Challenging the value of self-sufficiency:

Understanding patient and care partner concerns about the effects of deep brain stimulation on personality

Devora Shapiro, PhD
Center for Bioethics,
Cleveland Clinic

Cynthia S. Kubu, PhD, ABPP-CN
Cleveland Clinic Lerner College of Medicine,
CWRU School of Medicine
Disclosure

- National Institute of Mental Health, Award Number R01MH114853

The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.
Question:

How do we account for the disparity between DBS patients’ personality changes noted under existing personality measures, and the data collected by Kubu et al?
THE SELF IN THE WESTERN TRADITION:
Personality:
The Self through Individualism and Self-Sufficiency
Feminist Empiricism: Challenging the Traditional Self
Feminist Empiricism:

“Feminist empiricists appeal to the pragmatist tradition to undermine the sharp dichotomy between fact and value .. and argue that the underdetermination of theory by evidence leads to a view of facts and values as mutually constituting”

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unpublished data
The Need for a New Model to Explain the Data

- Existing personality measures do not comprehensively assess what matters most to patients
- DBS does not result in negative personality changes in 92% of participants
- DBS may be restorative to valued personality characteristics in patients with PD
Intersectionality: Relational, Multi-Dimensional

Intersectionality is a lens through which you can see where power comes and collides, where it locks and intersects. It is the acknowledgement that everyone has their own unique experiences of discrimination and privilege.

— Kimberlé Crenshaw —
The History of Intersectionality:

• “Intersectionality” refers to the now well-known theory first articulated by legal theorist and professor, Kimberlé Crenshaw, in 1989.

• Intersectional theory is an outgrowth of the Black feminist thought of the 1970s and 80s, and challenges standard approaches to evaluating social and political problems; rather than identifying group characteristics as single-variable, unitary wholes or as additive identities piled atop one another, intersectional theory conceptualizes identity as multidimensional, thus not confining it to a single-axis analysis that distorts and cannot capture, for example, Black women’s experiences in the US, in the 1970s.
Q: How do we account for the disparity between DBS patients’ personality measures noted under existing personality measures, and the data collected by Kubu et al?

A: By acknowledging the role of values that are built in to the assessment tools and in the narratives available to patients and caregivers, that are now made visible by a feminist empiricist approach, through an intersectional lens.