

Brain tumor patients' views on deception: a qualitative study

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Abstract Given the trust the public places in the medical profession, the question of when it might be acceptable to minimally deceive patients, in their best interests, is a challenging one to answer. In this study, we explore neuro-oncology patients' attitudes towards dilemmas in which they may feel deceived, and with that information make recommendations on what steps physicians can take to avoid breaking that trust. Qualitative case study methodology was used. Thirty-two face-to-face interviews with post-operative brain tumor patients were conducted and recorded. Interviews were transcribed and subjected to modified thematic analysis. The majority of patients had a postsecondary education, and there was substantial religious and ethnic diversity among them. Five prominent themes arose from the analysis: (1) patients are hesitant about trainees working on their case, but they are more open to it if they expect the occurrence ahead of time; (2) patients wish to know the exact details when an error has occurred, even if it is of inconsequential effect for them; (3) patients generally prefer to know exactly what the doctor knows, even if nothing can be changed; (4) patients expect physicians to provide them with all the options and resources available; and (5) there are special cases in which patients accept a delay in knowing. Most neuro-oncology patients trust their physicians to make the best decisions for them, but that does not mean they would accept subtle forms of deception. Patients prefer to have all the information necessary in order to make their own decision.

Keywords Deception · Patient perception · Qualitative research · Trust

Introduction

In modern day medicine, physicians are expected to not only disclose information necessary for informed consent, but also to maintain an honest relationship where the patient is clear about all that's involved in his/her care [1]. However, while it is generally considered highly unprofessional if a physician lies to his/her patients, what constitutes lesser deceptions can be ambiguous. Small deceptions may be deemed to be in the patient's best interest at the time. The dilemma of ensuring patients' autonomy is challenged by physicians misleading or omitting "inconsequential" details with the best interest of the patient in mind. Several reviews have been written on the topic from ethicists' points of view [2–7], but little empirical evidence has been collected that surveys how patients feel about the issue.

In this study we explore neuro-oncology patients' ideas and thoughts towards dilemmas involving deception by physicians. While the majority of the healthcare community agrees that the covenant of trust between physician and patient is critical to their developing relationship [8], deception in one form or another still occurs in the practice of medicine [9–13]. A previous study has found that most neuro-oncology patients trust their physicians to make the best decisions for them, even if it means overlooking ambiguities and gaps in their knowledge about the complex hospital microcosm [14]. Thus, our initial hypothesis was that "small deceptions" done to save patients grief in situations in which full disclosure would not alter the course of action taken, would be acceptable to brain tumor patients.

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The results of this study could provide insight into how much, if at all, different forms of deception undermine patients' confidence in the medical profession. Understanding this issue can shed light on how physicians should approach these dilemmas, and in turn encourage them to modify their behaviours appropriately to promote optimal physician-patient relationships.

Methods

Study design

Qualitative case study methodology was used. Open-ended face-to-face interviews were conducted with post-operative brain tumor patients.

Setting and participants

Participants were selected from patients seen in the ambulatory clinic of the senior investigator (MB) at Toronto Western Hospital. Convenience sampling was used. Informed consent was obtained from all individuals and objectives of the study explained prior to the interview. Only post-operative patients were selected; those who had not yet undergone treatment were not recruited as they may be more vulnerable about discussing sensitive issues that might arise in their management. Patients were also excluded from participating if they: (1) are not cognitively intact; (2) are unable to communicate adequately in English; (3) are deemed to be emotionally too fragile.

Sample size

Thirty-two interviews were conducted. Thirty is the number that conforms to typical sample sizes used in other qualitative research projects [15–17] related to surgical patients and at which point saturation of themes is achieved. Saturation is a term used in qualitative methodology to denote the point at which no new themes are expected to arise during subsequent interviews [18].

Data collection

Open-ended, face-to-face, semi-structured interviews with patients were conducted in private clinic rooms. The interviews were audiotaped for subsequent transcription and analysis. Interviews were based on a guide (Appendix) containing explicit scenarios, although various ideas were discussed as patients introduced them. Demographic data were also collected on each patient.

Analysis

Modified thematic analysis was undertaken in which overarching themes were extracted from the interview transcripts. This analysis involved both open and axial coding [18]. First, reading fragments were grouped according to shared ideas (open coding), then dominant ideas that emerged were organized into overarching themes (axial coding).

Research ethics

Written informed consent was obtained from each participant. All data were kept confidential. Audiotapes and transcripts were held in a secure location. This study was approved by the Research Ethics Board at the University Health Network.

Results

Patient information

Thirty-two patients were interviewed in a 3 month period between June 2010 and August 2010. Out of the 32 patients, 12 had low-grade glioma, 4 had high grade glioma, 10 had meningioma, and 6 had brain metastasis. Demographic data for the 32 patients who participated are shown in Table 1. A second year medical student (J.Y.), who had no direct therapeutic relationship with the patients, conducted all the interviews.

Thematic analysis

Analysis of the interviews yielded five overarching themes. They are described below and illustrated with verbatim quotes from the patients.

1. *Neuro-oncology patients are hesitant about trainees working on their case, but they are more open to it if they expect the occurrence ahead of time.* The results from cases 1 and 2 contributed to this analysis. Whether or not patients agree to other medical staff participating in their care depends partially on the level of expertise that a particular task requires. When it comes to allowing a medical student to take their history before seeing the staff neurosurgeon, most patients are open to the idea. When it comes to performing the actual neurosurgical procedure however, most patients are not comfortable with anyone else other than the neurosurgeon. Most patients did state that if they were told about the participation of residents ahead of time, they might be more accepting of it.

“Yes it is deceptive. It is believed that the doctor that you saw and talked to is the one to do the surgery.”

Table 1 Summary of characteristics of 32 patients interviewed

Characteristic	No.
Age (years)	
Range	21–73
Mean	46
Median	50
Sex	
Male/female	9/23
Marital status	
Married/Single	20:12
Religion	
Atheist	8
Agnostic	1
Catholic	9
Christian	7
Hindu	1
Jewish	5
Mennonite	1
Education	
Masters/PhD	5
University degree	14
College diploma	8
High school diploma	5
Employment	
Employed	18
Unemployed	6
Retired	8
Pathological entity	
Low grade glioma	12
High grade glioma	4
Meningioma	10
Metastasis	6
Time after operation	
Range	3 days to 20 years
Mean	2.8 years
Median	9 months

“It’s acceptable in a teaching hospital because you have to learn somehow. But being aware of it prior would be nice.”

“Ideally I’d want the expert to be doing it. I guess the ideal situation is to obtain consent beforehand. I would vote to be told.”

“It’s acceptable if the patient has a choice, and is made aware, and comes to an agreement that the student will be doing the surgery... but if it’s done without the explicit knowledge of the patient, then it’s totally unacceptable”

2. *Neuro-oncology patients wish to know the exact details when an error has occurred, even if it is of*

inconsequential effect for them. The results from cases 3 and 4 contributed to this analysis. When something unexpected occurs during neurosurgery, most patients prefer to know exactly what went wrong and why, regardless of how insignificant the mistake is. As long as the doctor is upfront about the error, and describes it in enough detail, most patients will understand and accept that mistakes can happen.

“When an error is made, it’s up to the physician to own up to that, even if it is inconsequential.”

“It’s my body and I need to know everything that’s going on with it.”

“I would prefer it if they tell me exactly what happened. It’s the mere fact that I would expect honesty from my surgeon, and if he comes in and tells me this is what happened it’s more understandable than hiding. We trust our physicians and we expect them to be honest with us.”

“Regardless of the fact that I’m injured with a weak arm, I know that I could trust him again for anything else because he was truthful.”

3. *Neuro-oncology patients generally prefer to know exactly what the doctor knows, even if nothing can be changed.* The results from cases 5, 6, and 9 contributed to this analysis. The field of neurosurgery is full of uncertainties. When the wait-and-see approach is employed, the general consensus among patients is to know about the shadows in the scans, even if doing so causes them unnecessary worry. As well, people prefer to be told about all the risks involved with the surgery, even if they are certain they’re going to have it regardless. Similarly, patients are not satisfied just knowing that their surgery will be in a month, but also they would like to know the exact cause of the delay, even if it be that the doctor is away on vacation.

“It’s not helpful to not have information when the doctor has it.”

“I’m the type of person who would like a lot of detail even if it’s going to cause me a lot of anxiety. More information for me helps me process things a little bit better.”

“I just think the patient has the right to know, to make the decision, whether that’s a right or wrong decision. Not everybody has the background to make the correct decision because we’re not medical, but I still think you should present it.”

4. *Neuro-oncology patients expect physicians to provide them with all the options and resources available.* The results from cases 7 and 8 contributed to this analysis. Allowing patients to ask for second opinions is common practice, thus it’s no surprise that patients would feel

deceived if the doctor purposefully delays that from happening. Patients all agree that it is also deceptive if the doctor does not inform them about an experimental treatment even if it is expensive and has no proven efficacy. It appears that patients expect complete disclosure from their physicians, giving themselves the power to make their own choice.

“I wouldn’t mind hearing about it, it doesn’t mean the doctor has to do it, it’s still knowledge as opposed to nothing.”

“It’s my right as a patient to do my due diligence, and ask the questions I want to ask. For the doctor to not give me the opportunity to have that dialogue..., takes away some of my power.”

“You have to go on the fact that this person is an adult and with more information they can make their own assessment about what treatment they want to do.”

“Anytime a doctor withholds information, whatever the reason may be... from that point on I would forever be suspicious. ...at the end of the day it’s my life, it’s my health, and having that trust broken is very hard, if at all possible to build up again.”

5. *There are special cases in which neuro-oncology patients are alright with a delay in knowing.* The results from cases 5, 9 and 10 contributed to this analysis. Patients are open to scenarios where perhaps knowing sooner rather than later would do more harm than good. In situations dealing with incurable diseases for example, patients agree that perhaps waiting until after a major event (e.g. a family wedding) might be compassionate. As well, in situations where the physician is unsure of the diagnosis, perhaps it would be a better idea to inform the patient after the physician is more certain.

“It’s a case-by-case thing; you’re stepping over some lines ethically there... But I think there are certain circumstances in which delaying would be acceptable.”

“Where such information would cost great disruptions to something else that has been planned, a wedding would be a good example, and that affects a whole bunch of people, where a couple of weeks would give time for it to resolve.”

“Perhaps if the diagnosis is uncertain and more has to be done before the diagnosis is made clear.”

Discussion

In this study, we explored neuro-oncology patients’ opinions towards selected case scenarios related to physician

actions that they may deem to be deceptive. To our knowledge, most of the literature on deception had been written from ethicists’ points of view [2–7], with very few qualitative studies reviewing physicians’ or patients’ thoughts [19–22]. Those that did survey patients’ attitudes typically focused on one area of deception. For example, two papers surveyed how patients would feel if they were not told about a medical error that occurred [12, 21]. Another paper surveyed how much disclosure surgical patients would like to have in regards to their procedure [20]. Our paper is unique in that: (1) more than one type of deception is surveyed, ranging from lying by omission to therapeutic privilege; (2) it employs the use of open-ended interviews, which allowed patients to further elaborate on their thoughts, as opposed to a finite choice questionnaire; and (3) participants were real post-operative neuro-oncology patients who could picture themselves in those cases presented.

Deception in one form or another occurs in medicine. One 20 year old study found that with difficult ethical choices, most physicians indicated some willingness to engage in some form of deception [9]. The justification was that their patients’ welfare and confidence in the medical field are more important than absolute truth telling [9]. Even in serious cases such as when an error has occurred, some physicians would choose to disclose little to no information [11, 12], and would often avoid stating why it happened or how recurrences could be prevented [12].

The main findings of this study were that most neuro-oncology patients prefer to know everything that the doctor knows, regardless of whether or not this causes them more anxiety or pain. Patients can accept some information being delayed for a certain period of time, but ultimately when the time is right, they would still prefer to know. Given that, we propose that some changes be implemented to ensure that we respect our patient’s wishes.

When it comes to the involvement of trainees in the care of a patient, it is important that the patient realizes and accepts the roles that other professionals play. Not everyone is familiar with how the medical system operates [14, 23] and it is important to inform patients ahead of time rather than have them find out after and feel deceived. In regards to the medical student taking a history of the patient instead of the staff physician, one can inform the patient that this is normally how the physician conducts his/her ambulatory practice. When the patient calls to book the appointment, one could provide a realistic estimate of the time spent with the staff physician versus other healthcare professionals. That way, patients will know what to expect and feel respected. The beginning of a new doctor-patient relationship is delicate, and it is important to reassure patients of our sincerity.

When it comes to the involvement of residents during the neurosurgical procedure itself, it is important to make the patients aware that the principal surgeon may be assisted by others when operating. Emphasize that the residents are trained professionals who the staff surgeon trusts to do just as good of a job as him/herself at the tasks they are delegated. This will instill in them more confidence in the medical team.

In regards to admitting error, the rule of the thumb should be to always own up to the mistake and explain everything honestly. Do not assume that patients lack the medical background to understand but instead, ask them first if they wish to have more detail, and then explain accordingly.

The need to offer neuro-oncology patients the whole range of options and allow them to decide for themselves is clear. All 32 patients unanimously agreed that doctors should not hesitate in granting second opinions or provide patients with all the resources available for their treatment, even therapies not yet approved locally. Thus, physicians should always offer the full armamentarium of information to patients without being paternalistic.

Finally, there are always exceptions to the rules. Most neuro-oncology patients do feel that there are times in which delaying informing them of their diagnosis can be appropriate. The best course of action in that case would be to discuss the issue with the patient ahead of time. Ask them what they would prefer if cases should occur in which perhaps they themselves would prefer not to know. Document such discussion and make sure both parties agree on a course of action. That way, not only will it spare physicians the moral angst, but the patients' wishes are respected as well.

Limitations

This study has limitations. Given the affiliation of the interviewer (J.Y.) with the neurosurgeon (M.B.; the former's supervisor), patients may feel the need to answer a certain way in order to please the latter. Subtle influences such as this cannot be disregarded as a factor in essentially all qualitative studies. Also, all patients were selected from one university-based neurosurgeon's practise. This gives rise to selection bias. As well, given that the hospital is located in a large urban center in Canada, the results of this study may not be generalizable to neuro-oncology patients everywhere. Regardless, the goal of this study is not to generalize to all patients, but to explore the attitudes of a sample of brain tumor patients in order to modify our behavior to better recognize their needs and to stimulate further study.

Conclusion

In this study, we explored neuro-oncology patients' opinions towards cases involving physician actions that may be deemed to be deceptive. A common theme among patients is that they wish to have the autonomy to make their own decisions, and they trust physicians to provide them with the means to do so. Given that, it is always appropriate to give patients all the available details so as to maintain their trust and autonomy. It appears that our initial hypothesis has been dispelled, and that neuro-oncology patients want full disclosure about all details of their case with rare exceptions.

Conflict of interest The authors do not report any conflict of interest concerning the materials or methods used in this study or the findings specified in this paper.

Appendix: Interview guide

This is a study about deception. Today's interview is intended to assess your opinions towards selected ethical cases related to physician actions that you may deem to be deceptive. These issues typically arise when physicians make attempts to balance what is in their opinion the best for the patient versus making sure that the patient is aware and knowledgeable about what's happening around them. In other words, physicians sometimes make decisions to not tell the whole truth to their patients in hopes of protecting them. We are not sure if the patients feel the same way, so we are interested in learning more about what patients do and do not wish to know. You will be presented with cases and be asked your opinion regarding each case. Please feel free to have the interviewer reread or further explain if there is anything you do not understand. Do you have any questions before we begin?

Case 1. You were just investigated for headache and your MRI (a scan) shows a brain tumour and you are obviously extremely anxious. But you are comforted by the fact that you have an upcoming consultation with Dr. X, a renowned brain tumour neurosurgeon. As you sit anxiously in the clinic room on the morning of the consult, you are greeted by a medical student who informs you that she will be taking your history. This ends up taking 40 min. Then the medical student leaves and returns after 5 min with Dr. X who examines your MRI, and talks to you about the details of the brain surgery you need. Would you feel deceived by the fact that you did not see Dr. X from the beginning? Should you have been told in advance that this is the way it would be done? Please explain why you feel this way.

Case 2. On the morning of the operation, you meet Drs. Y and Z, a junior and senior resident (i.e. neurosurgeon-in-training) who will be helping with your operation. In reality, Dr. X may only be there to guide the residents through the procedure. Would you feel that you've been deceived if such knowledge was not made explicitly clear to you ahead of the surgery? Or would this be acceptable and expected behaviour in a teaching hospital? Please explain why you feel this way.

Case 3. During the surgery and just after the tumour is removed, the skull flap accidentally gets dropped on the floor. This happens from time to time. When it does, it is standard practice for the surgeon to discard the contaminated bone flap and replace the defect using space-age epoxy and metal mesh. This procedure leaves no skull weakness or deformity and you will not notice any difference. Given this is an error with inconsequential effects for you, the surgeon might choose not to inform you to save you unnecessary worry. Would this be deceptive? If so is this deception acceptable. Please explain why you feel this way.

Case 4. During your brain tumour operation an important artery is accidentally cut—it was almost impossible to avoid as it was inside the tumour. This leads to severe weakness of your right arm. When you ask why you have a weak arm, Dr. X responds: “You'll recall the discussion about the risks we had before your surgery. It was a technically difficult operation. It's unfortunate but hopefully it will improve over time. I'm sorry about this”. Is this a deceptive response? Should the surgeon be more explicit? Please explain why you feel this way.

Case 5. After successful surgery for your brain tumour, you are discharged from hospital with instructions that you will be coming back in 3 months for an MRI. On your 3-month MRI, Dr. X notices some funny shadows which can be either post-surgery changes or possibly a little bit of tumour that was inadvertently left behind. Dr. X will need to keep a close eye on subsequent MRI's. When you ask how the MRI looks, so as to not cause you any unnecessary worry, he responds: “Looks OK. Let's see how the next MRI looks in 6 months.” Do you think Dr. X made the right choice in not informing you, or was this deceptive? If so, is this deception acceptable? Please explain why you feel this way.

Case 6. A 23 year old woman is referred to Dr. X with a large brain tumour. Without surgery she will die and with surgery she will very likely be cured but at a 5% risk of major paralysis. Either way, the decision for surgery should be a simple one because otherwise she'd die. Dr. X feels the patient is quite delicate and psychologically anxious and when asked about the risks of surgery he says: “You'll be fine. I'll treat you as if you were my daughter”. When she smiles he takes the conversation no further and she

does not ask anything else and he does not say anything more, to save her unnecessary worry. Is this deceptive?

Case 7. Dr. T has cared for a patient with brain cancer for 2 years and the tumour is coming back now and she is running out of options. She asks Dr. T if there is anything else worth trying. There are two experimental treatments with some international interest about but neither is covered by OHIP and both are exceedingly expensive (over \$1500.00/month). The patient is a woman of very simple means who clearly can't afford this. It's also not clear how well the treatment work to begin with, and there might be some risks associated with it. Therefore, Dr. T decides not to inform the patient about these treatments. Is this deceptive? Please explain why you feel this way.

Case 8. You have a brain tumour which needs to be removed. But you are very nervous and even a bit indecisive about going forward with surgery. You have heard Dr. T is excellent but you wish to have a second opinion. When you suggest this to Dr. T she responds: “No problem, but it'll probably take months to arrange it—other surgeons aren't quite as efficient with their time as I am”. In fact, she knows that if she works hard enough she can get someone to see you quickly. She doesn't do this, however, mainly because she thinks she will do the best job for you. Was her response deceptive? If so, is this deception acceptable? Please explain why you feel this way.

Case 9. You have a benign brain tumour which needs to be removed electively. Dr. T is just about to go away for a month and your surgery will perfectly fill her first operating room day back in a month from now which was until now empty. Nervously you ask: “I'm really anxious. Can't it be done sooner?” Dr. T responds: “It's not growing quickly and I think a month is about perfect timing”. Is this deceptive? Please explain why you feel this way.

Case 10. Do you think it's deceptive for a doctor to withhold a patient's diagnosis of an incurable disease until the patient returns from his daughter's wedding in British Columbia in 2 weeks? Would there ever be a circumstance in which delaying informing the patient of his/her diagnosis is appropriate? Please explain why you feel this way.

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