

“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.¹⁻⁵ Of note, these research contexts raise the threat of therapeutic misconception, and efforts have been made to maximize participant understanding of (i) the extent to which participation will not benefit them, and (ii) 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.⁸

Results

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

Those with similar diagnoses	Participants' relatives	Surgeon and research team	Unspecified future beneficiaries
<ul style="list-style-type: none">Well, I belong to the Parkinson's Association of [my local area]. And, in the last year... half the people I was dealing with over the years passed away, which is a little depressing...And so, I guess I'm doing it in their memory.I decided to join it so that hopefully I can help somebody else in the same situation or similar circumstances... to benefit the research and keep things moving up and up. (P12)	<ul style="list-style-type: none">I feel that anything that we can do to get rid of this horrible illness... I feel like my life has been stocked by Parkinson's, I have so many friends who've had it... And I'm also worried that one of my [children] or one of my grandchildren may inherit Parkinson's from me. (P8)Hoping the research gets better, so for my next generation, they don't get any disease like this. (P7)	<ul style="list-style-type: none">I guess the answer would be, I wanted to help the doctors involved, because they made such a large difference in my life. (P4)Just a way to give back...I guess [to help] the doctor first, he's the face of whatever it is... if it's something that'd be helpful to him, he's doing something so big to help me. (P3)	<ul style="list-style-type: none">I think it's important to help in the advancement of human knowledge and to support other researchers and scientists. (P13)It might [help] down the road. You never know what kind of small detail can be connected...in my mind it's like you never quite know what little, tiny thought is going to help something else down the road. (P5)

Patient-Participant role

Some participants viewed themselves and their ability to receive beneficial medical treatment as the result of past basic science studies and the willingness of others to participate.
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 benefitting from it...and I'm the benefit of a million people going through tests...somebody has to be the first to do something. (P3)
Well, everybody who's benefited from deep brain surgery, I think has a responsibility morally to come forward and help. (P8)
Well, I think getting in there and actually seeing it and seeing how it works is [of] the utmost importance. It's like no other research could be because you're actually in there in the brain and seeing. (P12)

Value of and optimism about basic research

Almost all interviewees (n=12) expressed hope that basic brain research would contribute to therapeutic interventions, and many indicated positive views of basic science and the translational process.
And so my hope was, well maybe this study will help with the development of that surgery and that implant. (P5)
The thing is, you never know with the way research is, they could find the cure tomorrow or 10 years down the road, or they could never find the cure. But I feel, as myself, as being like a donor, when my body goes on. If anything, a part of my body can help save somebody else, that's great. (P9)
Just because you miss the dart board when you throw a dart, doesn't mean that you're not going to hit the bullseye eventually down the road because you got to take a stab at it.You've got to throw it once in a while. (P9)



None of the interviews revealed a therapeutic misconception.¹

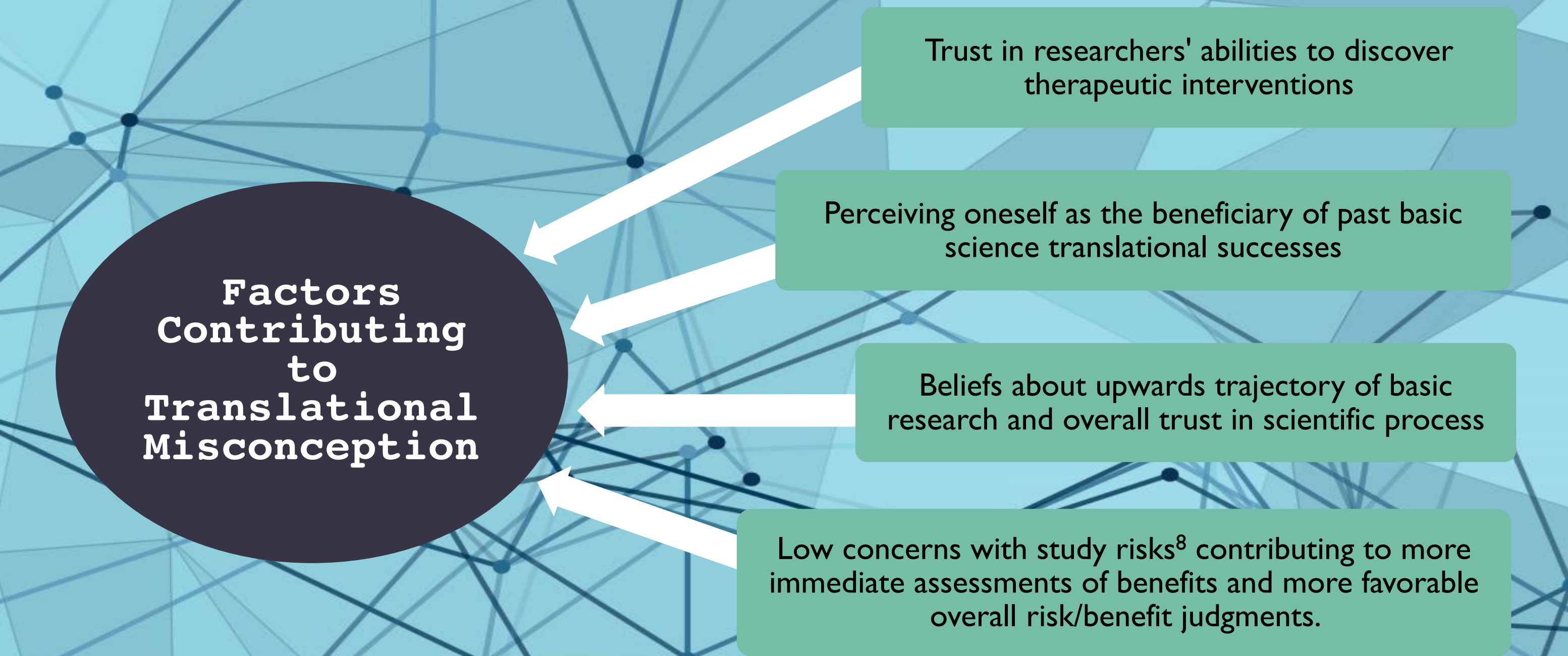


None of the narratives revealed an “unrealistic optimism bias.”⁵

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.

A translational misconception?

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.



Why does this matter?

- Narratives include mixed, potentially traumatic experiences of participation, which participants cannot foresee at time of recruitment.

If optimism about translation is in part based on views about the translational likelihood of research that are inaccurate or inflated, then this may threaten valid consent.

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.

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