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Criteria employed by potential recipients considering adopting emerging visual technologies: The case of visual prostheses

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Abstract

The manner in which emerging technologies like visual prostheses – implantable devices intended to restore functional sight to people with vision impairment – are implemented by relevant healthcare providers and systems should be informed from multiple stakeholder viewpoints, including that of potential recipients. Visual prostheses are approaching use by healthcare professionals involved in the treatment and/or rehabilitation of vision impairment, however, there is very little available data describing what people with vision impairment want from the performance and functioning of such devices. Exploring their decision-making regarding experimental visual prostheses may help provide such insights. After receiving information on a cortical visual prosthesis, three focus groups and one interview were conducted with 13 adults with vision impairment to discuss factors involved in their decision-making around participation in its experimental trials. The study illuminated several of their expectations and concerns regarding visual prostheses: they hoped the device would afford greater independence, mobility and engagement in an active and social life, and wanted it to be safe, upgradable, inconspicuous and practically manageable. These findings reinforce many of those obtained in the sparse previously published literature while contributing some useful additional insights into what people with vision impairment want from the user interface, device's functioning and regarding tasks it will aid. These insights will be useful to service providers to guide this technology's gradual adoption into their practise. Variation in participant considerations with level of remaining vision and age indicate further focused research with larger and more varied samples is needed.

Introduction

Visual prostheses (VPs), implantable technologies intended to restore some functional sight to people with vision impairment, are an important emerging health technology. VPs involve the

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implantation of electrodes into the visual pathway, stimulating the visual pathway in accordance with information received via computer processor from a camera positioned on glasses worn by the user [5]. Through this, they produce the percept of a corresponding pattern of spots of light called "phosphenes". VPs currently under development utilize different implantation sites including optic nerve, lateral geniculate nucleus, retinal and cortical incarnations and are progressing towards implementation as part of broader vision impairment treatment and rehabilitation programs [1–4].

The adoption of new health technologies like VPs involves an ongoing and complicated decision-making process in which numerous factors are weighed including – but not limited to – difficulties in understanding its implementation and utilization; efficacy or cost-effectiveness; and associated risks or harms [6–9]. Methods devised for use in considering these multiple factors (e.g., multi-criteria decision analysis) stipulate that the decision process should commence with a full-set of well-defined, operationalized, distinct and independently assessable criteria that reflect the interests of different stakeholders [6,7,10]. Thus, effort should be invested into understanding what people with vision impairment as end-users – one stakeholder group – want from these technologies. As little is known about the perspective of recipients, such consideration is essential: the inclusion of those with disabilities (the "target population") in the selection of assistive technologies intended for their use reduces levels of technology abandonment [11]. Furthermore, aligning technology performance and characteristics with the needs and expectations of recipients may also maximize the likelihood of achieving meaningful (as defined by recipients) functional improvements and ameliorative benefits [12,13]. Lane et al. [14,15] focus group study of the decision-making of adults with vision impairment regarding hypothetical participation in an experimental cortical VP trial offers some insight into the expectations of potential recipients. Their participants described certain expected therapeutic benefits as a major motivation for participation: while some participants desired enough sight to drive or read [14], most had conservative expectations or hopes regarding the VP's ameliorative benefits [15]. Their findings also indicated that greater residual vision and vision stability were associated with higher desires and expectations of the VP [14, p. 144]. However, the participants overwhelmingly asserted that they would be satisfied with any level of vision restoration that improved their self-sufficiency and safety, particularly in relation to mobility. For some, this related to improved light perception while others hoped to be able to see obstacle outlines (e.g., doors, tables).

Considerable concerns were highlighted by Lane et al. [14,15] participants. Specific concerns about the risks associated with the VP's implantation were identified, including its impact on existing health issues and brain functionality, or whether it would produce seizures. Such concern is not unique to cortical VPs. In exploring participation decision-making for retinal VP experimental trials, Xia et al. [16] similarly found that expected remedial benefits were the most prominent motivator while the safety of the device and its implantation was the most prominent barrier to participation. The substantive content of these expectations and concerns was not provided in this latter study.

These studies offer preliminary insights into potential VP recipient expectations. It is clear from the extant research that VPs should enable greater independence and safety in mobility, and should be safe in terms of both implantation and use. Nonetheless, the published literature is limited and a more comprehensive understanding of the expectations and perceptions of people with vision impairment is required to help inform the criteria used to guide the adoption of VPs into the treatment and rehabilitation of vision impairment. This paper therefore presents the expectations and concerns of people with vision impairment during their discussions about a cortical VP.

Method

The data reported here comprise a subset of an Australian study exploring the decision-making of potential recipients about hypothetical participation in a trial of a cortical VP. An exploratory qualitative focus group study design was utilized and ethics approval was obtained from Monash University Human Research Ethics Committee.

Recruitment and sampling

To be eligible for participation, individuals with vision impairment were required to: (1) be aged 18–70 years-old; (2) have lost significant vision after turning 18 years-old; (3) have English fluency; and (4) have no significant acquired brain injury. Fulfilment of criterias 2 and 4 were self-determined by the potential participants. Both criterias 3 and 4 were included to ensure that all participants could fully participate in the study. Information about the cortical VP under development was provided to all potential participants prior to them taking part.

Three Australian vision-related non-government organizations (NGOs) assisted in recruitment across two sampling rounds: the study was advertised via flyers (both rounds of recruitment) and through a radio broadcast (the first round only). In the first round, interested people were invited to attend a 60-min information session presented by the neurosurgeon leading the VP's development. At the conclusion of the session, attendees were invited to subsequently participate in a focus group; those interested in the study were advised to contact the first author. This yielded only seven participants and so a second round of recruitment occurred in order to achieve a larger study sample and thus increase the number of hypothetical recipient perspectives. After seeing the flyers in the second recruitment round, potential participants were invited to contact the first author if they were interested in listening to an audio-recording of the information session and then partaking in a focus group on the same day, after a 15-min break. An additional seven participants were recruited in this way. All who expressed interest and met the study eligibility criteria were sent study information sheets and consent forms in regular or large print, or in electronic format (so accessible to screen-reading software) to facilitate accessibility. After reading study documentation and with consent, participants were invited to take part in a focus group session that was convenient to them.