

Relationship between patients' desired control of their deep brain stimulator and subjective global control

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Background

- ❖ Controversy surrounding whether deep brain stimulation (DBS) results in a loss of control exists in the neuroethics' literature (e.g., Gisquet, 2008; Gilbert et al. 2018; Kubu et al 2019).
- ❖ Patients with Parkinson's Disease (PD) who undergo DBS relinquish some bodily control to their DBS team to gain more control of symptoms and restore the ability to engage in valued activities which raises interesting ethical questions regarding different kinds of control.

Aims

- ❖ Examine the relationship between patients' desired control of the deep brain stimulator and perception of global life control.
- ❖ Explore patient-identified themes related to their desired level of control of their deep brain stimulator, and themes related to their perceived levels of global life control.

Methods

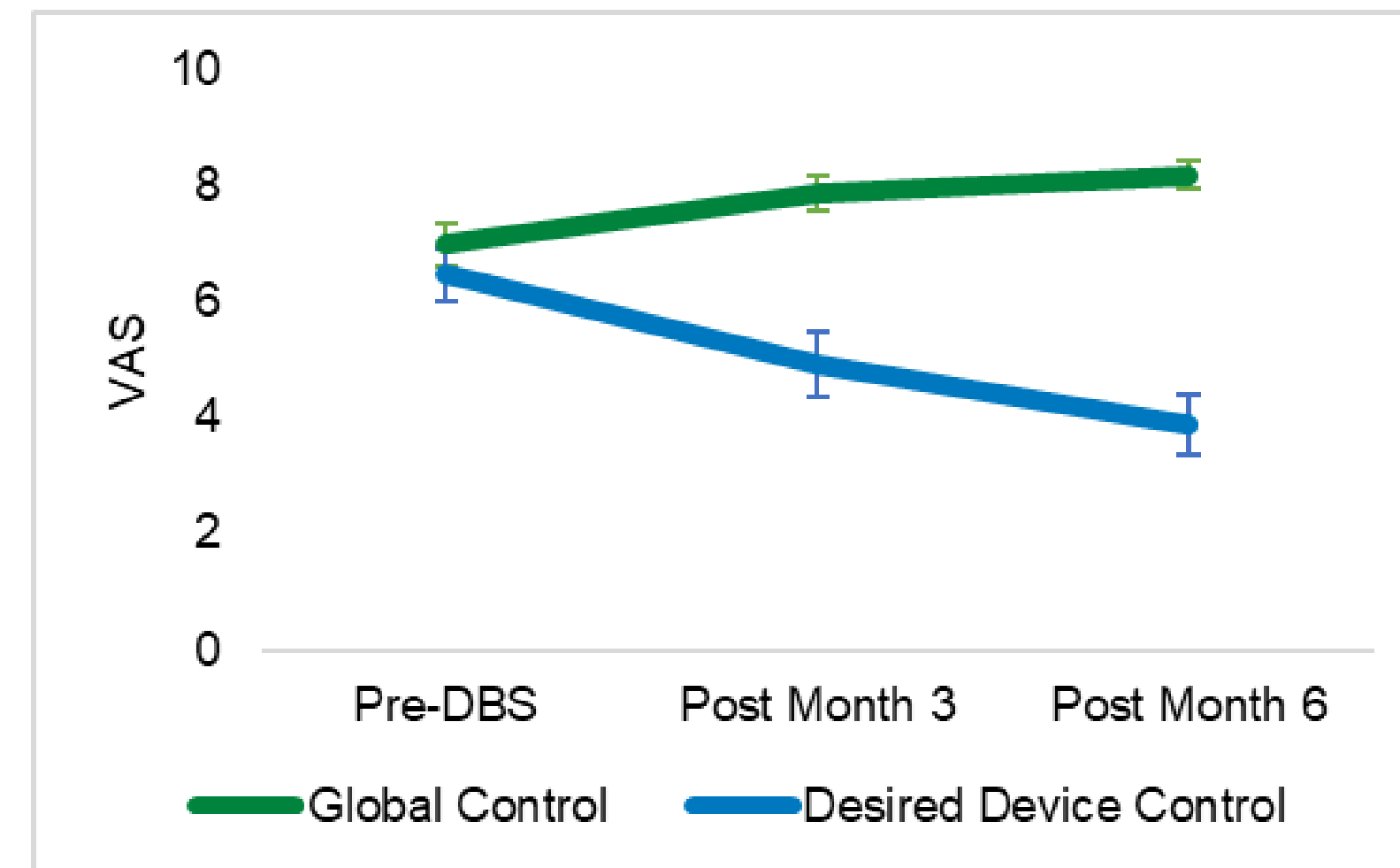
- ❖ Mixed methodology incorporating qualitative and quantitative analyses of a consecutive series of 52 patients with PD undergoing DBS surgery.
- ❖ Semi-structured interviews were conducted at three time points (Pre-DBS, Post Month 3, Post Month 6). Visual analogue scales (VAS) were embedded in the interviews to quantify perceptions of global life control and patients' desired levels of control over their stimulator device.

Analyses

- ❖ Quantitative data from VAS were analyzed using Generalized estimating equation (GEE) models.
- ❖ Qualitative data from a subset (N=39) patients underwent thematic content analysis to inductively and iteratively identify recurring patient-reported themes relating to desired control of stimulator devices and their perceptions of global life control.

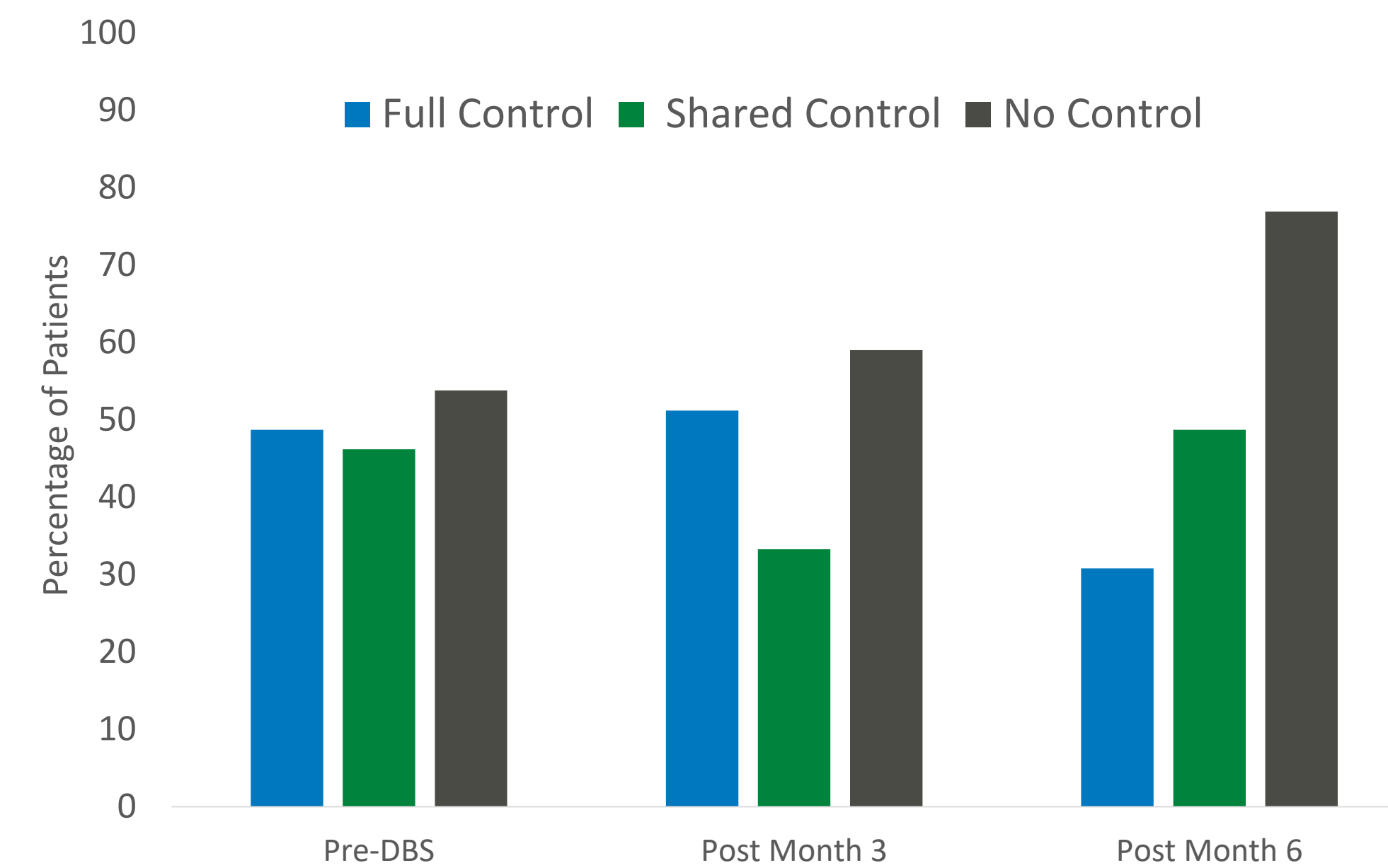
Results

Figure 1. Patient-reported themes related to desired control of stimulator device



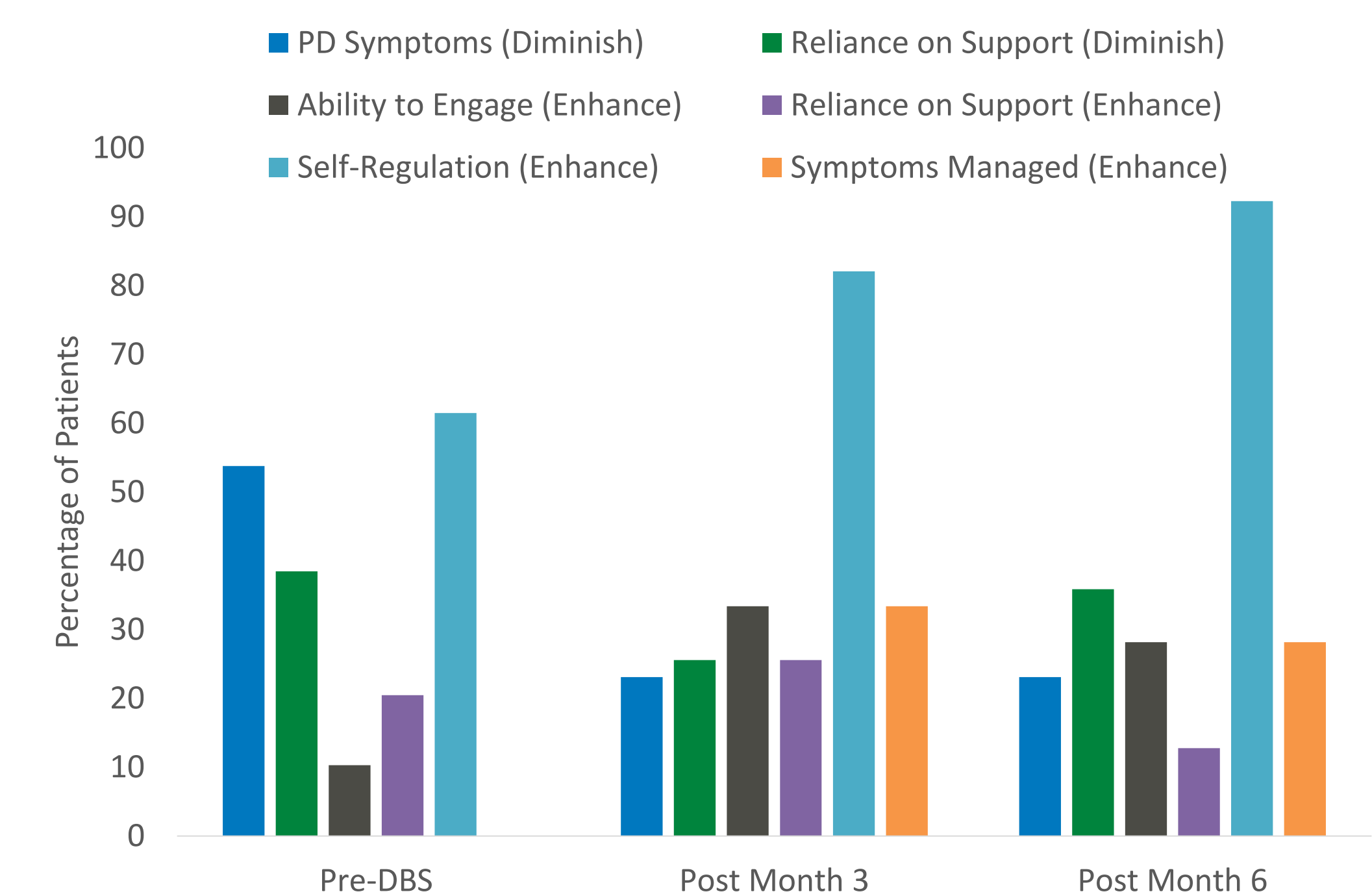
- ❖ Participants reported significant improvements in their self-ratings of global life control over time (Mean Change=1.42, SD=2.55).
- ❖ Participants reported significant declines in desired device control over time (Mean Change=-2.41, SD=4.41).
- ❖ Improvements in global control were negatively correlated with decline in desired device control ($r=-.31$, $p=0.038$).
- ❖ Changes in the control measures were not significantly correlated with changes in motor symptoms measured using the UPDRS-III (Desired Control, $r=-0.10$, $p=0.518$; Global Control, $r=0.02$, $p=0.903$).

Figure 2. Patient-reported themes related to desired control of stimulator device



- ❖ Participants identified several reasons for desiring more or less control of their DBS stimulators.
- ❖ These themes fell under three broad categories: Full Control, Shared Control, and No Control.
- ❖ Over time, from pre-DBS to 6 months post-surgery, a growing number of participants reported desiring shared control or no control. Many patients indicated that their reduced desire to control the DBS stimulator reflected a sense of collaboration with, trust in, and respect for the DBS team's expertise.

Figure 3. Patient-reported themes related to global life control



- ❖ Participants identified many aspects of their lives that contributed to either enhancing or diminishing feelings of global life control.*
- ❖ These themes fell under six broader categories including:
 - ❖ PD Symptoms (Diminish)
 - ❖ Ability to engage in valued activities (Enhance)
 - ❖ Reliance on Support Systems (Mixed Effects)
 - ❖ Internal Self-Regulation (Mixed Effects)**
 - ❖ PD Symptoms Managed (Enhance)
 - ❖ Other (Diminish)***
- ❖ Over time, from pre-DBS to 6 months post-surgery, participants reported increases in ability to engage with others, improvement in PD symptom management, and increased ability to self-regulate across various domains of functioning.
- ❖ *Most participants' responses included more than one category
- ❖ **Only enhancing internal self-regulation themes are reported here due to the low (<2) instances at each time point
- ❖ ***Other category had only 1 data point at each interview time point, and is not reported here

Description of Qualitative Themes

Device Control Themes

- ❖ **Full Control:** Desire to adjust and control symptoms, control their own bodies, and reduce burden of travel to see programmer
- ❖ **Shared Control:** Partnership with team in which patient provides input to the team, patient controls the device with assistance from the team, and basic ON/OFF functions
- ❖ **No Control:** Patient trusts team and their expertise; patient feels the system is working well; patient feels they don't have the training or don't want this responsibility; fears of harming self or device

Global Life Control Themes

- ❖ **PD Symptoms (Diminish):** Feeling as though PD controls body and life; challenges from PD symptoms
- ❖ **Reliance on Support Systems (Diminish/Enhance):** Reliance on family/friends, DBS team, DBS treatment and PD medications, Faith.
- ❖ **Continued ability to engage in valued activities (Enhance):** Ability to engage in hobbies, work, volunteer; ability to engage with friends and family
- ❖ **Internal Self-Regulation (Enhance):** Patient feels cognitively and emotionally in control; able to make decisions; feels independent
- ❖ **PD Symptoms Managed (Enhance):** PD Symptoms improved; patient feels better physically

Discussion

- ❖ Participants indicated a significant increase in perceived global control following DBS while indicating significantly less desire to control the stimulator
- ❖ The qualitative data illustrate that reduced desire to control the stimulator was related to a sense of collaboration with, trust in, and respect for the DBS team's expertise over time
- ❖ Improvements in global control over time appear to be related to participants' increased ability to engage in valued activities following DBS as well as the ability to internally self-regulate across cognitive, affective, and interpersonal domains to maintain a sense of control over their lives
- ❖ Our data highlight the important distinction between different aspects of control and how patients may be willing to cede some bodily control to the medical team to gain greater global control over their lives

References and Funding

- Gilbert, F., Viana, J. N. M., & Ineichen, C. (2018). Deflating the "DBS causes personality changes" bubble. *Neuroethics*, 1-17.
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