



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

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References/Resources



BACKGROUND

- **Obsessive-compulsive disorder (OCD)** is a severe mental illness characterized by obsessions (recurring and unwanted thoughts/urges) that lead to compulsions (repetitive behaviors/rituals)
- **Deep brain stimulation (DBS)**, a surgical procedure originally developed to treat movement conditions such as Parkinson's disease, was approved to treat **treatment-refractory OCD** under a humanitarian device exemption (HDE) in 2009
 - Involves **electrodes** being placed in the brain and connected to **pulse generators** in the chest which are programmed to stimulate targeted areas of the brain
- Some patients treated with DBS for OCD verbally report improvements in **quality of life (QoL)**, however, assessment scores alone do not always align with this
- **This ongoing research aims to explore what areas and QoL domains change and/or need more attention for DBS patients being treated for treatment-refractory OCD**
 - Goal of understanding patients' lived experiences, the impact of DBS on their QoL, and what factors influence QoL
 - Improved understanding is important for **individualizing treatment** and in turn reducing OCD symptoms

METHODS

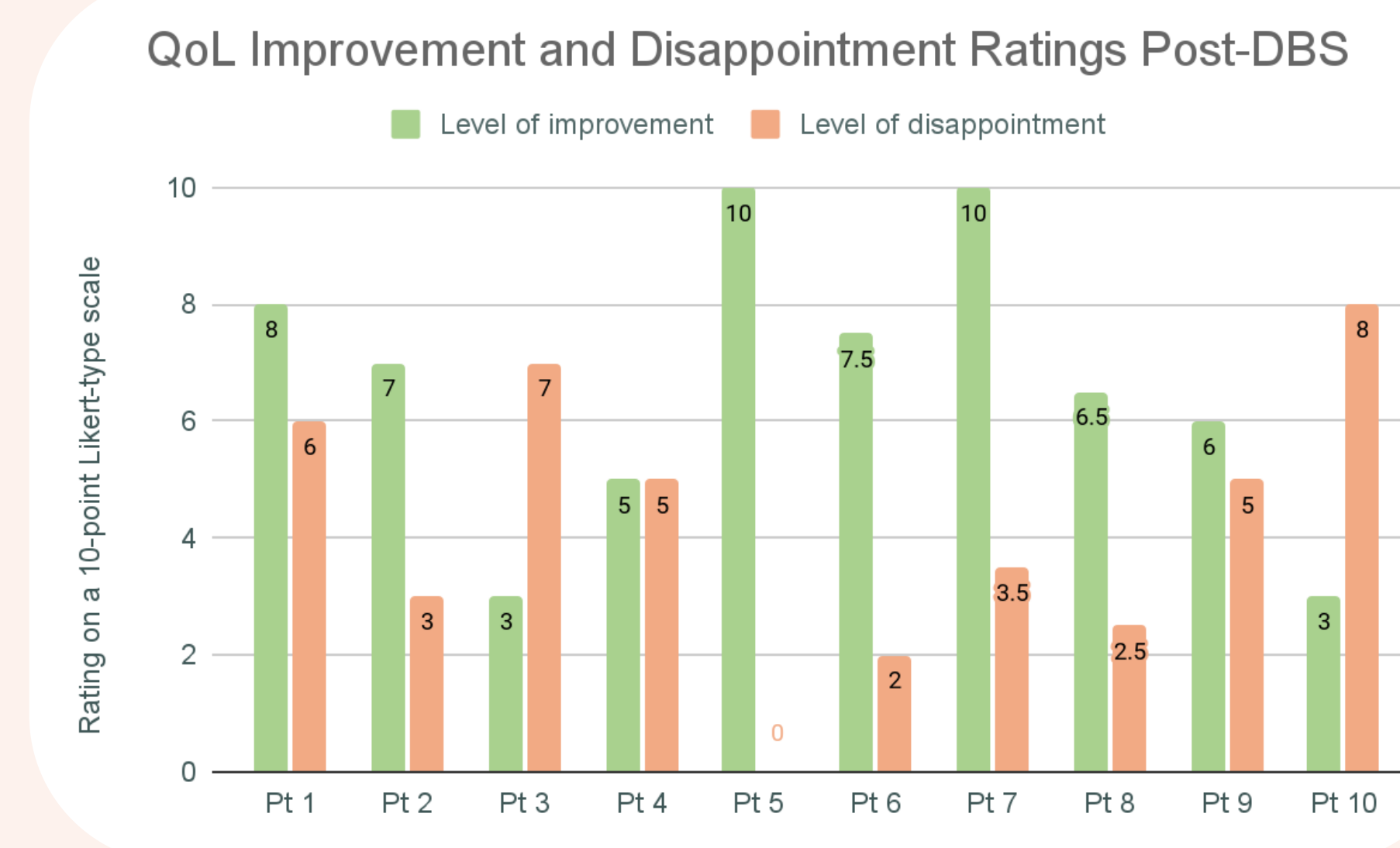
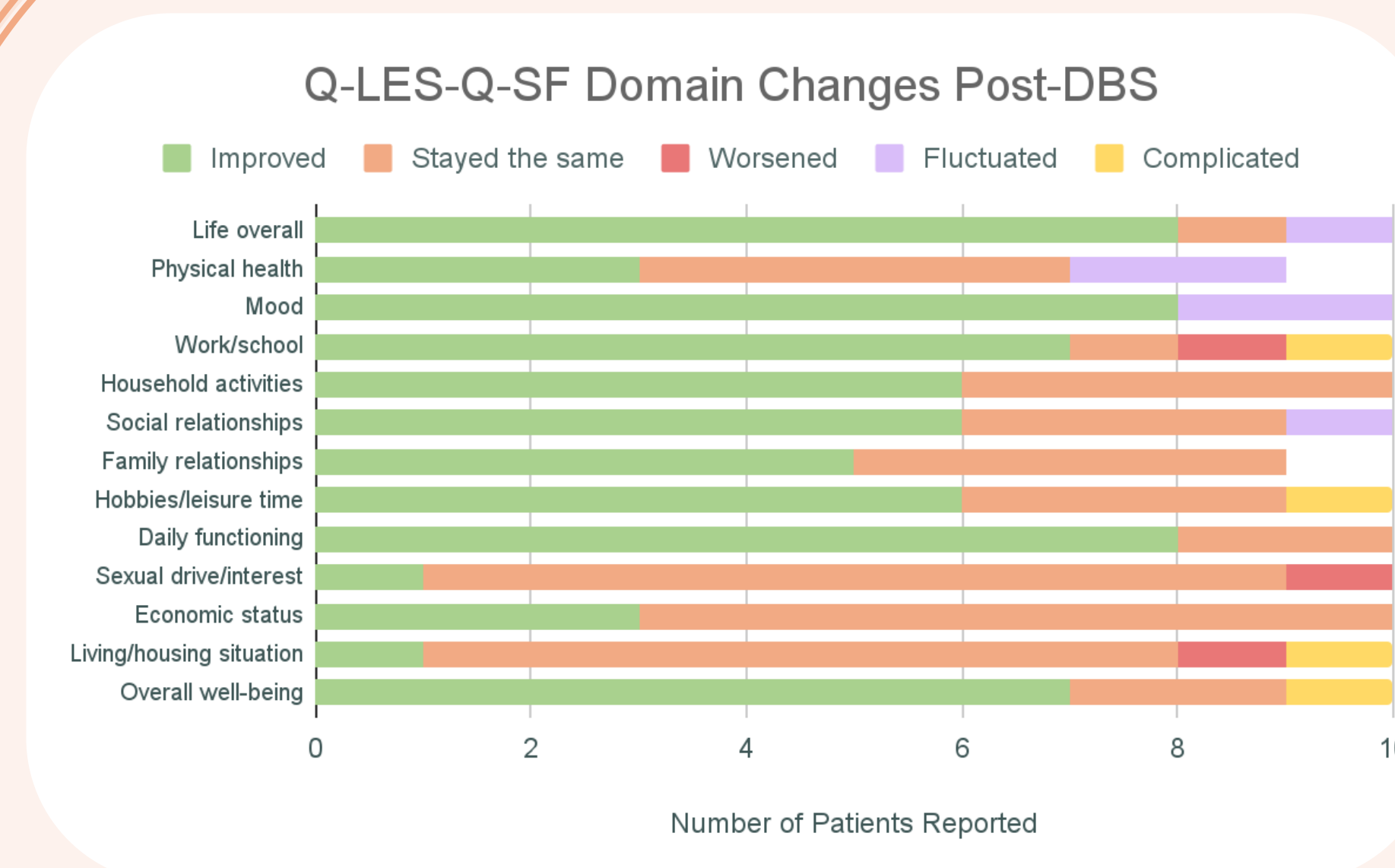
Sample and Insights

- **10 patients** treated with DBS for treatment-refractory OCD at CU Anschutz since 2015
 - 3 female, 7 male (age range: 23-54)
- **Comorbidities:**
 - 9/10 patients with major depressive disorder dx
 - 1/10 patients with bipolar disorder dx
 - 4/10 patients with eating disorder dx
 - 5/10 patients with tic disorder/Tourette syndrome dx

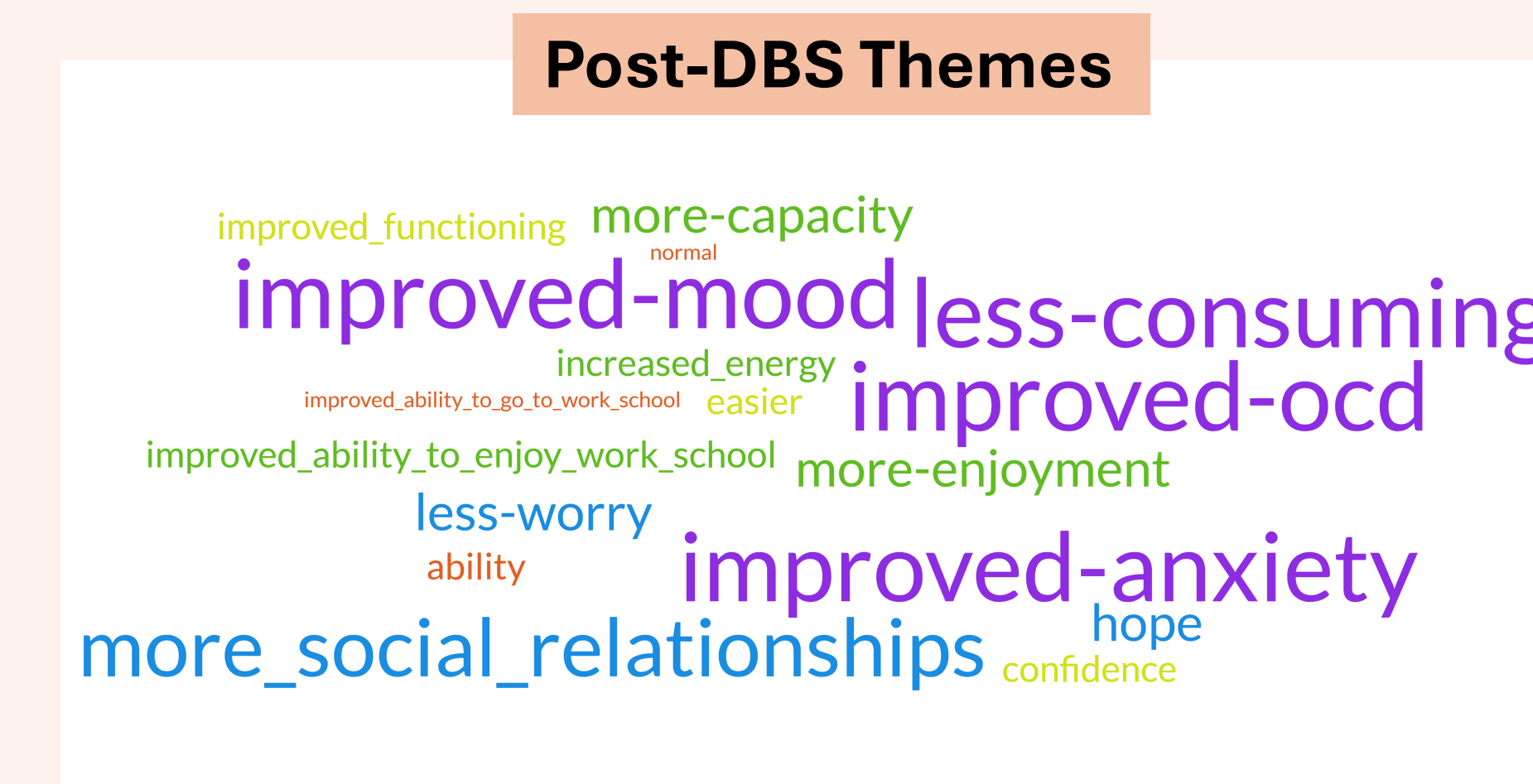
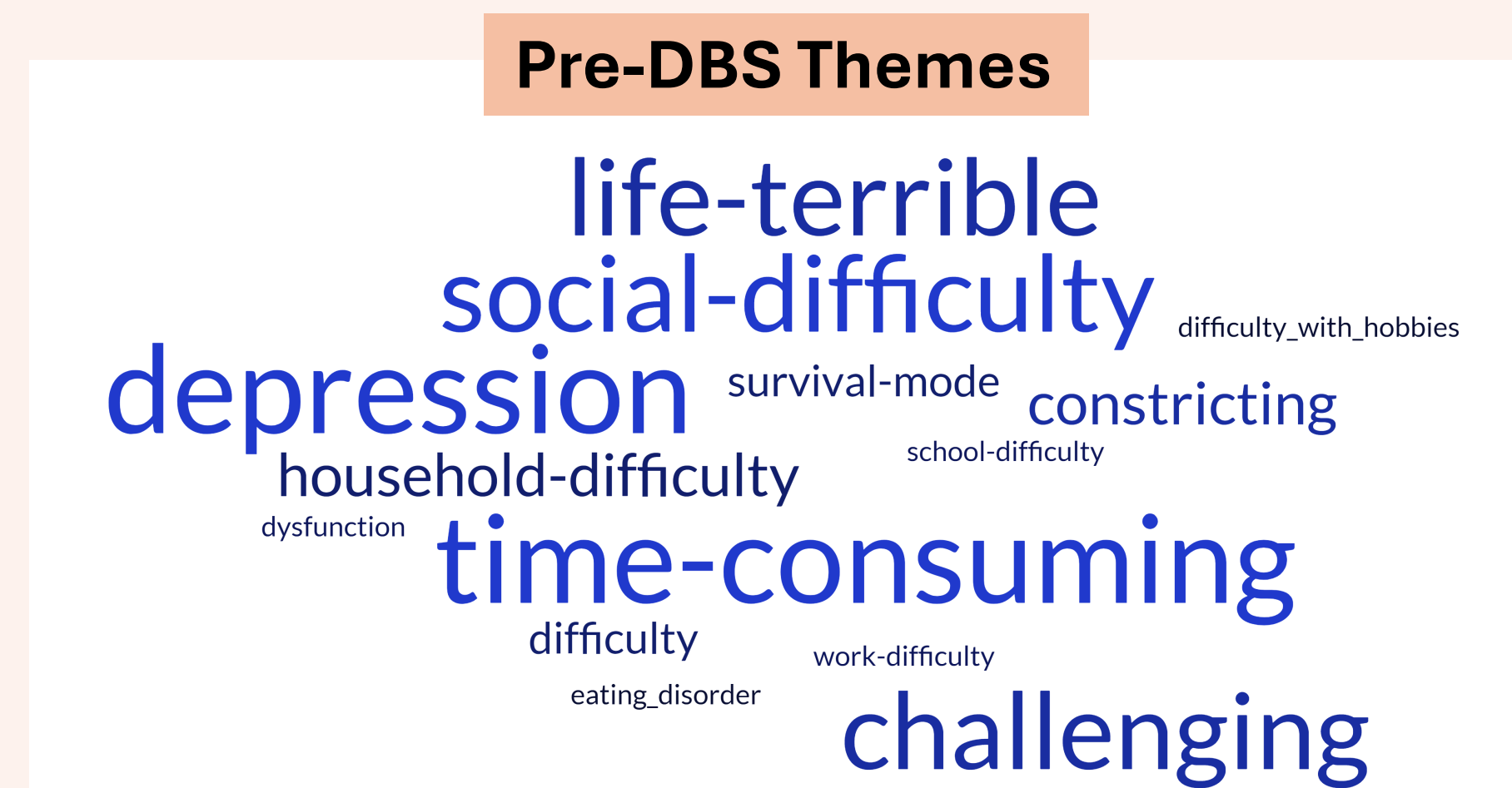
Qualitative Data Collection

- **1:1 interviews** conducted July 2023 – Nov 2023
 - Qualitative coding ongoing since Jan 2024
 - **Thematic analysis** used to organize/conceptualize themes within the interview transcripts

RESULTS



- Most patients reported **improvements in 8 Q-LES-Q-SF (quality of life) domains**, aside from physical health, sexual drive/interest/performance, economic status, and living/housing situation, in which most patients reported no changes
- The 2 patients with the lowest improvement scores and highest disappointment scores have **comorbid and active anorexia nervosa**
- All 8 other patients reported greater improvement ratings (M = 7.5) than disappointment ratings (M = 3.4) regarding QoL post-DBS
 - Patients noted disappointments mostly around **lack of improvement in social life and remaining OCD/anxiety symptoms**, however patients acknowledged that they were mainly due to outside factors, and they did not expect DBS to help with all their concerns



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?"

"Before DBS I was just surviving, like, I wasn't doing any hobbies because surviving was all I could focus on... I was just there, kind of sitting. So, after... I've been able to do a lot more that I've always wanted to do but never had the ability to mentally handle."

"Everyone who I worked with [was] saying like, this isn't going to cure you... So, I feel like I was prepared for that. But the level of disappointment. I mean, like especially for like the social aspect... I mean, super disappointed."

"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."

DISCUSSION

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 and Limitations

- **Comorbidities** and **external factors** may impact DBS outcomes and maintaining improvements
- **Rigid thought patterns** that are 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
 - Patients may also benefit from life skills training
- **Small sample size** limits generalizability of results

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