Themes Examples of Patient Statements

Most Stressful Aspects of the Procedure

Intra-operative Sights, Sounds, and Sensations

- The eye part was probably the most distressing...I couldn't see and it was because there was the sheet and then my scalp was pulled down over the top of that. So yeah, it's a little bit funky. I think all I can remember seeing was the plastic and seeing like a little bit of blood drops on it. [17]
- I don't want to necessarily compare it to a sander, but there was a noise related to some sort of machinery that was happening that obviously was being used by the doctor or surgeon or surgeon's assistant or something. I didn't know what exactly it was, but it seemed related to removing the tumor and that just connection in my mind of like something powerful with the tool is being used inside my cranium...I was just anxious about somebody using a tool on my brain. (12)
- I think the thing that stood out the most I can remember from the actual procedure was seeing the screen that I think my brain was on. I spoke with the anesthesiologist after he came in. He said they turn it off after they realized I could see it. [17]

Lack of Information or Misinformation

- ... I misunderstood... like I thought I was going to be under general anesthesia. But like five minutes before surgery they said wasn't the case. (10)
- I really had no idea how difficult it was going to be. I completely... I think underestimated what was required, physically. I think mentally I prepared myself. Rolling into that operating room, I felt like I know what's going to, I have a sense of what's going to happen and what it's going to take to make it through this, but physically I had no idea what the toll was going to be (afterwards). I figured after a week, it would be like I'm going to be up and about I mean, I there were days where I didn't want to get out of bed. I couldn't get out of bed. I felt like every cell would had been used.[12]
- And then they explained to me that I needed to be strapped in. I was under the impression that I was going to have more mobility than I did. [14]
- But when the saw went off... that was a buzz saw... (*interviewer said*, "And you knew where that saw was going?) No! I did not know where that was going! I mean it went off and nobody said anything. Can you rate how disturbing the noise was to your experience using the 1-10 scale? Nine! (21)

Misunderstanding of What is Happening

• I think I asked you if I was dying. I thought it was a defibrillator...and so I was kind of like oh, Is this like...did something go wrong and are they shocking me to bring me back? and then I realized I felt my arm twitch and I definitely remember it feeling like a muscle spasm and they said, "Okay, it's good" and then I realized like, oh it's Okay. It's not a defibrillator.

Immobility for a Long Procedure

- I mean to be screwed down....To be completely incapacitated physically, and having someone work on you, and not being able to move is a is a claustrophobic feeling and that is something that I feel more now that I am out of the process. [12]
- I was disappointed with not being able to maneuver. I operate better when... I think better when I move. [14]
- It was the fact that I was in one position very much rightfully so push down to one side. And it was obviously very firm.[31]

Clinical Practices that Alleviated Intraoperative Distress

Compassionate and Authentic Relationships

Perceived Sense of Support

Appendix 4.

- I thought the communication was really great back and forth between the team and that was really helpful for me to almost have a more humanized experience with people in the room who are here to help you, 'we understand this is tough, we understand that you're not comfortable, what can we do to help you?' [12]
- They kept complimenting me and saying, 'Oh you're doing so well, and it's thanks to you we're getting this done, such and such.' I forget what she said, but anyway, she seemed to think I was contributing. [23]
- And the people who give you the medicine.... I think they were asking me if was feeling okay, or if I felt pain, and... They're just people who want to help you. [35]

Human Connection and Authentic Presence

- Thank you for allowing me to hold your hand. It was very comforting to like.... It was just very comforting to have a
 human there, that was like very present with me. Yeah, made me feel safe in like an environment where there's a lot
 going on and there's a lot of machines connected to me and a lot of people not necessarily paying attention to me, but
 doing a lot of different things to have that like connection with one other person was a very positive part of it, and that
 was not insignificant. I remember that this was very significant in feeling safe through the surgery process. So thank
 you. [10]
- Yeah, there's only a few parts that I remember but I remember you holding my hand. Thank you for that. That was really nice.[5]
- Your calmness was good. I realized when I was getting scared that I think you were holding my hand and telling me like it's okay and that helped me...kind of bring me back... to be like 'Okay, if she's this calm, it can't be an emergency situation.' [17]

Communication

- The communication between myself and the team I thought was really positive. I felt pretty calm from the for the most part and I think that's attributable to the team again of just keeping me in a spot of knowing what's happening, what's about to happen, and then what's going on as it happened [12]
- It was communicated well with me what was happening at every step. [10]

Clinical Practices that Promoted Patient Perceptions of Empowerment and Control

(Was there anything that facilitated a sense of control or agency?)

Information

- I felt like it started in the preoperative appointment where all of the... between what Dr. X and yourself had told me beforehand about the exercises we would be going through and what I could expect from it. I felt very involved and prepared for both what we were going to be doing why were we going to be doing it and...that felt very empowering and like I was part of it...and that continued into the surgery where I knew why we were doing each part of it and I felt involved and respected in all of that. So that was very positive. [10]
- I can specifically remember not being able to talk. ... The fact that you guys knew that I wasn't speaking....it made sense. So that is an indicator that we prepared you well... Absolutely. You said this might happen, and if so, it's actually a good thing it'll tell us what's going on. Yes. [31]

Provider Responsiveness During the Procedure

- I think just the quick responses from people when I asked for water. I felt immediately that I was getting some water.. and the anesthesiologist too. it felt like he was responding right away when I said something.
- So...Oh so getting the feedback. You know, it was just a reassurance that they're listening to me [17]

Appendix 4.

Perception of teamwork

- I was full partner. [21]
- I think everyone was part of the team. I have to let them know where my pain is for them to be able to help me, or like when I was doing your tests, let them know if I see any changes, so then they can know more areas not to touch or what areas to touch. So, like we all have to work in a team. [35]

Tasks and Timeframes

- But just those reminders you know take a deep breath [17]
- I think being tasked is really important, even if they're simplistic things that are meaningless to the team and to the surgeon, it sure meant a lot to me psychologically, being in that process of, 'okay, what's next? What do you need me to do? You need me to count, say words, count backwards, name the days, whatever...' so that I'm focused on something other than the pain, and the discomfort, and the anxiety. The little sponge water actually was a really successful thing for me because I felt like it was something I could depend on, you know, it was a system that we had going of like, 'okay, I need a little bit water' and I could focus on that and think about that and forget about some of the other things, and then think about the next time that I'm going to get a little more water. That helped me through the process. [12]
- You recommend it beforehand that I pick up my meditation practice. So I did that and I, especially with your cues, I was able to use that during the procedure. It wasn't like, I was necessarily thinking of it myself....so like that's why I used that. *It was helpful once prompted...* Oh, yeah. Yes, absolutely. [10]