Deep Brain Stimulation Enhances Control and Restores Valued Personality Characteristics

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Parkinson's Foundation
CENTER OF EXCELLENCE

Disclosure

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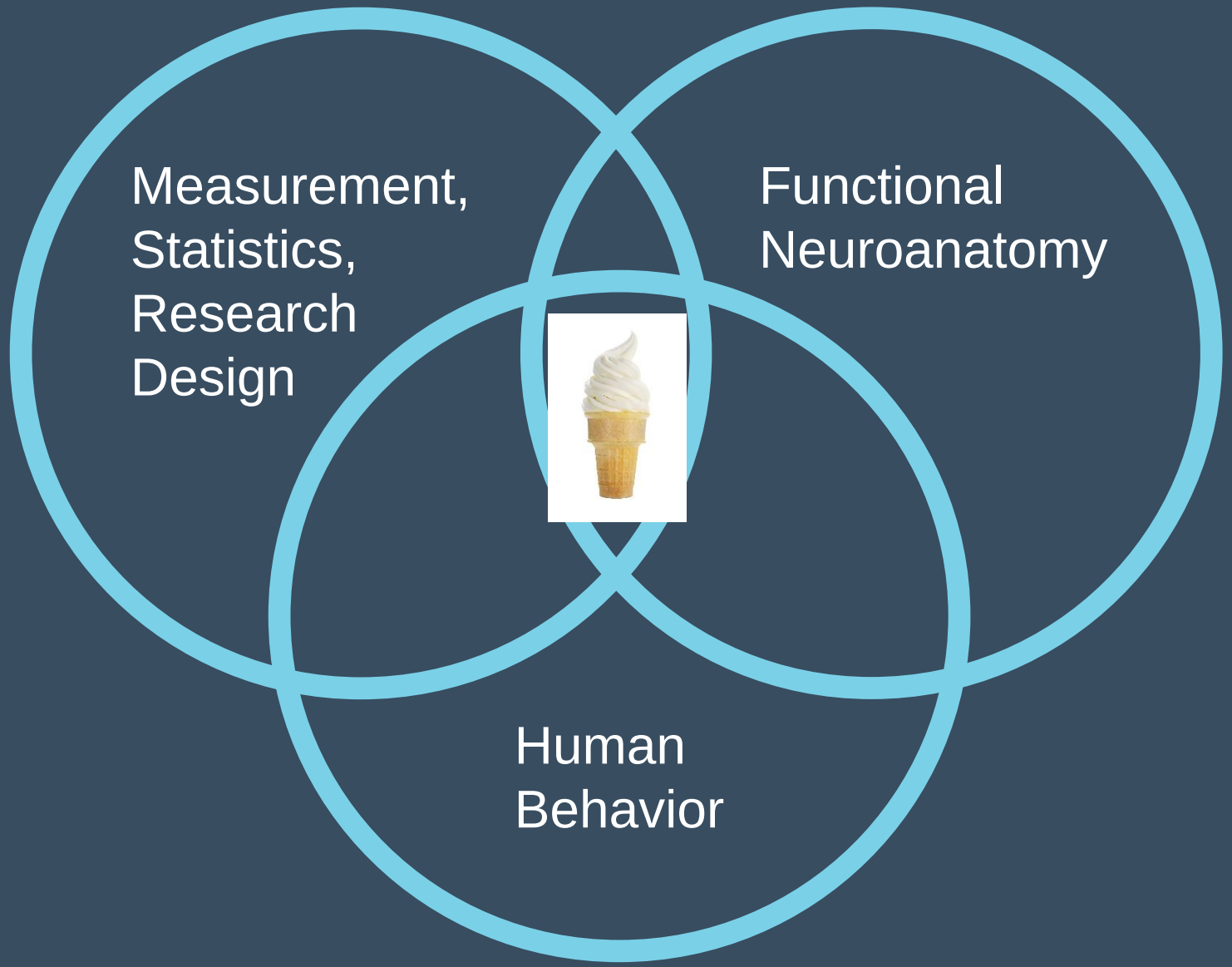
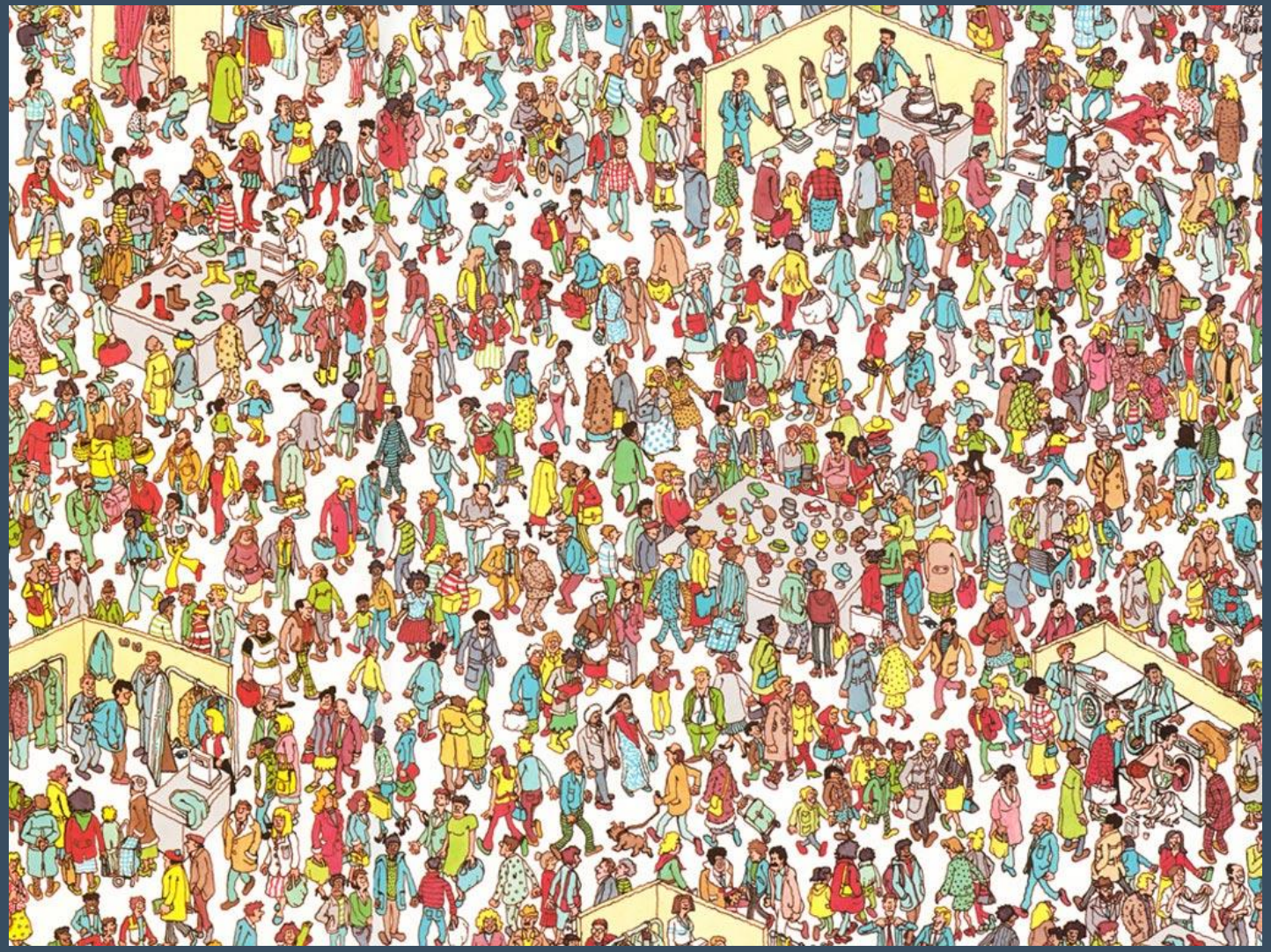
Neuropsychology



Where in the brain is the human soul?



Pragmatism

- Peirce, Dewey, James
- “Truth in ideas is their power to work”
- Empirical methods are a useful tool for addressing questions, including ethical questions
- Experiential knowledge is important (e.g., different stakeholders’ perspectives, impact of context on moral agents, humility)
- “The task was twofold – to make the budding field of psychology accountable to the most rigorous methods of the natural sciences and to simultaneously explain how this empirical study of the human mind avoided scientific reductionism” (Kaag, 2020, p 69)

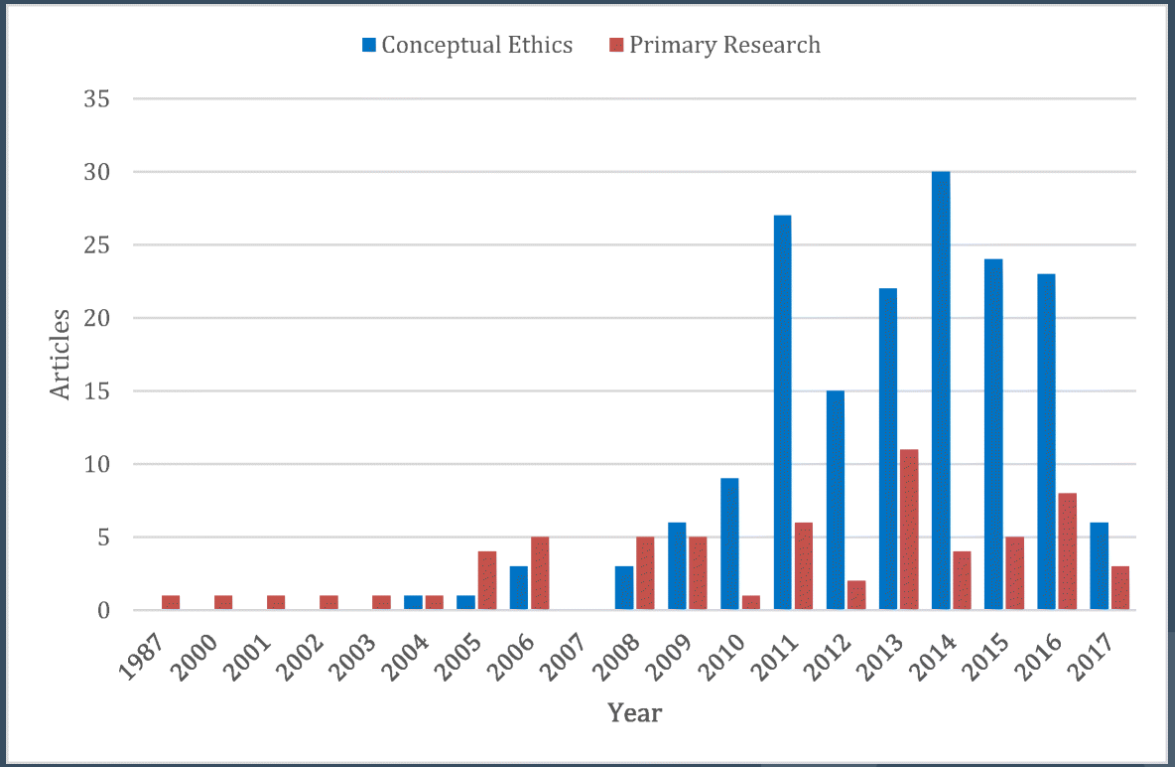
Dewey,1922; Kaag, 2020; Kubu et al, 2019; Racine 2010

Values

- Patient Centered
  - Directly solicit patients' and care partners' perspectives in their own language
- Clinically relevant
  - Use this information to improve patient care
- Team based
  - Incorporate different perspectives and disciplines
- Stewardship (Patient, Profession, Science, Public)
  - Respectful, Communication, Resources, Scientific Methods

DBS and Control

- Gisquet (2008) argued that DBS can be a uniquely disruptive experience for patients due to the associated loss of control of the illness **and loss of control of one's life** and negative, unwanted, personality changes



Gisquet, 2008; Gilbert et al 2018

Control in DBS for Parkinson's Disease

- Systematically solicited patients' top Symptom and Functional goals.
- Prospectively measured changes in patients' perception of control with respect to:
  - Symptom control refers to one's ability to control disease symptoms, such as tremor.
  - Personal control refers to one's ability to autonomously and volitionally act to achieve functional personal goals.
  - Device control refers to one's ability to adjust the actual stimulator settings.
  - Global control

Why do Patients with PD want DBS?

Symptom Control

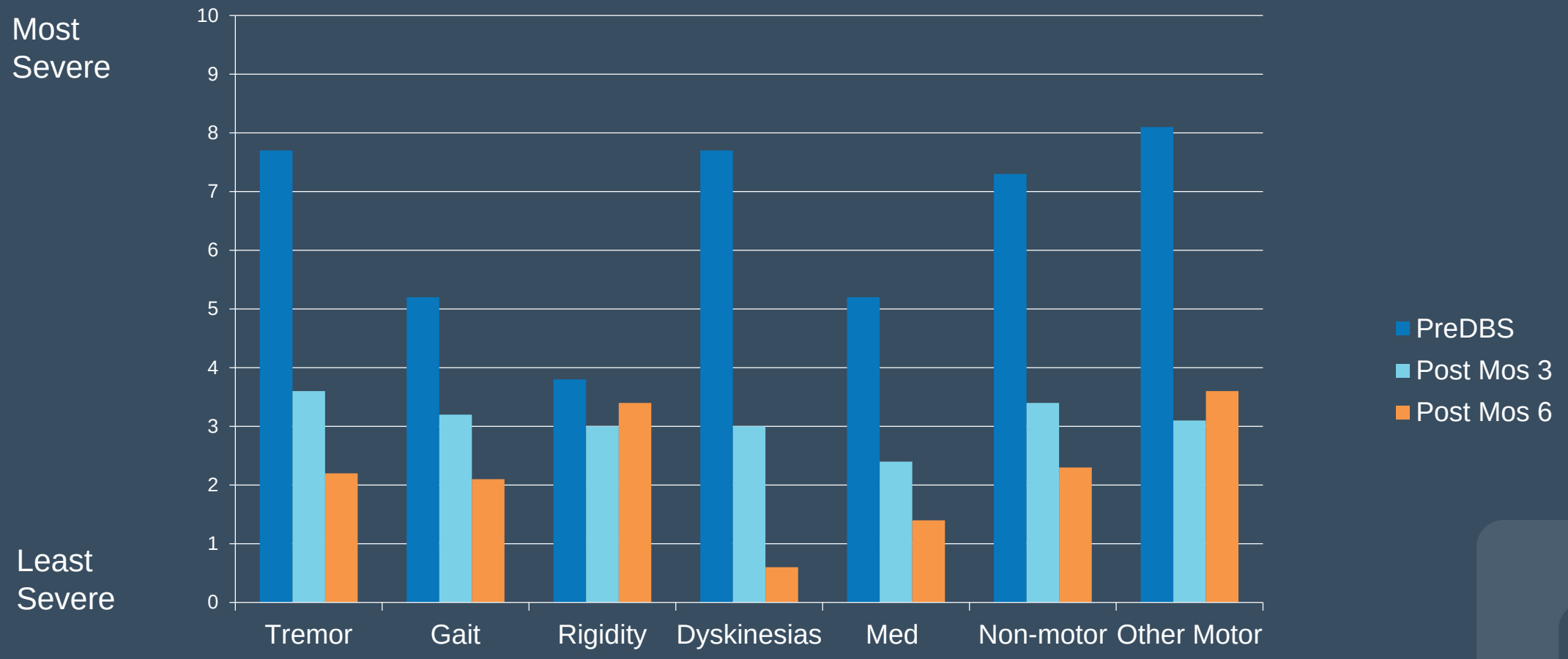
Tremor
Gait
Rigidity
Dyskinesias
Medication Side Effects
Non-motor
Other

Personal/Functional Control

Social
Avocational
Activities of Daily Living
Work
Driving
Other

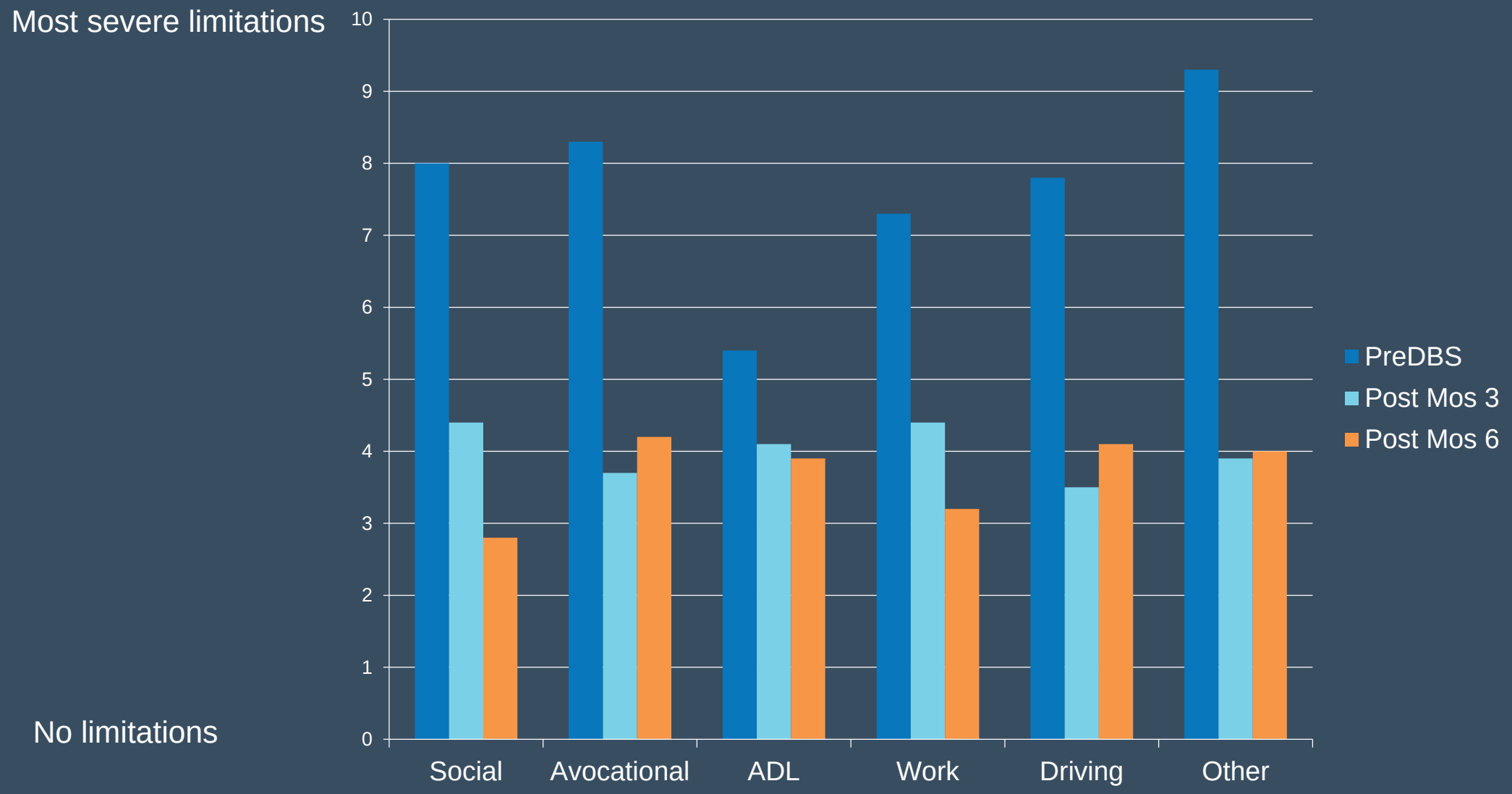
Kubu et al, 2017, Neurology; Kleiner-Fisman et al. 2010

Changes in Symptom Control following DBS



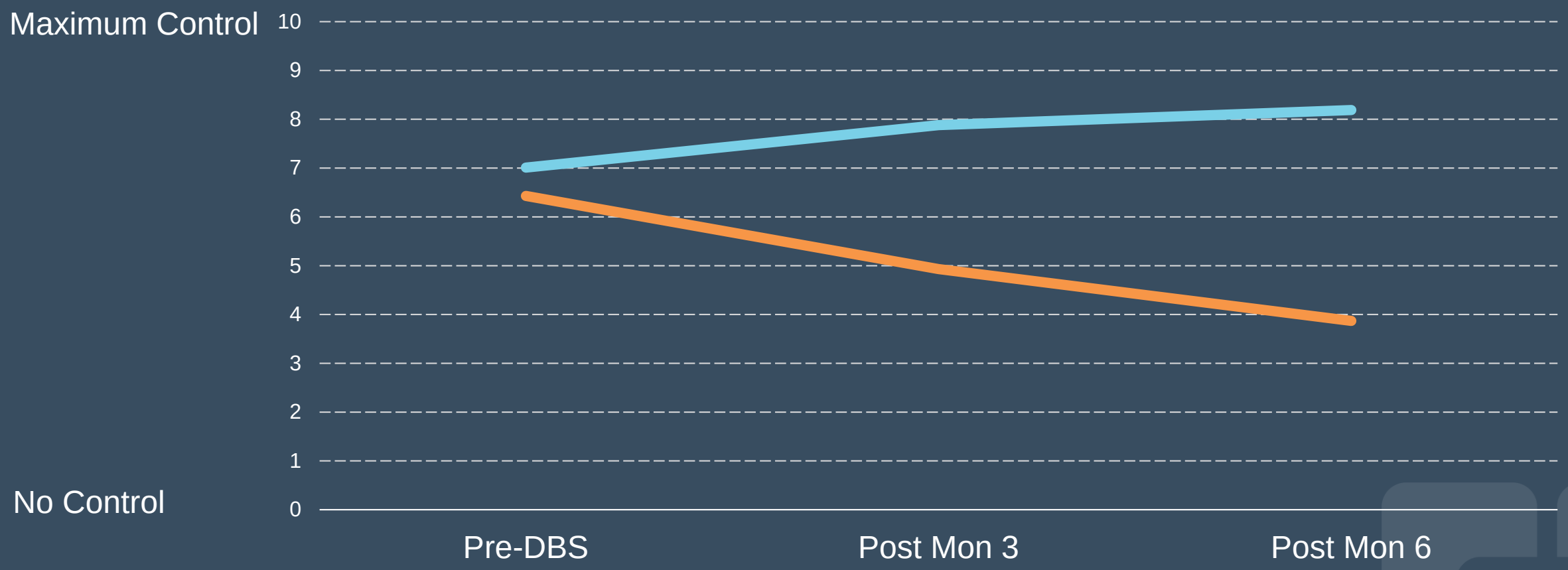
Kubu et al, 2017, Neurology

Changes in Patients Control of Personal Goals



Kubu et al, 2017, Neurology

Changes in Device and Global Life Control with DBS

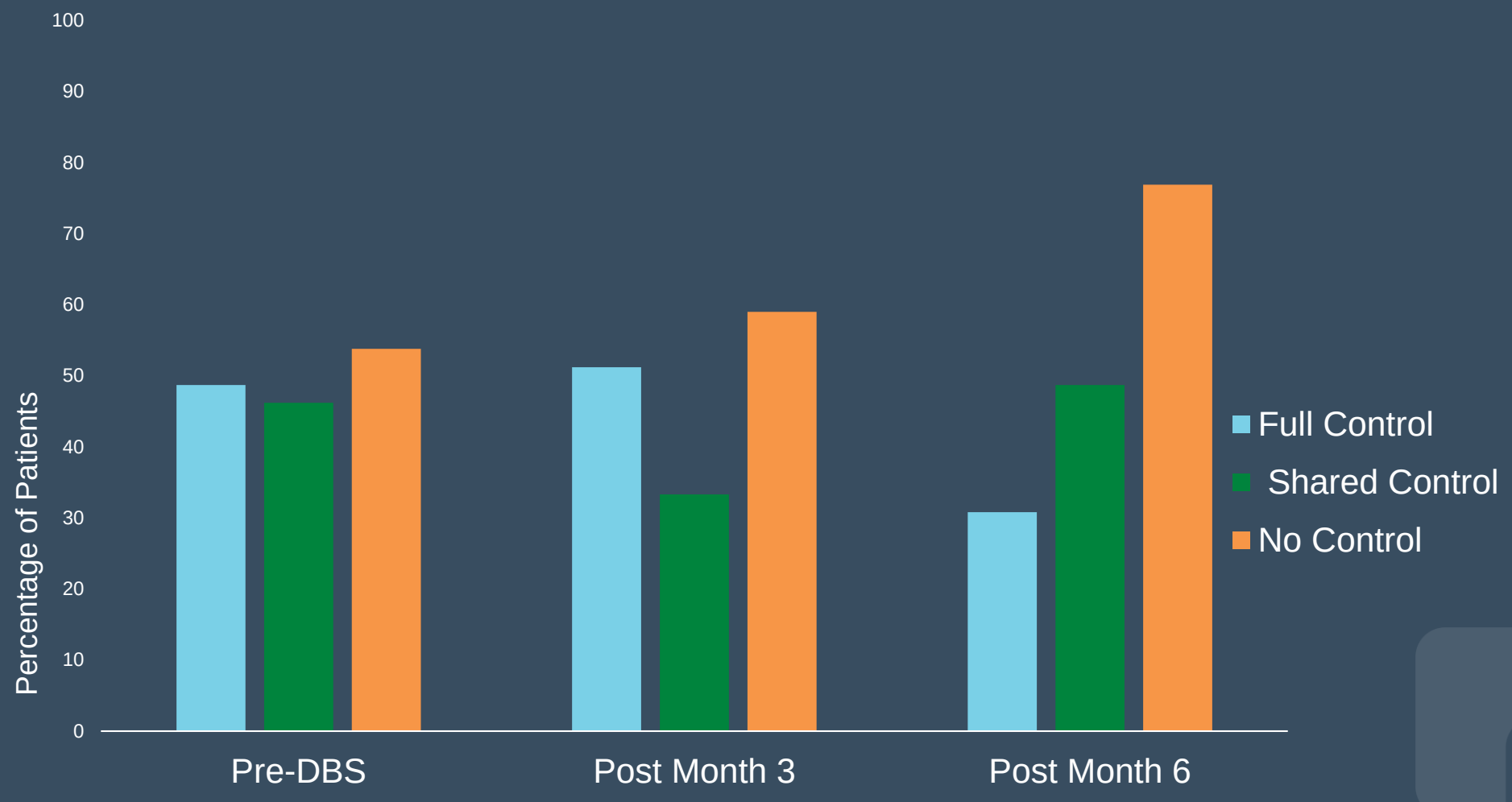


Global Control, $X^2(2,144)=11.11$, $p=0.004$
Device Control, $X^2(2,142)=18.36$, $p<0.001$
$r = -0.31$, $p = 0.038$

Global Control Desired Device Control

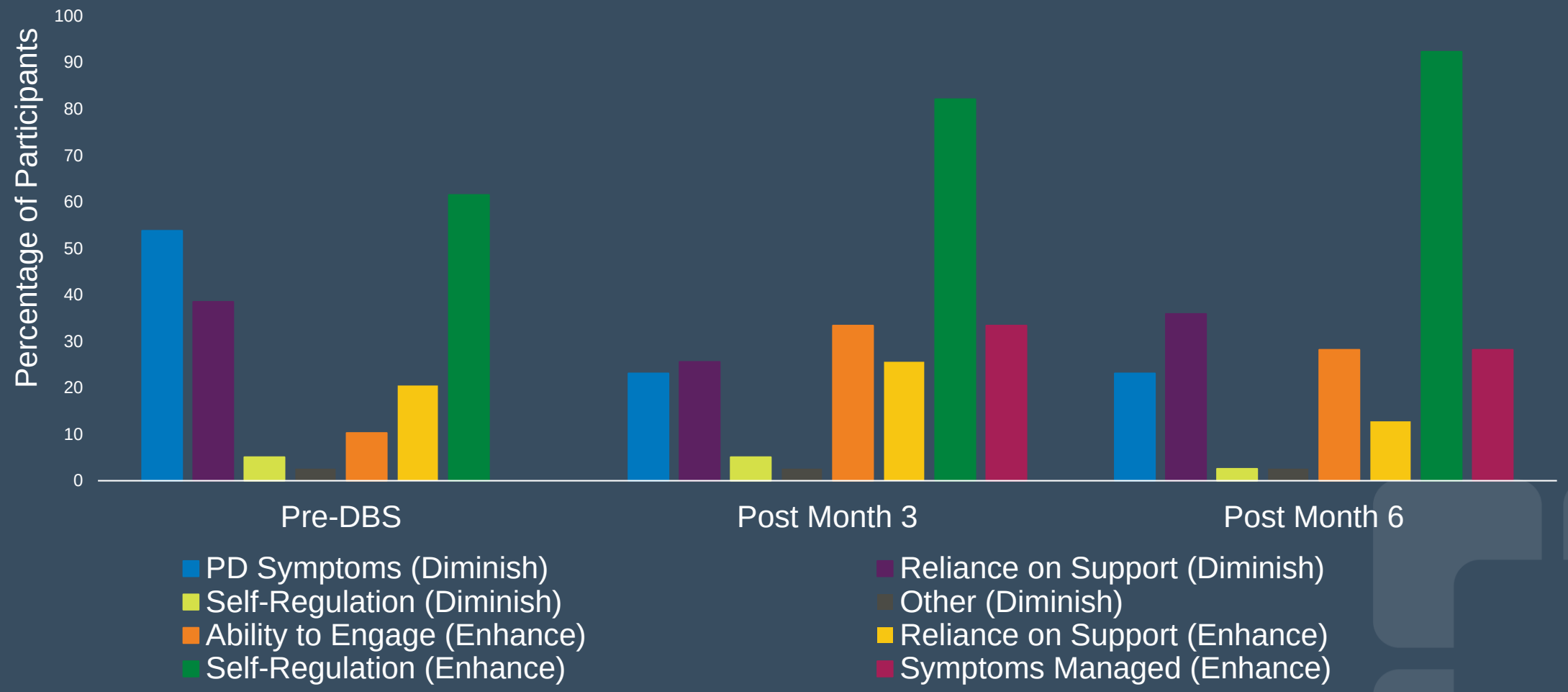
Merner et al, 2021, Frontiers in Human Neurosci

Desired Device Control



Merner et al, 2021, Frontiers in Human Neurosci

Global Control Themes



Merner et al, 2021, Frontiers in Human Neurosci

Primary Findings, 1

- Despite conversations with multiple team members regarding expectations, symptoms that typically don’t respond as well to DBS were among the most often cited symptom goals

- Patients’ motivations to seek out DBS were primarily related to larger life goals including relationships, avocational pursuits, and working - illustrating the importance of identifying the underlying motivations and functional goals for DBS

Kubu & Ford, 2012 AJOB; Kubu et al, 2017, Neurology; Kubu et al 2018, Neurology

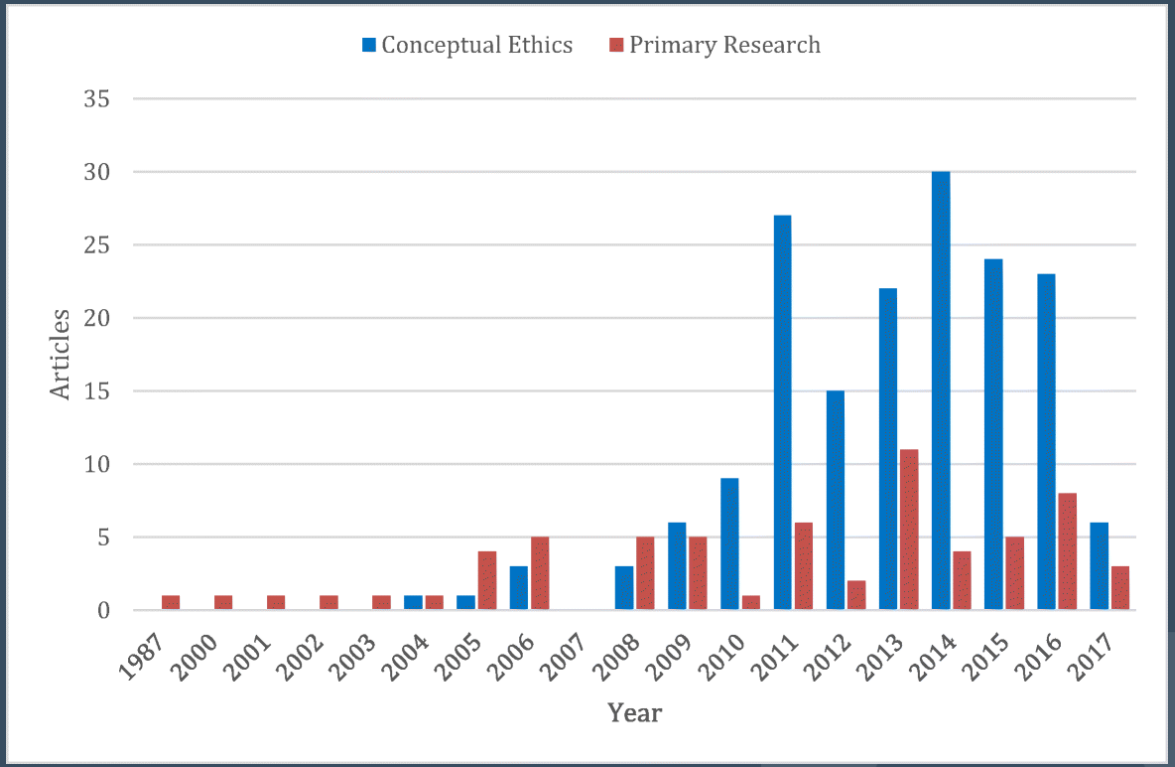
Primary Findings, 2

- Existing standard clinical outcome measures do not fully capture patients' goals and motivations
- DBS significantly improved patients' control of their symptoms (except rigidity), ability to achieve personal goals, and global sense of control
- Patients desired less control of the stimulator over time. Qualitative data indicate this reflects increased respect for and trust in the team's expertise as well as an increased sense of their ability to regulate their behavior

Kubu et al, 2017 Neurology; Kubu et al 2018, Neurology; Merner et al, 2021, Frontiers in Human Neurosci

DBS and Control

- Gisquet (2008) argued that DBS can be a uniquely disruptive experience for patients due to the associated loss of control of the illness and loss of control of one's life and **negative, unwanted personality change**



Gisquet, 2008; Gilbert et al 2018

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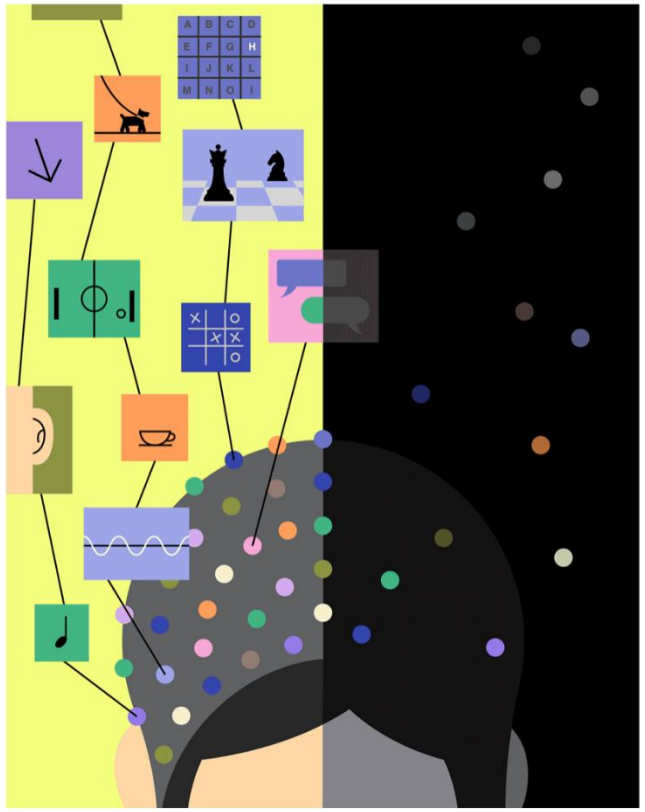
DO BRAIN IMPLANTS CHANGE YOUR IDENTITY?

As neural devices proliferate, so do reports of personality changes, foundering relationships, and people who want to leave their careers.

By Christine Kenneally

April 19, 2021



Does DBS result in unwanted personality changes?

- Enrolled 150 patients with Parkinson's disease (PD) and their Care Partners
- Patients divided into three cohorts based on time since diagnosis (<1 year, 5-7 years) or DBS candidate
- All participants completed a semi-structured interview and standard personality tests (NEO, Frontal Systems Behavior Inventory, Iowa Scales of Personality, Beck Depression Inventory, Beck Anxiety Inventory)

Does DBS result in negative personality changes assessed using standard tests??

- Depression (BDI), Anxiety (BAI), and Apathy (FRSBE Patient and Family report), and Distress (Iowa Scales) improve significantly following DBS
- No significant changes on the NEO from the patients' perspectives; Care Partners reported significantly less Neuroticism and slightly less Agreeableness and Conscientiousness over time.
- The mean changes were not clinically meaningful on the personality measures

Summary

- DBS results in **statistically significant improvements in depression, anxiety, apathy, and distress** from the patients' and/or care partners' perspectives.
- Care Partners reported **significant declines in Agreeableness and Conscientiousness** over time
- Group mean changes were **not clinically meaningful** on the personality tests

What are the participants' conceptions of personality?

- 150 Care Partners described their Patient's personality
- All unique responses (886) were coded using 32 codes developed using a content analysis approach

What are non-academic conceptions of personality?

- Two naïve independent raters indicated the extent to which each unique personality descriptor was reflected in the code using a 4-point scale
- Computed average ratings
- Conducted an exploratory factor analysis to ascertain underlying factor structure of the codes based on the average ratings

Eight Big Buckets of “Personality”

- Prosocial (e.g., loving, kindness, generosity)
- Physical (e.g., basic motor, athletic)
- Cognitive (e.g., intelligence, memory, ”brilliant”)
- Self-Discipline (e.g., hard worker, reliable, fortitude)
- Virtues (e.g., faith in God, integrity, humility, loving fidelity/commitment to family/friends, nonjudgmental)
- Positive Emotionality (e.g., extravert, happy, energetic, humor)
- Internalizing Negative Emotionality (e.g., sad, anxious)
- Externalizing Negative Emotionality (e.g., irritable, inflexible, angry)

Does DBS result in Personality Changes?

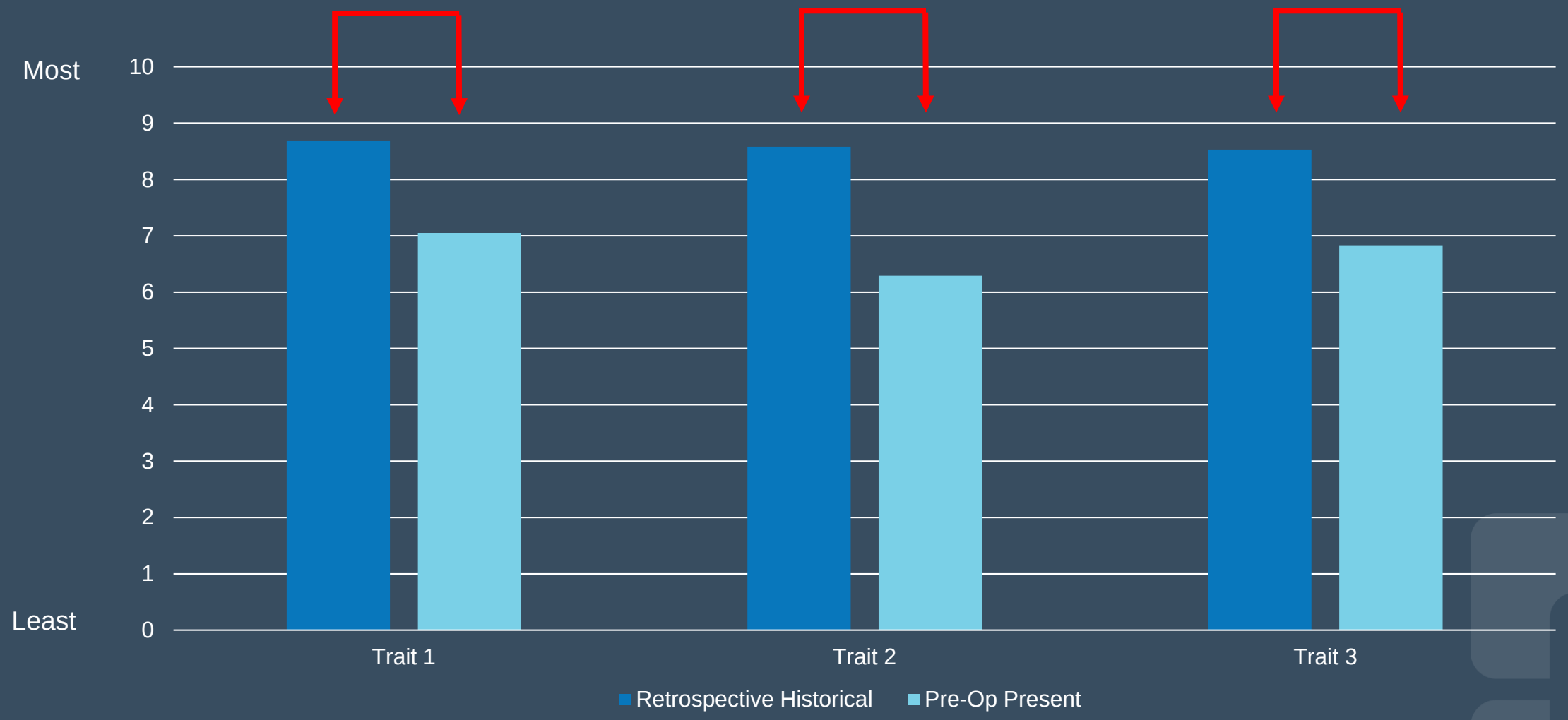
- Prospectively assessed 50 patients prior to and at 6- and 12-months post surgery
- Top 3 personality characteristics patients most fear losing and current ratings on VAS

Least Embodiment

Greatest Embodiment

Does PD Change Personality?

Significant Main Effect for Time $F(2,98)=19.63$, $p<.001$, $\eta^2=.29$



unpublished data

Does DBS Change Personality?

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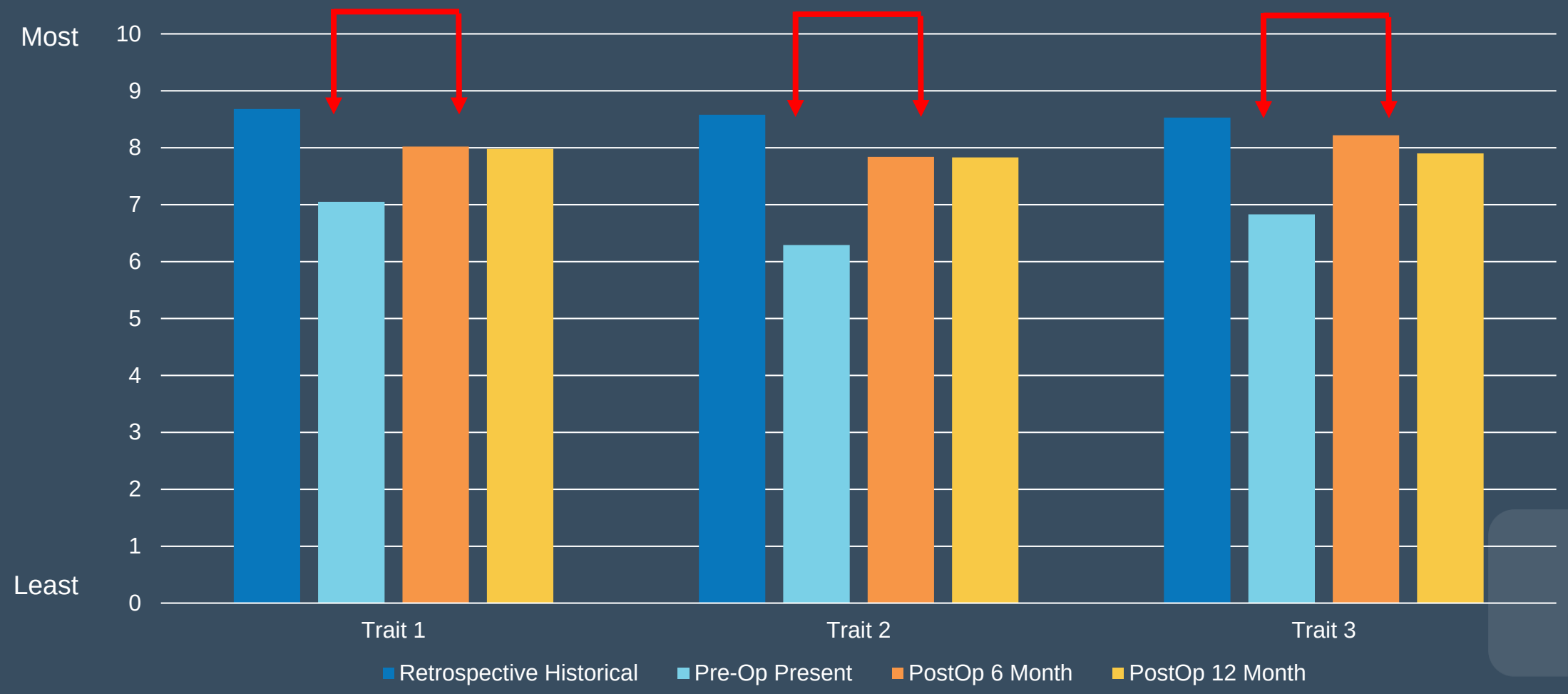

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Proportion of top ranked Characteristics Patients fear losing most

• Positive Emotionality	27%
• Cognitive	20%
• Virtues	20%
• Self-Discipline	16%
• Prosocial	11%
• Physical	6%

unpublished data

Does DBS Change Personality at the Individual Patient level in a Meaningful Way?

- Examined all changes >/= -/+ 1 SD from Pre to Post-Op Month 6
- 43/150 change scores (28%) met criteria
- 11.6% were negative changes (5 changes in 4 patients)
- 88.4% were positive changes (38 changes in 23 patients)
- 92% of all patients did not have a negative change

unpublished data

Summary

- Existing personality measures **do not comprehensively assess what matters most** to patients
- DBS **does not result in negative personality changes in 92% of participants** based on what matters most to them
- DBS is associated with personality ratings **closer** to retrospective historical scores
- DBS may be **restorative** to valued personality characteristics in patients with PD

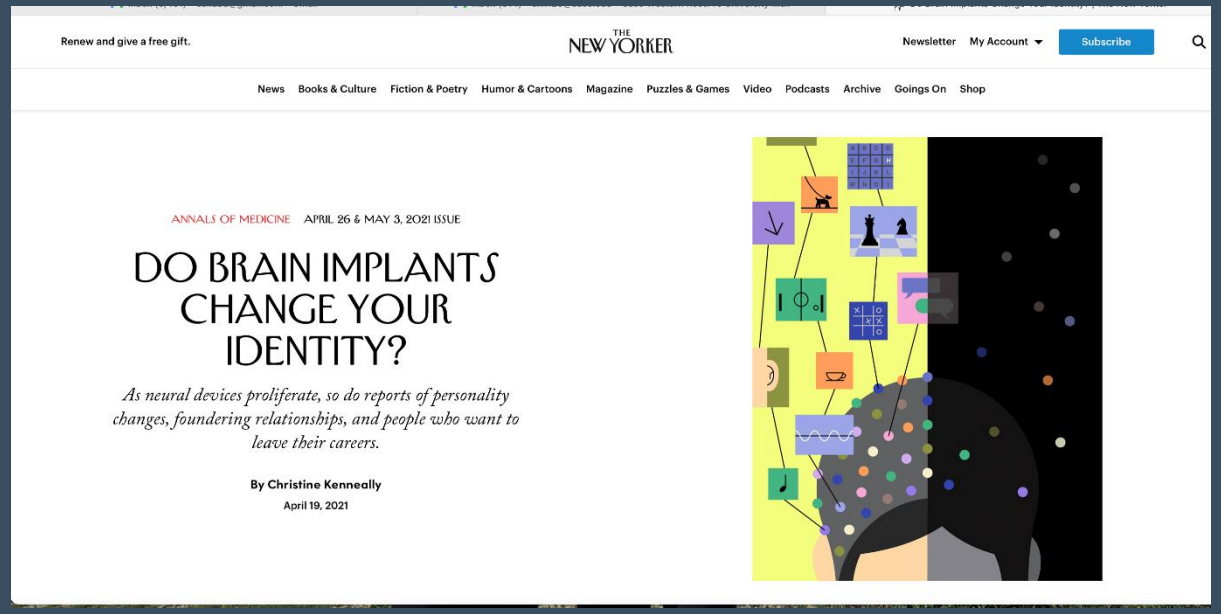
unpublished data

Ethical Implications

- Are we assessing outcome in a patient centered way?
- Informed consent
- Communication with patients and the public

Ethical Implications

- How have previous papers based on limited empirical data contributed to stigma in patients with brain implants?



Ethical Implications

- How do our conceptions of personality and autonomy impact how we assess outcomes? What are the underlying assumptions or dominant voices?

Which (or whose) values do we prioritize?

Cognition
Autonomy

Virtues
Physical Being
Relationships/Relational Autonomy
Joy/Eudaimonia

Whose voices are missing?

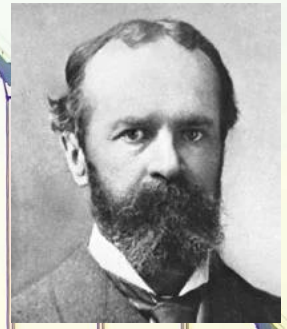
Patients

Under-represented/Diverse patients

The Humanities

Recommendations

- Be humble
- Embrace interdisciplinarity and diverse voices
- Listen to our patients and their families
- Ascertain their functional goals, motivations, and values
- Partner with minority community leaders to develop relationships and learn from them how to incorporate their voices in research and healthcare decisions



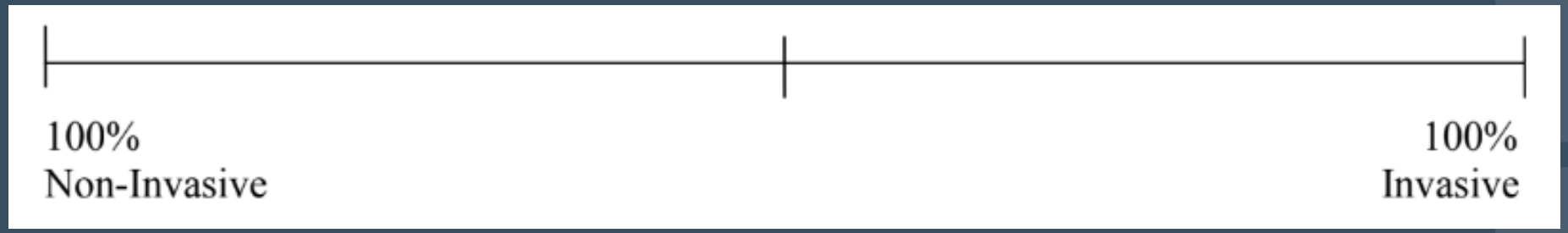
Building bridges by respecting different ways of knowing

Questions?

kubuc@ccf.org

Methods

- Participants: N=73
- Participants indicate extent to which they felt each treatment was invasive and risky using visual analogue scales:
  - Medication
  - DBS
  - MRgFUS



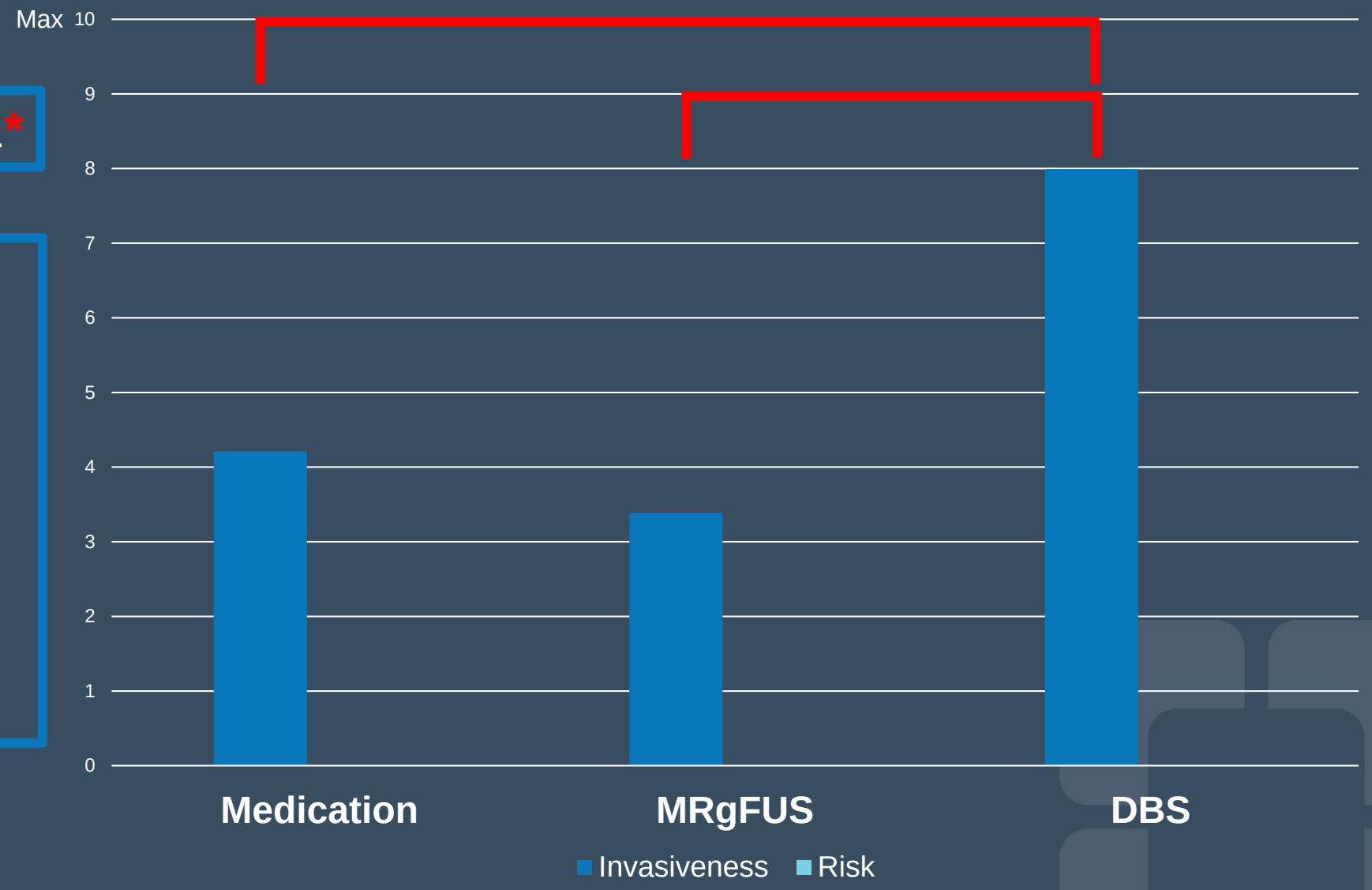
Average Patient Ratings for ET Treatments (Invasiveness)

F(2,144)=41.881, p<.001*

<u>Med vs MRgFUS</u>
- t(72)=-1.526, p=.131

<u>Med vs DBS</u>
- t(72)=7.186, p<.001*

<u>MRgFUS vs DBS</u>
- t(72)=-8.453, p<.001*



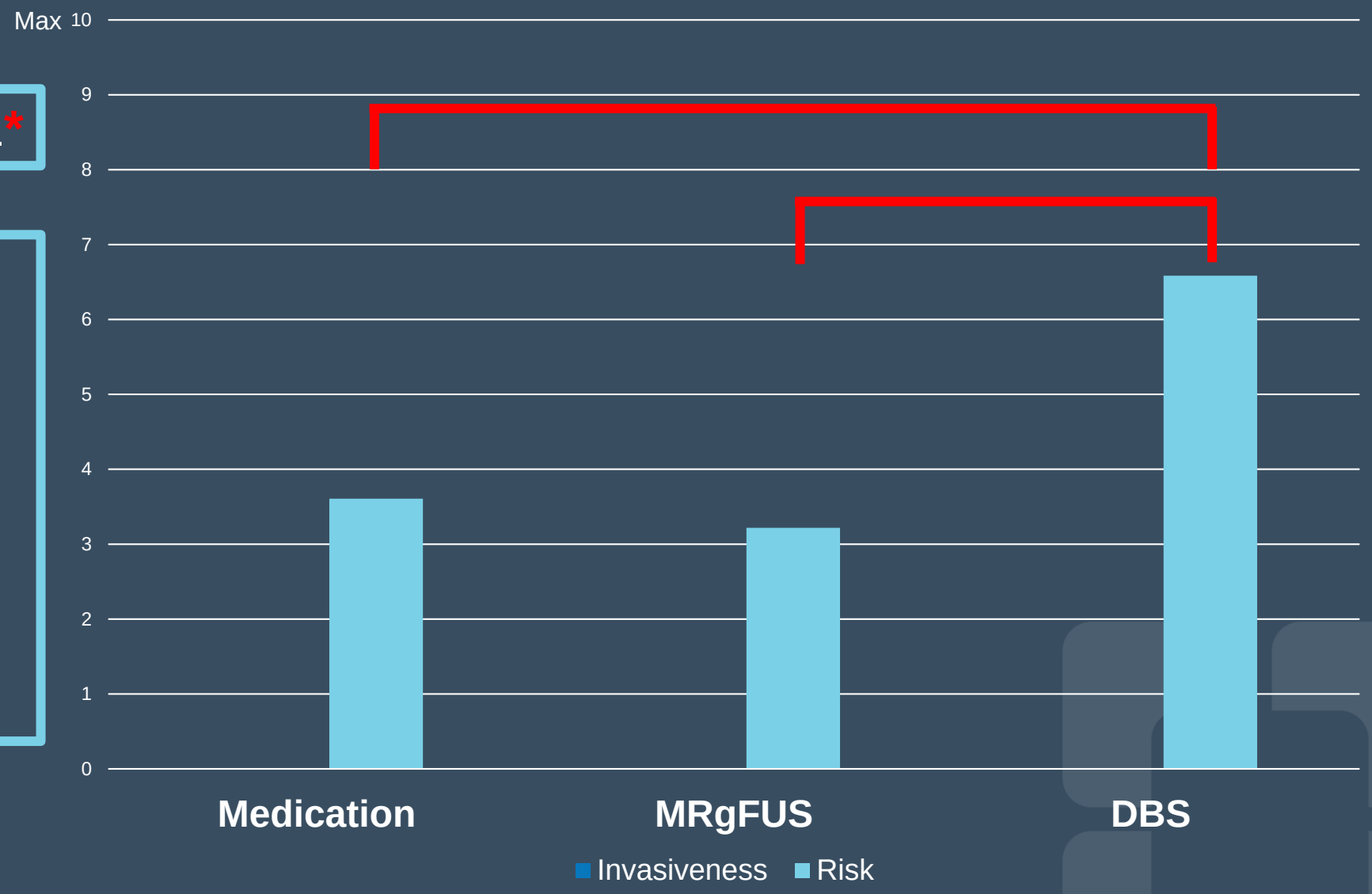
Average Patient Ratings for ET Treatments (Risk)

F(2,144)=41.217, p<.001*

<u>Med vs MRgFUS</u>
- t(72)=-.882, p=.381

<u>Med vs DBS</u>
- t(72)=7.346, p<.001*

<u>MRgFUS vs DBS</u>
- t(72)=-9.184, p<.001*



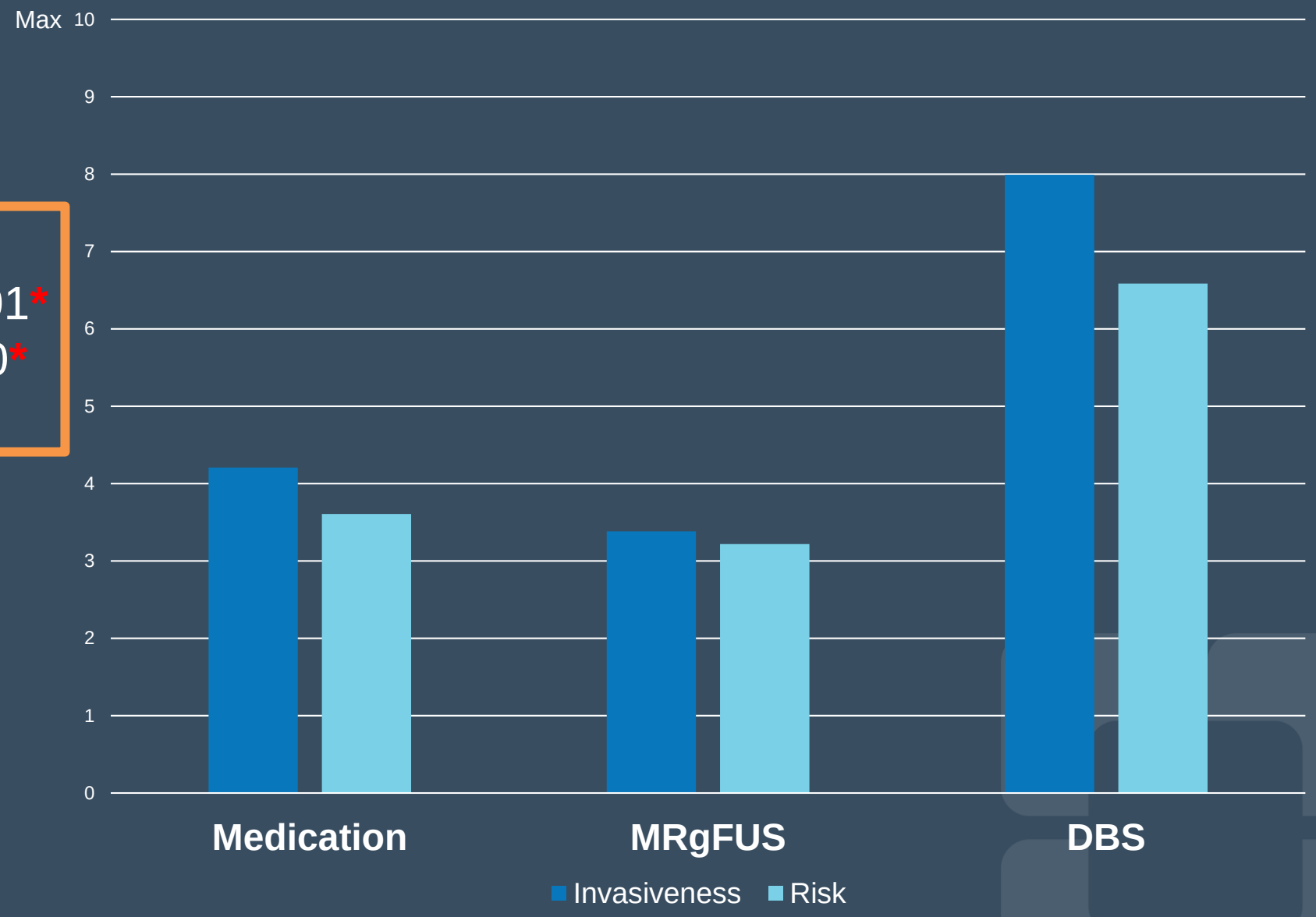
Average Patient Ratings for ET Treatments

Pearson Correlations

Medication: r(71)=.391, p<.001*

MRgFUS: r(71)=.301 , p=.010*

DBS: r(71)=.632 , p<.001*



Preliminary Findings

1. Ratings for invasiveness and risk differ significantly by treatment
2. Patients perceive DBS as significantly riskier and more invasive
3. Significant correlation between perceptions of invasiveness and risk
4. Higher perception of risk may not take permanency of treatment into account