

Background

- My work: ethics and public policy of emerging neurotechnologies such as deep brain stimulation (DBS) and adaptive DBS (aDBS), including conducting and analyzing **qualitative interviews** with stakeholders (patients, caregivers, and researchers) involved in clinical trials of next-generation DBS systems.
- There is great interest in and emphasis on the importance of stakeholder perspectives for bio- and neuroethics research. The purpose of gathering these perspectives is often assumed to be solely **discovering ethically relevant facts**, but I argue that there is more of ethical relevance that can be discerned by engaging with them.

Summary

- A widely shared view in bio- and neuroethics says that empirical data can inform normative analysis by **revealing relevant facts**.
- But we can also treat stakeholders' normative views as **claims in a dialectic**, and doing so yields a distinct (but complementary) approach that can enrich qualitative research.
- Doing so opens up a range of questions about norms governing **neuroethics research design**, questions whose answers will depend on a deeper examination of respect for persons.

1. The Methodological Question

The question: *How can empirical data gathered via qualitative, social scientific approaches have normative ethical and policy implications?* [1]

One standard answer:

- By identifying ethical issues arising in practice along with current processes for addressing them, and by supplying facts that contribute to consequence-based analysis.
- But that's all, because of the **is-ought gap**: No amount of information about how things **are** can tell us how they **ought to be**, so no **normative** conclusions about what ought to be done can be derived from **purely descriptive** premises about what is the case [1,2].
- There are many attempts to articulate **additional** ways empirical data can contribute, but little consensus thus far [3,4].

2. Expanding the Standard Answer

Facts about **subjective experience** are a special class of facts (*particularly in neuroethics contexts*):

- Subjective experience figures in several **key neuroethics concepts**: e.g., quality of life, agency, alienation, personality, and identity.
- Each of these is, at least in part, **constituted** by a person's subjective experience [5].
 - A person's **quality of life** is determined, at least in part, by how they themselves feels about their life.
 - **Agency** centrally involves the experience of deliberation and choice.
 - Various aspects of a person's **identity** are determined by their own self-understanding.

3. Limits of the Standard Answer

This expansion of the standard answer can potentially take us quite far, but it still doesn't explain the relevance of data about **stakeholder's own normative views** and their reasons for holding those views.

4. A Dialogical Approach

To capture the relevance of stakeholders' own normative views, we need to treat interview data in a **fundamentally different (but complementary) way**. Distinguish between:

- 1) the empirical fact that someone made a normative claim
- 2) **the normative claim as *normative claim* (its role in a dialectic between interlocutors)**
 - When we treat a stakeholder claim in the **second** way, we're treating qualitative research as an extended **normative conversation** and thereby taking what [3] call a **dialogical approach**.
 - Qualitative interview questions soliciting stakeholders' normative views are a form of **intellectual engagement** in which they express those views, reasons for holding them, and their definitions of key concepts.
 - Stakeholders' views then bear on normative analysis **directly** as claims to be considered in that analysis, rather than as empirical facts from which we must somehow **infer** normative claims (in apparent violation of the is-ought gap).

5. Implications for Research Design

If qualitative interviews are a form of intellectual dialogue, then in addition to standard human subject protections, some **norms governing intellectual dialogue** are also in force during qualitative research.

- When, and under what conditions, could it be appropriate to **challenge or question the views** of stakeholders during interviews?
- How can participants be adequately credited for **intellectual contributions** without compromising anonymity?
- How can we avoid **epistemic injustice** in interviews and subsequent assessment of stakeholders' views and arguments? [6]
- How can we best practice **charity in interpretation** during interviews and subsequent assessment? [7]

We can answer these questions through renewed attention to the ethical value of **respect for persons**:

- In addition to **Kantian** approaches to respect for persons, we should also look to a **Millian** liberal approach grounded in our ability to assert claims [8,9], as well as **relational approaches** to autonomy [10] and identity [11] that robustly capture the **social** nature of respect. Considering the upshots of each of these approaches for dialogical norms will help us articulate these norms for the neuroethics context.

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