HELPING OTHERS AND TRANSLATIONAL MISCONCEPTION

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Background

Patients undergoing invasive neurosurgical procedures offer researchers unique opportunities to study basic neuroscientific questions about the brain. Given the high prevalence of clinician-investigators and the potential overlap of care and research in both space and time, ethical discussions have highlighted persistent challenges in consent. Of note, these research contexts raise the threat of therapeutic misconception, and efforts have been made to maximize participant understanding of its extent to which participation will not benefit them, and the extent to which care is separate from research.

However, this research context raises the potential for another kind of misconception which has yet to garner attention: what we call a “translational misconception.”

Rooted in participant narratives about benefit in the context of basic science, we argue that:

(1) participants’ beliefs about translation could threaten informed consent, and
(2) researchers may be responsible for exploring participants’ views about translation, as they may affect assessments of risks and benefits and reasoning about enrollment.

The qualitative data presented is from our study with 14 patient-participants who consented to intraoperative basic brain research during their DBS surgery.

Results

Broad views about helping others: Participants identified four groups of potential beneficiaries in discussion of enrollment motivations.

- **I think that’s why I did it.** You feel good that you’re able to do something that helps someone else down the line. Somebody is benefiting from it...and I’m the benefit of a million people going through tests...somebody has to be the first to do something. (P9)
- **Well, everybody who’s benefited from deep brain surgery, I think has a responsibility to come forward and help.** (P8)
- **Well, I think getting in there and actually seeing it and seeing how it works is [off] the utmost importance.** It’s like no other research could be because you’re actually in there in the brain and seeing. (P12)

None of the interviews revealed a therapeutic misconception.1

None of the narratives revealed an “unrealistic optimism bias.” 2

There are no cases of “unrealistic optimism bias,” a form of misconception in which one believes their participation will bring about better outcomes than those of others.3

A translational misconception, as we call it, is different from both a therapeutic misconception and unrealistic optimism: it has to do with misperceptions about the likelihood that research will have eventual clinical benefits for others, not oneself.

A translational misconception

- **Trust in researchers’ abilities to discover therapeutic interventions**
- **Perceiving oneself as the beneficiary of past basic science translational successes**
- **Beliefs about upwards trajectory of basic research and overall trust in scientific process**

Factors Contributing to Translational Misconception

- **Low concerns with study risks** contributing to more immediate assessments of benefits and more favorable overall risk/benefit judgments.

Ethical Implications

Not all beliefs about translational likelihood are warranted. Beliefs that basic science research will benefit those with similar diagnoses, for example, may be more or less warranted depending on the study question and design.

There may be the potential for participants to overestimate or misunderstand the nature or likelihood of the translational path of the research’s findings. These over-estimations and associated hopes may influence participant enrollment and color how participants think about benefits and risks.

The full impact of the surgical context may go beyond obscuring distinctions between care and research. Even when participants realize they will not benefit, surgical context may still influence beliefs about who will benefit, how likely that benefit will be realized, and how participation is related to that benefit.

Researchers may have obligations to explore whether translational misconceptions exist, on what basis, and to what extent. If these expectations are in part created or encouraged by current research practices, including the language used to discuss benefit in consent or the mere fact that surgery and research happen together, then ethical considerations may require revisions of those practices.

References:


Given that participation in basic research is neither no-cost nor risk free for participants, adequate understanding of benefits may require more than avoiding the therapeutic misconception.