Pediatric Deep Brain Stimulation for Dystonia: Patient and Caregiver Experiences
Pham MT1, Campbell TA2, Torgerson L3, Freedberg KJ2, Tang C3, Eappen B3, Dorfman N3, Kostick Quenet K3, Storch EA4, Blumenthal-Barby J3, Lázaro-Muñoz G2,5

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%)
- One patient struggled with programming side effects (n=1; 86%)

> “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)

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

“[They 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. [...] ‘You want me to put him in a car and drive him three and a half hours home to [CITY]. If something happens, who am I supposed to do?’” (003)

Temporal 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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