The History, Future, and Ethics of Brain-Based Visual Prosthetics Research

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Introduction

- Brain-based visual prosthetics (BBVPs) aim to restore sight or a functional analogue for people with acquired blindness.
- Have received little attention from neuroethicists compared to other invasive neuromodulation.
- Raise complex questions about non-clinical risks and benefits, access, and how to conceptualize and measure research success.

History of BBVPs

- First prototype BBVP electrode array implanted in 1968.
- Advanced considerably by William Dobelle from 1970s to early 2000s, with limited parallel NIH work occurring in the 1990s.
- Dobelle’s work ended with his abrupt death in 2004.
- Several groups are now working to develop similar systems.

Ethical Problems in Dobelle’s Work

- To skirt FDA regulations, Dobelle arranged for participants to undergo surgery in Portugal [2].
- One participant suffered a seizure after being allowed to control the stimulation of their own brain [2].
- Interviews with 13 of Dobelle’s former research participants [3] identified issues related to:
  - informed consent
  - therapeutic misconception
  - unmet expectations
  - financial burdens
  - post-trial access

Learning from Past Mistakes

- Contemporary work on BBVPs must avoid similar ethical missteps.

Future Directions

- Conduct ethnographic observation of researchers to determine conceptions and measures of success in the research enterprise.
- Conduct semi-structured interviews with researchers and current research participants to understand key perspectives.

References


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