

Deep–Brain Stimulation for Alzheimer's Disease: Narratives, Stigmas, and Therapeutic Goals

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Deep-Brain Stimulation for Alzheimer's

Clinical trials (like ADvance II) are underway to test the safety of Deep-Brain Stimulation (DBS) of the Fornix (DBS-f) as a treatment for mild Alzheimer's Disease (AD). [1]

DBS-f is hypothesized to slow the rate of cognitive decline by modulating memory-related neurocircuitry. [1][2] The efficacy of DBS-f is not yet known. [2]



Will DBS for Alzheimer's erode self-trust?

Many of the cultural and interpersonal problems are as-of-yet unexplored. It is not clear:

1. What role will DBS-f play in how people with AD perceive and trust themselves?
2. How will DBS-f change the relationships between users, families, and caretakers?
3. What are (or *should be*) the goals of therapy related to 1 and 2?

We must consult patient testimonies and cultural narratives to answer these questions given the stigmas surrounding AD.

Why is AD so tragic?—AD's 'horror stories'

We've identified three "horror stories" in narratives about AD that give us a picture of what people worry:

- **The Gothic Plot:** when "a person you love, and to whom you are bound by unbreakable ties, turns out to be someone you do not know at all, who does not 'care' about you and may even seek to harm you." [3]
- **The Zombie Narrative:** "I grieve for her exactly as if she'd died. She's gone, I've lost her, but I'm still responsible for her living, breathing body and the ghosts in her head." [3][4]
- **The Monster Narrative:** where the disease itself is personified as a feared 'other'—a monster that takes, tears away, ruins a life, and removes a person. [5]

These stories are *pervasive*, and they *perpetuate harmful stigmas* against people with AD.

These stories about AD can be *internalized* by people with AD and their families. **This could lead people to stigmatize themselves and one another**—and worry that they (or loved-ones) will become zombies or monsters.

People who internalize these narratives might seek out, or pressure family members with AD into DBS-f to avoid living out these narratives.

DBS-f, horror stories, and self-trust

People with AD might take up these narratives to describe their own worries and fears. In so doing, they might *lose trust in their capacities* and *fear becoming dependent on others*.

People with AD, and their families, may see DBS-f as a means of slowing down the gothic plot. **We must, however, interrogate and shift these narratives.**

We can think of identity, agency, and remembering as *relational*: who we are, how we act, and what is remembered is the product of relationships with friends, family, communities, etc. [6]

On this view, the onset of AD doesn't entail becoming a zombie or a monster. [3][4] Instead, it entails a renegotiating of how memory and action work in these relationships.

It is not clear what role DBS-f should play in AD care if we also want to discourage/counter these stigmas.

Future studies of DBS-f ought to conduct qualitative assessments of patient and family goals, hopes, and worries about DBS-f therapy.

References

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