

'Alright, everything went well. Nothing happened as I feared, but I still am worried. The funny thing is I don't know why.'

'I am worried about the weakness I am experiencing on my right hand. I am also unable to sleep. I did talk to the doctor, but I am not sure he understands my state of mind.'

'Although the doctor discussed everything with me, I am seriously worried about my biopsy results.

'I was never worried, to begin with, but now the swelling I have in my right eye is of concern.'

'The doctor has communicated adequately, but whenever I experience pain, I think that the disease is coming back. That thought disturbs me so much.'

## Discussion

This study explores the perception of patients and their attitude towards neurosurgery using qualitative research methodology. Surprisingly, there are not many studies on this topic – qualitatively or quantitatively. An extensive search on the internet yielded no results regarding any previous work on the same.

Studying attitudes are important because they can guide thought, behaviour, and feelings, and an attitude change can occur when it is modified [6]. The perception and attitudes of the patients about neurosurgery in the preoperative phase was coloured by the worry they had experienced at the outset. They perceived surgery as something that will cause to lose their functionality and mobility. They thought surgery had the potential to make them dependent and may bring about personality changes. Several patients were also worried about the impact the surgery may have on their families. Many patients were not worried about the biopsy result and its implication on prognosis and further treatment as expected. Instead, their concern focused on the procedure and its probable side effects. There were fears and misconceptions regarding the loss of functionality, aesthetics (hair loss), and being comatose. Some patients expressed unease about having to be at home immediately after surgery. This was a distressing prospect which coloured their attitude to neurosurgery. There was also a lone voice that spoke of the perceived stigma.

There was an evident decrease in anxiety in the patients postoperatively. Communication and information delivery are powerful tools which can bring about significant attitude change. These are also instrumental in changing preconceived notions about neurosurgery. Communication with the doctor was

seen to be a moderating factor where the perceptions and attitudes to the neurosurgery are concerned. Effective communication of information in physician-patient interactions is essential for fostering patient rapport, enabling informed decision-making, and minimizing patient anxiety [7]. The educative and motivational approaches adopted by the doctor in his communication with the patient could also be an important contributor to attitude change. The changes in the attitudes were very evident in the post-operative scenario. The majority of the patients reported a shift from their preoperative interview responses to being worried. This shift could also be the result of the relief at the much-anticipated surgery now over. The other factor which could have brought about a change in attitude could be the patients' growing trust in their surgeon.

Postoperatively, the most frequently voiced worry was that of the biopsy result. Another concern that coloured the perception of neurosurgery was the difficult postoperative period and infections. Overprotection and overreactions of the family, transient difficulties in mobility and speech, fear of recurrence, and sleep issues are the other factors that moderated the attitudes and perceptions of the patients towards neurosurgery. Despite the support and reassurances extended by the treating team and the positive surgical outcomes, a small percentage reported free-floating generalized anxiety. Some patients reported a significant reduction in the worry, even though their communication with the doctor was inadequate. The reduction of worry can be because of the motivational relevance of the communication between the doctor and the patient, and the source expertise [8].

While most of the patients communicated their concerns to the doctor and were reassured in the preoperative scenario, a relatively small percentage refrained from the same. This was reportedly due to the lack of comfort with the doctor as their worries were not specifically addressed. As a result, they felt there is no need to communicate their fears to the doctor. They also thought that since the doctors did not communicate enough, and there was no point in asking/expressing their apprehensions. In this context, it is relevant to keep in mind that posited ideal qualities of communication skills, surgical acuity, and humility in judgment can play a role in choosing the neurosurgeon [9]. These qualities can foster and facilitate positive attitudes to neurosurgery. Postoperatively, while a large percentage indicated satisfaction regarding the information they had received from the doctors' side, a small percentage felt that the doctors did not share all the necessary information. A significant percentage of the patients admitted that all the necessary information relevant to the surgery and the post-operative state was shared with them. However, they were not convinced of the same. This could be because of the post-operative physical discomfort, mobility and speech difficulties, and financial worries.

## Conclusion

Patients reported increased general optimism after the surgery. They reported having experienced less difficulty than anticipated. The group despite experiencing a marked reduction in the levels of anxiety when compared with the pre-surgery status had concerns about the mobility and functionality, the prospect of becoming dependent on others, personality changes, speech difficulties and sensory difficulties. Some of them also mentioned dissatisfaction about the communication with the doctor.

There is no doubt that communication skills and empathy of the surgeon are a major moderating factor where attitudes and perceptions about neurosurgery are concerned.

## Declarations

The authors assure that we have received no funding of any kind towards the execution of this study.

Institutional Ethics Committee approval obtained for the study

We also assure that we have no conflicts of interests/competing interests to declare.

Consent to participate and publish was obtained from the participants.

The datasets generated during and/or analysed during the current study are available from the corresponding author on reasonable request.

### ***Statement of authorship***

Conception and designing of the study: Sandhya Cherkil and Liza Cherian

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Critical revision and final approval: Dilip Panikar, Prashanth Narayanan and Anup Parameswaran Nair

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