

Clinical and Psychosocial Factors Considered When Deciding Whether to Offer Deep Brain Stimulation for Childhood Dystonia

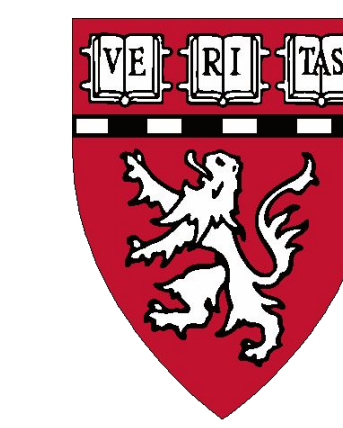
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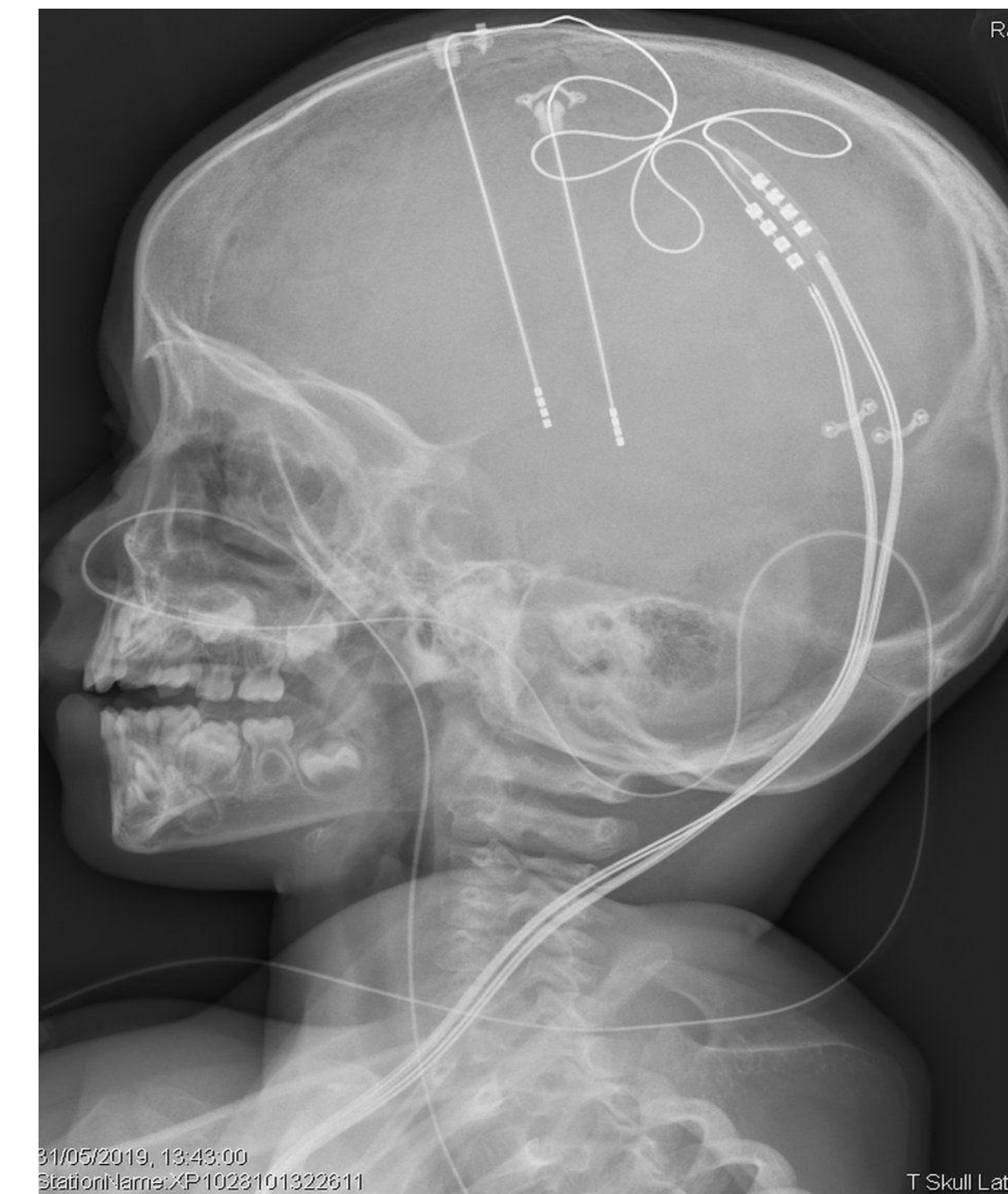


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Study Objective Identify and understand the criteria pediatric movement disorders clinicians use when considering whether to offer pDBS for dystonia to a patient.

Methods

- We conducted **29 in-depth, semi-structured interviews** with dystonia clinicians who treat children and work in active DBS programs.
- Interviews were **audio-recorded, transcribed, and analyzed** using MAXQDA software.
- Interviews were **coded to identify thematic patterns** in clinicians' responses to three questions related to decision-making about pDBS.



Clinical Characteristics

What clinical characteristics make a good candidate for pDBS?

- **Early Intervention: 86%** of clinicians emphasized the importance of shorter disease duration not only to avoid fixed skeletal contractures but to allow for normal social and physical childhood development.
- **Disease Progression: 83%** evaluated severity of disease to determine necessity of DBS, with a focus on specific symptoms that may be controlled by stimulation.
- **Etiology / Genetic Status: 79%** cite knowing the underlying cause of the dystonia and whether the dystonia is the primary issue or inherited like in the case of DYT1 versus secondary causes of dystonia, or acquired, as sometimes seen in children with cerebral palsy or brain injury due to toxins or medications.
- **Perceived Risks & Benefits: 79%** weighed perceived risks of infection, stroke, and other complications against the perceived benefits on a case-by-case basis to determine if DBS may improve function, reduce pain, ease caregiving, and help overall quality of life.
- **Exhaustion of Treatment Options: 55%** stated the importance of trying all other treatment options prior to considering DBS surgery with some clinicians noting a higher threshold for children with secondary dystonia.

Psychosocial Characteristics

What social and psychological factors make a good candidate for pDBS?

- **Family Support: 97%** was the most commonly mentioned factor due to the importance of families attending all appointments, being compliant with wound care, communicating well during programming visits, and juggling jobs and other children with the many visits and necessary attention required for a child getting DBS therapy.
- **Realistic Expectations: 86%** worked with families to ensure they had a good understanding of the DBS process and held reasonable expectations of outcomes.
- **Quality of Life: 69%** evaluate whether DBS can improve the patient's quality of life by decreasing pain, increasing functionality, or facilitating typical development, both socially and physically.
- **Access to Care / Financial Resources: 31%** consider whether families have adequate insurance and recognize challenges for families located long distances from pediatric DBS centers.

Key Takaways

- **Conflicting views** on exhaustion of treatment options with some clinicians disagreeing it is necessary for patients with DYT1.
- **Potential for bias** when evaluating a family's level of social support, financial resources, and a child's Quality of Life.
- Two limitations of our study are:
 - **results are not necessarily generalizable** across all movement disorder specialists due to the small number of participants and
 - **Additional data and research are necessary** to determine which clinical and psychosocial factors impact outcomes.



BBC News

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