Narratives of patients with skull base tumours and their family members: Lessons for nursing practice

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Abstract

The meaning of the experience of being told you or a family member have/has a serious brain tumour was revealed during a descriptive research study conducted to determine pre-operative education needs. Eighteen patients and 15 family members participated immediately following the office visit with the neurosurgeon and/or on admission to hospital, for a total of 29 interviews and 13 questionnaires. Twenty-four interviews were conducted with 13 patients and 11 family members in the pre-discharge phase of the research. The key themes of hearing the news, education needs and information needs were identified through content analysis of transcribed interviews and questionnaire data.

Patients and family members portrayed experiences, revealed emotions related to hearing the news, and shared ways of coping. Interviews with patients and their family members that contained clear narratives were identified. From these interviews, three sets of narratives were selected. Each of the narratives was analyzed to determine how the patients and their key family members articulated and made sense of the diagnosis and surgical treatment of a skull base tumour. The themes of a sense of comfort, the known is better than the unknown, waiting for news of the surgical outcome, and quality of recovery emerged from the analysis. Lessons learned about the individuality of patients’ and family members’ needs and approaches to support effective coping were identified.

Introduction

You know it is just an absolutely incredible time of your life.1

The illness experiences of patients with brain tumours and their family members are complex. The diagnostic and treatment phases are known to be times of stress, fear and anxiety (Amato, 1991; Fox, 1998; Newton & Mateo, 1994; Vavaroutsos, undated). Research and case-based knowledge about these experiences, related needs and care are limited (Dupuis, Barnier & Givens, 1996; Leavitt, Lamb & Voss, 1996; Salander, 1996; Salander, Bergenheim, Hamberg & Henriksson, 1999). Leavitt, Lamb & Voss noted that, “Patients with brain tumours and their families comprise a unique diagnostic and treatment group requiring specialized knowledge” (p. 1248). A significant reason for this uniqueness is that the tumour and related treatment affect brain function. For many people, the possible impact on cognitive function is a significant concern.

For one distinct group of brain tumour patients, those with a skull base tumour, there is little literature focused on the patients’ and family members’ psychosocial and education needs during the diagnostic and acute hospital phases of care (Borozny, Gray & Ratel, 1993; Borozny Durity, Wyness,
Durity & Ratel, 2000; Brown, Cowden, Gates, Davis & Richmond, 1986). Anecdotal reports (Sekhar, Goel, & Sen, 1993; Sievers & Borczykowski, 1998) indicate that skull base patients have a poor understanding of the nature of their problem. Undergoing surgery of any kind and severity is known to be stressful (DeBruin, Schaefer, Krohne & Dreyer, 2001; Fortner, 1998; Salmon, 1993) and one research study has shown that diagnosis of a skull base tumour and the related surgical experience generates fear that is pervasive (Borzyn-Durity, Wyness, Durity, & Ratel).

Approaches to care in the peri-operative period are changing. With these changes, nurses are recognizing that the visit to the neurosurgeon’s office is the beginning of the preparation for surgery. It is at this visit that the diagnosis is discussed and a decision to undergo surgery is made (Fortner, 1998). The changes include the use of pre-admission clinics, same-day admission for surgery, earlier discharge and at-home recovery that involves increased responsibilities for families. To date, insufficient understanding about the perspectives, experiences, needs and ways of coping of brain tumour patients and their family members in the context of these changes exists. This understanding is needed as a base for effective nursing care.

To develop nursing and interprofessional practice knowledge further, narratives of selected patients with skull base tumours and their key family members were examined. These narratives were identified in the interview data collected during a broader research study that looked at pre-operative education and information needs. The results of the examination of the narratives are shared in this paper with the aims of generating ideas about ways effective patient- and family-centred nursing care may be designed, encouraging reflection on practice, and considering research questions to be explored in future studies.

**Characteristics of skull base tumours**

Skull base tumours are an assorted group of lesions that, despite their diversity, possess certain similar features (Sekhar, & Schramm, 1987; Sekhar, Goel & Sen, 1993). They share a common anatomical location, either rising at the base of the brain from the bones of the cranial base itself, or from below the cranial base with extension into the cranium through foramina or bone destruction. This location, together with the complexities of the bony anatomy, produces a restricted surgical view which may result in a histologically benign neoplasm being considered malignant. The anatomical location and the complex bony anatomy led to collaboration among surgical specialists to improve access through the development of innovative surgical techniques (Rootman & Durity, 1993). In some complex cases such as a petroclival meningioma, the bone removal may account for half of the sometimes 18-hour or longer surgical procedure.

Skull base tumours are often slowly progressive. Due to cerebral plasticity, they can be of significant size with involvement of cranial nerves and major vessels before obvious symptoms appear. Tumour encroachment on cranial nerves and on major cerebral vessels accounts for pre-existing, pre-operative deficits, the known potential intra-operative complications, and possible post-operative neurovascular and cranial nerve deficits. All of these characteristics contribute to the complexities of peri-operative care.
Overview of the research study
The narratives were identified in the interview data collected during a descriptive research study examining patients’ and family members’ perceptions of their pre-operative education and information needs related to surgery for a skull base tumour. The study was conducted in a major tertiary/quaternary care referral and teaching hospital in British Columbia. Non-probability convenience sampling was used. Eighteen patients and 15 family members participated immediately following the office visit with the neurosurgeon and/or on admission to hospital. Data available for analysis in this first phase of the study included 29 interviews conducted at the time of the office visit and/or on admission to hospital and 13 questionnaires completed by family members at the time of the office visit. Thirteen patients and 11 family members participated in the second phase providing 24 pre-discharge interviews for analysis. Characteristics of the sample are in Tables One and Two. The sample was obtained from the practice of one neurosurgeon.

The themes of education and information needs were evident in the data. The theme of hearing the news was an unanticipated theme that emerged during the data analysis. This theme revealed the meaning of being told you or a family member have/has an extensive brain tumour and that treatment is associated with the potential for major morbidity (Borozny-Durity, Wynn, Durity & Ratel, 2000). All of the participants’ accounts in phase I included statements describing the impact in the data. The theme of hearing the news was an unanticipated theme that emerged during the data analysis. This theme revealed the meaning of being told you or a family member have/has an extensive brain tumour and that treatment is associated with the potential for major morbidity (Borozny-Durity, Wynn, Durity & Ratel, 2000). All of the participants’ accounts in phase I included statements describing the impact of hearing the news. Accounts of 15 (83%) patients and 12 (80%) family members revealed a fear that was pervasive. For three (17%) patients, their statements revealed a resigned acceptance on hearing the news. Recollected fear rather than pervasive fear was apparent in the analysis of the phase II, pre-discharge interviews.

Narratives: A way of understanding
A narrative is a story. It is a way of making sense of an experience and is perceived as an opportunity to tap into individual experiences of illness (McCance, McKenna, & Boore, 2001; McKevitt, 2000). Greenhalgh & Hurwitz (1999) stated that, “Narratives offer a method of addressing existential qualities such as inner hurt, despair, hope, grief and moral pain which frequently accompany, and may even constitute, people’s illnesses” (p. 2). Narratives allow for the construction of meaning, may provide analytical clues and categories, and may generate new hypotheses (Greenhalgh & Hurwitz). Mathieson & Barrie (1998) viewed narratives as components of an ongoing larger narrative that is set in motion when a person becomes ill.

Debate exists in relation to the definition and characteristics of a narrative or story (McCance, McKenna, & Boore, 2001). In this paper, Denzin’s (1989) definition of narrative is used:

A ‘narrative’ is a story that tells a sequence of events that are significant for the narrator and his or her audience. A narrative as a story has a plot, a beginning, a middle, and an end. It has an internal logic that makes sense to the narrator. A narrative relates events in a temporal, causal sequence. Every narrative describes a sequence of events that have happened (p. 37).

Narratives offer a way of uncovering the experiences of patients with skull base tumours and their key family members. They provide a way to explore the nature of a surgical experience that carries with it a major threat to life and the potential for significant disability. Analysis of narratives provides us, as health professionals, with an understanding of ways to improve the care we provide related to the surgical management of skull base tumours.

Narratives in the context of the research study
A narrative methodology was not used in the design of the research study. However, during the process of data analysis it became clear that patients and family members were revealing the meaning of their experiences, particularly those associated with the theme of hearing the news. Mathieson & Barrie (1998) described how they interpreted semi-structured interviews with cancer patients as a narrative process. Their work supports our discovery that narratives were frequently embedded in the interviews.

Interviews with patients and their family members that contained clear narratives were identified from phases I and II. From these interviews, three sets of narratives were selected. One set of narratives was from interviews carried out pre-operatively with a patient and her husband. The second set of narratives was drawn from interviews with a patient and his partner who participated in both phases I and II of the study, providing three patient interviews and two family member interviews for consideration in this set. The third set was from interviews carried out in the pre-discharge phase with a patient and her husband. Characteristics of patient and family member participants are summarized in Tables Three and Four.

Each of the narratives was analyzed to determine how the patients and their key family members articulated and made sense of the experience of the diagnosis and surgical treatment of a skull base tumour. In conducting this analysis, it was recognized that each narrative was constructed by both the participant and the interviewer, and every interview represented “…only a slice of time” (Mathieson & Barrie, 1998, p. 12). The analysis focused on both the particulars of the experience and locating the experience in time, and on identifying themes that cut across the narratives to produce general concepts (McCance, McKenna & Boore, 2001). The process of analysis provided unique insights from which lessons for nursing practice could be derived.

Patient and family member narratives: Set one

Mrs. T.M.: I was very, very upset and shocked and had lots of anxiety – really scared. Because right away you think that it’s…you’re going to die…. 

Mr. J.M.: I’m really scared and worried for her. I have gone off and cried a couple of times by myself but I wanted to do it away from her to try and be strong for her.

2. To ensure confidentiality, the initials of all participants have been changed.
Case data
Mrs. T.M., age 36, and Mr. J.M., age 40 live in a large northern community. They have two daughters ages 16 and 19.

For approximately five years, Mrs. M. had intermittent right-sided headaches that were associated with blurred vision at the peak of the headache. For three years, she complained of night sweats, a propensity to retain water, weight gain, fatigue, breast tenderness and a tendency to feel unwell. Two weeks prior to seeing the neurosurgeon, Mrs. M. changed her family physician at the urging of her husband. When she saw her new physician, her visual fields were tested and a gross bitemporal field defect was noted. On this basis, a CT scan was performed. It demonstrated a 4 cm tuberculum sella menigioma encasing bilaterally the vessels of the anterior circulation and displacement of the optic chiasm and third ventricle (Figure One). Of note, the northern community radiologist, ophthalmologist and family physician interpreted the CT scan as demonstrating a pituitary tumour.

The ophthalmologist who examined her in her hometown reported that:

A long discussion was carried out with Mrs. M. who is understandably still under significant shock because of the diagnosis. She is awaiting… examination and surgery in [city]. Very gently, I tried to tell her that her visual field defect may be permanent (Ophthalmology Referral Note, 1996).

Mr. and Mrs. M. were seen by the neurosurgeon in… [city]. They arrived at the neurosurgeon’s office under the mistaken impression that her tumour would be removed ‘through the nose’ (trans-sphenoidal approach). They were not interviewed at this time because they had a flight booked for immediate return to their hometown. The neurosurgeon noted:

This lady is to have repeat scanning to try and prove whether this is a menigioma or a pituitary adenoma, although I strongly favour the former. The risks of surgery are considerably greater with the former. We will then need possibly pre-op angiography to map out vessels, or a pre-op MRI may solve the issue for us. I have explained to her and her husband the different risks involved with these two differential diagnoses, including the possibility of major disability and visual difficulties if the tuberculum sella menigioma is indeed the diagnosis (Office Record, 1996).

Mrs. M. was admitted for pre-operative angiograms and surgery 10 days after the office visit. The cerebral angiograms showed:

An alarming situation with the internal carotids… being encased completely within the tumour, including the bifurcation of both carotid arteries, all of the anterior

![Figure One: MRI of Mrs. TM demonstrating a 4 cm tuberculum sella menigioma encasing bilaterally the vessels of the anterior circulation.](image)

**Table Three: Characteristics of the three patient participants**

<table>
<thead>
<tr>
<th>Patient Participants</th>
<th>TM</th>
<th>JH</th>
<th>RY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>36</td>
<td>54</td>
<td>41</td>
</tr>
<tr>
<td>Sex</td>
<td>F</td>
<td>M</td>
<td>F</td>
</tr>
<tr>
<td>Highest Education Level Achieved</td>
<td>High School</td>
<td>University</td>
<td>University</td>
</tr>
<tr>
<td>Employment Status Pre-surgery</td>
<td>Full Time</td>
<td>Sick Leave – self employed</td>
<td>Full Time</td>
</tr>
</tbody>
</table>

**Table Four: Characteristics of the three family member participants**

<table>
<thead>
<tr>
<th>Family Member Participants</th>
<th>JM</th>
<th>SV</th>
<th>CY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>40</td>
<td>Not given</td>
<td>47</td>
</tr>
<tr>
<td>Sex</td>
<td>M</td>
<td>F</td>
<td>M</td>
</tr>
<tr>
<td>Highest Education Level Achieved</td>
<td>Vocational/Technical</td>
<td>College</td>
<td>University</td>
</tr>
<tr>
<td>Employment Status Pre-surgery</td>
<td>Full Time</td>
<td>Full Time – self employed</td>
<td>Full Time</td>
</tr>
<tr>
<td>Relationship to Patient</td>
<td>Husband</td>
<td>Fiancée/common-law</td>
<td>Husband</td>
</tr>
</tbody>
</table>
In summary, throughout this narrative, Mrs. M. expresses openly the overwhelming fear she has lived with since she learned that she had a serious brain tumour. Her anxiety and ambivalence about knowing about her tumour and surgery are threads interwoven throughout the narrative. She conveys a sense of searching for comfort as a way to cope with her overwhelming anxiety. In relation to knowledge, she communicates her uncertainty about whether or not the known is better than the unknown and recognizes that for her, fear blocks her ability to learn.

Pre-operative hospital narrative: Mrs. M.

The narrative that unfolded in the interview with Mrs. M. revealed her feelings about hearing the news that she had a serious brain tumour, her knowledge about the tumour and surgery, and her concerns. She seemed to have a great need to share how frightened she was and to be reassured. Mrs. M. began by recounting her sense of unreality when she saw the tumour on CT scan during the office visit.

When we had the appointment with Dr. D., he showed us this shadow where he thought [it] didn’t look like it was the pituitary, but showed the tumour. But I was saying to myself that it can’t be true, I’m not sick like I should be you know. It’s not fair. ...I thought with the tumour like that you have to be sick.

Mrs. M. conveyed how difficult it had been for her to hear the news from the neurosurgeon and how fearful she was.

When Dr. D. called me that same night after the MRI, I had to get my husband to talk to him because I just heard I had more bad news and that was it. I was just out of it - really scared.

She was very worried about the seriousness of her surgery and she sought verification that her life was not at risk.

...I’m really scared, because I don’t know what’s going to happen. I know I’m in good hands but I’m really having a hard time coping with this.

Her confidence in the neurosurgeon helped her to cope.

Every place that I’ve been in the hospital, my MRI and my CT scan, they’ve asked me who my doctor was - Dr. D. - everybody has said you are in the best hands, don’t worry.... like just people talking know his name, even in [hometown], so it’s really helped me try to be positive.

She recognized that her fear had made it difficult for her to understand and remember what she was told about her tumour and surgery. She shared her sense that having things explained to her in person was the best way for her to learn and to feel reassured. Her ambivalence about whether or not she wanted knowledge about her surgery was evident. When asked what she understood about the surgery she stated:

I don’t know. I was thinking is it best that I don’t know what they’re doing, do I just wait until after they’re finished? Then I don’t have to worry about what - you know. Or should I know what they’re going to do? I’m not sure.

In summary, throughout this narrative, Mrs. M. expresses openly the overwhelming fear she has lived with since she learned that she had a serious brain tumour. Her anxiety and ambivalence about knowing about her tumour and surgery are threads interwoven throughout the narrative. She conveys a sense of searching for comfort as a way to cope with her overwhelming anxiety. In relation to knowledge, she communicates her uncertainty about whether or not the known is better than the unknown and recognizes that for her, fear blocks her ability to learn.

Pre-operative hospital narrative: Mr. M.

Essentially, Mr. M.’s narrative unfolded in the same way as his wife’s narrative. He clearly understood how fearful she was about the surgery and possible outcomes. Mr. M. was not present for the visit with the physician in their hometown because Mrs. M. preferred to go alone to the appointment. In talking about this visit, he showed his understanding of the effect it had on his wife.

I didn’t know how bad it was going to be and she said she wanted to go by herself. So I didn’t push the issue with her, but I wish I would have been there for her, because it was pretty traumatic.

Mr. M. clearly recognized the impact hearing from Dr. D. about the seriousness of the tumour had on his wife.

When she saw Dr. D., he did some other tests, they found out it was much worse. Then she went back into a trauma situation.

Prior to the visit with Dr. D., Mr. M. sought knowledge from an ‘old, big, thick medical book in the house’ and used it, along with humour, to help her cope with her anxiety. On their return home after the visit, he sought and received support and knowledge by talking with others. While this approach helped him to cope with his fear, it is not clear that it helped his wife.

A fellow that I worked with... - his girl friend had the exact same operation, different type of tumour, a few years ago, done by Dr. D. So we went out and had dinner with them and she explained it all to us and - showed pictures of her with staples in her head. Kind of scared her [Mrs. M]. I have talked to so many different people who know about it now - I don’t know, maybe it’s my way of dealing with it - telling people that we have this problem..... ...it’s been so good for us, being able to talk about it.

Mr. M. shared his knowledge about the tumour and surgery. He was able to learn in spite of his fear. His wife, who heard the same information, was not. His account also demonstrated that he heard a positive message from Dr. D.

From what I remember he told me was that it was a meningioma, that it was much worse and it was at an angle with three main arteries coming to the front of her brain, that it was going to be a very risky operation, that he didn’t think he was going to be able to get all of the tumour out, but he was going to go in there with the aspect of getting as much as he can, and before - at the point in time that he figures it’s going to be too dangerous, he will back out and treat the rest with radiation. But he feels very, very positive about it and we just have to hope for the best.
Confidence in the neurosurgeon was a thread throughout the narrative and, like his wife, this sense of confidence reassured Mr. M.

Everybody's given us such positive feedback about it that I feel comfortable having Dr. D. do it. I’ve been told by so many different people how good a person we have to do it.

Dr. D.’s a very comfortable person to talk to. He came across that he really knew what he was talking about. He explained everything....

Mr. M. was fascinated with surgery. This fascination may have helped him to cope and to learn.

If I could be allowed I would be in there watching - I’m just fascinated. I watch every operating show that I can watch on TV.

In discussing the risks associated with surgery, Mr. M. revealed his own ambivalence about knowing the risks as they related to his feelings and ability to support his wife. When asked how he would like to receive information about risks, Mr. M. stated his preference for one-on-one communication.

I think he said something about that if he was to cut or damage one of the arteries, that there could be brain damage.... Other than that, you’re going into the brain, I know it’s a very, very risky thing.

Mr. M. shared his knowledge about the plans for her care in the immediate post-operative period and his fears about his wife’s recovery.

I understand she’s going to be in [neurosciences] intensive care for two days, or even three days, depending on how she comes out of it - as far as I know nothing else of how she’s going to be looked after, after that.

I know that Dr. D. said that depending on how much he moves her brain, is going to depend on how much and how long she’s disoriented. I have this thing that I’ve thought about that she’s not going to know who we are for a length of time, how bad is this disorientation going to be, that’s something that I’m wondering about.

How long is the recovery going to be - what steps does she have to do.... What’s she going to be doing for recovery, once she gets home - the different things that I should have to watch out for.

In summary, Mr. M.’s narrative demonstrates his concern for his wife, his ability to learn from the explanations they both heard about the tumour and surgery, his ways of coping, and his perception of his role as a support for his wife. Mr. M.

| Table Five: Summary of the case data of the three patient participants |
|---------------------------------|-----------------|---------------|-----------------|
| **Case Data of Patient Participants** | **TM** | **JH** | **RY** |
| **Initial Complaint** | Intermittent right sided headaches x 5 years Night Sweats x3 years | Vertigo & nausea x 1 year Right suboccipital neck pain Difficulty swallowing liquids | Severe Headaches |
| **Time to Diagnosis** | 3-5 years | 1 year | Days |
| **Pre-op Status** | Gross bitemporal field defect with potential to develop sliding visual fields* Near vision 20/30 bilaterally Far vision 20/40 Right; 20/20 Left Rest of neurological exam entirely within normal limits | Impaired left corneal reflex Decreased sensation in the ophthalmic division of cranial nerve V Single episode of double vision | Entireneurological exam within normal limits Visual acuity 20/20 bilaterally |
| **Neoplasm** | Tuberculum sella meningioma - 4 cm | Trigeminal neurinoma - 4.2 cm x 3.5 cm x 3.8 cm | Clinoid meningioma - 3 cm |
| **Surgical Approach** | Bifrontal craniotomy and right sided orbitotomy | Stage 1 - left supra and infratentorial approach and posterior petrosectomy | Right pterional craniotomy and frontotemporal approach |
| **Surgical Time** | 17 hours 35 minutes | 16 hours 30 minutes | 8 hours 45 minutes |

* A sliding visual field means she can see the right visual field with her left eye and the left visual field with her right eye. When she reads and tracks, she is effectively shifting fixation, which is quite confusing.
shares his feelings of being scared, but balanced with those feelings is his resolve to be strong for his wife. Overall, he conveys a sense of comfort and that, for him, the known is better than the unknown.

**Surgical procedure**

A bifrontal craniotomy and right-sided orbitotomy and microsurgical removal of meningioma was performed. Surgery began at 0730 hours and finished at 0105 hours the next day – some 17 hours and 35 minutes (Table Five). With the operating microscope, the first order of the day was to dissect out the olfactory bulbs so as to try to preserve them… hopefully by this manoeuvre to save some sense of smell for the patient. The optic nerve, optic chiasm, carotid arteries could not be seen… “then it became a frightening experience to see a very thinned out, markedly laterally bald optic nerve strapped intimately onto the side of the tumour” (Operative Report, 1996).

**Patient and family**

**member narratives: Set two**

**Mr. J.H.:** Having my head open is not something I [look forward to]. I don’t know how I’ll feel afterward… Any permanent damage would be terrible

**Ms. S.V.:** When I heard “brain tumour” the first time, I don’t think anybody could have said anything more frightening… You don’t know how to handle it, you have no experience with it whatsoever and yet there are so many people that do experience things like this… You feel you have to be strong.

**Case data**

Mr. H. is a 54-year-old Italian male who is separated from his wife and lives with his significant other, Ms. V., in her urban townhome. Mr. H. and Ms. V. each have two adult children. Mr. H. is self-employed and on a sick leave. His impending divorce and inability to work have created major financial stress. Ms. V., who did not provide her age, is also self-employed and is working full-time. She listed her relationship as that of fiancée/common-law.

Approximately one year prior to seeing the neurosurgeon, Mr. H. noted a sudden onset of vertigo and accompanying nausea. He subsequently had three chiropractic manipulations for persisting, motion-induced vertigo. He also developed persistent, vague right suboccipital neck pain, and some difficulty swallowing liquids. Examination revealed bilateral optic disc blurring, diminished left corneal reflex, decreased sensation in the left ophthalmic distribution of the trigeminal nerve, and palate deviation to the left. He had some difficulty with tandem gait and he had slight drifting with rapid turns. He reported a sense of numbness in his left cheek and chin and a single isolated episode of double vision (Office Record, 1998).

His MRI scan (Figure Two) showed a ‘voluminous’ 4.2 cm x 3.5 cm x 3.8 cm trigeminal neurinoma that would require a planned two-staged removal. Distortion of the carotid artery and brain stem, along with obstructive hydrocephalus were noted (Office record, 1998).

**Pre-operative narratives: Mr. H.**

Mr. H. was interviewed immediately following the office visit with the neurosurgeon and at home two days prior to admission (pre-operative hospital narrative) as he was to be admitted the day of his surgery. Though in both of these narratives Mr. H comes across as ‘matter-of-fact’, underlying concerns are evident.

**Office visit narrative**

Mr. H. began by relating the process of the discovery of the tumour. He conveyed his understanding of the tumour.

It’s something that has been there for awhile. We don’t know what’s causing it. You know, the size of it… really got me.

The way Dr. D. explained it is that it’s amazing how the brain adjusts itself around the growth. It moved over ‘til it couldn’t go any farther… the symptoms I’m having from it, considering how big it is, they’re not really bad. I think they could be much worse.

In relation to his surgery he said:

I asked him specifically where the incision will be because that is very important. … so yes, there is nothing I can do, that’s the incision they have to make. … … some of the parts of the bone have to be removed and he says he’ll put most of it back, … that’s freaking me out a bit, I’m having trouble with bone removal.

Mr. H. articulated clearly problems he understood might result from the surgery.

Well, the only thing that I probably am concerned about is that they cut up some nerves responsible for hearing and the facial movements and so forth… and the blood loss, also because I don’t really want to take too much of the blood supply. … Dr. D. wasn’t too concerned about it [the blood loss], he didn’t think that maybe we would have to replace it.
Mr. H. shared the fact that talking to others, including a nurse who cared for him at another hospital and who had a brain tumour removed, helped him to cope. This statement was the only one during the interview where he referred to his fear and it was indirect.

[People]...are trying to be helpful in a certain way and try to calm me down. [They] say this is happening very often, you know.

When asked by the interviewer if there was anything particular about his stay in hospital that he would like to know about, Mr. H. talked at some length about a previous experience when he was in the same room as a person with a stroke who was incontinent and unable to care for himself. He expressed his concern that on this hospitalization he would experience a roommate with similar problems and said he would not be able to handle it. In this part of the narrative, he may have been indirectly expressing the concern he had about his potential incapacity after surgery, given that the risk of a stroke had been explained to him.

Stinky diapers on a 68-year-old man. ...It could happen to me, right?

Pre-operative hospital narrative
At the beginning of this narrative, Mr. H. shared his understanding of the reason for his referral to Dr. D. and described his symptoms with prompting from the interviewer. He then moved on to describe his understanding of his tumour and surgery. In this narrative, his description of the tumour was more precise, possibly reflecting the education he had received during his visit with the clinical nurse specialist in the pre-admission clinic.

My tumour is benign and very slow-growing....it's been there for a long, long time and it's grown like that. It's the size of a golf ball and it's located deep inside the skull, I guess.

It's possible it's going to be two interventions to get it. The second intervention will get it. ...they're going to cut some bones and he's going to try to [put] everything back, or as much as he can....[He] plans to remove the growth and I don't know how hard a time he is going to have trying to do that.

He described his need for education about the tumour and surgery as follows:

I just need general information about what it is. You know, I don't like to get too deep into it.

He talked about risks, when prompted to do so by the interviewer.

...the surgeon and the other doctors, they have to tell you the worst scenario just in case something happens, that maybe is a little bit that I don't want to know...I don't mind for them to tell me what could happen, but ...a stroke, it's pretty serious.

Mr. H. shared his concerns about the surgery and the outcome. He was clearly concerned about being incapacitated and asked specific questions about bowel and bladder function post-operatively.

[I am concerned about] the way I am going to feel with a big cut like that on my head. ...I don't know how I'll feel afterwards...because now I am in one piece. After it is going to be like open and sewed up.

The hearing will be left on one side and swallowing does not concern me...the most important is the basic things in life, like being able to walk...be able to go to the bathroom and having no pain. I don't know, there will be some pain.

Mr. H. described what he saw as his role at this time and in doing so, conveyed a sense of how anxious he actually was about the surgery and outcome.

I'm trying to do my job. That is, my job is to completely relax so that I present my body to someone who's going to work on it in – not in a worried way. In a relaxed manner. That's all I can do...be there and be relaxed about it and let people go there and look.

In summary, Mr. H.'s narrative in the pre-operative hospital interview is richer in terms of expression of fears, emotion and knowledge than the narrative in the office visit interview. In both narratives, he expresses concerns about the outcomes of the surgery, particularly related to deficits he may experience. It is difficult to determine the sense of comfort Mr. H. has at the time of either interview. While his expression of his fears and anxieties is not overt, there is an underlying thread of worry. Mr. H. appears to think that the unknown is better than the known in terms of knowledge about the tumour, surgery and related risks.

The clinical nurse specialist recorded in her pre-admission clinic consultation notes (1998) that, “Throughout our meeting, both Mr. H. and Ms. V. were tear-y-eyed. Mr. H. put on his sunglasses halfway through the meeting.” This observation provides an insight into the feelings both Mr. H. and his partner were coping with in the period prior to admission for surgery.

Pre-operative hospital narrative: Ms. V.
Ms. V.'s interview prior to Mr. H.'s surgery contained a vivid, lengthy narrative. The interviewer responded to the concerns and expression of needs for knowledge conveyed by Ms. V. by providing reassurance and teaching throughout the narrative. In the narrative, Ms. V. demonstrated knowledge about the type and location of the tumour, but this topic was not a focus.

Ms. V. described the fear that she had when she heard the news about the tumour and surgery and the importance of hope. She conveyed how anxious they both were.

I think that the brain tumour is perhaps one of the biggest shocks. I would say beyond that is of course the cancer. Everybody is terrified of the cancer word. Right?

I don't want to kind of imagine him a vegetable and I don't want to imagine him dead. I don't want to imagine...
the funeral before that would even happen... Because you have to hold onto hope, and the minute you let go of that, the hope is gone. It's like you just - you crash. It's just like a horrible, horrible cloud that kind of enters your body.... So as bad as this tumour is, it's the hope that's holding us together.

Ms. V. searched for comfort as she conveyed her concerns about the risks of surgery and the related outcomes to the interviewer.

If everything goes absolutely perfect, okay? There's no complications, no strokes, I think that is the biggest one, right, is the stroke? If there is no stroke and everything is perfect, would you say he would be pretty good in two months? Four months? Six months?

Ms. V. wanted to hope that the tumour could be removed in one operation, but realized that this hope was not realistic.

Well, I asked the question, is it possible that when they go in, can he just get all the tumour in one.... If we're in there 16 hours, can't he just take it so we don't have to go in there the second time? Dr. D. did say that the second operation would not be as risky or as long as the first one. So there's comfort in that. But naturally, I would rather have the one operation. Have it over with. Because I mean, hey, one brain operation is pretty big stuff. When we talk about two, that gets to be, you know, major league.

Ms. V. anticipated the difficulty she would have waiting for news of the surgical outcome.

You know, and I think the big question still in my mind, is how am I going to deal with that day of surgery? That has just got to be like a really big one in my mind. Like I can't work, I can't do this, I can't do that. You know. And I don't want to sit and cry and I want to be strong for him when I get there and I just feel like I'm going to be exhausted before they let me see him. So, but I guess everybody thinks the same.

Ms. V. perceived that she would have the support of her family, but also felt that she had a responsibility to provide support.

Ms. V. had concerns about Mr. H.'s recovery and the care he might need at home, though she tried not to anticipate in this regard.

I think about when he comes home, how the care will be. And if I'm going to be able to handle it and I keep saying, well, that depends what kind of condition he's in. .... So there's no sense in me trying to worry about what's happening because I don't know. It's premature.

Like Mr. H., Ms. V. shared the fact that talking to others who have had successful brain tumour surgery was helpful. However, though she knew there were people she could talk to for support, she had reservations.

The most important information that I could have ever had is that there are successful brain tumour operations here.

I haven't accessed it [the support of talking with others] because they had different situations and every situation is going to be different and again, I think I want to handle these problems as we have them ... rather than dealing with everyone else.

Ms. V. indicated that she derived some comfort and confidence from her interactions with the neurosurgeon and with others.

He was very specific. And I got to tell you he was great. Very professional and you know. I think Dr. D. has a bedside manner that does help.

...one of the best things that made me feel better, [is that] ...every doctor we went to, Dr. M., the ear doctor, the hearing centre, our own GP, [said], if it were their head, they'd sure want Dr. D. doing that operation. So a tremendous compliment to him.... and his incredible amount of ability. So that makes us feel, I think, more confident going in there Thursday because of him.

At the end of the narrative, after revealing her fears and need for hope and comfort, Ms. V. seemed to further reveal her search for ways to cope with this very frightening experience by concluding:

There's a lot of growth in this. Tremendous amount of growth in this.

In summary, Ms. V. clearly articulates her fears for herself and her partner and her search for comfort and hope. She does not focus on specific areas of knowledge about the tumour and surgery. Either these education needs have been met for her to the extent that she wishes, or she prefers not to know. She anticipates the difficulties she will have waiting while her partner is in surgery and is most worried about the outcome.

Surgical procedure

The craniotomy involved a left supratentorial and infratentorial approach and posterior petrosectomy with removal of the posterior fossa tumour components (Table Five). Surgery started at 0745 hours and finished at 0115 hours the next morning for a total of 16.5 hours. On opening, the brain was extremely tight, 15 cc of cerebral spinal fluid was drained and the brain slackened... “we were afraid to drain too much with an intact dura for fear of producing herniation... it [tumour] obviously arose from the fifth nerve, underlay the seventh and eighth nerve, extended down to kiss the lower cranial nerves nine, ten and eleven, and extended up to the fourth cranial nerve... the brain stem had to be extensively dissected... the basilar artery was dissected off... as well as the anterior inferior cerebellar artery and the sixth nerve” (Operative Report, 1998).

Mr. H. experienced a stormy post-operative course. Immediately post-operatively, he had unexpected airway compromise due to massive facial and neck swelling. Prolonged intra-operative positioning and a possible drug reaction in the presence of a short, stocky neck were thought to be the underlying causes. He was in intensive care for three weeks and in hospital a total of four weeks.
Discharge narrative: Mr. H.
Mr. H. was interviewed at home one day after discharge. His post-operative narrative is short and the content is limited with few details offered. As his surgery involved an infratemporal component on the dominant hemisphere, he did sustain the related post-operative recent memory deficits. Hence, his narrative reflects these deficits and his still early stage of recovery. His statement to the interviewer illustrated his insight into his difficulties:

I don’t think I am telling you things like I used to tell them.

Mr. H.’s key question was:

What’s happening to me? Will I be able to be the person I was?

He talked about his family and their support:

My family is encouraging me. Because when I say, oh my God, look what happened, they say, well listen, you could have died. My family knows very well ...my surgery and the way it has been.

In relation to knowledge, he shared his perception that he was given ‘lots of information’ before surgery and he was satisfied with this information. He recalled being told that one risk of surgery was a stroke, perhaps indicating the significance this risk had for him.

I knew there was going to be complications after surgery. I knew that I could have one of those things, you know, when you get paralyzed half way.

He denied that anxiety influenced his ability to remember what he was told in the pre-operative period. It is likely that he was unable to remember his anxiety pre-operatively, either for psychological or cognitive reasons. Of interest was his perception that it would be helpful for others having brain tumour surgery to talk to someone who has deficits as a result of surgery. However, he also wondered if it would make them worry.

I mean it would be good for someone who is going to have my surgery to look at me now and talk to me. See the way I can’t walk. ...but I don’t know if you are going to make them worry.

Discharge narrative: Ms. V.
Ms. V. was also interviewed at home one day after Mr. H.’s discharge. She came to the discharge interview with many worries. Her lengthy narrative indicated that she experienced anxiety and fear throughout the immediate pre-operative period, the intra-operative period and post-operatively up to the time of discharge. Concurrently, she was living with considerable stress related to their financial problems.

In relation to his admission for surgery, she said:

It was the most frightening experience in the world. ...I don’t know and I thought about this after, how could this hospital make this any easier on you? I don’t know that they can. That wait is like sitting on death row. ...when you’re facing something like open heart surgery or brain surgery like this.... it wasn’t humane enough. It was very cold and clinical. Walk into this room, put on your gown. Sit on this table and wait here. Everybody’s laying in there waiting for their surgeon and their surgery. Okay? My daughter, who was 22, after we walked out, she said, mom, I felt I just walked out of the morgue. ...you’re by yourself, he panicked at that point, and he hadn’t up until then. That’s when he panicked.

The waiting time when Mr. H. was in surgery was a difficult time for Ms. V. and the family. She opted to wait at home during his surgery.

I left him there at 7:30 in the morning. ...I watched every hour go by so slowly and at 7:30 that night I realized it was 12 hours. The doctor called me at 1:30 in the morning.

If you are at home with your family [the waiting] is a little easier. I worked, I scrubbed, did anything to keep busy....

Tell people that it could be [longer than it is] so that you don’t sit there and wait to the minute, because now you are terrified. You are terrified.

Ms. V. shared her feelings of being terrified once he was out of surgery and in the recovery room and her perception that if she had answers to her questions, she would have been less terrified. In fact, it is likely no one could provide her with the answers she sought at that time.

When he comes out of that surgery, you are scared. As a family, you’re terrified. Right? What’s next? What’s he going to be? They said well he has some droop in his face on the left side. It looks like he has some weakness on his left side. Well, I wanted to look into something here and do my part, you know. Yeah, if you could find some intelligent information, you’re not as terrified.

You don’t know what to expect.... How do you prepare somebody for that? I can understand someone not wanting to tell you what it is going to feel like when you walk through that critical care unit. But actually you need information.

At the time of the interview, four weeks after surgery, Ms. V. was searching for answers about her partner’s recovery and having difficulty coping with her uncertainty about it.

I’m still looking at him and saying, I don’t know. Is he going to get better? Like I don’t know next week if he’s going to be stronger. I don’t know when I’m going to get my man back, because that isn’t my man.

I still don’t know what went wrong.... I don’t know why he was so critical for so long.

Ms. V. related her concerns about the second phase of the surgery:

...he is not at this point strong enough for another surgery of this magnitude.... So with all my heart, this second surgery is not very appealing to either of us. Now if it’s a difference between life and death, there is not a choice. I want to know more about other alternatives.
It could change his quality of life so drastically that there is no quality left.

Throughout the narrative, she articulated her need to actively do something to promote his recovery and her continuous search for answers to her questions about what she could do. She also shared her fears about the extent of his recovery and the responsibilities she would have to assume during his recovery.

When they told me...that he may never swallow again, I just about fell over.....I have to know, what can you do for this, besides praying, what else can you do?

Now he can see, if he closes one eye he can see. Together he sees double....I want to know if that’s going to get better or is there an operation that can make it better.

His memory, holy shabummers! He knows the name of his daughter but the name won’t come out. ....I’m reading that that is a normal thing. ....I didn’t know that before.

I have so many questions it is unbelievable. ....Am I doing the right thing for him? I don’t know. I’m not a nurse by trade so this is really, really scary.....I’d like to know, does time really heal this....?

At this time, one of her major expressed needs was for information about home care.

I would love to know what kind of home care I should be giving him. What am I doing wrong? I’m scared, you know.

Ms. V. undoubtedly needed reassurance and support at this time as she reflected on the ‘roller coaster’ of the last four weeks and looked ahead to the care he would require at home. She said:

I’m together.... There were times when I wasn’t. ....I really felt apart about two weeks ago and you find yourself very alone with it.

I’m still numb, raw and frazzled....I’m still in shock. ....I feel like I have a shield in front of me, you can’t hurt me anymore.

She shared in her narrative her sense that ‘a little compassion goes a long way’ and that it was important she had confidence in the nurses who were caring for her loved one: ‘you want to know that when you leave him that he’s being properly cared for.’

In summary, Ms. V’s narrative post-operatively is multifaceted and detailed. She communicates her fears and search for comfort throughout. The experiences during his difficult post-operative recovery have been exceedingly challenging for her. She is focused on the present situation and the future. Therefore, her narrative contains limited information about her perception of her education and information needs pre-operatively and how effectively they were met. Possibly because of the complications her partner experienced, she identifies complications as the main area where more information pre-operatively would have been helpful. She does acknowledge that stress has made it difficult for her to understand explanations given to her by members of the health care team. Ms. V.’s difficulty remembering what she was told pre-operatively about possible complications influences her perception about her education needs. The interaction between the interviewer and Ms. V. throughout the narrative demonstrates the reassurance that Ms. V. sought and received. Telling her story appears to have been therapeutic for Ms. V.

Patient and family member narratives: Set three

Mrs. Y.: The whole thing was pretty shocking.... It’s other-worldly, it really is. ....It’s not a good day when you have to go in to see a brain surgeon, you know.

Mr. Y.: I think to take the patient and family ...through everything that’s going to happen...is very important. So there is no mystery to it. There is probably more anxiety from the unknown than the known.

Case data

Mrs. Y., age 41, and her husband Mr. Y., age 47, live in a large city. They have a son, age six. Both of them are university-educated professionals who work full-time.

Approximately two months prior to seeing the neurosurgeon, Mrs. Y. was hospitalized for a very virulent pneumonia. During this hospitalization she was having severe headaches. A CT scan and MRI revealed a 3 cm clinoidal meningioma encasing the right carotid artery and abutting the right optic

Figure Three: MRI of Mrs. RY demonstrating a 3 cm clinoidal meningioma encasing the right carotid artery and abutting the right optic nerve.
nerve (Figure Three). On examination, her entire neurological exam was within normal limits, including visual acuity.

At the time of the initial office visit, the neurosurgeon noted that: “She was understandably anxious about the interview... She has asked troubling questions about the risks to her higher cortical functions, which of course exist since this is done through a frontotemporal approach” (Office Record, 1998).

Mrs. Y. requested a second office visit prior to deciding to proceed with surgery. After the second office visit, the neurosurgeon recorded the following note:

...this patient and her husband returned for an office visit with a compilation of a variety of questions they needed answered. I have indicated to them that there is no guarantee with this surgery of anything: she could lose her life, can be rendered blind, hemiplegic, and could have significant cognitive problems. I have indicated that I will be careful and hope that these things will not occur, but there can be no guarantees. They also understand that the tumour encases her major vessels, and probably does either encase or severely contact the right optic nerve so that visual failure is a distinct risk (Office Record, 1998).

**Surgical procedure**

Surgery was a right pterional craniotomy that involved a frontotemporal approach to the right anterior clinoid meningioma. At the surgery, the right optic nerve could be seen 'kissing the tumour'. There was gross total removal of the tumour with salvage of the right optic nerve and the right carotid artery. The surgery lasted 8.75 hours. (Table Five)

**Discharge narrative: Mrs. Y.**

Mrs. Y. had an uneventful surgical recovery and was discharged her fourth post-operative day. In her narrative, Mrs. Y. described with eloquence and in detail her experiences from the time of her first visit to the neurosurgeon until the post-operative interview a day prior to her discharge. For her, the process of booking the angiogram appointment and going for this procedure brought home to her the seriousness of what was happening.

> I went to see Dr. D. ...to discuss this situation and that’s when he told me it would have to come out. That was a Monday and I went back to my office and it wasn’t until Thursday morning when a lady called [about]...the angiogram and said there was a cancellation and could I come the next day. It wasn’t really until then that the full effect of what was happening really came to me. ...You know, suddenly you realize that you...have to rearrange your life.

Mrs. Y. took a leave from work as a way of coping with her anxiety while waiting for the surgery and used this time to prepare herself.

> I just - I thought, I can’t do this. I can’t cope with it. ...You can’t really handle working and it was a good thing, too, because it meant that I had much less stress and I started exercising more so I went into surgery being more rested.

While Mrs. Y. found that it helped when she had a date for her surgery, she still found waiting for surgery difficult.

> ...it was hard waiting for it, really. Having it hanging over.

> I mean it wasn’t - it wasn’t terrible, but it’s a funny state of mind to be in, waiting for brain surgery.

As Mrs. Y. narrated her experiences, it was evident that she actively sought knowledge during the diagnostic and pre-operative preparation phases of her care. For her, this process of seeking knowledge was comforting.

> My information did come from Dr. D., from the clinical nurse specialist and from our friend who I had a long talk with. And I didn’t feel the need to then go further. I had an initial interview with Dr. D. I wanted to meet him again, we were going to be sort of dealing with him on such an intimate level.

> I am glad to have gone in and seen him again. And it was comforting because he said a couple of things then. One of them was, you know, I thought I’d be on my back again ...I was in bed for a month this past summer which is very hard on my son. He really was affected by that and I was concerned about that and Dr. D. sort of laid that fear to rest and he also said I’m not going to have to shave your head which has got to be the least of the problems but, you know...it’s one less thing to fear, looking like a freak in front of a little child, you know, so it was quite a comforting interview.

> ...when I met [the clinical nurse specialist], she had a skull and a photograph from a book. I found that very useful, too, because I could actually sit and look right over it and... she’s very good at explaining things, too.

Mrs. Y. described the fact that a frank and full discussion of the risks associated with surgery helped her to cope.

> He told me there was a risk of stroke. He told me that... there was a risk to the optic nerve and he didn’t dwell on risks, but I asked quite a bit more. I think he was concerned about worrying me. My husband didn’t really want me to ask a lot about it, but I wanted to know. And so he did go over risks. I think he went over it pretty fully.

Mrs. Y. expressed her concerns about surgery and the concern about her ability to ‘get mentally back on top of things’. She continued to have this concern post-operatively.

> Whether it was malignant or not, that was the big thing. And whether it had to be removed or not. Because we have a friend who has a meningioma and he had been told that it didn’t have to be removed. Does it have to come out or not? And then, I guess finally, the third area of real concern was what are the implications of it for cognitive functioning for me because I need the ability to analyze and remember like a lot of people do in their work. And it is a real concern to me that I’m going to be able to function at the same cognitive level as I was before.
She described her confidence in Dr. D. and shared her feeling that this confidence promoted comfort and trust that helped her to cope with her fear pre-operatively.

I didn’t have any second thoughts about him because we had had so much feedback from so many different sources that he was just the best in the country and internationally known and that, I mean nothing but just superb recommendations, so I - it wasn’t I felt that I had to confirm my trust in him, I didn’t.

...all along he said ‘but I am optimistic’. He was very encouraging. Reinforced what he said.

Mrs. Y. also found the specific teaching she received from health team members during her pre-admission clinic visit helpful. The fact that what she was told at this time happened post-operatively promoted her confidence in the care she was receiving.

...that was another very useful piece of information that the nurse and anaesthetist went over ...all the various lines I would have so that was very handy ...and I told my husband so he knew what to expect and we also had an idea because we wanted to sort of try to assess how early we could get my son in to see me. ...I knew that I’d have all the lines that I had, and I had them, too. So what I was told was borne out.

She shared her perspective about whether or not it would be helpful for patients and family members to talk with others who had similar surgery in the pre-operative period. Her preference was for information from experts.

You know, it’s hard to say, really because people do offer, you know, when they found out what I had, people tend to offer a lot of... anecdotes ...I think there’s a little bit of danger in, you know, drawing from someone else’s experience when I’m not going to appreciate the medical differences between their situation and mine.

Post-operatively, Mrs. Y. found the transition to the ward from the neurosciences intensive care unit went well. She stated that she received support from all health professionals who cared for her and from her family and friends. However, as would be expected, she did have concerns about her recovery and shared these as follows:

What am I going to be like in six months? Am I going to be basically the same person mentally and personality? I don’t mind if I change for the better personality-wise.

I’m discombobulated because I’ve got this swollen eye so I’m not seeing right. And although it is resolving every day a little bit. It’s just a bit too soon. I feel a bit fragile and tired. [but] it’s not as if I have great fears at the moment.

In summary, Mrs. Y.’s narrative is an articulate description of her pre-operative and post-operative experiences. It is important to remember that this narrative occurs just prior to her discharge when she knows that the surgery has not resulted in any deficits and that her recovery is proceeding very well. Mrs. Y. shares freely her pre-operative fears and anxieties and the ways she coped with these feelings by seeking specific knowledge about the tumour, the surgery and associated risks, and the plans for her care. Because her questions were dealt with thoughtfully and in detail by all of the health professionals involved in her care, she gained a sense of comfort that helped her to cope.

Discharge narrative: Mr. Y.

Like his wife, Mr. Y. was very articulate about his experiences throughout the phases of his wife’s care. His narrative supported a number of the points his wife made in her narrative, indicating that they had shared the experiences and communicated openly. Mr. Y. described concerns related to the time his wife was in the operating room and about her recovery that were unique to him as a family member.

Mr. Y. described the process of the discovery of the tumour and events prior to the office visit with the neurosurgeon clearly.

...this was discovered when [my wife] was in the hospital for pneumonia last summer and they did a CT scan, almost serendipitously because she’d been getting such bad headaches with the pneumonia, and so we’d been told in the course of that process what a meningioma was. It had been with the CT scan a potential for some sort of aneurysm and so we were on tenterhooks for about eight hours while the x-rays were shipped over to Dr. D. who decided, just from having seen the CT scan, that it was a meningioma.... We didn’t have to do a quick move from [one hospital to over here] to do an emergency craniotomy for aneurysm. So through that process of having dealt with Dr. B., the internist, and the GP and having been told by the internist that Dr. D. had made an assessment and [it was] related to us that it was a complex meningioma because of the vascularization, we had a pretty good idea and then we met with Dr. D. who gave us far more information.

Mr. Y. was satisfied with the knowledge he and his wife gained during the initial visit with the neurosurgeon. He conveyed his understanding of his wife’s need for further knowledge.

My wife had a need for more information. ...she requested a second meeting and had a list of questions which were based on things that her medical friends had told her which I thought were a little over the top. And from his response, so did Dr. D.

I felt that she felt that it was important for her to be as inquisitive as she could be about it. I didn’t need any more information.

His narrative demonstrates that he was very well-informed about the tumour, the planned surgery and associated risks, and the results of diagnostic procedures as is illustrated by his explanation about the complexities of the surgery.

Dr. D. had explained to us prior to [the angiogram] that one of the difficulties of the...tumour that [my wife] had was that the tumour in that area was often well vascularized and that it was getting through the
capillaries and the blood vessels that would cause the most difficulty because of the necessity to stop the bleeding at different stages and the different complications from the bleeding, etc. Not to mention the fact that it appeared that the tumour was surrounding the carotid artery.

Mr. Y. described his optimism about his wife’s intellectual and physical recovery:

I was the eternal optimist in the sense of never really thinking that it was going to impair [my wife] intellectually or physically. ...I had some reservations about the optic nerve, but that, to me, was a complication which in the worst case scenario ain’t so bad.

He stated that the most important thing he wanted to know was whether or not the tumour was ‘carcinogenic’. He described what he said was a grave concern as follows:

...my concern was that Dr. D. had expressed some scepticism as to whether he could get it all. And was, in fact, on the side of saying, no, he would not get it all. It was a matter of finding out how much he could get, but that he would not get it all because of the location. [He said that] it was up in the air as to whether or not radiation would be required later, but probably. And that, to me, was of great concern because I suppose I wanted some finality for the whole thing.

Mr. Y. found that being able to talk with the clinical nurse specialist after the meetings with the neurosurgeon was helpful.

[The clinical nurse specialist] ...was great. ...there is a reluctance, I think, to ask too many questions of the doctor. Whereas [the clinical nurse specialist] seemed to know as much as he did. And that was great. So, it’s nice to have that after, so [you can ask] what did he mean when he said that?

Mr. Y. stated that the information he received pre-operatively about his wife’s care in the neurosciences intensive care unit gave him a sense of comfort.

...it was comforting to know that [my wife] would be there for the amount of attention that she would get. Although he [Dr. D.] had indicated that she wasn’t going to be the sickest person there. In fact, she would probably be the welllest person there. So that was comforting, so I had no fear of the [neurosciences] ICU.

An area of concern for Mr. Y. and his wife was about how to help their six-year-old son cope with his mother’s illness. They sought advice pre-operatively from a friend.

We talked to our friend who is a psychiatrist who referred us to a psychologist, but we never actually followed up with that and we didn’t know how to deal with a younger child in anticipation of this. And we still don’t, but we’re just playing it by ear. ...he seems to be fairly untraumatized by this.

Mr. Y. shared his perceptions about the value of same-day admission for surgery. While he linked these perceptions to his own surgical experiences, this element of his narrative also vividly revealed the fear that he and his wife experienced pre-operatively.

I remember distinctly the terror that I had the night before [my surgeries] in anticipation of the fairly unknown process that was about to happen and that, of course, would pale in comparison to the terror that one would anticipate before a brain surgery. And so it was, to me, a tremendous relief not to spend the night before surgery in the hospital which would serve to accentuate the whole terror of anticipation and for us to have had the night before together I think was really important. So the whole idea of same-day admittance for neurosurgery I think was brilliant.

For Mr. Y., the experience of his wife’s admission the morning of surgery and the time in the pre-operative waiting area were difficult, in part because of his experiences with surgery earlier in his life. He was comforted by the fact that their family doctor was with them in the immediate pre-operative period and had arranged to assist with the surgery.

I remember at one point I said to her in the room that everyone went to before they sort of got wheeled to their various operating rooms that it reminded me of the bus exchange. ...I was bowled over by the efficiency of everything.

P. [our family doctor] showed up, we didn’t know he was going to be assisting, but it was a great comfort to know that he was. It was a comfort to me because ...I had some trepidation about [my wife] being wheeled away because having been through a number of surgeries myself in my life, it’s a horrible thing being wheeled on that gurney into a strange environment with lights and... ...I was very afraid for her going in. ...So to have somebody there who can convey a personal element - it was very significant for me so I was really pleased that he did that.

Waiting during surgery is in essence a family member experience. Mr. Y. recalled this period of waiting as a time that ‘was all such a blur’. When asked to comment on what it was like to wait, he described it and shared how he had hoped for the best of outcomes.

And he’d [Dr. D.] indicated that it could take from six to 16 hours. ...So one was fairly sure that it would take a lengthy period of time. However, I was hoping that it would be the simplest of cases and it would pop out like a pea as I’ve heard described for some tumours. And so even though on the morning of the [surgery], we had been given an estimate of eight hours, I started checking...at four hours to see whether or not there was any news. By the fifth hour I was in the critical care waiting room and waiting. And I would leave to wander around the cafeteria or something from time to time, but for short periods. ...The operation could take until 3:45 was the notification I’d been given in writing and that I
should be available from 3:30 on for the surgeon to come and see me. And so I stayed in the waiting room from 3:30 on for that very reason.

Mr. Y. shared suggestions about how the waiting period might have been made easier for him. He stated that these would have helped him to cope with the fears and anxieties he experienced as he waited for news of the outcomes of surgery.

I had a lot of uncertainty and I felt badly about phoning [neurosciences] ICU to see whether she was there. If there was some reassurance to spouses or relatives that - don’t worry if it’s sooner than the eight-hour prediction we will post a notice for you and, you know, so you can go for a walk. And that you can check every 15 minutes at this board and if there’s a development there will be news for you. And if there’s no news, that’s good news. That would have been helpful. Or if there was a number you could call and they would say, no news. But I felt that I was imposing, obviously I was imposing on [neurosciences] ICU. They’ve got more things to do than answer my calls. But they were very good.

Hearing the news of the outcome of surgery was a significant moment for Mr. Y.

So when I learned that he got it all, I was in full bloom. ...Because [off] the discovery that she wasn’t going to - she didn’t have a stroke, she didn’t die, she didn’t suffer an injured memory loss, neurological deficit.

Mr. Y. found the experiences he had when his wife was in the neurosciences intensive care unit (NICU), her transition to the ward and care on the ward positive ones. The knowledge that he could stay with her in the NICU was a comfort to him.

I went home every night, but I knew that I didn’t have to. I mean that’s a comfort. And, in fact, [my wife] had said someone had said to her that there is a family room that you can have if you want to get some sleep. I think that would be great - I didn’t really want that, but I think it’s a fantastic thing for people like me who want to basically be around the whole time.

Mr. Y. summed up the impact that his wife’s surgery had on his personal and professional life:

Since the day of surgery, I’ve had no leisure activities, no work, no social life and I would say that it’s been all-consuming. I’ve been to the office twice, but that’s it.

Mr. Y. had thought about his wife’s discharge from hospital and about the care she would need at home. He had planned what he would do if his wife experienced any problems once she was at home.

My understanding of the plan is that she will go home and will suffer from significant fatigue because of the basic surgery, that she will require some close monitoring which I hope to be able to do with the help of her mother. We’re debating whether to bring ...a home care nurse ... in. I think that she’s doing so well that it would actually be more disruptive than not to have somebody there. So I don’t expect over the course of the next two weeks for the care and attention that she’ll need, which will be fairly intensive, to be sufficiently onerous to be a great hardship. ...I don’t expect it now, although I did. Going in [to surgery], I thought that she would be needing of that care for a good month, if not more. ...I’m much encouraged now that it’ll be shortened by a great deal, although I expect that she will still be recuperating that whole time, I think she’ll be much more able to care for herself after two weeks.

Mr. Y. shared the way he and his wife had searched for knowledge about the neurosurgeon’s expertise and the confidence they gained in this process.

I think at bottom, the most significant thing for us was just how good Dr. D. was. And we had - because we’d had such a bad experience last summer with getting an internist who was an idiot, we were very concerned that we not get dealt off to an unskilled surgeon. And [we] made numerous inquiries of numerous sources to ascertain his skill and reputation. And by the time we got to the hospital, we were satisfied that he was probably the top guy in North America. So that gives one a great sense of confidence.

For Mr. Y., the positive surgical outcome validated this confidence and he was clearly very happy:

I can now say that he is the greatest in North America, if not the world. I mean, who could do such delicate work so successfully except someone who is obviously very good. Now, I suppose the result will often dictate the opinion. In this case, the result is perfect so the opinion is perfect.

At the end of the interview, he talked with the interviewer about his wife’s recovery at home and the interviewer noted that, “he did appear quite confident, but it did seem to be a fairly big concern for him.” She provided him with teaching and reassurance related to his wife’s care at home and actions to take if they had concerns.

Mr. Y. summed up his feelings at the time of this pre-discharge narrative when he said:

It’s like we have a new lease on life and at least in the short term, [it] puts everything else in perspective. ...with the successful result, it is so joyful an experience right now.

In summary, Mr. Y., like his wife, knows at the time of his narrative that his wife is recovering well from successful surgery. He conveys his elation with the outcome, and it is apparent that he is experiencing a sense of relief. Balanced with these feelings are some concerns about her recovery at home and the role he may have to play during this recovery. Throughout his fluent narrative, Mr. Y. describes the sense of comfort he gained from the education, information and support he received from all health professionals during all phases of his wife’s care. The focus of his narrative is on experiences the day of surgery and during the post-operative period while his wife’s narrative focuses to a greater extent on the pre-operative phase.
The difference in focus is interesting and may indicate that the time when family members need the most support is when they wait during surgery and following surgery as they prepare to care for the patient at home. As Mr. Y. states in his narrative, he and his wife are inquisitive, analytic people who value knowledge – for them the known is better than the unknown. Mr. Y.’s narrative also clearly indicates the amount of support he and his wife called upon from family and knowledgeable friends. The support they received enabled them to cope.

Postscripts

Following discharge, each patient participant encountered challenges and one can assume that these challenges had an impact on the family members. The following data were obtained from the neurosurgeon’s office records and offer insight into another phase of the illness experience.

Mrs. T.M., on discharge, had marked deterioration in her vision and could only count fingers. By one-and-a-half months post-discharge her visual acuity was 20/40 on the right and 20/30 on the left. However, her pre-operative bitemporal hemianopsia persisted. At one year post surgery, she had “a permanent debilitating disability which restricts her in basic activities of daily living and functioning” due to visual confusion and poor balance attributed to her sliding visual field and a divergent strabismus (Ophthalmology Report, 1997). Her good vision disqualified her for Canadian National Institute for the Blind (CNIB) registration.

On discharge, Mr. J.H. had the expected permanent left-sided hearing loss. The pre-operative left-sided facial numbness continued and he had recent memory problems due to the surgical approach. At his six-month office visit he had, except for his hearing loss, regained the vast majority of his neurological function, including short-term memory. At his request, he underwent stereotactic radiosurgery for the remaining tumour 13 months post-discharge. As a result of this treatment, his short-term memory deteriorated and two years post-treatment he had not returned to work and his major complaint was poor memory.

At Mrs. Y’s discharge, the neurosurgeon noted that, “although tired and fatigued, her visual acuity was good at 20/25 and she had no focal neurological deficit” (Office Record Discharge Note, 1998). Post-discharge, the family made four phone calls on four consecutive days to either the neurosurgeon or the clinical nurse specialist, and Mrs. Y. made one visit to an emergency department for severe headaches. When seen by the neurosurgeon two-and-a-half weeks following discharge, she was “very anxious and worked up” (Office Record, 1998). She complained of fuzzy vision, but her acuity was 20/20 bilaterally. No deficits were noted. She returned to work 10 months after surgery. She was still bothered by headaches in the area of the craniotomy site. These headaches tended to be present in the morning and with stressful events.

Lessons for nursing practice

Patients who have a skull base tumour requiring surgery and their family members respond to the experience from their own unique perspectives. Factors that may impact the individual’s and family’s ability to cope, as illustrated by the narratives, include pervasive fear, concurrent family stresses and strains, cancellations of surgery that lengthen the waiting time, complications resulting from surgery that increase the recovery time, and whether or not the surgery is done in one or two stages. These factors and related strengths and resources should be assessed when nurses work with patients and families.

Whether or not one or more of these factors is part of the experience of patients and family members, the narratives demonstrate that some feelings and experiences are common to all. An important theme exemplified by the narratives is a sense of comfort. This theme is linked to a main theme identified in the broader study, that of pervasive fear. For Mr. and Mrs. Y., many of their experiences provided them with a sense of comfort, though it is interesting to note that for each of them, this sense of comfort occurred at different times in the course of the diagnostic process and surgical treatment. Mrs. M. searched for comfort as she sought to deal with her anxiety and fear while her husband, Mr. M., seemed to experience a greater sense of comfort. Mr. H. was the least articulate in his narrative and while his sense of comfort was difficult to determine, he conveyed the impression that he was searching for comfort pre-operatively related to his fear of being incapacitated. His partner, Ms. V., unmistakably articulated her need for comfort in both her pre-operative and post-operative narratives.

The work of Benner, Hooper-Kyriakidis & Stannard (1999) in the field of critical care nursing practice is relevant to this theme. These researchers stated that “…to comfort means to strengthen, aid, and encourage as well as to soothe and console” (p. 244). They viewed comfort as the opposite of fear, distress and anxiety and comforting as involving connecting with “…another in ways that sustain a sense of trust and being cared for” (p. 258). One of the domains of critical care nursing practice they identified was providing comfort measures. Based on our findings, a crucial aspect of practice for neuroscience nurses, and indeed all health professionals in the neurosciences, is providing comfort to both skull base surgery patients and their family members. Establishing and maintaining relationships that provide encouragement, reassurance and support clearly is a significant way of helping. Allowing the person to express their fears may encourage productive worry or reduce feelings of helplessness (Salmon, 1993). It may also enable people to ask questions and seek knowledge, as demonstrated in some of the narratives. Further research about providing comfort as a domain of neuroscience nursing practice would be valuable.

In the narratives of Mr. and Mrs. Y., the theme that the known is better than the unknown came across strongly. Mr. M. conveyed the importance knowing as a way of coping had for him. In the other narratives, this theme was not as clear and Mrs. M., for example, was very uncertain about whether the known was better than the unknown. It is
interesting to note that a greater sense of comfort seemed to be present among those who felt the known was better than the unknown.

Anxiety and fear about surgery and other aversive procedures is well-recognized (Salmon, 1993; Slangen, Kleeman, & Krohne, 1993). It is unrealistic to expect that the fear associated with the diagnosis of a skull base tumour and surgery can be eliminated. Indeed, it is known that anxiety may help to prepare the person to face the threat (Salmon). However, the extent of the fear and its effect on pre-operative coping, intra-operative responses and post-operative recovery requires further investigation (De Bruin, Schaefer, Krohne, & Dreyer, 2001; Salmon).

Research about surgical stress has shown that individuals cope by using vigilance and cognitive avoidance. Vigilance is characterized by an “...intensified search for and processing of threat-related information in order to reduce the subjective uncertainty evoked by the threatening situations” (De Bruin, Schaefer, Krohne, & Dreyer, p. 255). Cognitive avoidance includes “…averting attention away from threat-relevant cues of a situation” (De Bruin, Schaefer, Krohne, & Dreyer, p. 255). In the narratives, the use of both vigilance and cognitive avoidance is evident and these coping behaviours appear to be related to the theme the known is better than the unknown. The guidance that these concepts may provide in the care of patients and families, particularly related to pre-operative education, should be explored. Nurses should examine the value of building assessment of these forms of coping into their practice. Providing education in the context of a therapeutic interaction rather than a task-focused interaction may help patients and their family members cope with pervasive fear (Schwartz-Barcott, Fortin, & Kim, 1994).

A theme that was unique to the family members interviewed prior to discharge was waiting for news of the surgical outcome. This theme was most evident in Mr. Y.’s narrative, but also occurred in Ms. V.’s narrative. Because Ms. V.’s partner had unanticipated complications post-operatively, it is likely that at the time she was interviewed this theme was not as significant for her. The needs of families who wait during surgery have not been examined to any extent (Silva, Geary, Manning & Zeccolo, 1984; Trimm, 1997) and no studies were found that considered this aspect of care for families of brain surgery patients. “Whether the operation is perceived as good or bad, the spouse who must wait is in a state of suspense until the outcome is known” (Trimms, p. 142). The narratives support the findings of Silva, Geary, Manning & Zeccolo that spouses had an altered time perception so that “time seemed to pass more slowly than usual” (p. 28), and that “little or no meaningful communication with any member of the health care team” occurred (p. 29). Family members of skull base surgery patients face a lengthy wait in the context of knowing that the surgery is life-threatening. Further research into the needs and coping behaviours of these family members during the surgical wait is required. For example, studies that explore the environments where family members wait and how nurses might reduce anxiety and promote a sense of comfort in these environments is necessary (O’Connell, 1989).

The quality of recovery is a theme illustrated particularly in the discharge narratives. This theme is linked to concerns about outcome expressed in the pre-operative narratives. The research interviews from which the narratives are selected were concerned with the pre-operative and acute hospital period and the recovery period was not a focus. However, the fact that this theme emerged clearly in the analysis of the narratives indicates that it is significant and merits exploration. Lang, Neil-Dwyer & Garfield (1999) examined outcomes, including quality of life, in patients who had a petroclival meningioma removed and assessed the impact of the surgery on the patients’ caregivers. These researchers found that, “The impact on the patient’s caregiver is profound...” (Lang, Neil-Dwyer & Garfield, p. 359). For some patients, the surgery may result in transient, worsening, or new disability. The patient’s disability (as illustrated by Mrs. M. and Mr. H.) creates burdens for the family that frequently are lifelong and may result in considerable costs to them personally. Mrs. Y.’s narrative illustrates that for other patients, the process of recovery may be uncertain and anxiety-provoking despite the fact that they have no deficits. Examining interventions to help patients and families cope with this type of anxiety after discharge would be valuable. As part of discharge planning, nurses should consider ways to provide anticipatory guidance to patients and families, including discussion of the resources and support that they need (Baker, 2001). Studies examining the experiences of skull base surgery patients and their families at home, and approaches to help them are needed.

Conclusion

Through the examination of narratives selected from interviews with patients with skull base tumours and their family members, the illness experience was illuminated. Nurses should continue to explore ways to care for these patients and their families. The themes of a sense of comfort, the known is better than the unknown, waiting for news of the surgical outcome, and quality of recovery, identified in the analysis and described in this paper, provide a basis for development of evidence-based practice in the field of surgery for skull base tumours.

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