A protocol paper on the preservation of identity: understanding the technology adoption patterns of older adults with age-related vision loss (ARVL)

Article

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ABSTRACT

There are a growing number of older adults with age-related vision loss (ARVL) for whom technology holds promise in supporting their engagement in daily activities. Despite the growing presence of technologies intended to support older adults with ARVL, there remains high rates of abandonment. This phenomenon of technology abandonment may be partly explained by the concept of self-image, meaning that older adults with ARVL avoid the use of particular technologies due to an underlying fear that use of such technologies may mark them as objects of pity, ridicule, and/or stigmatization. In response to this, the proposed study aims to understand how the decision-making processes of older adults with ARVL, as it relates to technology adoption, is influenced by the negotiation of identity. The study protocol will justify the need for this critical ethnographic study, unpack the theoretical underpinnings of this work, detail the sampling/recruitment strategy, describe the methods which included a home tour, go-along, and semi-structured in-depth interview, as well as the collective approach taken to analyze the data. The protocol concludes by examining the ethical tensions associated with this study, including a focus on the methods adopted as well as the ethical challenges inherent when working with an older adult population experiencing vision loss.

BACKGROUND

Worldwide the population is aging. In Canada, by 2030, an estimated 9.5 million people will be 65 years or older, accounting for 23 percent of the Canadian population (Statistics Canada, 2015). The rate of low vision among older adults is also steadily increasing (World Health Organization [WHO], 2014). Low vision refers to a permanent
loss of vision that interferes “with the performance of common age-appropriate seeing tasks” (Vision Rehabilitation Evidence Based Review Team, 2005, p. 10) and cannot be corrected by eyeglasses, contact lenses, medication, or surgical intervention. In industrialized countries, older adults constitute the fastest growing segment of the population with low vision, including macular degeneration, glaucoma, and diabetic retinopathy, with such conditions often collectively referred to as age-related vision loss (ARVL) (Watson, 2001). Given these projections, it is increasingly vital to optimize approaches that support the well-being and functioning of older adults with age-related vision loss.

Technology offers a versatile, innovative approach directly beneficial to older adults, caregivers, and other sectors of society affected by the aging shift (Schaie & Charness, 2003). For example, when selected, accepted, and used appropriately, technology has the potential to help older adults with ARVL stay in their homes longer (McCreadie & Tinker, 2005; Peek, Wouters, can Hoof, Luijkkx, Boeije & Vrijhoef, 2014), enhance personal safety (McGrath & Astell, 2016; Wielandt & Strong, 2000), promote social and community involvement (Fok, Polgar, Shaw & Jutai, 2011), and enhance performance of everyday occupations (McGrath & Astell, 2016) such as reading, shopping, cooking, watching television, and writing (Copolillo, 2009; Fok et al., 2011; Schoessow, 2010). Despite the availability of technologies to support persons with ARVL, many older adults either never acquire technologies, including low vision assistive devices (LVADs), or abandon them shortly after purchase, often within four months or less (Strong, Jutai, Bevers, Hartley, Plotkin, 2003). LVADs refer to “any item, piece of equipment, or product system, whether acquired commercially, modified, or
customized, that is used to increase, maintain, or improve the functional visual capabilities of an individual with a disability” (Copolillo, 2009, p. 147). Although statistics are lacking on the abandonment of LVADs by older adults with vision loss, Mann, Goodall, Justiss, and Tomita (2002) found that approximately 32.4% (297 of 916) and 26.5% (110 of 415) respectively of the canes and magnifiers owned by 1056 frail older adults, were not used long-term.

Older adults’ technology adoption, in general, is influenced by a multitude of economic, practical, and psychosocial factors. These include: cost (McCreadie & Tinker, 2005; Peek et al., 2014; McGrath & Astell, 2016; Pape, Kim, & Weiner, 2002; Lupton & Seymour, 2000; Copolillo & Teitelman, 2005; Davenport, Mann & Lutz, 2012), limited knowledge of the types of assistive technology available or how to use them (McGrath & Astell, 2016; Copolillo & Teitelman, 2005; Leonard, 2002), concerns regarding privacy (Peek et al., 2014; Davenport, Mann & Lutz, 2012) and a perceived 'poor fit' with the environment (Kraskowsky & Finlayson, 2001). Usability factors including the efficiency, reliability, simplicity, and safety of the technology (McCreadie & Tinker, 2005; McGrath & Astell, 2016; Copolillo & Teitelman, 2005; Davenport, Mann & Lutz, 2012), ease of use, and appearance of the technology, namely that it is not too noticeable or obtrusive (Peek et al., 2014), are also important factors influencing adoption. While much research has looked at how these factors influence the use of technologies by older adults generally, there are only a few studies in which the decision-making processes of older adults regarding technology adoption have been addressed (Copolillo, Collins, Randall, & Cash, 2002; Lund & Nygård, 2003). Of those, relatively few have focused on ARVL with a few notable exceptions (McGrath & Astell, 2016; Copolillo & Teitelman,
In fact, the complex processes behind an older adults' decision to adopt (i.e. accept and regularly use) or abandon (i.e. reject or no longer use) technology remain underexplored, resulting in not only under-utilization of available technologies but also decreased capability of older adults to contribute meaningfully to their communities. Although such factors as affordability, perceived need, usability, availability, and lack of instruction have all been identified as barriers to technology adoption (Wu, Wrobel, Cornuet, Kerhervé, Damnée & Rigaud, 2014), these do not account for all aspects of the decision-making process.

Although less researched, it appears that other important factors relate to how context, such as societal attitudes towards technology and the stigma associated with aging and disability, ultimately shape the meanings that older adults ascribe with technology use as well as its relationship with maintaining an acceptable personal and social identity. Some research suggests that the preservation of ‘self-image’ may be an important factor in the decision-making process. For example, older adults often resist the use of technologies such as assistive robots, wireless sensor networks, and mobility devices because they are perceived as reinforcing negative stereotypes of aging such as ‘frailty’, ‘dependence’, ‘inactivity’, or ‘incompetence’ (Wu et al., 2014). When technology is used, older adults often advocate for a ‘discrete’ or ‘unobtrusive’ aesthetic design and technology that is not too ‘medicalized’ or ‘institutional looking’. The electric scooter provides a clear example of this. Gardner (2014), Hirsch et al., (2000), and Resnik et al., (2009) all spoke to how older adults make conscious and purposeful decisions to use “de-medicalized” devices, such as a scooter, to support community mobility because scooters are perceived as portraying an image of youth, sportiness,
and sexiness; an image consistent with contemporary discourses of ‘positive’ or ‘successful’ aging (Carmel, Hamblin & Papadopoulos, 2007; Laliberte Rudman & Molke, 2009). In relation to these broader discourses of aging, seniors are made to feel ‘successful’ if they maintain a sense of independence, self-reliance, and competence but are seen to have ‘failed’ if they take on the characteristics stereotypically associated with ‘oldness’ which may include the use of certain technologies. For example, one study, by McGrath & Astell (2016), reported findings regarding self-image specifically from the perspective of older adults with ARVL. They found that seniors intentionally avoided the use of ‘obvious’ markers of vision loss (i.e. white cane, dark sunglasses, and ‘Traveler with Vision Loss’ sign) in public spaces, because they were fearful that use of such technologies would mark them as objects of pity, ridicule, and stigmatization.

**STUDY OBJECTIVES**

The goal of the proposed study focuses on how the decision-making processes of older adults with ARVL, as it relates to technology adoption, is influenced by the negotiation of identity; that is, how older adults’ decisions are shaped in relation to broader societal discourses regarding the ideal aging identity and a personal desire to convey the self in particular ways (i.e. as independent, competent and self-reliant). To accomplish this goal, the objectives of the project included:

1. Examining how older adults with age-related vision loss make decisions about adopting a new technology (both for use in the home and the community), inclusive of those technologies specifically designed to accommodate for vision loss (i.e. low vision assistive devices [LVADs]) as well
as those technologies that are not specifically LVADs, but are used in ways that address the needs of older adults with ARVL.

2. Understanding if/how the desire to promote an ideal aging identity impacts the decision-making processes of older adults with ARVL as it pertains to technology adoption.

3. Comparing how the desire to promote the ideal aging identity, impacts the use of technologies in private (i.e. home) versus public (i.e. community) spheres.

EXPLANATION AND JUSTIFICATION OF METHOD

Theoretical Underpinnings

Identity theory (Burke & Stets, 2009) and critical gerontology (Estes, Biggs, & Phillipson, 2003; Minkler & Holstein, 2008; Ray & Cole, 2009) provided the theoretical underpinnings for this study. Identity theory seeks to explain the meanings that individuals ascribe to the multiple identities they employ; how these identities relate to one another; and how these identities influence behaviour, thoughts, feelings, or emotions. Each person can occupy several positions and thus have multiple identities. In fact, identity theory recognizes the interaction of social (or group) identities, role identities, and personal identities, which operate simultaneously in any given situation to create an account of the individual’s sense of self. According to identity theory, humans strive to maintain a balanced and stable environment in the face of disturbances, and they do so by changing their actions to make their perceptions match a reference standard or ideal self (Burke & Stets, 2009). This was evident in a study conducted by Parette & Scherer (2004) who reported that stigma associated with disability and
assistive technology use were found to be one of the main reasons people with developmental disabilities rejected mobility devices. In this example, discrepancies between the desired identity of the users and the identity portrayed by using the devices resulted in withdrawal from both the device and the user image associated with it (Parette & Scherer, 2004). These findings suggest that inconsistency between the desired identity of older adults and the identity portrayed by device use may alter decision-making patterns, resulting in abandonment of devices.

Critical gerontology aims to question taken-for-granted assumptions about what it means to age well and “the seemingly un-reflexive ways in which gerontological knowledge is created” (Holstein & Minkler, 2003; p.789). It aims to make the inequality of the aging process visible and highlights how older adults are disenfranchised by political and social oppressive forces (Estes, Biggs & Phillipson, 2003; Minkler & Holstein, 2008). In relation to the proposed study, critical gerontology was drawn on to frame how older adults talk about and negotiate desired self-image, in relation to technology, and in relation to broader discursive power structures that shape societal images and beliefs about how to age well/successfully.

Methodology

The study adopted a critical ethnographic approach. Critical ethnography is focused on eliciting not only the research participants’ point of view, but also questioning the prevailing status quo and dominant power structures present within a specific culture that serve to constrict marginalized people’s lives (Cook, 2005; Simon & Dippo, 1986; Thomas, 1993). Critical ethnography aims to reveal the social practices amongst a specific group of individuals and investigate how these practices are historically
constructed to regulate and organize facets of living and being in the world (Simon & Dippo, 1986). The preferred ‘audience’ for critical ethnographic work is a collection of individuals who are “brought together by the experience of lived contradictions and desiring a mutual examination of the fabric of social relations of which they are a part and a sense of what they might do to enhance the range of possibilities in their lives” (Simon & Dippo, 1986; p.199). In line with the principles of critical ethnography, this study focused not only on understanding decision-making processes from the perspective of older adults with ARVL, but also how decision-making is influenced by broader ageist and ableist social assumptions. The participants in this study were those keen on sharing their experiences of age-related vision loss so that others may be better able to access technologies, or that the current technologies developed be better equipped to fulfill the needs of this population. A modified version of Carspecken’s (1996) five-stage approach for critical ethnography was adopted. These stages include: 1) building a primary record; 2) preliminary reconstructive analysis; 3) dialogical data generation; 4) discovering system relations and; 5) using system relations to explain findings.

**SAMPLING AND RECRUITMENT**

A variety of recruitment strategies were utilized, including facilitating discussions with relevant low vision rehabilitation services, attending senior-friendly conferences in Southwestern Ontario, and advertising in a free local newspaper that is delivered door-to-door in the city where the study took place. As well, a recruitment flyer was distributed via email to all members of an educational group for retired seniors. These advertisements included the study researcher’s contact information so that those
interested in the study were able to contact the researcher directly to participate. Lastly, the primary author had previously engaged in research projects that involved older adults with age-related vision loss and as such, the primary author reached out to those participants who had consented to being contacted for future research studies. These recruitment methods had been used successfully in previous low-vision research projects (McGrath, Laliberte Rudman, Spafford, Trentham & Polgar, 2017; McGrath, Laliberte Rudman, Polgar, Spafford & Trentham, 2016; Laliberte Rudman, Huot, Klinger, Leipert & Spafford, 2010; Spafford, Laliberte Rudman, Leipert, Klinger & Huot, 2010) and proved successful for this research project as well.

Participants who contacted the research team were enrolled if they met the following inclusion criteria: 1) 65 years of age and older; 2) a diagnosis of ARVL (macular degeneration, glaucoma, and/or diabetic retinopathy); 3) able to communicate in conversational English; and 4) cognitive ability necessary to participate in the data collection process. A total of 11 seniors who had rich lived experience with vision loss were recruited. Seven participants were recruited via a low vision rehabilitation service or had participated in previous research, two were recruited from the advertisement placed in the local newspaper, one from the flyer distributed to members of an educational group for retired seniors, and one from a seniors' conference in the community.

When the low vision rehabilitation service identified a potential participant, the older adult was provided with a copy of the recruitment flyer, including the contact information of the principal investigator and research assistants. If the older adult was interested in participating, the participant contacted the researcher directly either via
email or telephone. All participants received a response from the researcher using either the ethics approved telephone script or email script to further inform them about the study and to screen for the inclusion criteria. The letter of information and consent form were reviewed with the participant both prior to as well as during the first meeting, and the consent form was signed prior to data collection beginning. The participants also completed a demographic questionnaire prior to data collection, in order to obtain basic personal information such as age, living situation, years since diagnosis, etc.

**DATA HANDLING**

Each participant met with the researcher(s) three separate times at a date and time of their choosing. A full copy of the session schedule for all participants can be seen in Table 1.

**Session #1**

During the first session, participants engaged in a home technology tour (Baillie & Benyon, 2008), which was video recorded. A rough paper and pencil sketch of their home was created, which depicted the placement of technologies throughout the home. Each home tour was attended by the two project research assistants (MLM and EJS) so that one researcher (MLM) could conduct the home tour using the video camera (a Canon Vixia HFR800), while the other (EJS) could create the sketches of the home. The home tour was focused around learning how older adults with ARVL make decisions to use technology within the private sphere of the home. It revolved around six key questions that are listed in Table 2. The questions were not asked prescriptively, but rather, served as prompts for the researchers. No technologies were excluded from the home tour nor was a definition of technology provided, thereby providing
participants with space to define technology as they saw fit. The sketches were then converted into digital renderings using floorplanner.com to aid in providing a visual map of the participants’ homes and their placement of technology within it. This specific online tool was used as it allowed the researchers to import images of LVADs into the renderings.

**Session #2**

During the second data collection session, the older adult and researcher(s) participated in the go-along method, also commonly referred to as ‘go-alongs’. Go-alongs, which are conducted by a researcher accompanying participants on outings in their local environments (Carpiano, 2009), combine participant observation and interview. This allows the researcher to explore the participants’ physical and social practices by asking questions, listening, and observing (Kusenback, 2003). In this study, the questions asked during the go-along were open-ended (see Table 3). Guiding and clarifying questions were crafted by the researcher(s) ad hoc. The focus of the go-along was on which technologies are used in public spaces, how older adults decide to use the technology, which occupations are supported by technology use, and what challenges are encountered in the absence of technology use. Field notes detailing any observations made by the researcher(s) during the go-along were written or audio recorded immediately following each session for later transcription. These community sessions allowed the researchers to understand decision-making processes related to the use of technologies within the public sphere, and how experiences of stigmatization, fear, and embarrassment may accompany the use of different technologies.
In order to record the audio of both the researcher and the participant, multiple pieces of equipment were used. The research assistant conducting the go-along had a password-protected iPhone SE™ with the app VoiceRecorder v3.5 to record the session. The iPhone was connected, by hard wire, to the researcher’s microphone and microphone transmitter (Azden Icoustics Pro XD). The participant also had a microphone transmitter and microphone. The researcher’s microphone transmitter was wirelessly connected to the microphone transmitter of the participant, and thus the iPhone recorded the audio of both the researcher and participant into a single audio channel. This equipment was found to be effective as it allowed for a discrete way of conducting a go-along interview, as it did not require the researcher to hold a traditional voice recorder between the speakers in public spaces. Additionally, the wireless nature of the microphone transmitters allowed for a physical distance between the researcher and participant of up to 40 feet, allowing for more comfortable community travel.

**Session #3**

The third, and final, data collection session was a semi-structured interview. In line with the inductive nature of critical ethnography, the contents of the semi-structured in-depth interview emerged from information gathered during the home technology tour and the go-along interview method. The general focus, however, was to allow the participants to reflect on if, and how, their sense of who they are and how they want to be seen by others impacts their decision-making regarding the use of technologies in private (i.e. home) versus public (i.e. community) spheres (see Table 4 for sample questions). This semi-structured interview also provided participants with an opportunity to clarify and elaborate on information shared during the first two sessions. The
researcher(s) followed a dialogical interview format, whereby open-ended questions were used to lightly structure the interview, but the researcher(s) also followed the lead of the participants (Manderson, Bennett & Andajani-Sutjahjo, 2006). Either one or both of the research assistants attended the final interview, which was audio recorded for later transcription and data analysis.

DATA ANALYSIS

Data analysis occurred simultaneously with data collection, such that emerging findings helped to inform subsequent data collection sessions. The home technology tours were video-recorded while the go-alongs and the semi-structured interview were audio recorded and transcribed verbatim. The video files were analyzed using Observer® XT, a software package designed for the collection, analysis, and presentation of observational data. For this study, Observer® XT was particularly helpful at capturing multiple aspects of behavior including facial expression, body language, levels of comfort/confidence, and the language used to describe the technologies. NVivo software was used for the audio transcripts, maps, and field notes. Whether textual or video files, a consistent approach to data analysis was adopted for this study. The analysis process began through immersion within “the context of the interactions” (Carspecken, 1996, p. 149) which involved reading each transcript or watching each video file individually to develop a rich understanding of the data before drawing comparisons between data sets. The research team began with low level coding which was close to the data with limited abstraction. It served to highlight the more objective components of the research and was ‘raw’ in the sense that no effort was “made to organize them into a tight hierarchical scheme” (Carspecken, 1996, p. 150).
low level coding, our research team proceeded to high level, or theoretical coding, which required abstraction and interpretation, as coding is no longer based on the transcripts alone. High-level codes were framed around our guiding theoretical frameworks of both identity theory and critical gerontology. In particular, our use of a critical gerontological perspective allowed us to investigate issues of power, status quo, and marginalization as it effects older adults aging with ARVL. After low and high-level coding was completed, our codes were compared within and across data sets to form categories and themes. Resulting codes, categories, and themes were refined through ongoing team meetings to engage in collective reflexivity, which expanded possibilities for coding. In addition, the researchers maintained a reflexive journal throughout the analysis process to challenge assumptions and be open to multiple ways of 'seeing' the data.

ETHICS

Informed Consent

The reading and signing of a consent form is often a taken-for-granted part of the research process. However, as our participants had varying levels of vision loss, in many cases the signing of a consent form was not possible for the participant to complete on his or her own. The consent process was altered so that no demands were made upon participants to read printed material. The information letter and consent form, in enlarged font, was read to each participant by the research assistant(s) and, depending on the participant’s preference, he or she either signed the consent form, or provided verbal consent. In cases where a participant chose to provide verbal consent, the person explaining the study noted that verbal consent was obtained and an impartial
witness was required to be present to confirm that the participant had been adequately informed about the study prior to providing consent. Any questions the participants had were asked to the research assistants and were answered fully and to the participants’ satisfaction before any consent forms were signed. In addition to explicit written consent or verbal consent from the older adults with ARVL, process consent was also obtained by the research assistants in subsequent stages of data collection to ensure that the participant still wished to be involved in the research study.

**Data Collection**

With regard to the data collection process, video recording can pose some ethical challenges. Filming the participants, as well as the inside of their homes, could potentially lead to the identification of the participants in the study. To mitigate this, the participants could decline video recordings in favour of audio recordings, if they preferred. For those who consented to video recordings, only the audio portion of the video files were sent for transcription. At the end of the study, the recorded media was analyzed by the primary investigator (CM), the two co-investigators (DLR and AA), and the two student research assistants (EJS and MLM). These video recordings were not viewed by individuals outside of the research team and were not used in any reports and/or publications.

For the equipment used in the go-along interviews, modifications were made to ensure data security. For example, the SIM card was removed from the iPhone used to record the go along sessions and a six-digit password was set. The VoiceRecorder application was purchased from the iTunes App Store so that the audio files could be transferred via hardwire to the computer, instead of through Wi-Fi or cloud-based
applications. Using this configuration of technology and software proved to be safer than using a traditional audio recorder as they are not password-protected and are more likely to pick up audio from others in the participant’s surroundings during the go-along session. Lastly, when conducting the go-alongs, if a participant was completing a task that was more personal in nature (e.g., discussing personal financial information at the bank), the research assistant would pause the audio recordings before the participant started their errand, so that any personal information was not recorded.

**Rigour**

Methodological rigour was adopted and maintained throughout the study. First, there were multiple types of data generation that took place in this study, which is a form of crystallization. Utilizing three different methods of data collection allowed the research team to see the multiple ways that contextual issues, including those related to identity, shaped decision-making regarding technology adoption and use. Rigour was also maintained by conducting a final semi-structured interview in order to substantiate and add to the information presented in the first and second sessions. This also allowed the participants to state anything they felt was important to discuss, but may not have had the opportunity to mention during the previous two sessions. In data analysis, rigour was maintained by having each researcher code the data separately, as well as conducting regular meetings with the research team throughout the progression of data collection and analysis. This allowed for challenges to be made to each researchers’ assumptions and expanded ways of ‘seeing’ the data.

**CONCLUSION & IMPLICATIONS**
Given the scarcity of research focused on how the decision-making processes of older adults with ARVL, relating to technology adoption, is influenced by the wish to convey a desired personal and social identity, the proposed study will make important and substantive contributions to the literature. As groundwork to future studies, this research will begin to map out the complexity of the decision-making process for older adults with ARVL. This study will also make important methodological contributions by combining innovative research methods that aim to understand technology adoption patterns in both private and public spheres, while also placing senior’s decision-making processes within the broader societal context. In turn, it is anticipated that such research can better support the acquisition and use of technology by older adults with ARVL, enhance the design of appropriate (i.e. non-stigmatizing) services and technologies for an aging market, and help to inform inclusive policies and practices that ensure the equitable distribution and availability of appropriate technologies to all older adults aging with vision loss.

**What is already known?**

Current low vision literature has demonstrated the high rates of abandonment of low vision assistive devices. It remains unclear, however, the influence of contextual factors, such as societal attitudes towards technology and the stigma associated with aging and disability, that ultimately serve to shape the meanings that older adults ascribe with technology use and adoption.

**What has the study added?**

This study aims to help explain one of the factors that may contribute to the high rates of abandonment of low vision assistive devices, namely how issues of self-
image/identity influence the decision-making processes of older adults with ARVL, as it relates to technology adoption.
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