

# Improving Information Provision for Neurosurgical Patients: A Qualitative Study

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**ABSTRACT:** *Background:* Patients confronted with the daunting prospect of a potentially life-altering procedure with uncertain outcome demonstrate high levels of anxiety and need for information. Regardless, many patients are left unsatisfied by the amount of information received from physicians. This study sought to examine the information-seeking patterns of patients and suggest ways to optimize the communication of medical information, specifically within the context of neurosurgery. *Methods:* Semi-structured interviews were conducted with 31 neurosurgical patients operated on for benign or malignant brain tumors. Interviews were transcribed and subjected to thematic analysis in NVivo10. *Results:* Three major themes relating to information-seeking by neurosurgical patients were identified: 1) almost all patients searched for information on the Internet; 2) in addition to characterizing the tumor as benign or malignant, patients sought additional information such as the location of the tumor in the brain; and 3) patients with malignant tumors were less likely to seek information online and more likely to consider alternative therapies. To improve the provision of information to neurosurgical patients, physicians can 1) offer to review imaging results with patients; 2) promote an environment open to questions; 3) provide information in a forthright manner, avoiding the use of medical jargon; and 4) consider guiding patients to reliable Internet sites and facilitating written records of consultations. *Conclusions:* There are many ways that physicians can improve the provision of information to patients, including providing written information and physician recommended online resources, and being mindful of patient perceived time constraints and barriers to effective communication.

**RÉSUMÉ:** *Amélioration de l'information transmise aux patients traités en neurochirurgie : une étude qualitative.* *Contexte :* Les patients qui font face à l'éventualité redoutable d'une chirurgie susceptible de changer leur vie et dont l'issue est incertaine ressentent énormément d'anxiété et ils ont besoin d'information. Cependant, plusieurs patients demeurent insatisfaits de la quantité d'information qu'ils reçoivent des médecins. Dans cette étude, nous avons examiné les modalités d'accès à l'information utilisées par les patients et nous suggérons des façons d'optimiser la communication de l'information médicale, spécifiquement dans le contexte de la neurochirurgie. *Méthode :* Nous avons procédé à des entrevues semi-structurées chez 31 patients traités en neurochirurgie pour des tumeurs cérébrales bénignes ou malignes. Les entrevues ont été transcrites et soumises à une analyse thématique au moyen du logiciel NVivo10. *Résultats :* Trois thèmes majeurs liés à la recherche d'information par les patients en neurochirurgie ont été identifiés : 1) presque tous les patients ont cherché de l'information dans Internet ; 2) en plus de caractériser la tumeur comme étant bénigne ou maligne, les patients ont cherché de l'information sur la localisation de la tumeur dans le cerveau et 3) les patients atteints de tumeurs malignes étaient moins susceptibles de chercher de l'information en ligne et plus susceptibles d'envisager recourir à des thérapies alternatives. Dans le but d'améliorer l'information fournie aux patients de neurochirurgie, les médecins peuvent : 1) offrir de revoir les résultats de l'imagerie avec les patients ; 2) favoriser un environnement propice aux questions ; 3) fournir de l'information d'une manière franche et directe en évitant d'utiliser un jargon médical et 4) considérer diriger les patients vers des sites Internet fiables et expliquer les rapports écrits de consultations. *Conclusions :* Il existe plusieurs façons d'améliorer l'information fournie aux patients par les médecins, dont leur fournir de l'information écrite et leur recommander des ressources Internet fiables ainsi que tenir compte des contraintes de temps perçues par les patients et des obstacles à une communication efficace.

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Effective communication of information in physician patient interactions is essential for fostering patient rapport, enabling informed decision-making, and minimizing patient anxiety. Neurosurgical patients, due to the possibility of life-threatening complications, exhibit a high need for information and greater levels of anxiety than other surgical patients<sup>1</sup>. When patients feel more anxious, post-operative pain rises<sup>2</sup>, the recovery period may be lengthened<sup>3</sup> and intraoperative anesthetic requirements increase<sup>4</sup>.

When information needs are not met, patients may consult sources such as the Internet. However, information obtained online or through other unaccredited sources may be inaccurate

and/or misleading<sup>5-7</sup>, leading to unrealistic expectations and further anxiety<sup>8</sup>. To promote greater information exchange during consultations and minimize the need for patients to seek outside sources of information, many suggestions have been

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proposed, such as audio recording consultations<sup>9</sup>, providing written information to patients<sup>10,11</sup>, and physician recommended web sites<sup>12,13</sup>.

To identify some of the loopholes in patient care, recent studies have examined the information and supportive care needs of neurosurgical patients with benign brain tumors<sup>14,15</sup>. Although these studies identified gaps in patient care, the ways in which patients attempt to overcome these imbalances have not been addressed. To begin to address these issues, this study sought to 1) characterize patterns of information-seeking by neurosurgical patients; and 2) create a list of suggestions for optimizing information provision. The findings of this study present steps that surgeons can take to ensure that patients are fully informed, more satisfied, and increasingly engaged in the medical decision-making process.

## METHODOLOGY

### Study Design

Semi-structured, qualitative face to face interviews were conducted. Postoperative patients with benign and malignant brain tumors were included. At the end of the study, some patients were selected to provide feedback on a draft of the manuscript; patients were considered for selection if they had previously demonstrated an interest in the outcome of the work and/or if the patient contributed to quotes contained within the manuscript.

### Setting and Participants

Study participants were post-operative patients recruited from the neurosurgery clinic of the senior investigator (MB) at Toronto Western Hospital, a tertiary referral centre. Participants were informed of the objectives, expected outcomes, any risks or benefits of participation and written informed consent was obtained. Patients were excluded if they 1) were operated more than five years prior; 2) lacked proficiency in English; 3) were emotionally labile; or 4) showed significant cognitive impairment. Family members were allowed to contribute to interviews to enrich the data.

### Sample Size

Thirty patient interviews were sought; a sufficient number to theoretically obtain data saturation. Data saturation is a qualitative research concept referring to the point at which no new themes emerge from succeeding interviews<sup>16</sup>.

### Data Collection

Thirty-one semi-structured interviews were completed over a five month period, using convenience sampling (i.e. almost consecutive except for logistic reasons such as the interviewer being absent for a clinic, etc). No patient who was approached declined to participate. Although an interview guide was used to direct patient responses (Appendix), patients were given the opportunity to elaborate on relevant issues. All interviews were digitally audio-recorded and demographic data, such as age, educational background, and marital status was documented using data collection forms. The interview guide was

continuously revised to incorporate major themes captured in preceding interviews.

### Data Analysis

NVivo10 was used to help analyze verbatim transcriptions of audio files and subsequent analyses. All transcripts were double-checked for accuracy. Consistent with grounded theory methodology, information was broken down into common ideas (open coding), and grouped according to overarching themes (axial coding)<sup>16</sup>.

### Research Ethics

Research ethics approval was obtained from the University Health Network Research Ethics Board. All patient information was maintained confidentially and transcripts and audio files were kept in a secure location on a password protected computer. Participation in the study was entirely voluntary and patients were reminded that they could stop the interview at any point and that their decision to participate would not affect their care in any way.

## RESULTS

### Patient Characteristics

The demographic and clinical characteristics of the 31 study participants are shown in Table 1. Patients were interviewed over a five month period, from January to May 2013. Nineteen of the 31 patients had benign, as opposed to malignant, brain tumors. Hemangiopericytoma was classified as malignant<sup>17</sup>. The predominance of female patients is not unexpected since meningiomas are more common in women than in men<sup>18</sup>.

### Thematic Analysis

Seven overarching themes arose from the data. Three of the seven<sup>1-3</sup> relate to patient information seeking behavior; the remaining four<sup>4-7</sup> highlight ways in which surgeons can improve the communication of medical information to patients.

#### *1. The Internet was the most widely used resource for seeking medical information*

The Internet is a commonly used resource for patients seeking medical information<sup>19,20</sup>. Internet use has been shown to correlate with younger age<sup>21</sup>, higher education<sup>22,23</sup>, female gender<sup>24,25</sup> and higher socioeconomic status<sup>26</sup>. In this study almost all patients used the Internet to supplement the information they received from the surgeon. Interestingly, patients sought medical information online irrespective of their level of satisfaction with the information obtained. Although subgroup analysis was not possible owing to the sample size, the Internet was used by almost all patients in this study, regardless of gender, self-perceived socioeconomic status, education, or age.

Patients were more likely to consult a small group of popular web sites for online medical information. Of the patients who could recall the details of their online searches, the majority used Wikipedia, the Mayo clinic, or WebMD, followed by the web site of the treating hospital. Many patients also browsed the web

**Table 1: Demographic characteristics of study participants**

Characteristic	Category	Value
<b>Age (years)</b>	Average	51
	Range	25-82
<b>Gender</b>	Male	12
	Female	19
<b>Birth Country</b>	Canada	16
	Outside Canada	15
<b>Marital Status</b>	Married	26
	Common law	2
	Single	3
<b>Self-reported Socioeconomic Status</b>	Low	2
	Low-Middle	2
	Middle	23
	Middle-Upper	4
<b>Highest Level of Education</b>	High School	5
	University Degree	19
	College Diploma	6
	PhD	1
<b>Time Since Surgery (months)</b>	Average	17
	Range	0.5-59
<b>Time Since Diagnosis (months)</b>	Average	24
	Range	0.75-60
<b>Diagnosis</b>	Meningioma (WHO Grade I or II)	19
	Glioblastoma Multiforme	6
	Anaplastic Astrocytoma	3
	Anaplastic Oligodendroglioma	1
	Metastasis	1
	Hemangiopericytoma	1

pages of high-profile neurosurgery departments in the United States, such as Johns Hopkins University and the University of Pittsburgh. Sites oriented towards health professionals such as Pubmed and Merck Manual were used by a few patients; these patients typically had a background in health care or a physician in the immediate family. Many patients also frequented blogs and online forums. Although some patients found these sites to be useful, other patients found them anxiety provoking. When patients were asked how they assessed online information for accuracy, most reported that the challenge of objectively evaluating online information is one of the greatest obstacles to the value of the Internet.

“Well, the problem with Google is when you're trying to look stuff up there is an overwhelming amount of information, some of which is relevant, some of which isn't...it's a trial and error process and you come out of it feeling fairly doubtful about the accuracy and what you've learned.”

Almost all patients who used the Internet also searched for information about the surgeon's competence and skill, two factors which have a strong influence on trust in the surgeon-patient relationship<sup>27</sup>. Despite minimal face time, many patients trusted the surgeon to do the best job possible, a sentiment which was intensified by flattering online reviews or encouraging

appraisals from other physicians. Patients who trusted their surgeon more spent less time searching the Internet for information.

Contrary to the pervasive use of Internet for medical information, few patients consulted books, journals, or other printed materials aside from pamphlets and binders provided by the hospital. Although some of these printed materials were also available online, patients not undergoing further treatment were frequently uninformed of these sites, suggesting that more should be done to promote patient awareness of existing resources. Patients with benign tumors may be especially disadvantaged in this regard and have less intensive follow-up<sup>14</sup>.

Not surprisingly, almost all patients discussed their diagnosis with family and friends. Slightly more than half of patients also discussed their diagnosis with physicians accessed through personal networks of acquaintances. Although most patients found these discussions to be helpful, many stated that their usefulness was also limited owing to the specialized nature of neurological surgery.

### *2. In addition to classifying the tumor as benign or malignant, patients sought information about tumor biology, etiology and anatomy of the brain*

To identify the pivotal concerns to patients during the preoperative period, patients were asked their most urgent questions when searching for information. Although many patients sought information about the surgical procedure, as expected<sup>14</sup>, most patients were interested in learning more about tumor biology and etiology, and the anatomy of the brain. First and foremost, patients wanted to verify the status of the tumor as benign or malignant. Second, patients wanted a detailed description of the tumor: what it is, where it is in the brain, what it is currently doing, and what it might do in the future.

Many patients were also interested in knowing the relationship of the tumor to surrounding structures, and possible causes of tumor development, including any known genetic associations. Some patients found a general description of the brain to be very helpful.

“Maybe explain a bit more about why is it happening...the why is always important because you wonder why is it growing in my brain and is it cancerous or could it turn cancerous ... what did I do, does it have to do with genetics, or does it have to do with hygiene. Maybe spending a little bit more time explaining how the brain works....”

### *3. A malignant diagnosis changed information-seeking behavior in three ways: 1) patients were less likely to use the Internet 2) patients felt more anxious with online information; and 3) patients were more likely to consider alternative therapies*

One classic definition of information-seeking divides individuals into two groups: monitors, who actively seek information, and blunters, who reject information<sup>28</sup>. Although the vast majority of patients were monitors, patients diagnosed with malignant tumors were more likely to exhibit a blunting coping style. Whereas patients with benign tumors often felt less anxious after going online, patients with malignant tumors frequently found online information to be anxiety-provoking;

these patients were scared of the information they might find. They did not want to read or hear stories about people who had succumbed to the same disease, and were less inclined to seek prognostic information.

“Why focus on what that percentage is? Just learn to find happiness and live life to the fullest whether you have 50 more years or two. That's what cancer and terrible diseases do; you have to find that peace and happiness through it...so the percentages and statistics don't really mean anything to me at all.”

While few patients with benign tumors considered alternative therapies, more than half of patients diagnosed with malignant brain tumors were either actively considering or had already engaged in the use of alternative therapies. Examples include herbal supplements, dietary modifications (e.g. low sugar diets), and other less conventional approaches (e.g. acupuncture etc.) Although these patients admitted to the lack of scientific evidence supporting the efficacy of alternative treatments compared with standard western medicine, patients wanted to feel like active combatants in the battle against their disease, and not just passive bystanders. The use of alternative, self-initiated treatment regimens may help patients feel more empowered, and relieve feelings of hopelessness and ineffectuality.

“Of course Western medicine is the faster method as far as killing the cancer cell is concerned. Herbal medicine is something very, very slow. ...It just makes us feel better that he's done something that will hopefully make him stronger.”

For some patients, the use of alternative medicine was a last resort. Moreover, patients felt that doctors should be doing more to integrate conventional and traditional treatment approaches and should be more open-minded about alternative medicine. Some patients showed frustration at a perceived lack of medical progress.

“what else is there.....they basically said there was no advancement in this treatment for the last two or three years or even longer. I work as an engineer and if you take that kind of approach in engineering we'd still be running around with horses and guns. If you don't think outside the box, things will stagnate. And that's what's frustrating. It's difficult to accept that it's somebody's life.”

#### *4. Patients should be allowed to view their own imaging with the surgeon*

Although a few patients were undecided about the benefits of viewing their MRI or CT with the surgeon, most patients preferred to see their own imaging. Patients also wanted the surgeon to review the key imaging findings with them, regardless of their level of understanding. Referring to a patient's scan facilitates patient understanding of the geography of the tumor in the brain in relation to other structures. Moreover, visual representation of the surgical site before and after surgery was much more meaningful to patients than simply being told their surgery was a success. Patients wanted to see exactly how much the original tumor site had changed.

“I think for my personality it's helpful to see the MRI. The last MRI I had it had moved but you don't get to see how it's moved, you just have to take it at your oncologist's face value.”

#### *5. The surgeon should be forthright about information, providing specific names whenever possible and avoiding the use of medical jargon*

Most patients wanted direct and candid communication from their surgeon. It has already been shown that patients do not want to have information “sugar-coated” to spare their feelings<sup>29</sup>. Notably, the quality, not quantity, of the interaction was important. Compassion, reflected in both verbal and nonverbal gestures and a willingness to answer questions<sup>14</sup>, enhances the quality of the physician patient relationship<sup>27</sup>. A surgeon should also be able to connect emotionally, a goal which a surgeon may strive for, but which may not always be possible in practice<sup>30</sup>.

“I think along the journey some specialists put up a barrier and disconnect with the patient because their job is tough. It's easier not to connect with a patient and lose them than to connect with a patient and lose them.”

Patients also wanted the information to be explicit and unambiguous. Surgeons should try to avoid using medical terms that patients may find difficult to understand or remember. Owing to the use of medical jargon, some patients were confused about their medical condition. In fact, two patients were not aware of their alleged diagnoses until long after the initial consultation with the neurosurgeon, owing to the use of the word lesion instead of tumor.

“I never remember them calling it a tumor because I was telling my friends it was a lesion. So I didn't know it was a cancerous lesion until I came here after my surgery.....the language that doctors use is different than people use normally, day to day.”

#### *6. Surgeons should be aware of how perceived time constraints may influence patient's willingness to ask questions*

The time sensitive nature of the surgical consultation is a familiar reality. Moreover, the majority of time during a surgical consultation is spent explaining test results or describing proposed procedures, with the patient responding to the surgeon's cues rather than initiating discussion<sup>31</sup>. In this study, more than a third of patients were not satisfied with the amount of information they obtained from the surgeon. Interestingly, many patients evoked time constraints to justify the discrepancy between the information they needed and the information they received. These patients felt that less than optimal information provision was defensible since surgeons have little time to spend chatting with patients, and generally displayed an attitude of submissive deference towards the surgeon. Many of these patients felt reluctant to ask questions which were important to them.

“I am sensitive to taking up [the surgeon's] time and I don't want to bother him with small questions even though they actually might be important to me. His job is to be a surgeon and not everyone can be a brain surgeon. I'm sure it takes up a lot of space so obviously that's where he has to focus his energy.”

Surgeons should thus be cognizant of how perceived time constraints may influence the dynamics of the patient physician relationship, and should try to encourage patients to ask questions by promoting an environment of uninhibited and open communication.

7. Surgeons should consider 1) ways to provide a permanent record of the surgical consultation to patients; and 2) guiding patients to reliable online information resources

It has been estimated that 40-80% of medical information provided by health care practitioners during a verbal exchange is forgotten immediately<sup>32</sup>. Consequently, the provision of written information by neurosurgeons has been proposed by others<sup>10</sup>. Not unexpectedly, almost all patients thought that a written record of the consultation would be very helpful. Patients often did not remember important details discussed and after the consultation, most patients performed a generic Google search using the name of the tumor as the input search function. As a result, patients with benign tumors sometimes ended up reading information about the treatment and prognosis of malignant conditions.

"Yeah I think it should be written. You have these medical terms which are long like this .....then I try to find them on Google based on phonetics..... there's an m and g in it. That would be fantastic."

One approach to facilitating the provision of written information for surgical patients would involve making pens and paper available outside and/or inside the clinic for patients to 1) write down any questions they might have while waiting for the surgeon; and 2) record important points discussed during the consultation. Alternatively, others have proposed audio recordings of consultations<sup>9,33</sup>.

Almost all patients said that surgeons should recommend accurate and reliable Internet sites, assuming such sites exist. Patients wanted these online sources to be 1) vetted by neurosurgical professionals; 2) frequently updated; and 3) written in plain language appropriate for a non-medical audience. Moreover, web site administrators should try to ensure that the information is as individualized as possible, providing instruction on a broad range of neurosurgical issues, and addressing the questions which are most important to patients.

"The problem with using the internet is that, unless you are fairly knowledgeable in a particular field, all the sources of information on the internet look the same to you. You don't know if it's a good source of information or questionable....so it would help if at an earlier stage the would suggest good sources of information.

## DISCUSSION

The purpose of this study was twofold: to 1) examine preoperative patterns of information seeking among neurosurgical patients; and 2) suggest ways in which surgeons can optimize the exchange of medical information with patients.

Since the advent of the Internet in the mid-90s, people have used it as a resource on a multitude of issues ranging from dating to the weather to international news. Patients frequently use the Internet to find information about neurosurgical procedures and specialists<sup>34</sup>. Studies have shown that the average American spends a little under 30 hours/week surfing the Net<sup>35</sup>. Moreover, the authority of the Internet as a medical resource has grown, with publicly moderated sites such as Meningioma Mommas and Crowdmed.com to mainstream medical databases like UpToDate and the Merck Manual. In a recent study, the Internet was found to be the most widely used health information resource<sup>25</sup>.

Similarly, almost all neurosurgical patients used the Internet to search for information about their tumor. Compared with existing estimates of patient use of online resources<sup>24,26,36,37</sup>, the percentage of patients in this study consulting online sources was higher than expected. Not surprisingly, compared to the Internet, few patients consulted books or other print materials other than booklets or pamphlets provided by the hospital.

Easy access to online information may be a boon to some, bestowing a wealth of knowledge with the click of a button, but detrimental to others, considering the overabundance of misleading information<sup>7</sup>. In support of the Internet as a beneficial resource, patients preferred to trust recognized medical sites rather than personal blogs or uncensored forums. Conversely, however, many patients were increasingly anxious after reading information online, especially if the message was discouraging.

Since most patients will invariably consult online resources for medical information, the Internet should be integrated into solutions to address the information needs of patients. For example, physicians could guide patients to web sites containing accurate and reliable medical information, termed by others as the 'Internet prescription'<sup>8,12,13,38</sup>. Almost all neurosurgical patients thought that surgeons should recommend specific websites, provided that the information is 1) presented at a level suitable for a non-medical audience; 2) vetted by professionals in the field; and 3) current and regularly updated. A published checklist outlines the content of patient information sources which could be adapted to sources online<sup>39</sup>. The checklist contains twelve recommendations, for example 1) using patient's questions as the starting point; 2) ensuring that common concerns and misconceptions are addressed; and 3) including questions and checklists to ask the doctor etc.

Competent and effective communication, which depends on factors such as trust and rapport<sup>27</sup> is essential to successful information provision. In North America there is approximately one active physician per 392 people<sup>40</sup> and one neurosurgeon per 85,000 people in the US<sup>34</sup>. The number of specialty neuro-oncologists is even smaller. Although reduced supply and increased demand may allow neurosurgeons to place less emphasis on some aspects of patient care without significant repercussions, the limit of alternatives for neurosurgical patients should compel neurosurgeons to place an even greater emphasis on all aspects of patient care. The quality of the interaction between a neurosurgeon and his or her patient is thus critically important and is influenced by many factors. For example, a sense of compassion contributes to effective communication whereas detachment can detract from it<sup>27</sup>. The ability of a surgeon to connect with a patient may be a prerequisite for successful interactions with patients.

To improve patient-centered care, physicians should focus on the issues that are most important to patients<sup>41</sup>. Although the majority of patients want to know as much information as possible<sup>42</sup>, some patients, notably patients with worse prognoses, may not want to know everything about their condition<sup>43</sup>. To overcome this potential constraint, physicians could first ask patients how much they would like to know.

In addition to compassion, connectedness, and a focus on the issues that are most important to patients, a physician's willingness to answer questions can influence the amount of

information provided during a consultation<sup>44</sup>. Consequently, patients must feel free to ask questions of the physician. Interestingly, a significant number of patients thought that time constraints were a reasonable excuse for the inadequate provision of information by surgeons. These patients displayed an almost unquestioning regard for the surgeon's supremacy in medical matters, and were reluctant to ask questions that could have been considered trivial to the surgeon. Perceived time constraints and the public perception of medical professionals may therefore limit the exchange of information between physicians and their patients. In addition to being aware of how perceived time constraints may influence physician patient interactions, physicians could attempt to create a more open and uninhibited environment in which patients are not deterred from asking questions.

Patient empowerment is also a key element of patient-centered care<sup>45</sup>. Physicians may contribute to patients' sense of control in a number of ways, such as allowing patients to view their own imaging, minimizing the use of medical jargon, and providing a written record of consultations. A visual image on MRI can transform an abstruse concept for most patients into something more digestible and concrete. The elimination of medical jargon also serves to empower patients by increasing patient understanding and participation. More specifically, the use of jargon such as the term 'lesion' instead of 'tumor' should be avoided. Furthermore, the provision of written, in addition to verbal information, such as consultation tapes and summary letters, can empower patients by increasing understanding and recall<sup>19,11,46</sup>. Similarly, almost all neurosurgical patients thought that a written record of the consultation would be helpful. For example, providing pens and paper to allow patients to 1) write down questions for the surgeon; and 2) record key points and conclusions, may increase patient participation in consultations and help patients feel more in charge of their own care.

The inclusion of patients with both benign and malignant tumors in this study permitted a direct comparison of information-seeking patterns among these two groups of patients. For example, neurosurgical patients with malignant tumors were less likely to go online in search of medical information and more likely to consider alternative therapies. Faced with a terminal illness with an extremely poor prognosis, patients needed to maintain a sense of hope to cope with the realities of their situation<sup>47</sup>. Furthermore, patients and their families wanted to know that they had exhausted all possible treatment avenues, regardless of the lack of scientific evidence for the utility of non-conventional therapies. Physicians should thus consider familiarizing themselves with the broad array of alternative therapies available, and should be open-minded to discussing these options with patients. As a result, patients using alternative treatments may be more inclined to inform the physician; physician's knowledge of patients' use of alternative treatments is important since many of these therapies can interact with standardized treatments<sup>48</sup>.

In summary, this study highlights the information-seeking patterns of neurosurgical patients and provides suggestions for improving the provision of information by neurosurgeons. There are a number of actions that can be taken to address the information needs of patients, improve patient satisfaction, and reduce patient anxiety. This study highlights some key areas for

improvement, such as providing written information and physician recommended online sources, and being cognizant of patient perceived time constraints and barriers to communication.

### Limitations

Although some of the conclusions of this study may be generalized, it is important to note that interview responses represent the views of a select group of neurosurgical patients at a busy hospital in a major metropolitan centre. Nonetheless, the goal of this study was not to generalize, but to suggest possible way of improving information provision for neurosurgical patients with benign and malignant brain tumors. Additionally, the affiliation of the interviewer (A.B.) with the senior investigator (M.B.) may adversely influence patient's freedom to offer opinions which may reflect negatively upon the senior investigator. A further limitation of this study was the length of time between the interview and operation, which exceeded one year for some patients, and may have resulted in some inaccuracy with respect to patient's recollections of their pre-operative information seeking behavior.

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*Appendix on the following page*

## Appendix: Interview Guide

We are conducting a study to determine the pre-operative information seeking patterns of neurosurgical patients. As a result, we will be asking you questions about your information seeking behavior after your consultation with the neurosurgeon and before your surgery. Moreover, we will be asking for your views on a number of suggestions for enhancing communication between neurosurgeons and their patients. The goal of this study is to identify ways that physicians can improve the provision of accurate and reliable medical information to help patients feel more satisfied, less anxious and more engaged in their care.

1. After consulting with the neurosurgeon and before your surgery, did you use the Internet or other online resources to find out more information about your tumor?
  - a. If yes, how did you go about searching for information online? (prompt: did you use a search engine such as Google and what did you type into the search box?)
  - b. If yes, what electronic sources did you use? Can you provide specific names?
  - c. If yes, did the information obtained from these sources affect any feelings you might have had before your surgery?
  - d. If yes, how did you judge the accuracy and/or reliability of the online sources you used?
2. After consulting with the neurosurgeon and before your surgery, did you use any printed materials to find out more information about your tumor, such as newspaper, pamphlets or anything else you can think of?
  - a. If yes, what sources did you use?
  - b. If yes, did the information obtained from these sources affect any feelings you might have had before your surgery?
  - c. If no, did you get any binders or pamphlets from the hospital?
    - i. If yes, did you find this information helpful?
3. What were the most important questions you searched for answers to using any of the resources you have mentioned?
  - a. Did you receive this information from the neurosurgeon?
4. Did you discuss your diagnosis with family and/or friends?
  - a. If yes, did the information obtained from family and/or friends affect any feelings you might have had before your surgery?
5. Did you discuss your diagnosis with any medical professionals other than the neurosurgeon?
  - a. If yes, were these medical professionals your friends and/or acquaintances?
  - b. If yes, did the information obtained from family and/or friends affect any feelings you might have had before your surgery?
6. Are there any other resources that you can remember using to find out more about your tumor?
7. Have you considered alternative and/or traditional medicine specifically for the purpose of treating the tumor?
  - a. If yes, what kind of alternative medicines have you considered and/or tried?
  - b. If yes, did you discuss your interest in or use of alternative medicine with the neurosurgeon? Why or why not?
8. Did you feel satisfied with the amount of information you obtained from the neurosurgeon before your surgery? Why or why not?
  - a. If no, what more would you have liked to know?
  - b. If no, why do you think that you didn't get all the information you needed?
9. Do you think that it is helpful for patients to be allowed to view their own imaging during consultations with the neurosurgeon? Why or why not?
  - a. Did you find viewing your imaging helpful to you? Why or why not?
10. Do you think that the physician should recommend online resources for patients interested in learning more about their condition? Why or why not?
  - a. If yes, what kind of information should these online resources have and how should it be presented to patients?
11. Do you think it would be helpful for physicians to facilitate the provision of written information to patients? Why or why not?
  - a. If yes, what do you think is the best way of providing this information?
  - b. If yes, what kind of information should this written record contain?
12. What characteristics of the neurosurgeon do you think are important for successful interactions with patients?
13. Do you have any further suggestions regarding ways that neurosurgeons can improve the provision of information for neurosurgical patients?
14. Are there any other recommendations you can think of that may not have already been addressed during our discussion?
15. Is there anything else you would like to add?