Changes Experienced in Quality of Life for Skull Base Surgical Patients: A Qualitative Case Study

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Abstract

Objective Skull base tumors are associated with quality of life (QOL) changes. A qualitative case-study approach may help better understand patients' experiences.

Methods A total of 34 skull base surgery patients were selected into focus groups using a criterion-based maximum variation sampling strategy from a sampling frame of 138 patients. Eight groups were organized based on a factorial design of surgical approach (endoscopic/pen) and tumor location (anterior/central). Data were analyzed using a conceptual framework. Qualitative analysis was performed on focus group transcripts to identify major themes and determine if surgical approach or tumor location had differential effects on QOL. Concepts were quantitatively tallied from written workbooks.

Results The 34 participants (19 men, 15 women; mean age: 48 years, standard deviation: 14 years) had mixed reactions to their diagnosis ranging from relief to fear. Participants reported physical and nonphysical changes in QOL with some variation in physical complaints by tumor location. Several major themes emerged from the analysis. Skull base tumors are associated with fear and frustration, loss of physical senses and self-identity, social isolation, and coping mechanisms.

Conclusions Skull base surgery may impact patients' lives. Qualitative study of patient experiences can provide rich information to better understand this disease.

Keywords

- skull base surgery
- endoscopic
- qualitative research
- focus group
- quality of life
- patient experience

Introduction

Patients undergoing skull base surgery experience changes in their quality of life (QOL) as a result of both the tumor and treatment.^{1–11} Because of its unique location and intimate relationship with the visual and nasal apparatus as well as with the brain, skull base pathology may affect patients' QOL that differ from those of other head and neck cancers.

Qualitative research methods have been used to better understand changes in QOL for patients with head and neck cancer.^{12–22} These studies, however, focus on patients with upper aerodigestive tract cancers, such as oral, laryngeal, and esophageal cancer.^{12,17–19} Although some of the experiences of these patients may overlap with those who have had skull base surgery, more research is needed in this area to ensure that the pre- and postsurgical needs of patients with these tumors are adequately met.

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Fig. 1 Conceptual framework of disease chronology for skull base pathology. Shaded box indicates theoretical propositions that may affect skull base patients' quality of life.

The literature to date on QOL in skull base patients has been exclusively quantitative, with most information from general and disease-specific questionnaires. For instance, using a disease-specific QOL instrument for skull base pathology, Gil et al demonstrated that a little over a third of patients improve after surgery, about a third stay the same, and a little less than a third of patients get worse after surgery.¹

QOL surveys cannot provide us with a deep understanding of patients' experiences and needs because they are intended to answer "whether" or "how much" questions numerically. Qualitative data, in contrast, help answer questions such as "why" and "how" when examining interactions, experiences, processes, and needs.²³ The mainstream medical and health service literature reflects the need for more of this type of research, with increasing numbers of qualitative studies appearing each year.^{24,25}

In this article, we report our results from the first qualitative study of patient experiences with QOL before and after skull base surgery. We designed the research as a post-positivist qualitative case study as described by Yin to better understand patient experiences and major themes across the life span of the disease, from disease detection to postsurgical life.²⁶ We also identified two propositions to test—that QOL may be affected (1) by surgical approach and (2) by tumor location to determine which of these two criteria have the greatest impact on skull base tumor patients' QOL.

Conceptual Framework

We hypothesized a "stages of disease" conceptual framework to capture various aspects of the participants' QOL (→Fig. 1). The left column depicts a chronology of the disease starting from detection, by symptom manifestation. Others have

described similar chronology in patients with early stages of cancer.^{13,22}

After surgery, patients with skull base pathology typically experience a physical decline followed by improvement over the next 6 to 12 months.¹ Various domains of QOL are affected over the disease trajectory (middle column). The ultimate end point for patients is cure, recurrence (restarting the cycle), or death. The shaded box emphasizes the theoretical propositions of this study—that surgical approach (endoscopic or open) and tumor location (anterior or central) can exert different effects on QOL.

Methods

Bounding the Case

Qualitative case studies require that the case be "bounded," or identified, in terms of topic, time, and place. The case of interest in our study is QOL for patients who have undergone skull base surgery at the University Health Network in Toronto, Ontario, Canada, between 1998 and 2008.

Sampling and Setting

We created a sampling frame of 138 consecutive patients who underwent skull base surgery at the University Health Network in Toronto, Ontario, Canada, between 1998 and 2008. Of these patients, 65 underwent endoscopic approaches and 73 underwent open approaches. Overall, 65 had anterior lesions (lesions transgressing the skull base between the frontal bone of the skull base and the planum sphenoidale), and 73 had central skull base lesions (lesions transgressing the skull base located posterior to the planum sphenoidale extending as far back as the foramen magnum).

Fig. 2 Focus Group Sampling Strategy. A total of 34 participants were selected to participate into one of four different group types. In all, 18 participants had endoscopic approaches, 16 had open approaches, 15 had anterior tumor locations, and 19 had central locations.

In qualitative research, sampling is done to identify information-rich data sources. The aim is to produce representative data with which to describe an issue in depth rather than a representative sample with which to generalize findings to a larger population. We used a criterion-based maximum variation strategy to recruit participants who met one of four conditions based on the surgical approach and location of lesion, as shown in **Fig. 2**. Participants were recruited to one of four focus groups based on combinations of these criteria: (1) having an endoscopic or open surgical approach, and (2) having an anterior or central skull base lesion. Groups were divided into four categories, or “types,” based on these two criteria: endoscopic/anterior, endoscopic/central, open/anterior, and open/central. A total of eight focus groups were conducted with three to six members per group, depending on the availability of participants meeting the criteria for a particular group. The first seven groups belonged to one of the four “group types” previously listed, and the last group was a mixed focus group consisting of patients who were classified as either endoscopic/central or open/central. We took this action because analysis of results from the earlier groups indicated we needed more experiences from endoscopic/central patients. This yielded three groups of the endoscopic/central type and two groups for each of the other types (**Table 1**).

The administrative staff of the primary surgeon initially contacted potential participants, explaining that participation in the study was voluntary and the primary researcher (JdA) then contacted people interested in learning more about the study. Inclusion criteria for participation in focus groups included (1) ability to consent to participate, (2) ability to communicate in English, and (3) meeting the criteria for membership in one of the four focus group types.

We decided to conduct at least two focus group per category to maximize our ability to develop an in-depth understanding of patient QOL based on themes we identified in the data. Within each group we ensured that we had an adequate number of participants representing both genders as well as various age groups, histopathologic diagnosis, and receipt of adjuvant treatment.

Data Types

We used three types of data to triangulate results, or compare findings from each type of data to gain a deeper understanding of participants' views and experiences. First we conducted chart reviews on the full sample of 138 patients to extract data on their disease, areas of life affected by the disease, and demographic or background information. From the focus group interviews we used two types of data provided by participants: transcripts (verbatim written document produced from audiotaped interviews) and information each participant entered into an individual workbook.

Focus Groups

A professional moderator conducted all focus group discussions using a moderator's guide (**Table 2**) or list of topics and suggested wording for questions and probes to be used during the interviews to ensure adequate coverage of all topics needed to test the propositions set at the start of the study. The discussion topics were selected based on information gathered during the chart review and from a panel of experts consisting of three otolaryngologists, one

Table 1 Participant identifiers

	Endoscopic (n = 18)	Open (n = 16)
Anterior (n = 15)	Group 1 (#1–#4) Group 5 (#1–#3)	Group 3 (#1–#3) Group 7 (#1–#5)
Central (n = 19)	Group 2 (#1–#5) Group 6 (#1–#3)	Group 4 (#1–#5)
Central (Mixed Group)	Central/Endo = 8–1, 8–2, 8–4	
	Central/Open = 8–3, 8–5, 8–6	

Note: Each participant was assigned a group number followed by an individual number with the group. Participants are categorized by their surgical approach as well as tumor location. Groups 1 to 7 are “pure types,” containing members who had the same surgical procedure and tumor location. Group 8 was a “mixed type,” with three members who fit the central/endoscopic classification (participants #1, #2, and #4), and three had the central/open classification (participants #3, #5, and #6).

Table 2 Interview themes/questions

Complete the following sentences
1. When I was first diagnosed with a skull base tumor, I felt...
2. My biggest concern after being diagnosed was...
3. After my surgeon discussed my operation with me, my biggest concern about the operation was ...
4. [For those who had other treatment (radiation, chemotherapy)] My biggest concern with radiation or chemotherapy was...
5. After treatment, the three biggest changes in my life were...
Key questions
6. Describe the changes that your treatment had on you physically. [Moderator specifically prompted complaints relating to endocrine, nasal, visual, other complaints]
7. Tell me how your social life is different now compared with before you were diagnosed.
8. How has your mindset or outlook in life changed now compared with before you were diagnosed?
9. Has your financial situation changed (if at all)?
10. How have your religious views changed compared with before you were diagnosed?
11. Describe the effect that your surgery had on your life. [Moderator specifically prompted complaints relating to cognitive, emotional, family, financial, social, spiritual domains]
12. Describe the effect of other treatments on your life (radiation therapy, chemotherapy) [Moderator specifically prompted complaints relating to cognitive, emotional, family, financial, social, spiritual domains]

neurosurgeon, and one radiation oncologist. These experts identified relevant items and domains of QOL affected by skull base surgery.

Because of the potentially sensitive nature of issues discussed in the focus groups, at the start of the focus group sessions the moderator gave each participant a workbook (Supplementary Appendix 1, online-only) that contained the same questions to be discussed in the group session. By having each participant individually answer a question prior to the group discussion, we ensured that group members had time to consider their responses and choose only to answer questions in the written workbook. The moderator was trained to ensure a balanced discussion and solicit feedback from each quiet group members while redirecting the discussion away from dominant members when necessary. Participants also provided demographic information in their workbooks.

Each focus group discussion lasted between 1.5 and 2 hours and began with a meal. To ensure fidelity and to fill in missing information, where possible the primary researcher “cleaned” the transcripts by comparing the audio and written versions of each focus group session.

Analysis

The primary research question was “How do skull base tumors and their management affect patients’ quality of life?” As is done in a post-positivist qualitative case study, we hypothesized a priori that surgical approach (either endoscopic or open) and tumor location (either anterior or central) might have a differential effect on QOL. These became the propositions that guided data collection and analysis, as per Yin,²⁶ a widely cited qualitative researcher in the health field. We then proposed a conceptual framework (→ Fig. 1) that delineates the stages of the disease at which QOL maybe

impacted and used this to help us identify relevant themes at various stages of the illness trajectory of living with a brain tumor. Although Yin outlines key features of the post-positivist case study, there is no stringent set of guidelines for analyzing data gathered in this type of study. We therefore identified another source of information about data analysis that would be appropriate for the research design we selected. This is a version of content analysis, as described by Miles and Huberman,²⁷ also referred to as the template style of analysis.²⁸ The steps in this type of analysis are as follows:

First, the primary researcher (JdA) read each focus group transcript several times to gain an overall understanding of participants’ experiences and to develop a coding scheme that grouped text segments by topic or theme. Transcripts were then reread to identify relevant text segments and sort them by theme, updating the recorded coding scheme as needed. As new themes emerged, previously analyzed transcripts were reviewed to determine if any of the newly found themes were present, and if so, the relevant passages were coded. Each code was applied to a relevant block of text (descriptor) and linked to the source (a focus group participant) that included the patient’s surgical approach and tumor location.

All qualitative analyses were performed using a specialized software package, N. Vivo, v.8.0 (QSR International, Cambridge, Massachusetts, United States) to help sort and locate segments of data sorted by theme. To address the study propositions, we analyzed the data at the case level (by participant), the surgical approach level (endoscopic or open approach), and tumor location level (anterior or central location). We identified patterns in the data for these three levels of analysis from all eight focus groups. We then mapped the findings onto the stage of disease to identify key points along this trajectory where differences in QOL appear. Finally,

we reviewed data from the workbooks as a way to verify responses provided during focus group discussions and present them in the form of tallies, rank orderings, and proportions. Information from the workbooks was cross-referenced with transcripts for consistency. Transcripts and workbooks were reviewed again in cases of inconsistency. Data from patient records, interviews, and workbooks were triangulated to ensure reliability of the data.

Presentation of Data

To distinguish between participants' views and our own, we have presented excerpts or quotes (verbatim statements from study participants). We selected excerpts because they are typical or vividly illustrate one of our findings on a particular QOL issue. We have identified the speaker for each quotation by focus group and individual ID number to ensure that we did not overemphasize the experience of some participants and ignore the views of others. For instance, a statement labeled "Ant/Endo #1-3" indicates it was made by the third member of Focus Group #1, which consists of patients with an anterior tumor who underwent endoscopic surgery for its removal (► Table 1).

Following standard procedure in qualitative research, we have modified participants' statements only when it would improve readability without changing the meaning of the quotation.²⁹ We used square brackets to indicate where we inserted additional words and ellipsis points (three consecutive periods) to show where we removed text.

Ethical Considerations

We obtained institutional research ethics board approval from the University Health Network prior to starting the study for both the chart review and the focus groups. We also obtained written informed consent from each participant before collecting data.

Results

Participants

Data from the charts of the 138 eligible patients were reviewed, and 34 subjects were interviewed in focus groups. Members of the groups included 19 men and 15 women who were, on average, 48 years old (standard deviation [SD]: 14 years). As shown in ► Table 1, five groups consisted of participants who had undergone endoscopic surgery ($n = 18$ participants) and four groups, those who underwent open surgery ($n = 16$ participants). Half of the groups consisted of participants who had anterior tumors ($n = 15$ participants), and four groups had participants with central tumors ($n = 19$ participants). Twenty-five individuals (74%) had a university degree or higher, and 28 participants (82%) had an income of \$100,000 per annum or less. Most of the participants ($n = 25$ [74%]) were white. A minority of participants lived alone ($n = 8$ [24%]); three was the mean number of members per household (SD: 2). Most of the participants ($n = 28$ [82%]) had only one surgery to address their brain tumor. Twenty-one (62%) of the participants received radiation therapy, whereas only three (9%) received some form of chemotherapy. The endoscopic group had significantly less

follow-up than the open group (20 months versus 58 months; $p < 0.01$). However, there was a minimum of 6 months of follow-up in each group. Demographic data are presented in ► Tables 3 and 4.

Concerns Regarding Tumor Detection and Diagnosis

When asked about how they felt during the time their tumors were being diagnosed, 16 of the 33 participants (48%) who answered this question described negative feelings about their initial diagnosis with words such as *fear*, *anxiety*, *terror*, *concern*, and *disbelief* to describe their initial reaction. Fewer participants ($n = 9$ [27%]) had a positive reaction to their diagnosis, usually feeling a sense of relief or feeling at ease. Positive reactions to a diagnosis tended to occur after experiencing frustration caused by delayed diagnosis:

I had been going to doctors for years, complaining about symptoms. They either minimized what I was feeling, or made me feel like I should just get over it. And they always tried to make me feel like I needed to accept who I was, how I was feeling. [They] sent me to shrinks, did this, did that, but nobody ever took the time to take a look at my head. So then when I was diagnosed, my next feelings were of relief.

—Cent/Endo #2–4

There were no apparent differences in rates of positive and negative responses to diagnosis between participants based on either surgical approach or tumor location. For example, one participant who had an endoscopic approach for an anterior tumor lesion described a feeling of relief after delayed diagnosis:

I felt relief. It took four years and four specialists [to get a diagnosis], and the symptoms lasted so long, and it was just getting worse and worse. So when they finally found something, it was [a feeling of] relief.

—Ant/Endo #1–3

Similar sentiments were shared by another participant who underwent an open approach for a central tumor location:

It took a long time.... I saw a neurosurgeon who had never seen a chordoma and would not diagnose me. I had to be very persistent until they spoke to me and told me what they guessed it was, and that they were sending me to Toronto [to see another specialist]. I was relieved when somebody actually used the word 'tumor' to me.

—Cent/Open #4–2

Once diagnosed, three themes emerged regarding the immediate concerns of participants. The most common issue was concerns about one's future QOL (44% of participants). As stated by one group member, "[My biggest concern] was *getting back to work*. I think the biggest thing was maybe the fear that everything would be different" (Cent/Open #8–5). Others voiced concerns relating to possible treatments and their complications ($n = 11$ [32%]) or about the curability of cancer and facing questions about their mortality ($n = 8$ [24%]). There were no differences in

Table 3 Demographic information by surgical approach

	Endoscopic (<i>n</i> = 18)	Open (<i>n</i> = 16)	<i>p</i> value ^a
Mean age, y (SD)	46 (16)	51 (12)	0.32
Gender (M:F)	10:8	9:7	0.97
Education (%)	No high school (6)	No high school (0)	0.26
	High school (33)	High school (13)	
	University (33)	University (63)	
	Graduate (28)	Graduate (25)	
Income (%)	0–19K (17)	0–19K (6)	0.84
	20–39K (22)	20–39K (19)	
	40–59K (17)	40–59K (25)	
	60–79K (17)	60–79K (13)	
	80–99K (11)	80–99K (19)	
	100–249K (11)	100–249K (19)	
	>250K (6)	>250K (0)	
Race (%)	White (56)	White (94)	0.25
	Indian/South Asian (22)	Indian/South Asian (0)	
	East Asian/Pacific Islander (11)	East. Asian/Pacific Islander (6)	
	Hispanic (6)	Hispanic (0)	
	Middle Eastern (6)	Middle Eastern (0)	
	African Canadian (0)	African Canadian (0)	
Mean no. in household (SD)	4 (2)	2 (2)	0.07
Diagnosis (%)	Esthesioneuroblastoma (22)	Chordoma (19)	0.44
	Chordoma (17)	Craniopharyngioma (13)	
	Craniopharyngioma (17)	Esthesioneuroblastoma (13)	
	Somatotropic adenoma (11)	Adenocarcinoma (6)	
	Adenoid cystic (6)	Cavernous Hemangioma (6)	
	Corticotropic Adenoma (6)	Chondrosarcoma (6)	
	Lactotrophic adenoma (6)	Hemangiopericytoma (6)	
	Meningioma (6)	Leiomyosarcoma (6)	
	Mucoepidermoid Ca (6)	Meningioma (13)	
	Rathke cyst (6)	Squamous cell carcinoma (13)	
Mean no. of surgeries (SD)	1.2 (0.6)	1.3 (0.7)	0.67
XRT (%)	Preoperative (22)	Preoperative (19)	0.47
	Postoperative (33)	Postoperative (50)	
Chemotherapy (%)	(0)	(19)	0.30
Time after surgery, mo (minimum–maximum)	20 (6–48)	58 (8–141)	<0.01

Abbreviations: Ca, cancer; SD, standard deviation; XRT, radiation therapy.

^aThe *p* values are derived from chi-square tests for categorical variables and *t* tests for continuous variables.

concerns postdiagnosis among participants based on either tumor location or surgical approach.

Concerns about Surgical Treatment

After diagnosis and before surgery, during the period when patients were discussing treatment options with their physicians, participants noted they faced different concerns. Most of the participants (*n* = 19 of 31 [61%]) focused on treatment-

related issues such as possible complications, the likelihood of treatment success, recovery time, and waiting time before treatment. Fewer participants (*n* = 11 of 31 [35%]) were concerned with the impact of surgery on their future QOL.

Participants with different tumor locations had similar concerns regarding surgical treatment, but those who had undergone different surgical approach expressed different concerns. For instance, one participant with an anterior

Table 4 Demographic information by tumor location

	Anterior location (n = 15)	Central location (n = 19)	p value ^a
Mean age, y (SD)	51 (15)	46 (14)	0.33
Gender (M:F)	9:6	10:9	0.67
Education (%)	No high school (0)	No high school (5)	0.65
	High school (27)	High school (21)	
	University (40)	University (53)	
	Graduate (33)	Graduate (21)	
Income (%)	0–19K (0)	0–19K (21)	0.19
	20–39K (27)	20–39K (16)	
	40–59K (27)	40–59K (16)	
	60–79K (13)	60–79K (16)	
	80–99K (7)	80–99K (21)	
	100–249K (27)	100–249K (5)	
	>250K (0)	>250K (5)	
Race (%)	White (87)	White (63)	0.35
	East Asian/Pacific Islander (13)	Indian/ South Asian (12)	
	African Canadian (0)	Hispanic (5)	
	Hispanic (0)	Middle Eastern (5)	
	Middle Eastern (0)	E. Asian/Pacific Islander (5)	
	Indian/South Asian (0)	African Canadian (0)	
Mean no. in household (SD)	3 (1)	3 (2)	0.70
Diagnosis	Esthesioneuroblastoma (40)	Chordoma (32)	0.008
	Squamous cell Ca (13)	Craniopharyngioma (26)	
	Meningioma (13)	Chondrosarcoma (5)	
	Adenocarcinoma (7)	Corticotrophic adenoma (5)	
	Adenoid cystic Ca (7)	Lactotrophic adenoma (5)	
	Cavernous hemangioma (7)	Leiomyosarcoma (5)	
	Hemangiopericytoma (7)	Meningioma (5)	
	Mucoepidermoid Ca (7)	Rathke cyst (5)	
Mean no. of surgeries (SD)	1.1 (0.5)	1.4 (0.7)	0.28
XRT (%)	Preoperative (40)	Preoperative (5)	0.10
	Postoperative (33)	Postoperative (47)	
Chemotherapy (%)	(13)	(5)	0.34
Time after Surgery, mo (minimum–maximum)	39 (6–119)	37 (6–141)	0.87

Abbreviations: Ca, cancer; SD, standard deviation; XRT, radiation therapy.

^aThe p values are derived from chi-square tests for categorical variables and t tests for continuous variables.

tumor who had been treated with endoscopic surgery was astonished at the relatively short recovery time (*“Dr. X did the operation, and then three days later [I was] walking outside. I think it’s so much better this way than if I had a normal [open] operation”* [Ant/Open #1–4]). In contrast, another person with an anterior tumor who had open surgery was concerned with the potential life-altering sequelae after a large operation:

I’m not a person to be in bed. [My surgeon] told me I would have to be in bed for a couple of weeks and he didn’t want me to be concerned about work.... But my biggest concern

was, how would my life turn out after all this? When will I get back to work? Because I do house-cleaning, if you don’t work, you don’t get paid. So the biggest thing was paying the rent, and my bills, and how long before I could get back into that.

—Ant/Open #7–3

Concerns about Neoadjuvant/Adjuvant Therapy

Twenty-one (62%) participants underwent some form of adjuvant therapy: 100% of them received radiotherapy with

three of them (14%) also receiving chemotherapy. Many participants spoke about the side effects of radiotherapy such as dry mouth, fatigue, and hair loss. Fatigue led to the inability to perform daily functions, which reinforced feelings of being sick, and dry mouth impaired eating and social relationships.

Reports on these effects did not vary by surgical approach or tumor location. The following are two accounts of participants with anterior tumors, the first from someone who had undergone endoscopic surgery and the second one, open approach:

As a result of [radiation], my salivary glands were severely impacted. And also too, I lost my hair on the back of head up to my ears. And same with my facial hair, but that wasn't really the biggest change. My energy level just hit rock bottom. Towards the end of it what energy I had was used to get up and eat breakfast. I would fall asleep, wake up, have lunch, fall asleep, wake up, have dinner, and go to bed. So that was my daily routine.

—Ant/Endo #1–1

When they did the radiation, it affected my tongue. I lost a lot of hair, a bit behind my ear, a piece in the middle, and a bit behind the other ear. My eyebrows were gone. My eyelashes were almost gone. When am I going to look like a normal person? I still can't eat salt, anything with lemon, anything with spice.... I have to be careful when I go out. I have to ask people not to cook certain foods for my own protection—'What are you cooking? What's in it?' People sometimes get annoyed.

—Ant/Open #7–3

Concerns about Physical Quality of Life

At the Time of Diagnosis

We asked participants to identify and rank-order the three most significant physical symptoms at the time of diagnosis, shortly after surgery, and currently. The most common physical complaints at the time of diagnosis were headaches ($n = 14$ [41%]), nasal congestion/obstruction ($n = 9$ [26%]), and altered vision ($n = 5$ [15%]).

Headaches

These symptoms, for example, were no more common in participants with endoscopic and open approaches ($n = 8$ of 18 [44%] and $n = 6$ of 16 [38%], respectively), but they were much more common in participants with central lesions ($n = 11$ of 19 [58%]) compared with those who had anterior lesions ($n = 3$ of 15 [20%]). One participant who had a central tumor recalls how debilitating headaches were:

The major thing was migraine headaches. I literally couldn't sleep. It was very stressful. I was tired all the time and couldn't concentrate on my job. And when they were really strong, I couldn't even work. I couldn't even take Tylenol or

anything.... [I would] stay in bed, in a dark room, and nobody bothered me. And eventually, some days [they would] go away in a few hours. I remember one time I had it first in the morning. It was Easter weekend, the year before I got the surgery. It was on Good Friday. I got up, took a shower, got ready to go to church, and I lay down because the service was not for a while. [I] went to church, came back and went right back to bed. And it didn't go away until six o'clock that night. That was the worst of them all.

—Cent/Open #8–3

Nasal Congestion

At the time of diagnosis, participants with anterior lesions had experienced nasal congestion ($n = 8$ of 15 [53%]) more commonly than those with central lesions ($n = 1$ of 19 [5%]), as did those who underwent endoscopic rather than open surgical approaches ($n = 7$ of 18 [39%] and $n = 2$ of 16 [13%], respectively). One participant whose anterior tumor was removed endoscopically described physical symptoms this way:

I can actually feel something in there. I had the nasal blockage. I had problems breathing through my nose. The only time that I could really breathe through my nose was after a very hard workout, like if I went for a run or something. I guess for whatever reason, I could breathe for a short period of time after that, and then it would block again.

—Ant/Endo #1–2

Visual Symptoms

People with central lesions more often reported visual symptoms such as double vision and decreased visual acuity ($n = 7$ of 18 [39%] and $n = 3$ of 14 [21%], respectively) than those with anterior tumors, as did participants who underwent open rather than endoscopic surgery ($n = 7$ of 16 [44%] and $n = 3$ of 18 [17%], respectively). Two participants with central tumors, the first who had it treated with an open approach and the second with an endoscopic approach, described their experience in these words:

I had double vision. I couldn't function. It was so bad that I could not see. I remember one time I drove down to see a specialist and I looked around, and I thought, 'I shouldn't be driving a car!' I can remember looking down the street and the street was like a blur. You know, it just looked like a kaleidoscope.... After a period of time I learned that wearing a patch over one eye solved that, and you know, I was able to function again ... I remember [being in the car] ... my wife was driving at the time. And I looked out my left eye and here's a truck right beside us on the [highway] and there was another truck on an angle. It looked like two of them [but it was the same truck]. And after a while, your brain sort of tries to figure this all out. And it's very difficult.

—Cent/Open #8–3

As a result of the surgery, I had double vision. At the time, I didn't have corrective prisms in my glasses to compensate so I had trouble walking down stairs, watching TV, reading—like pretty much anything you have to see.

—Cent/Endo #2–7

After Surgery

When asked to recall physical changes in QOL shortly after surgery, participants' complaints centered around a lack of energy ($n = 10$ [29%], nasal congestion ($n = 7$ [21%]), and pain ($n = 5$ [15%]).

Lack of Energy

This seemed to affect all participants, particularly after surgery ($n = 6$ of 18 [33%]) for those participants who had endoscopic surgery ($n = 4$ of 16 [25%]) versus those who had an open approach ($n = 4$ of 15 [27%]) or those with anterior lesions ($n = 7$ of 19 [37%]) versus those with central lesions. One participant who underwent an open surgical approach for an anterior tumor recalls the troubles experienced with diminished energy levels:

I had no energy at all. [I was] just tired after working but it was sort of a lack of energy. Regardless of what I was doing, how much I was sleeping, it was just never enough. I was always tired.

—Ant/Open #7–2

Nasal Symptoms

More participants with endoscopic approaches recalled nasal physical symptoms ($n = 11$ of 18 [61%] versus $n = 6$ of 16 [38%]), although more of them who had anterior tumors reported nasal symptoms after surgery ($n = 8$ of 15 [53%] versus $n = 8$ of 18 [44%]).

Pain

This was reported less commonly in the endoscopic than the open surgery group ($n = 2$ [11%] versus $n = 3$ [19%]) and in the anterior rather than the central tumor group ($n = 2$ [13%] versus $n = 3$ [16%]).

Current Physical Symptoms

Physical changes that bothered participants at the time of the interview included nasal changes (an ongoing issue for $n = 25$ [73%] of participants), specifically nasal congestion and crusting ($n = 10$ [29%] and altered sense of smell ($n = 6$ [18%]). In addition, some participants also noted decreased energy ($n = 7$ [21%]).

Nasal Changes

This continued to be a more common an issue for the endoscopic than for the open surgery group ($n = 7$ of 18 [39%] versus $n = 3$ of 16 [19%]), which was also the pattern immediately after surgery. Participants with anterior tumors and central tumors had similar rates of annoyance with ongoing nasal congestion ($n = 5$ of 15 [33%] versus $n = 5$ of 19 [26%]).

Table 5 Quality-of-life changes in nonphysical domains by surgical approach

	Endoscopic ($N = 18$) n (%)	Open ($N = 16$) n (%)	Total ($N = 34$) n (%)
Cognitive	10 (56)	4 (25)	14 (41)
Emotional	10 (56)	8 (50)	18 (53)
Family	10 (56)	7 (44)	17 (50)
Financial	8 (44)	6 (38)	14 (41)
Social	12 (67)	12 (75)	24 (71)
Spiritual	6 (33)	6 (38)	12 (35)

Note: Numbers are derived from tallies of domains and specific mentions from the workbook.

Nonphysical Quality-of-Life Changes

There were many other changes in participants' QOL since their surgery, as shown in ►Tables 5 and 6. These include cognitive, emotional, family, financial, social relations, and spiritual life.

Cognitive Issues

Fourteen of 34 participants (41%) complained of some type of cognitive change, ranging from changes in behavior to concentration deficits and memory loss (►Tables 5 and 6). One participant who had undergone an open approach for an anterior tumor experienced behavioral changes. Memory loss and lack of ability to concentrate were more common in participants with central tumors ($n = 9$ of 19 [47%] versus $n = 4$ of 15 [27%]) and those who underwent endoscopic approaches ($n = 10$ of 18 [56%] versus $n = 3$ of 16 [19%]). Reduced memory and concentration problems affected participants in several domains of life such as family and work life, as described by one participant who had an undergone endoscopic surgery for a central tumor:

I'd lose my way very easily, whether it was during a thought process, or performing a task, or driving. I found that I had to take a lot of notes because if I didn't take notes about what I was talking to my husband about, then I was likely going to get called on it or get caught. So I had to do a lot of pretending

Table 6 Quality-of-life changes in nonphysical domains by tumor location

	Anterior ($N = 15$) n (%)	Central ($N = 19$) n (%)	Total ($N = 34$) n (%)
Cognitive	5 (33)	9 (47)	14 (41)
Emotional	6 (40)	12 (63)	18 (53)
Family	5 (33)	12 (63)	17 (50)
Financial	5 (33)	9 (47)	14 (41)
Social	7 (47)	17 (90)	24 (71)
Spiritual	4 (27)	8 (42)	12 (35)

Note: Numbers are derived from tallies of domains and specific mentions from the workbook.

that I always knew what was going on because I really had no idea.

—Cent/Endo #2–2

Cognitive issues were particularly important for elderly participants. With one 77-year-old participant who had undergone an endoscopic resection of a mucoepidermoid carcinoma of the anterior cranial base (accompanied by her son), the concerns of safety were raised due to memory loss. The son notes that his mom experienced some cognitive changes after surgery.

There is some impact on us as a family, worrying about her memory. [We] almost want to give her a tag just in case she forgets where she lives or you know. So we do worry about her remembering even to come home or walk an hour once a day, so it's a concern.

—Ant/Endo #1–4

Emotional Issues

Eighteen of the participants described having experienced emotional changes since their diagnosis. Some participants complained of feeling depressed, whereas others felt anxious and stressed due to fears about tumor recurrence or multiple doctor visits: “[I had] a lot of depression. I have had a tendency to isolate myself and obviously I still have the concern every time I go for an MRI” (Cent/Open #4–3). Although a similar proportion of participants with endoscopic and open approaches noted emotional issues, those with central tumor locations had more emotional issues than those with anterior lesions (►Table 5 and 6). The emotional impact of skull base pathology was more significant on individuals without a support system. A 55-year-old male participant who was treated for a chordoma and lived alone described a vivid experience with depression.

A lot of depression, a lot of ... for example, I take antidepressants, I take antipsychotic medication because of my night time ... what I would describe as a horror show, I go through during the night.

—Cent/Open #4–5

Family Issue

Family life also suffered in people with skull base tumors. Participants complained of failure to fulfill their familial duties as well as changes in their intimate relationships. This was particularly the case with middle-aged participants who had dependent children. The concerns of not being able to fulfill important family duties as well as the concerns of being physically and emotionally unavailable for their children during and after lengthy treatment regimens were commonly voiced. A 36-year-old female participant with a somatotrophic adenoma shared:

I have a husband, a mother who is very close to me, and a child that is nine right now, and a child that is five. So the kids

have been spending most of their lives watching me lie down on the couch; watching me being miserable [while I've] been on different kinds of pain medications. So I haven't really been there for them in the past at least five years. [After surgery], I got my life back. They, more importantly, got [me] back.

—Cent/Endo #2–2

The sentiment was also shared by a 57-year-old male participant who had a sinonasal adenocarcinoma: “I have two daughters ... [and my concern] was that that they would grow up without a father” (Ant/Cent #3–2). In contrast to middle-aged individuals, those in the more advanced age group tended to turn to familial supports during this time. One 73-year-old participant said,

Before whenever there was a task to be done, if it was a problem in the family, I was the fixer upper. I would fix it with my own strength and my own time and effort. When this hit me, it shocked me into a realization that ... We need other people.

—Ant/Endo #5–3

A sense of embarrassment of the diagnosis affected the way some participants interacted with their families:

I think it's a self-centered thing. I don't want to keep explaining how I feel, how I am, how I'm doing. So I just get tired of lying. ... I have to lie so much to keep people happy.

—Cent/Open #4–5

Participants with central tumors reported more family issues (►Table 6) than those with anterior tumors.

Financial Issues

Many participants had alternative sources of income (including spousal income) and were able to recover financially after receiving short-term disability insurance. Nonetheless, 14 of the 34 participants (41%) described experiencing some type of financial difficulty related to out-of-pocket treatment-related expenses and/or an inability to work. One participant described a large loss of income because she was the sole income earner in her household and could not work for over a year.

Social Issues

Of all the nonphysical domains associated with QOL for the study participants, problems with their social life were the most common (mentioned by 24 participants [71% of all participants]). For some people, it meant they could no longer participate in their hobbies, whereas others noted negative impacts on their relationships. Participants with central tumors made references to social issues more often than those with anterior tumors ($n = 17$ of 19 [89%] versus $n = 7$ of 15 [47%]) who often noted how reduced sense of taste or smell prevented them from enjoying meals:

People ask me about smells—like, ‘Do you smell this?’, or ‘How does that taste?’—anything like that. I have to explain to them about my cancer and my experience and relive it. I

try to forget, because ... you probably can't even imagine what it's like having no smell. You just try to forget so you're not in pain because it's painful emotionally not being able to smell.

—Ant/Endo #5–2

Participants with central tumors, especially those associated with pituitary dysfunction, described differences in their interactions with friends as well as changes in social relationships that reduced their motivation to socialize:

I wasn't participating in many activities with friends. I would refuse to go swimming because I didn't want anyone to see my skin. I was extremely weak, I couldn't do many sports because of my weight gain. I didn't like going out anyways. It completely nullified any sort of social activity.

—Cent/Endo #2–4

The younger participants were more concerned with social stigmas, particularly if they had open surgical approaches with visible scars or deforming surgeries such as craniectomies or orbital exenterations. One of the younger participants, 29 years old, who was treated for a sinonasal squamous cell carcinoma recounts:

The biggest issue for me was, socially, I was really self-conscious about the changes in my appearance, especially at first, and then mostly it got back to normal. I've had another plate put in my head, so I have a scar across here.

—Ant/Open #7–1

Spiritual Issues

Of all nonphysical domains of QOL, participants least often mentioned spiritual concerns. Eight participants (24% of the

sample) described how they had reappraised their relationship with God or a higher power; all but one of them noted a more positive relationship after their experience with cancer:

I had my surgery in November. Since [then], I've become a bit more connected to God. ...I have a better connection now, and the surgery really helped to find the connection with God.

—Cent/Endo #2–2

Some participants explained that their faith helped them through the difficult time of treatment:

I am a Christian, and I've been a Christian for a long time. I go to church quite regularly ... different groups and things. And every time I'm there, while I was going through the operation and while I was going through radiation, they always said, 'You wouldn't know what you've gone through. You're always smiling. You're always in a good spirit.'

—Ant/Open #7–3

Even some participants who did not see themselves as particularly spiritual gained some solace in religion (*"I'm not religious but my husband's family is really religious. And in a way, it is a little bit comforting to know that they're praying for you"* [Cent/Open #4–3]).

Major Changes in Quality of Life

We asked participants to list up to three of the biggest changes in the quality of their lives since their diagnosis. They are listed, by surgical approach, in ► **Table 7**. Twenty-six participants (76%; 14 with endoscopic surgery, 12 with open surgery) described 73 changes (39 and 34 changes,

Table 7 Biggest changes in quality-of-life domain by surgical approach

Domain	Subdomain	Endoscopic (N = 39) n (%)	Open (N = 34) n (%)	Total (N = 73) n (%)
Cognitive		1 (3)	1 (3)	2 (3)
Emotional		3 (8)	5 (15)	8 (11)
Family		0 (0)	1 (3)	1 (2)
Financial		2 (5)	1 (3)	3 (4)
Physical		27 (69)	24 (71)	51 (70)
Physical	Endocrine	0 (0)	0 (0)	0 (0)
Physical	Nasal	5 (13)	3 (9)	8 (11)
Physical	Neurologic	4 (10)	1 (3)	5 (7)
Physical	Visual	2 (5)	5 (15)	7 (10)
Physical	Other	16 (41)	15 (44)	31 (43)
Social		1 (3)	1 (3)	2 (3)
Spiritual		5 (13)	1 (3)	6 (8)

Note: Values represent the total number of changes reported in quality of life for surgical approach (each participant was asked to list up to three). N represents the number of times an issue for a particular domain was reported.

Table 8 Biggest changes in quality of life by tumor location

Domain	Subdomain	Anterior (N = 33) n (%)	Central (n = 40) n (%)	Total (N = 73) n (%)
Cognitive		0 (0)	2 (5)	2 (3)
Emotional		3 (9)	5 (13)	8 (11)
Family		1 (3)	0 (0)	1 (1)
Financial		2 (6)	1 (3)	3 (4)
Physical		22 (67)	29 (73)	51 (70)
Physical	Endocrine	0 (0)	0 (0)	0 (0)
Physical	Nasal	6 (18)	2 (5)	8 (11)
Physical	Neurologic	0 (0)	5 (13)	5 (7)
Physical	Visual	1 (3)	6 (15)	7 (10)
Physical	Other	15 (45)	16 (40)	31 (43)
Social		2 (6)	0 (0)	2 (3)
Spiritual		3 (9)	3 (8)	6 (8)

Values represent the total number of changes reported in quality of life for surgical approach (each participant was asked to list up to three). N represents the number of times an issue for a particular domain was reported.

respectively). These participants most often noted physical changes (70% of all changes noted) in virtually equivalent proportions for the two surgical groups.

We also compared results by tumor location. ►Table 8 lists QOL changes by tumor location. In total, participants with anterior tumors listed 33 complaints; those with central tumors listed 40 complaints. Nasal symptoms were described more frequently by people who had anterior than central lesions ($n = 6$ of 33 [18%] versus $n = 2$ of 40 [5%]), whereas neurologic ($n = 5$ of 40 [13%] versus $n = 0$ of 33 [0%]) and visual symptoms ($n = 6$ of 40 [15%] versus $n = 1$ of 33 [3%]) were more commonly listed by those with central lesions.

The participants noting changes in their physical symptoms described dramatic changes in their overall QOL:

We were all [participant's family and friends] suffering incredibly before we found out what was wrong with me—and I'm talking about five plus years! I would say that the last two years of my life, I wasn't functioning [and] I lost my job. Since the surgery, I'm happy to say that I have 100% of my life back.

—Cent/Endo #2–2

As one might expect, participants who had developed new physical complaints since their surgery or were left with residual disease had less positive views on their lives, such as the man living alone and left with residual disease and persistent headaches explained:

A lot of depression ... [so] I take antidepressants [and] I take antipsychotic medication because of ... what I would describe as a horror show [that] I go through during the night.

—Cent/Open #4–5

Major Themes

Emotional Response of Fear and Frustration to Diagnosis and Treatment

Participants demonstrated a strong emotional response throughout the illness trajectory. At the point of diagnosis this varied from fear and anxiety to relief. During treatment, these emotional responses pervaded participant responses. The sense of frustration with the physical responses to treatment was consistently voiced by participants. This frustration reflects the large spectrum of impairments from cognitive, to visual, to nasal, to neurologic. Participants with endoscopic approaches were generally less frustrated with physical impairments. One participant recalls, “Dr. X did the operation, and then three days later [I was] walking outside. I think it's so much better this way than if I had a normal [open] operation” (Ant/Open #1–4).

Participants voiced a sense of frustration with their changes in cognitive functioning, social functioning, and family relationships. Interestingly, some participants with endoscopic approaches also voiced this frustration with cognitive function even though this type of approach is not typically associated with brain retraction. This was mainly the case in participants who had some type of intradural manipulation.

I found that I had to take a lot of notes because if I didn't take notes about what I was talking to my husband about, then I was likely going to get called on it or get caught. So I had to do a lot of pretending that I always knew what was going on because I really had no idea.

—Cent/Endo #2–2

The sense of frustration and emotional disturbances throughout the illness trajectory reflect the impact that skull base pathology has on participants in all aspects of life.

Physical Changes, Loss of Senses, and Identity

Skull base pathology and treatment of these pathologies can affect vision, smell, cognition, hearing, taste, sensation, and motor function. Participants voiced a change in the way they sense and interact with their environment. One participant expressed her concerns with not being able to smell. *"You probably can't even imagine what it's like having no smell. ... It's painful emotionally not being able to smell"* (Ant/Endo # 5-2). Another participant discussed his physical changes affecting his normality. He asked, *"When am I going to look like a normal person?"* (Ant/Open #7-3). In addition to losing the senses that help one interact with the environment, many participants divulged their change in cognitive capacity that defines one as human.

My problem was memory. I lost my dad in a car accident in February of '08. So one of my biggest fears was that I was not going to be able remember things about him, things that we used to do. That was the biggest thing for me.

—Endo/Cent #6-2

In many cases, this loss of senses and loss of identity returned after treatment.

After my first operation, the three biggest changes were, I think my senses of smell returned, I could smell flowers after I haven't smelled them for 5 years, my energy level returned, and overall my quality of life improved greatly.

—Endo/Ant #1-3

Social Isolation

Many participants described a social withdrawal prior to and during treatment. This social withdrawal was attributable to fatigue, pain, depressed mood, or endocrinopathies associated with their skull base pathology among other reasons. One participant noted social isolation from her family that resolved after treatment.

So the kids have been spending most of their lives watching me lie down on the couch; watching me being miserable [while I've] been on different kinds of pain medications. So I haven't really been there for them in the past at least five years. [After surgery], I got my life back. They, more importantly, got [me] back.

—Cent/Endo #2-6

Another participant discussed her reservations with social eating because of her altered sense of smell.

I have to be careful when I go out. I have to ask people not to cook certain foods for my own protection—"What are you cooking? What's in it?" People sometimes get annoyed.

—Ant/Open #7-3

One participant describes the social stigmas associated with his dysconjugate gaze following surgery.

Socially, I basically didn't see anybody for a long time. I'm like more of an antisocial kind of guy right now. Like I have my close friends who I see sometimes, but I only like to go out and as a small group because I get a lot of dumb questions and really arrogant people asking questions about the eye, or asking me if I'm drunk or on drugs.

—Cent/Endo #8-6

Coping and Compensatory Strategies

A common theme throughout focus group discussions and analysis of workbooks was the immense capacity to cope with hardship. Some coped with physical ailment by learning behaviors to minimize the disabilities. For example, one participant described his difficulty with double vision:

After a period of time I learned that wearing a patch over one eye solved that, and you know, I was able to function again

—Cent/Open #8-3

Many attributed a relationship with a higher being as a coping strategy and as a means to deal with the psychological distress. *"I have a better connection now, and the surgery really helped to find the connection with God"* (Cent/Endo #2-2). One participant describes placing her future in the hands of a higher being to cope with the unknowns.

I have been through a lot of surgeries so I know at some point, many points, I gave up on understanding that medicine doesn't know all the answers, and really the only support I had was spiritual hope.

—Ant/Endo #1-3

Participants without social supports in their household seemed to have greater difficulty coping with the diagnosis and treatment. One participant who was treated for a clival chordoma and lived alone had a bitter experience with depression. Unlike other participants who used their religious beliefs to help them through a tumultuous time, this participant described distancing himself from a higher being.

Let's say before all of this happened I had been through a period where I became more spiritually aware and more spiritually giving of myself. I would say a lot of that has changed. ... I'm not antisocial or anything, I just really, how can I explain it, I guess I'm just more negative towards a spiritual entity.

—Cent/Open #4-5

For participants without the social support network, work and financial concerns were also a bigger consideration. Without having a spouse to help with finances during treatment, these individuals found it more

challenging to get through treatment. One participant who had no household supports and was self-employed described a large monetary loss related to her diagnosis.

Well [I'm], just, worried. The business has not been doing well. There was a huge loss. So it's a constant worry over my head

—Cent/Endo #6–3

Discussion

Understanding the subjective experiences of patients at various stages of a disease is an important source of evidence for health care providers. To date there is a poor correlation between health care providers' understanding of patients' QOL and what patients report, particularly for those undergoing skull base surgery.³⁰ Despite this apparent discrepancy, no qualitative studies have examined patients' experiences and changes in their QOL.

In part, this can be attributed to the different worldviews of providers and patients. Providers are concerned with disease and patients with illness. Illness has been described as “what the patient feels when he goes to the doctor,” and disease is “what he has on the way home from the doctor's office”³¹ This is such an important distinction that it is worth examining this issue in more detail. In the scientific paradigm of modern medicine, disease refers to:

...abnormalities of the structure and function of body organs and systems ... which can be specifically identified and described by reference to certain biological, chemical or evidence which can be specifically identified and described by reference to certain biological or chemical evidence. In a sense, diseases are seen as abstract 'things' or independent entities ... Their etiology, symptoms and signs, natural history, treatment and prognoses are considered to be similar in whatever individual, culture or group they occur. ... Illness refers to the subjective response of the patient to being unwell; how he, and those around him, perceive the origin and significance of this event; how it affects his behavior or relationships with other people; and the steps he takes to remedy this situation. ... It includes not only his experience of ill-health, but the meaning he gives to that experience. Illness, therefore, is the patient's perspective on his ill-health, a perspective that is very different from disease models.³¹

Based on findings in this study, we proposed a conceptual framework (—Fig. 1) of changes in people's QOL due to symptoms and surgical treatment for skull base tumors based on the stages of disease. We explored symptoms that affect their QOL based on the proposition that surgical approach and tumor location may have different effects on QOL.

Symptoms associated with skull base lesions were often detected prior to diagnosis. Some participants had a positive reaction toward their diagnosis, particularly when there was a significant delay between symptom detection and a con-

firmed medical diagnosis.^{13,22} Molassiotis et al note that this delay can be due to patient factors (appraisal delay, behavioral delay) or system factors (scheduling delay and treatment delay).¹³ In the present study, another factor seemed to emerge. Physician-related delays in reaching a diagnosis delayed the start of treatment.

When asked about the biggest changes in their lives, the overwhelming majority of participants focused on physical changes. These differed by tumor location. Participants with anterior tumors had more nasal changes; those with central tumors had more neurologic and visual complaints. After surgery, participants who had undergone endoscopic procedures more commonly described nasal complaints than those who had open approaches. One might suggest that the difference in physical symptoms between endoscopic and open groups maybe accounted for by the longer follow-up for the patients with open approaches. Indeed, previous studies have suggested that there is an improvement in QOL over time.^{1,5,6} However, these same studies have suggested that the QOL scores plateau at roughly 6 months following surgery.^{1,5} The minimum follow-up for any patient in our groups was 6 months, suggesting any time-sensitive QOL differences should not be apparent in our cohort. Only a comparative prospective study with equal follow-up between groups can confirm this difference noted in our study. Patients who had anterior tumors also experienced more nasal complaints than those with central lesions. Rates at which study participants reported experiencing other physical issues, such as loss of energy and pain, seemed to be similar across surgical approach and tumor location. A recent study reported significantly better scores in physical function in patients undergoing endoscopic versus open surgical approaches for skull base tumors.³² The present study is not a quantitative study and does not purport to detect clinical or statistical differences. Our goal is, however, to generate hypotheses. Both the previous mentioned study as well as ours suggest there may be appreciable QOL differences between patients who have endoscopic versus open skull base approaches. Further prospective studies with homogenous groups are needed to better address these hypotheses.

We identified some major themes across the focus groups. First, participants described a vigorous emotional response accompanied by fear or relief at the time of diagnosis and followed by frustration during and after treatment. Although this finding has not been described for skull base cancers, it has been described in patients with head and neck cancers.³³ In one study, patients with head and neck cancer often have frustration with social eating due to treatment of their cancers. For patients with skull base surgery, the frustration is caused by disease- and treatment-specific impairments. We found participants voiced frustration with cognitive impairments, with changes in visual and nasal functioning. Fear and anxiety were part of the emotional response to diagnosis of a skull base tumor. In patients with head and neck cancer, fear is a highly prevalent issue with > 35% of patients experiencing significant fear.³⁴ This problem stems mainly from a fear of recurrence of disease. This problem of fear and anxiety is poorly understood³⁴ and requires better

communication by physicians and prompt referrals for psychological or psychiatric evaluation.³⁵

Another theme that emerged was the loss of physical senses, function, and loss of identity that often resolved after treatment. This loss of identity has been discussed by other authors with regard to head and neck cancer. Locher et al state, "Cancer and treatment related alterations in self-identity due to changes in their bodies, in taste, and in the manner in which they must eat caused cancer patients to experience frustration and embarrassment."³³ This description corroborates our findings that patients with head and neck cancer or skull base tumors are at risk for loss of self-identity, particularly because they are unable to engage or interact normally with their environment. The loss of vision, smell, taste, and cognition can impair one's ability to interact with the environment and is unique to patients with tumors of the skull base or head and neck.

Social isolation was another theme that prevailed in the focus group discussions. Participants often distanced themselves from family and friends for multiple reasons. This finding is incongruent with the notion that social supports improve QOL in patients with cancer. However, feelings of embarrassment³³ and concerns about social stigmatization because of abnormal appearance³⁶ seem to supersede the need to surround oneself with social supports. There is, however, evidence that poor social supports may be a risk factor for poor physical recovery and poor adjustment to treatment side effects.³⁷ As such, encouraging social and family supports during treatment is imperative.

Patients with skull base tumors show a remarkable capacity for coping with their disease. There is little literature regarding coping in the skull base tumor population; however, in patients with head and neck cancer, patients self-report that coping strategies often involve the use of family and friend support.³⁸ Similarly, we found that participants without supports in the household had difficulty coping emotionally and financially. We also observed a strong spiritual shift to help cope with the diagnosis of a skull base tumor. One study suggests that avoiding coping strategies are associated with poor QOL.³⁹ As such, it is important that patients develop strategies to deal with their disease.

In qualitative research, there is some controversy on how best to establish reliability and validity because these have traditionally been concepts related to quantitative studies. Some experts contend that these concepts involve measurement and are not relevant to qualitative research. Stenbacka suggests, "The concept of reliability is even misleading in qualitative research. If a qualitative study is discussed with reliability as a criterion, the consequence is rather that the study is no good" (p. 552).⁴⁰ Similarly, some researchers suggest that the concept of validity should not apply to qualitative research.⁴¹ Nevertheless, there is a need for establishing methodological rigor. Golafshani suggests that triangulation is a method for improving validity and reliability in qualitative research.⁴¹ In the present study, we attempted to gather data from different sources including a review of the medical records of participants, workbooks, as well as interviews. Furthermore, we attempted to use quantitative meth-

ods by measuring frequencies of specific themes from workbooks as well as a qualitative analysis of the interviews in our analysis. Patton suggests "triangulation strengthens a study by combining methods. This can mean using several kinds of methods or data, including using both quantitative and qualitative approaches"⁴² (p. 247). We further attempted to test the validity of our study by using a post-positivist approach as described by Yin.²⁶ The findings were interpreted based on both a conceptual framework as well as two propositions.

There were, however, some threats to both the reliability as well as the validity of this study. First, the analysis was completed by a single author and not in duplicate. The lack of duplicate coding can threaten the reliability of the data. Furthermore, a single-author analysis may be biased by the author's educational and cultural background. Second, the study was based on a case study of patients from a single-institution over a finite period of time. As such the generalizability of the findings are limited. The inability to generalize is a feature, however, that has been suggested is a differentiating factor between qualitative and quantitative research.⁴³

There are other limitations in the present study. First, the interpretations of participants' experiences with their disease are based on the contents of the focus group sessions, which in turn were guided by a list of topics generated prior to the interviews. The group sessions were intended to be open ended; however, some degree of direction was needed. Second, the purposeful sampling strategy for selection of participants precludes the use of statistical comparisons. Even if there are suggestions of differences between participants with different surgical approaches or different tumor locations, these are only hypotheses and require quantitative methods for confirmation. Third, qualitative sampling often requires repetitive sampling until saturation has been achieved. Due to cost limitations, we did not sample until saturation. Instead we used a factorial design that ensured a minimum of four groups for each surgical approach and tumor location. The goal of this study, however, is to describe the rich body of experiences of patients who undergo skull base surgery and to provide clinicians, other health care providers, and patients a glimpse into the lives of these patients.

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