Sharing Memories: Co-Designing Assistive Technology with Aphasic Adults and Support Staff

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ABSTRACT

This article describes how for people suffering from aphasia, everyday verbal and bodily interpersonal communication is challenging. To increase aphasics’ ability to share memories, an assistive technology (the MemoryBook) was conceptualized based on explicit, observable and tacit knowledge gathered from the practices in which it was to be contextualized and through a close partnership between aphasics and their caretakers. The underlying design methodology for the MemoryBook is a participatory design manifested through the collaboration and creations by two aphasic residents and one member of the support staff. The idea of the MemoryBook is materialized, and inspired by a photo album, which uses photos and audio recordings to present memories digitally. The MemoryBook was evaluated and found to be a useful approach to a wicked problem of allowing aphasics to digitally capture and communicate memories without caretaker intervention.

KEYWORDS

Aphasia, Co-Design, Assistive Technology, Ethnography, Memories, Participatory Design, Sharing Memories, Wicked Problems

INTRODUCTION

The ability to communicate verbally can easily be taken for granted because we as social beings are used to do so on a daily basis. We share memories with friends or family, discuss the weather with colleagues or engage in heated debates about the current political rule. However, not all share the privilege of being able to communicate freely. Brain damage can strike abruptly and forever change the life of an individual. Aphasia is a neurological brain injury, typically acquired from a stroke or blood clot in the left hemisphere of the brain. Aphasia patients are often categorized as suffering from one of two types; expressive or receptive. Expressive aphasia influences language production; the individual understands what they are told, but lack the ability to accumulate words to produce a sentence. Receptive aphasia patients do not understand language but can produce speech, however, their words can be made-up and sentences might be void of structure and meaning. Each instance of aphasia should be considered unique because of the brain’s complexity. Two individuals diagnosed with the same type of aphasia can have vastly varying difficulties communicating (Hjernesagen.dk, 2017; StrokeAssociation, 2015). Partial or full paralysis is often a consequence of brain injury, which further limits self-determination and social interaction.

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Aphasia is mostly found among individuals above 50 years of age, as strokes and blood clots are more frequent in this age group (Hjernesagen.dk, 2017). This means the individual has been able to communicate while growing up and throughout their work- and family life. By suddenly losing the ability to communicate can significantly impact the quality of life: Going from a reality where problems, moods, ideas, opinions and beliefs could be communicated freely, to the struggle of asking for a glass of water. Participating in social arrangements will often impose the aphasic with a passive role, as they are usually incapable of contributing verbally (Daemen et al., 2007). The constant struggle of trying to participate, or having difficulties expressing basic needs and feelings often result in stress or depression. 62% - 70% of aphasics suffer from post stroke depressions (Worrall et al., 2016). Thus, the feeling of loneliness is often accompanying aphasia. One natural reason for loneliness is to be transferred to a full-time care facility away from relatives and friends, but being surrounded by people, whom you cannot communicate and interact with socially can also induce loneliness (Kagan et al., 2008).

RELATED WORKS

Assistive technologies are often used to help individuals suffering from aphasia to communicate. These technologies are known as Augmentative and Alternative Communication (AAC) devices. Most AAC devices aim to help the individual express their basic needs such as “I’m hungry…” or “I must go to the bathroom…” (Siriaraya & Ang, 2014). For AAC devices to transcend their usefulness in basic communication needs, they must be able to assist the aphasics with ways of communicating more personal matters.

With present-day technology constantly being available from your pocket, memories are often stored in digital form as photos, video and audio, while they are via the same technologies quickly and easily shared with family members and friends.

Extending the experiences of stored past events as memories to be experienced in the present has been the focus point for a selection of design projects. Common for many digital solutions is that they use physical objects from which the digital memory can be accessed to shape the space in which the memory sharing takes place. An example of this is the Resonant Rocking Chair by Bennett, Hinder, & Cater (2016), where a rocking chair is used as the gathering point for memory sharing. It imitates the old tradition of gathering around a knitting (grand)-mom telling stories in the evening. By allowing an MP3 player to be inserted, the chair can play recorded stories or music to the ones sitting in and/or around the chair. Thus, the Resonant Rocking Chair uses the audio modality to represent memories in the digital space.

Two common approaches for representing memories digitally were found by surveying the literature. According to the first approach, a project could focus on the use of a single modality, like photos or audio, and utilize as many aspects of that modality (Zmily & Abu-Saymeh, 2013; Lazar, 2014; Biemans & Dijk, 2009). An example of this is Biemans and Dijk (2009), where photos were used to keep elderly living at a nursing home up to date on the small aspects of their families’ lives. Family members were able to send photos to a digital photo frame, located in the elder’s apartment. When receiving new photos, the frame would include them in a slideshow constantly looping through photos. It was found, that even these small insights into what is happening in their relative’s lives can impact their mood positively.

For the other approach, projects could include as many modalities as possible to stimulate multiple senses at once (Siriaraya & Ang, 2014; Stapleton et al. 2014; Gowans et al., 2004). By creating a virtual world which can be tailored to the individual, it is possible to not just show photos, videos and play audio, but immerse people completely in memories through virtual reality. This approach was generally used for rehabilitation, instead of memory sharing. Giving the aphasics different stimuli, which they can relate to, was found to encourage storytelling and/or memory sharing (Siriaraya & Ang, 2014).
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