

Pediatric Deep Brain Stimulation for Dystonia: Patient and Caregiver Experiences



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Background

- Deep brain stimulation (DBS) is currently offered to pediatric patients with treatment-resistant dystonia, though no randomized controlled trials are available.
- There is currently no research on families’ experiences undergoing DBS surgery for childhood dystonia. Our preliminary results offer insight into the experiences of patients and caregivers.

Methods

- In-depth, semi-structured interviews were conducted with 41 stakeholders, **pediatric patients (n=13)** and **caregivers (n=28)**, who have undergone the process of receiving DBS surgery for dystonia.
- Interview transcripts were analyzed using thematic content analysis.

Results: Pediatric Patients

- Some patients’ symptoms improved after undergoing a period of programming adjustments (n=7; 54%)

“**So it was actually pretty effective pretty fast.** [...] I was able to control my spine a little bit easier. [...] Then it was slow, and then I started standing. Just standing, not walking yet. **Standing, and that was about four or five months after my surgery.**” (010)

“So I had surgery in July [YEAR] and then I think we waited two weeks to turn them on and program them. And then we went up there every couple of months and I think **they tweaked it for maybe a year [...] before they like found my perfect settings.**” (003)

“**They adjusted me every day for about two months. After that, is when I saw some improvement.** Beginning of the summer, I was probably in a wheelchair and end summer, I wasn't in a wheelchair.” (007)

- One patient struggled with programming side effects (n=1; 8%)

“**I have a really big struggle with programming [...].** I always get this weird pulling in my mouth, but what we have found is one of the **side effects of the DBS is my hands, this one I can move fine but this one, it's like I can't really straighten it all the way and when we turn my DBS off, my hand is fine but I can't walk.**” (005)

Results: Caregivers

- Post-surgery, some caregivers experienced challenges (n=10; 36%)

Long process

“**They should have told us it's going to take a long time. We go up gradually. We can't adjust her every day. It doesn't work like that. It's trial and error, we just have to keep playing with it.** Because then you come out of that appointment a little disappointed, like, okay, I thought we were going to be okay. [...] Yeah. We went through the surgery, so I guess we were hoping for a quick fix.” (007)

“And it's a long road. This is the thing is that this surgery is an absolute long road. You have to be prepared and anybody who's going through this, **you have to be prepared for a long haul [...]**” (003)

Finding appropriate setting

“It is literally **trial and error**. We have still not perfected what setting she needs to be on. We're still looking.” (011)

Caring for patient

“[T]hey were releasing us from the hospital and telling me to take him home. I was literally like, "I'm sorry. You must not know me. **I am not capable of taking care of this child in this state.** [...] [Y]ou want me to put him in a car and drive him three and a half hours home to [CITY 1]. If something happens, what am I supposed to do?” (003)

“Then the other thing that I was not at all prepared for is so [...] when you do DBS and you drill holes in your head, air gets in your cranial cavity. Then you plug those holes. Now this air is in your head. We wake up the first day that we're home and the kid looks like Frankenstein. His forehead is out to here. **I'm like, I don't know anything about medicine.** I'm literally, like, oh my God, is that an infection?” (004)

Temporary impact on cognitive skills

“**It makes sense in hindsight that we're poking around in his brain and that might affect his cognitive skills, at least in the short term, but I was not prepared for [it]** ... Processing time was really slow. You would ask him a question, three to five seconds would pass, and then you could see he had registered the question, then there would be three to five more seconds, and then he had an answer ” (026)

Conclusion

- Our preliminary results provide some insight about the experiences of pediatric patients and caregivers. This data will be useful as researchers work to further identify ethical challenges and areas of improvement to minimize potential harms to current and prospective families undergoing DBS for dystonia.

References

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Acknowledgements

Research for this work was supported by a BRAIN Initiative grants from the US National Institutes of Health under Award Number **R01MH121371**. The views expressed are those of the authors alone, and do not necessarily reflect views of the NIH, Harvard Medical School, Massachusetts General Hospital, or Baylor College of Medicine.