

# Patient-Participant Narratives of the Decision to Join Non-Therapeutic Intraoperative Neurophysiology Research: A Qualitative Analysis

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## Background

- Non-therapeutic intraoperative neurophysiology studies involve basic neuroscience research conducted during a neurosurgical procedure, such as the implantation of a deep brain stimulator (DBS) device for Parkinson’s disease (PD).
- Such research includes electrical recording or stimulation, unrelated to the patient’s clinical care, for the purpose of advancing knowledge of the human brain.<sup>1</sup>
- Since this research is non-therapeutic, these studies do not offer any added clinical benefit but may subject already vulnerable patients to further risk.
- This evolving field of research raises novel ethical concerns related to informed consent, acceptable risk, and overlap of clinical and research components of neurosurgical care.<sup>1,2</sup>
- Most ethical and qualitative research about this field has focused on perspectives of researchers and physicians with little focus on the patient experience of non-therapeutic research during DBS surgery.

## Objective

Explore patient-participant narratives surrounding their decision to join non-therapeutic intraoperative neurophysiology research.

## Methods

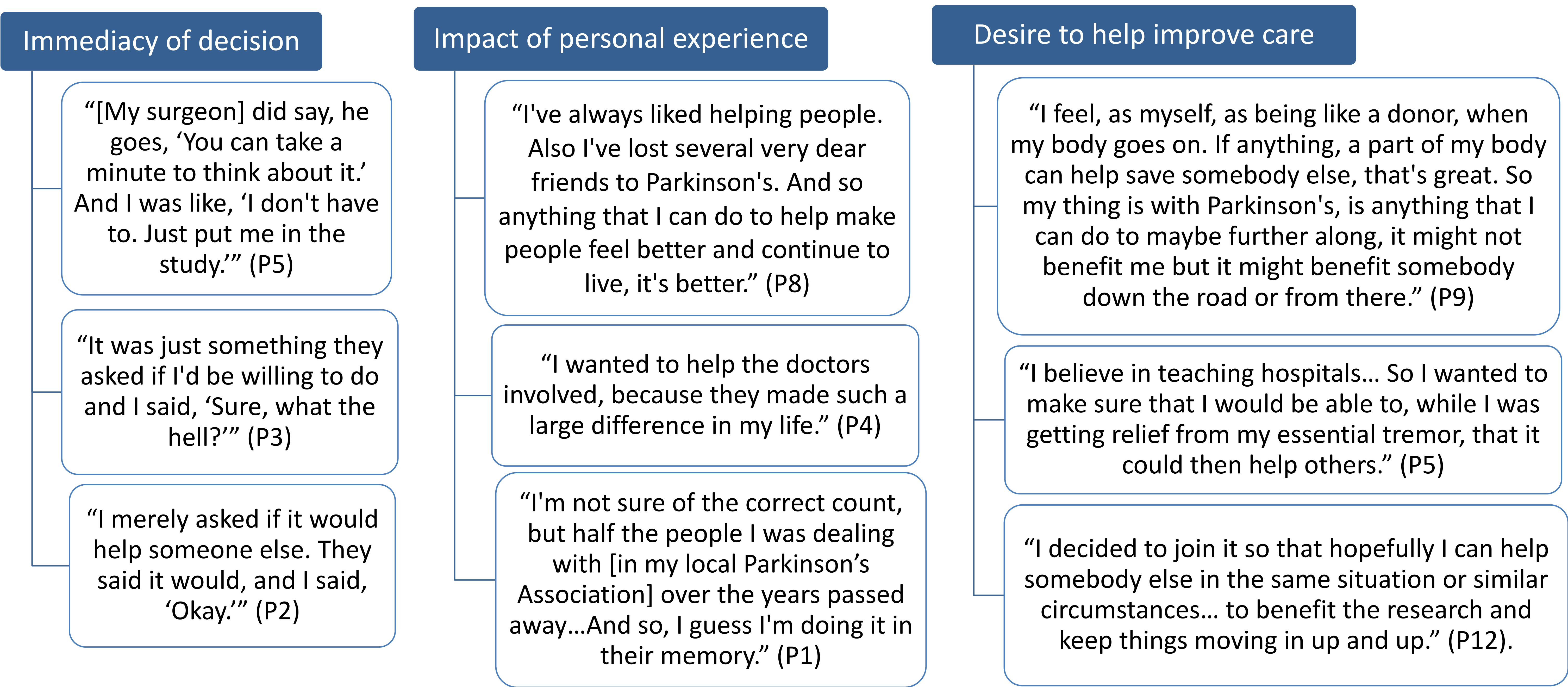
- As part of an ongoing qualitative study funded by the BRAIN Initiative, semi-structured interviews were conducted with 12 patients (P1-P12) who had participated in non-therapeutic research during their surgical implantation of a deep brain stimulator for Parkinson’s disease, dystonia, or essential tremor.
- The interviews were transcribed and coded using a codebook emphasizing risk, patient engagement, and motivations to participate.
- A focused thematic analysis of the narratives involving the decision to participate in the intraoperative research was completed.

<sup>1</sup>Joncarmen V. Mergenthaler, et al. (2021) A Qualitative Analysis of Ethical Perspectives on Recruitment and Consent for Human Intracranial Electrophysiology Studies, *AJOB Neuroscience*, 12:1, 57-67, DOI: 10.1080/21507740.2020.1866098

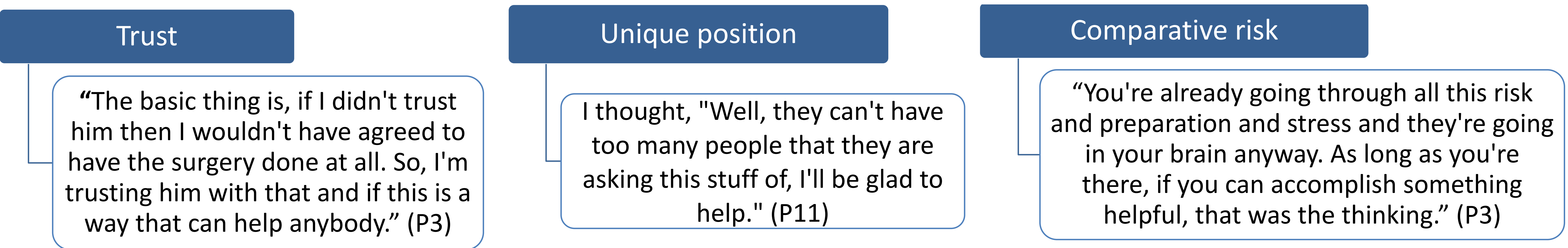
<sup>2</sup>Winston Chiong, et al. (2018) Neurosurgical Patients as Human Research Subjects: Ethical Considerations in Intracranial Neurophysiology Research, *Neurosurgery*, 83:29-37, DOI:10.1093/neuros/nyx361

## Results

An analysis of patient responses when asked about their decision to join indicated the following themes:



Analysis of quotes addressing decision making throughout the interviews yielded the following additional themes:



## Conclusion

- The decision to participate in non-therapeutic research during DBS implantation was immediate for several patient-participants, suggesting some patients have reason to feel comfortable joining intraoperative research without hesitation.
- When all interviewees were asked about their decision, their responses revealed that personal experience and the desire to improve care were primary motivations; additional factors, such as trust, their unique position as neurosurgical patients, and the minimal risk compared to the DBS surgery provided further context to patients’ reasoning and/or lack of concern.
- These personal and contextual factors are not all traditionally emphasized in the process of informed consent yet seem to play an important role in patients’ decision-making.
- Therefore, patient-participant narratives provide valuable insight towards patient-centered informed consent practices and should be incorporated when determining acceptable risk of future non-therapeutic research as the field evolves.
- This qualitative analysis is limited by the selection of patients who consented to both DBS placement and intraoperative research; further studies should explore the perspectives of those who decline to participate.