ABSTRACT

In the UK, 20% of people aged 75 years and over are living with sight loss and age-related macular degeneration (AMD) is the most common cause of sight loss in the UK, impacting nearly 10% of those over 80; regrettably, these figures are expected to increase in coming decades as the population ages (RNIB, 2012). This paper reports on the authors’ design activities conducted for the purpose of informing the development of an assistive self-monitoring, ability-reactive technology (SMART) for older adults with AMD. The authors reflect on their experience of adopting and adapting the PICTIVE (Plastic Interface for Collaborative Technology Initiatives through Video Exploration) participatory design approach (Muller, 1992) to support effective design with and for their special needs user group, reflect on participants’ views of being part of the process, and discuss the design themes identified via their PD activities.

Keywords: Age-Related Macular Degeneration (AMD), Mobile Assistive Technology, Older Adults, Participatory Design, User-Centered Design (UCD)

1. INTRODUCTION

Vision loss is the most serious sensory disability as a consequence of ageing (Coccharella & Andersson, 2000). Age-related macular degeneration (AMD) is the UK’s leading cause of severe visual impairment amongst the elderly. It accounts for 16,000 blind/partial sight registrations per year and is the leading cause of blindness among people aged 55 years and older in western countries (Bressler, 2004). As a progressive, degenerative disease of the eye it severely affects the macula which is vital for clear central vision. The progress of the disease is typically slow and peripheral vision is usually retained (Mitchell & Bradley, 2006). In most cases, people with AMD have “dry” AMD where pigment and light detection cells in the retina die off and the person experiences gradual loss of central vision. With some people this can, however, progress to “wet” AMD which can result in rapidly reduced central vision (Klein, et al., 1995): in the UK, “wet” AMD impacts 4.8% of the over 65s and 12.2% of the over 80s (Owen, et al., 2012). AMD significantly limits individuals’ independence as a result.
of the increased challenges associated with completion of daily activities (Cahill, et al., 2005) and reduces their quality of life (Mitchell, et al., 2008), with 48% of visually impaired people reported as feeling ‘moderately’ or ‘completely’ cut off from society (RNIB, 2012). Strategies to combat AMD are now focusing on prevention of AMD progression rather than expensive pharmaceutical treatments which are not universally effective. There is evidence that there is a link between dietary factors, AMD risk (Beatty, et al., 2001), and AMD progression (AREDS, 2001).

In other domains – e.g., diabetes (Tsang, et al., 2001) – electronic diet diaries have proven to be successful aids for improving independent living. Various electronic diet diaries are available on mobile platforms – e.g., Health and Diet Manager (Softpedia, 2012) – but comprise visually-intensive UIs which are not adapted to people with visual impairment and have not been used in the specific context of dietary recommendation for AMD risk mitigation and progress retardation. Our ultimate goal is to develop an assistive mobile application (SMART) to support accurate and convenient diet data collection on which basis to then provide customised dietary advice and recommendations in order to help support individuals with AMD to mitigate their ongoing risk and retard the progression of the disease.

As highlighted by Figure 1, AMD presents a significant challenge in terms of UI design – a challenge which is further complicated by the degenerative nature of the disease. In recognition of this challenge, we are adopting user-centred design (UCD) – in fact, truly participatory design (PD) approaches (Muller, et al., 1993) throughout our research in order to provide participants with an extended sense of being part of the research agenda. Their involvement provides them with a direct mechanism by which to communicate concerns and desires with regard to technology designs, and will hopefully ultimately increase scope for acceptance and impact of the technology once developed. In this paper, we report on our experience of adopting and adapting a PICTIVE (Muller, 1992) participatory design approach to inclusively create paper prototype designs of a self-monitoring, ability-reactive technology (SMART) for users with AMD to support their dietary-based AMD progression retardation over time. We also discuss participants’ reflections on being part of the process and highlight the emergent design themes we identified. Our hope is that, in so doing, we can (a) persuade others that adopting such methods to work directly with special needs users is possible and is useful, and (b) provide some further insight as to how direct involvement of such users might be successfully achieved with relatively easy adaptation and/or accommodation.

2. BACKGROUND

While impairments (physical and/or sensory) that are associated with ageing (Hawthorn, 2000), and age itself (Heart & Kalderon, 2011), can essentially make technologies much harder to use (Hawthorn, 2000), the biggest limitation of technology use by the elderly is the fact that such technologies are not typically specifically designed to meet older adults’ needs, wants, and capabilities (Czaja, et al., 2006; Klein, et al., 1995; Sayago & Blat, 2010).

A recent study examining the experiences and attitudes of older adults towards technology has found that (a) older adults are highly motivated to learn (or continue to learn) to use technology and (b), consideration of their lifestyles and the role of proposed technology is crucial to the successful design of such technology (Caprani, et al., 2012). To overcome the aforementioned limitations researchers have increasingly involved target users in the design and development of assistive technologies by adopting PD approaches. For instance, Wu et al. (2004) adopted PD methods to design and develop an orientation aid—Orienting Tool—for amnesics to assist them when they feel lost or disoriented by providing information regarding their whereabouts and intentions. Their experiences (including outcome of the project) demonstrated that PD is a viable approach.
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