Responses of potential users to the intracortical visual prosthesis: final themes from the analysis of focus group data

Frank John Lane¹, Margaret Huyck¹, Philip Troyk² & Kenneth Schug³

¹Department of Rehabilitation Psychology, ²Biomedical Engineering, and ³Department of Chemistry, Illinois Institute of Technology, Chicago, IL

Although visual implant prosthesis projects are advancing, little exists in the literature on the factors that would lead an individual to volunteer for such an experimental procedure. Many ethical issues are raised in recruiting and involving individuals in experimental implant procedures, most involving autonomy and informed consent. This report provides perspectives of 30 totally or legally blind older individuals on their expectations about a potential visual implant, their motivations for volunteering, and the processes they would use for decision making. Data were collected in eight focus groups, using semistructured focus group processes. Among the primary reasons a person with seriously impaired vision would volunteer for a new implant procedure are helping others, exploring the unknown, and restoring perception. The decision to participate in an experimental brain implant procedure is complex. Potential recipients have many questions about the device and the procedure, the perceived risks, and the commitment of a research team to the participants once a device has been implanted. Some would involve their family in a decision; others are more comfortable making the decision independent, after consulting others. The themes identified provide a guide for recruiting and ensuring an ethical experience for participants in experimental protocols.

Keywords: Ethics, qualitative methodology, technology, vision implant

Introduction

The use of technology to restore or enhance bodily function is an example of human effort to overcome adversity, for example, converting natural resources into the “invention” of simple tools. A prosthesis can be thought of as a tool that replaces or augments a missing or impaired body part such as an artificial leg found in Italy dated at 300 B.C. [1] and an artificial toe in Egypt dated between 1069 and 664 B.C., which, if intended to be functional, would be the earliest prosthesis yet identified [1]. Although prosthetic toes or legs may seem crude today, they represent early examples of humans using technology to restore function. Today, a wide variety of prosthetic devices are in use. Their need is indicated by the report that approximately 56 million Americans have health conditions that interfere with their ability to effectively participate in work activity [2]. The International Classification of Functioning Disability and Health (ICF) states that assistive technology not only restores function but also enables people with disabilities to participate in meaningful activities such as working and living independently [3]. From the perspective of the ICF model, disability is a socially imposed construct that occurs when individuals do not have access to restorative technology.

The importance of employment and independent living, as individual values within American culture, is reflected in the Rehabilitation Act of 1973 (as amended), which earmarks funding for state and federal vocational rehabilitation and independent living programs [4].

Assistive technologies, for example, wheelchairs and prosthetic limbs or joints are now regarded as standard rehabilitation devices [5]. Technologies still regarded as experimental

Implications for Rehabilitation

- The motivation to participate in vision restoration experiments may include altruism and the experience of pioneering research.
- Phosphenes (dots of light in the visual field) can improve safety and independence of an individual who is blind.
- The decision to participate in vision restoration experiments is unique for each individual and may include consultation with family members, friends, spiritual guides, individuals who are blind and health professionals.