



University of Colorado
Anschutz Medical Campus

Beyond Numbers: A Qualitative Study on Deep Brain Stimulation and Quality of Life for Patients with Obsessive-Compulsive Disorder

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BRAIN HEALTH for all, for life.

BACKGROUND

- **Obsessive-compulsive disorder (OCD):** a severe mental illness characterized by **obsessions** (recurring and unwanted thoughts/urges) that lead to **compulsions** (repetitive behaviors/rituals) [4]
 - Affects approximately 1-3% of the world population [1]
- **Deep brain stimulation (DBS)**
 - **Electrodes** in the brain connected to **pulse generators** in the chest [5]
 - Programmed to stimulate targeted areas of the brain
 - Approved to treat **severe treatment-refractory OCD** in 2009



10 patients treated with DBS for treatment-refractory OCD at CU Anschutz since 2015



More on
DBS

Inclusion Criteria	Exclusion Criteria
Severe-extreme OCD (Y-BOCS score ≥ 28)	Active substance use disorder
Participated in ≥ 20 sessions of ERP therapy	Severe personality disorder
Has tried ≥ 3 serotonergic medications for ≥ 12 weeks each at max dose (one of which must be clomipramine)	Primary psychotic or bipolar disorder
Has taken a long-acting benzodiazepine in addition to a serotonergic medication for ≥ 1 month	Imminent suicidality (recent or current suicidal behaviors or plans)
Has taken an antipsychotic in addition to a serotonergic medication for ≥ 1 month	

Timeline of DBS/QoL Study

1

Initial quantitative data collection began in 2015

2

Qualitative (interview) element added in 2023



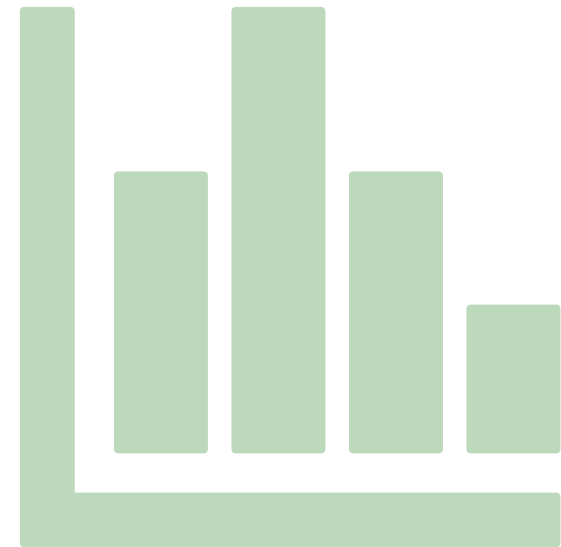
PATIENT DEMOGRAPHICS

- **10 patients** treated with DBS for treatment-refractory OCD at CU Anschutz
 - 3 female, 7 male (age range: 23-54)
 - 8 patients had pre-DBS data for quantitative assessments (2 patients had their surgeries done elsewhere)
 - Patients had DBS surgery at different times; some patients had one surgery, and others had multiple surgeries
- **Comorbidities:**
 - 9 patients with major depressive disorder dx
 - 1 patient with bipolar disorder dx
 - 4 patients with eating disorder dx
 - 5 patients with tic disorder/Tourette syndrome dx

The Initial Study: Methods

- **Quantitative measures:**

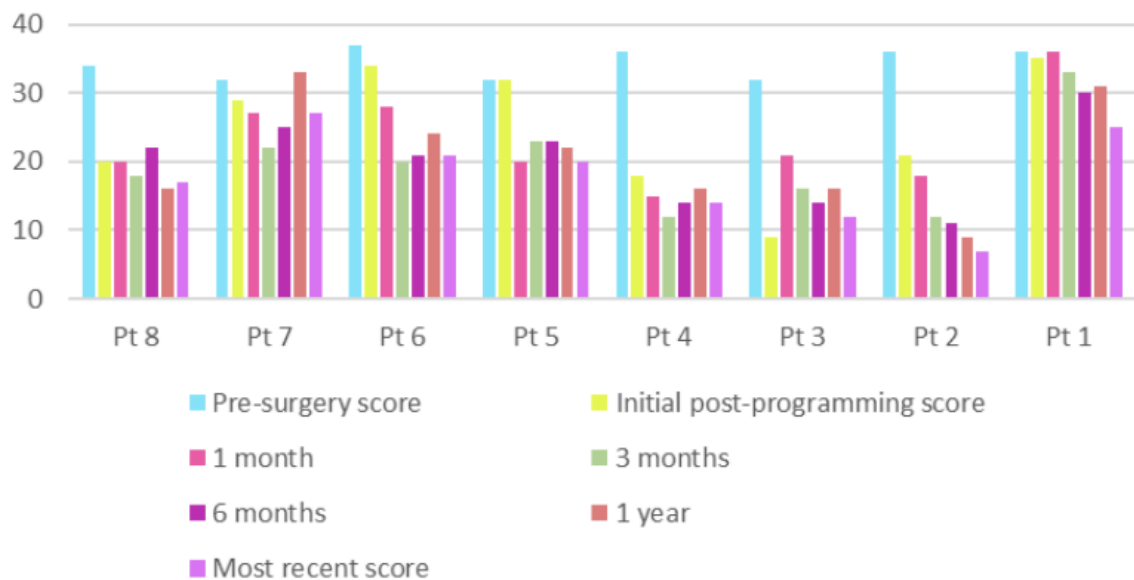
- Quality of Life Enjoyment and Satisfaction Questionnaire (Q-LES-Q-SF)
- Yale-Brown Obsessive Compulsive Scale (**Y-BOCS**)
- Young Mania Rating Scale (**YMRS**)
- Hamilton Anxiety Rating Scale (**HAM-A**)
- Montgomery–Åsberg Depression Rating Scale (**MADRS**)



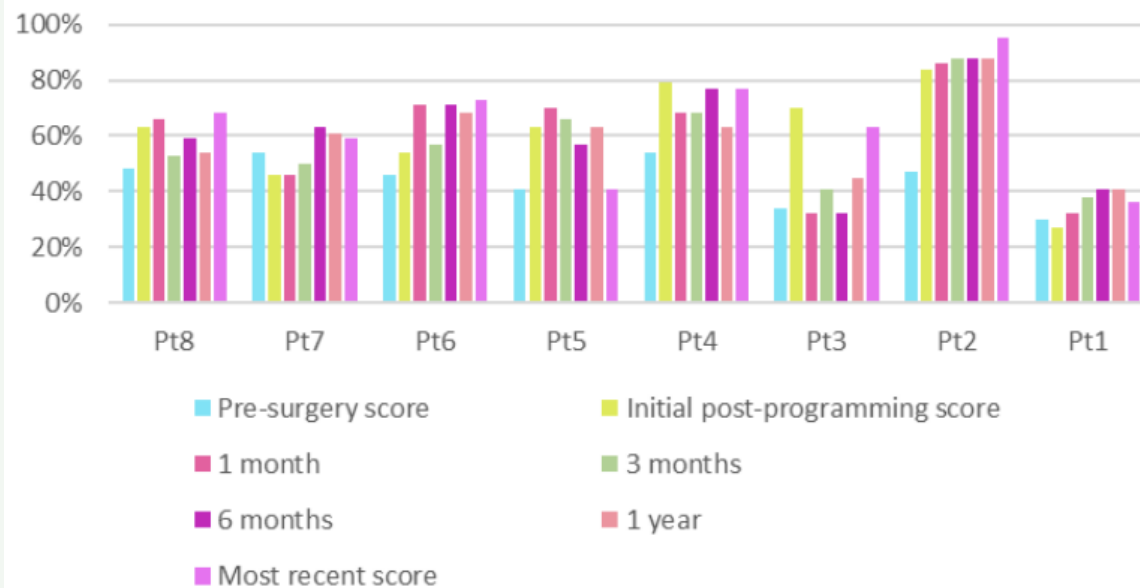
Quantitative Results

General trends toward improvements, but fluctuates; need more information

Y-BOCS (OCD Symptoms)



Q-LES-Q-SF (Quality of Life)



Study Objectives



Some patients treated with DBS for OCD verbally report improvements in quality of life (QoL), however, assessment scores alone do not always reflect this



Aims to explore what areas and QoL domains change and/or need more attention for DBS patients being treated for treatment-refractory OCD



Improved understanding is important for individualizing treatment and in turn reducing OCD symptoms and improving QoL

RESEARCH QUESTIONS



What are the lived experiences and QoL of people with OCD pre- and post-DBS?



How does DBS impact QoL in people with OCD?



What factors influence QoL in people with OCD pre- and post-DBS?

The Present Study: Methods



Qualitative interview comprising of questions about...

Each Q-LES-Q-SF domain → stayed the same, improved, or worsened?

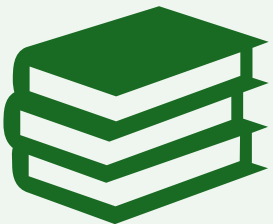
What life was like pre-DBS

When life improved after DBS

What life was like 1 month, 3 months, 6 months, 1 year, and 2(+ if applicable) years post-DBS

Ranked level of improvement in QoL since DBS on a scale of 0-10

Disappointment around potential QoL domains that haven't changed + ranked level of disappointment on a scale of 0-10

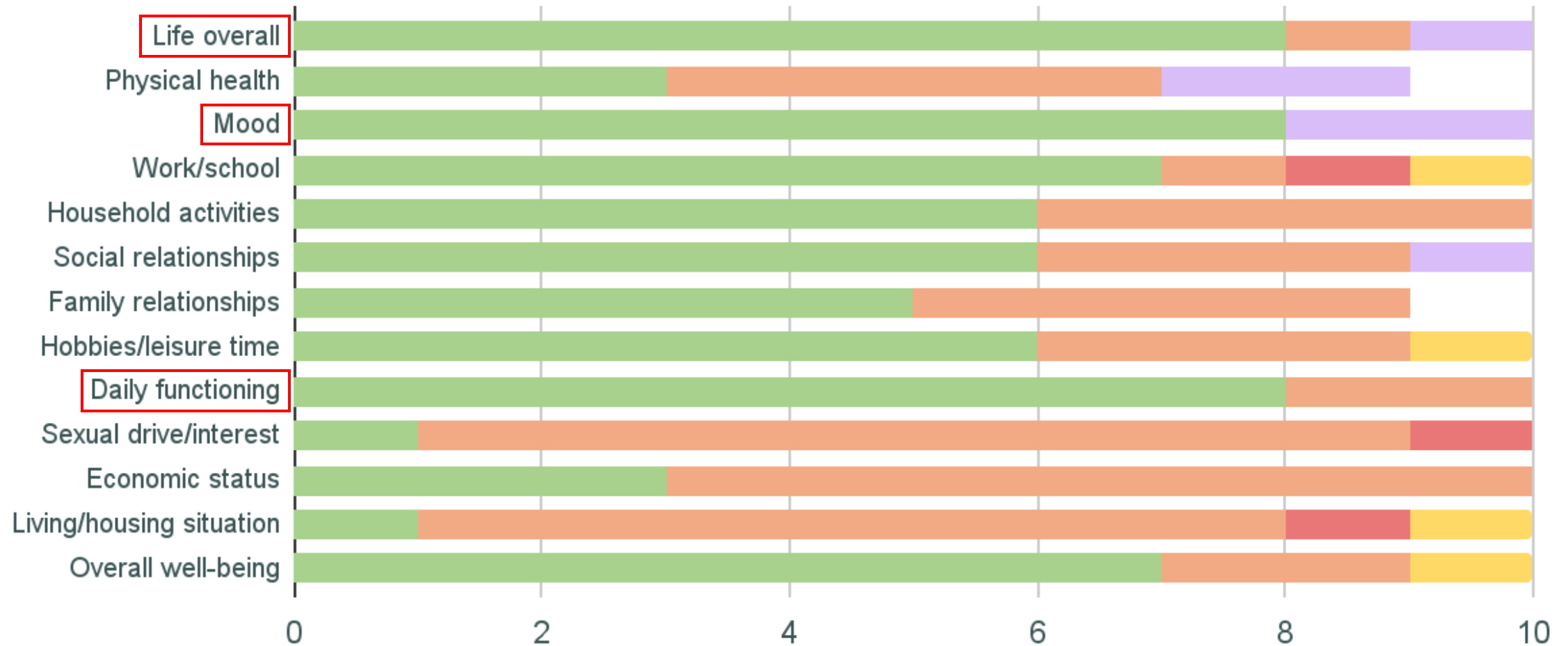


Inductive coding used to organize and conceptualize themes

Interviews are ongoing and conducted on an annual basis; this study focuses on data from 2023 interviews

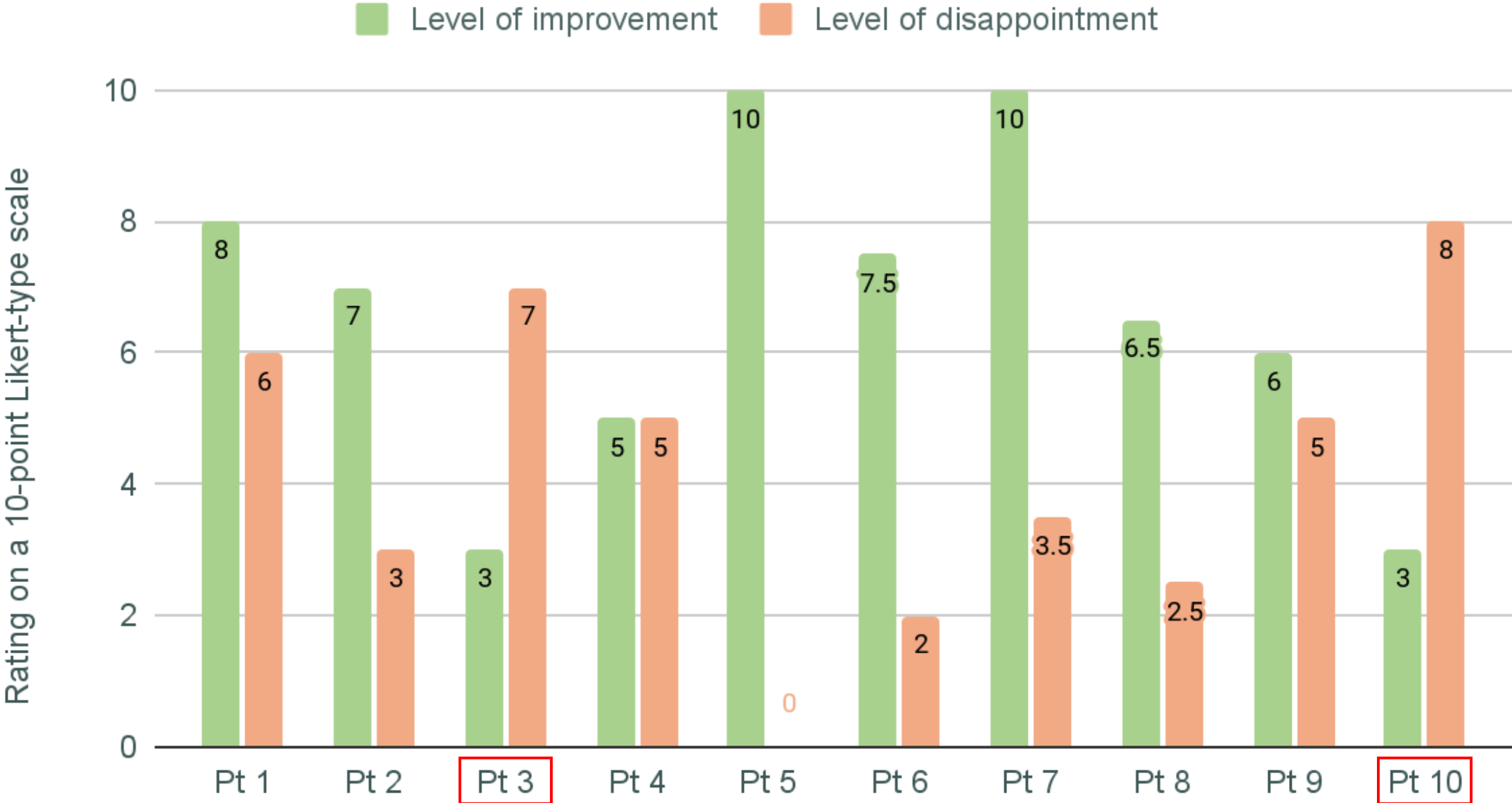
Q-LES-Q-SF Domain Changes Post-DBS

Improved Stayed the same Worsened Fluctuated Complicated



Number of Patients Reported

QoL Improvement and Disappointment Ratings Post-DBS



Common Pre- and Post-DBS Themes

Pre-DBS



Post-DBS



Patient Quotes

“Before [DBS], I had no will to do anything, no desire, no excitement. And now I feel a bit more like the so-called normal human that can actually, like, feel things and live life being excited about things.”

“I think having the surgery was the best thing I could ever do for myself... But I, you know, I knew going in that I wasn't going to get rid of all of the OCD, no matter what [DBS] did, you know?”

“I have so much more RAM or bandwidth in my head because it's not full of obsessions. And so, trying to fill that with productive activities and social support and meaningful things is trying to build a life that's not consumed by OCD. I think that part is lagging and still taking some work, but my headspace is tremendously better.”

CONCLUSIONS

Most notable improvements in QoL post-DBS:

- Mood and hopefulness
- Daily functioning – “normal” tasks feel easier
- OCD symptoms less time-consuming and constricting
- Capacity for interests and general life enjoyment

Remaining symptoms/ongoing concerns themes:

- Depressive symptoms improved but still present
- Desire for continued improvement and comfortability in social relationships
- Desire for more independence in living situation

Outside factors themes:

- Medication changes (impacting physical health, mood, and sexual interest)
- Recurrent disordered eating
- Miscellaneous (relational issues, illness)



Considerations & Limitations

Comorbidities and **external factors** may impact DBS outcomes and maintaining improvements

Cognitive rigidity that is common with OCD may influence recognition of improvements

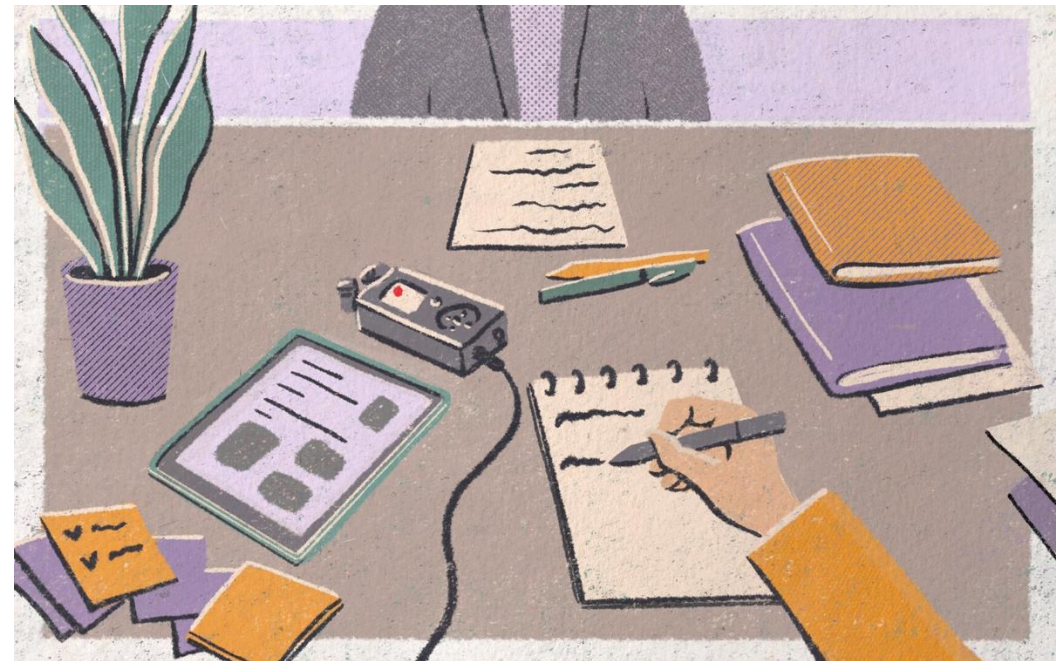
DBS can be effective at treating treatment-refractory OCD, but it is **not a stand-alone treatment**

Patients reported that following up with **therapy** and **medication management** were important

Small sample size limits generalizability of findings

Future Directions

- Mixed-methods study on QoL of DBS patients' caregivers/loved ones
 - **Quantitative measures:** Zarit Burden Interview (ZBI), Family Accommodation Scale (FAS), Quality of Life Enjoyment and Satisfaction Questionnaire (Q-LES-Q-SF)
 - **Qualitative interview** on perception of loved one's QoL, their own QoL, and family accommodation pre- and post-DBS
- Patients may benefit from **life skills training** in addition to therapeutic follow-up



Special Thanks To...

- Emily Hemendinger, Clinical Director of OCD Program
- Katie Sinsko, Social Work Fellow/IOP Therapist
- Dr. Rachel Davis, Medical Director of OCD Program
- Yunliang (Lily) Luo, Director of PURPLE Program
- Shanna Trott, Director of PURPLE Program
- Dr. Merlin Ariefdjohan, PURPLE Program Founder and Faculty Advisor
- Dr. Ron-Li Liaw, Chair of PMHI
- Dr. Neill Epperson, Chair of Department of Psychiatry
- Dr. Dominic Martinez, Dir. Office of Inclusion and Outreach, CCTSI



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A photograph of a modern university building featuring a prominent glass skybridge connecting two wings. The building has a mix of brick and dark metal panels. In the foreground, a paved walkway leads through a green lawn, with several people walking away from the camera. The sky is clear and blue.

QUESTIONS?