A Qualitative Approach to Understanding User Needs for Aging with Disability

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Abstract— **There is a growing population of adults with long-term sensory and mobility impairments who are aging into older adulthood. Little is known about the everyday challenges and accessibility issues experienced by these individuals as they age and acquire age-related declines in addition to a pre-existing impairment. The present paper provides an overview of a large-scale interview study, currently in progress, exploring user needs of older adults with long-term vision, hearing, and mobility impairments. The structured interview is designed to elicit detailed information on task performance challenges across a wide range of daily activities, as well as strategies to manage those challenges. In this paper we provide case-study examples from each of the three impairment groups to convey the potential depth and breadth of insights about user needs among individuals aging with impairments that can be realized through this novel qualitative approach.**

Keywords-aging; disability; technology; impairment; Deaf/hard of hearing; vision impairment; mobility impairment.

I. INTRODUCTION

Worldwide, advances in healthcare, rehabilitation, and technology are enabling individuals with impairments to live longer lives than ever before. In the U.S., nearly 40% of older adults (over age 65) reported having one or more disabilities, including vision (19% of those with disabilities), hearing (40%), and ambulatory (67%) impairments [1]. Despite the prevalence of older adults with sensory and mobility impairments, very little is known about the segment of this population who acquired their impairments in early or mid-life, said to be "aging with disability" [2][3]. An estimated 12 – 15 million adults in the U.S are aging with impairments that began prior to age 40 [4]. For these individuals, the addition of normative age-related changes, such as declines in vision, cognition, and motor functioning, can create new barriers in carrying out everyday activities and increase the likelihood of disability.

Technology holds great potential to support older adults with long-term impairments in maintaining daily activities and living as independently as possible [5]. To effectively design technologies that meet the needs of these individuals, it is necessary to understand more about the experiences of people aging with impairment. How do their support needs change across the lifespan? Are the same assistive technologies that someone used as a child, or as younger adult, still effective for them as an older adult? How do new impairments and chronic conditions impact routines for everyday activities? To begin answering these questions, researchers must engage the individuals who are experiencing aging with impairment first-hand.

Currently in progress, the Aging Concerns, Challenges, and Everyday Solution Strategies (ACCESS) study is a large-scale, mixed method study investigating user needs of individuals aging with impairment. This project is part of the Technologies to Support Successful Aging with Disability Center (TechSAge). The goal of the ACCESS study is to understand the nature and distribution of task performance problems with everyday activities for older adults with long-term vision, hearing, or mobility impairment. In addition to activity challenges, the study explores the various strategies individuals in these three distinct populations employ to manage them. The ACCESS study utilizes both quantitative (questionnaires) and qualitative (structured interview) methods to assess perceptions of task difficulty and the nature of participants' challenges and solutions.

The current paper provides a brief overview of the interview component of the study and presents case study examples that convey the potential value of this novel approach in understanding user needs for this understudied population. In section 2, the study methods are described with regard to participant characteristics, materials (interview guide and questionnaires), procedures, accommodations for participants with sensory impairments, and analysis. Section 3 is comprised of case study examples from a participant in each of the three target populations (n=3). This section includes a table with descriptive characteristics about the participant sample as well as examples of challenges mentioned in the interview. Finally, Section 4 features a discussion of the emerging findings from the analysis of case study examples and implications for the qualitative component of the broader study in progress.

II. METHOD

A. Participants

The goal of the ACCESS study is to enroll 60 participants in each of the three target populations (vision, hearing, mobility; total n = 180). To be eligible for this

study, participants must be between the ages of 60 and 79 and have a vision, hearing, or mobility impairment that began prior to age 50. There are additional inclusion criteria specific to each impairment group. Vision participants must self-identify as Blind or Low Vision, operationally defined as "unable to see" or "having serious difficulty seeing even when wearing glasses or contact lenses." Participants in the Hearing impairment group must self-identify as Deaf or hard of hearing and use American Sign Language (ASL) as their primary language for communication. Mobility participants must self-identify as having a mobility impairment and either use a mobility aid or have serious difficulty walking or climbing stairs. All participants must live in the Unites States and be able to complete the interview in English or ASL.

Participants to date were primarily recruited through outreach to local and national disability resource organizations and conferences as well as from the Georgia Institute of Technology Human Factors and Aging Participant Registry and the University of Illinois Disability Resources and Education Services Research Registry. Participants receive $30 USD compensation for completing the questionnaires (1 hour) and interview (1-1.5 hours).

B. Materials

1) Interview guide: A structured interview guide was developed to elicit participants' challenges with everyday activities as well as the strategies they employ to overcome those challenges. The scope of activities covered in the interview guide was selected based on findings from an earlier study wherein subject matter experts with personal and/or professional experiences with older adults with sensory and mobility impairments (e.g., caregivers, medical professionals) gave their perspectives on the challenges experienced by these populations [6].

For each activity category, there is a rating activity followed by open-ended interview questions. The purpose of the rating activity is to identify which specific types of activities are the most difficult for participants to do. Participants rate topics within the activity category based on how difficult it is for them to do using a 3-point scale (1 = not at all difficult, 2 = a little difficult, 3 = very difficult, or N/A = not applicable). The interviewer uses a worksheet to document the difficulty ratings for each topic. Participants are instructed to give ratings based on the way they currently do the activity now, including any help or support they receive. Once all ratings have been provided, the interviewer reviews the worksheet to identify the topic with the highest difficulty rating which will be the subject of follow-up, open-ended questions. Following the rating activity, there are open-ended questions that focus on overall activity category, and how activities may have changed as they have gotten older. These questions were designed to capture how participants are adapting their activity routines and managing challenges in relation to the Selection, Optimization, and Compensation (SOC) framework. Stemming for the aging literature, the SOC framework is used to describe how individuals adapt to developmental challenges across the life span via the processes of selection, optimization, and compensation [7]. Interview questions ask participants how they are handling their challenge in distinct ways by probing for different types of solutions they might be employing, such as using a technology or getting help from someone.

2) Questionnaires: The current paper focuses on the qualitative component of the study. However, participants also complete self-report questionnaires to assess demographic and individual charactics (e.g., functional abilities, information about the nature and degree of participants' impairment).

C. Procedures

Eligible participants are scheduled for an interview appointment, which takes approximately 1-1.5 hours to complete. Interviews and are either conducted in-person or remotely via telephone or Video Phone, which is a common technology in most households with a Deaf resident. Participants located in Metro Atlanta GA or Champaign-Urbana IL have the option to complete the interview with a researcher or in-person.

Once the study is complete, audio recordings of the interview are transcribed into text files. For ASL video interviews, screen recording software is used to record the entire interview, onto which voice-over translation for both the interviewer and participant is later recorded. To ensure accuracy, ASL-to-English translations of completed interviews are conducted by hearing native ASL signers who are highly familiar with the project and the questions being asked. The voice-over English translations are then transcribed into text.

D. Accomodations

The study was designed with flexible administration options to accommodate participants with sensory impairments. In addition to the standard paper consent form, participants were provided with an audio recording of the content. Recognizing that some Deaf participants may have challenges reading English, the research team developed a summary of the consent form in ASL. Interviews with Deaf older adult participants are being conducted in ASL by interviewers who are also Deaf to ensure authenticity and cultural/linguistic appropriateness. One of the project investigators, who is fluent in ASL, worked with a native-signing sign language interpreter to develop a parallel ASL translation of the ACCESS Interview script. The Deaf interviewers were trained on all study procedures and completed necessary human subjects research certifications.

E. Analysis

As data collection continues, researchers are beginning to review interview transcripts and develop the coding scheme for qualitative analysis. The present paper presents examples of activity challenges as three case studies, one from each of the three impairment groups. Descriptive

information regarding participant characteristics were compiled from responses to questionnaires.

III. CASE STUDY EXAMPLES

The current paper presents initial insights from a participant in each of the three impairment groups (n = 3). Table 1 features descriptive characteristics about the participant sample as well as examples of challenges mentioned in the interview. For the purpose of this paper, the three participants are identified as V1, D1, & M1, with the letter signifying their respective impairment group (vision, hearing, and mobility). Participants represent distinct impairment characteristics with regard to type, onset age, underlying cause, nature (limitations/abilities), and use of supportive aids. Each participant reported having at least two chronic conditions, such as arthritis and diabetes.

Interviews with participants revealed a wide range of challenges across the different domains of activities, as depicted in Table 1. Quotation marks indicate a verbatim quote from the participant, whereas examples without quotations indicates that the researcher paraphrased the participant's comments. The topic that participants rated as the most difficult in each category is listed in parentheses alongside examples. Participants mentioned at least one challenge for each of the six categories, with the exception of Shopping and Finances category for which V1 did not report any challenges. In many cases, the topic participants identified as the most difficult in each category was different than that of their counterparts.

Most of the activity challenges mentioned were unique to each impairment group. In one instance, two participants, V1 and D1, shared the same most difficult topic (working, volunteering or other civic activities), but described distinct challenges relating to fatigue and communication barriers respectively. There were some activity challenges, however, that were shared among participants. For example, D1 and V1 both described challenges keeping track of medications due to forgetfulness. Similarly, D1 and M1 discussed changes in their physical abilities that have made housekeeping tasks more difficult overtime.

Participants generally attributed task performance problems to their primary impairment. For example, M1 discussed the extensive planning she has to do to ensure that group activities in the community are wheelchair accessible. One interesting finding is that each participant discussed a challenge that they did not attribute to their primary impairment, but rather to other conditions or aging. For example, V1 expressed that his challenge with grooming tasks, such as shaving and brushing his teeth, was remembering to do them; he attributed these memory issues to a recent brain tumor. Similarly, D1 discussed that she periodically gets vertigo and loses her balance, which can make it hard to move around at home.

All participants described needs that could potentially be addressed through technology innovations. Having multiple co-morbid conditions, V1 has a complicated medication regimen and could benefit from some kind of reminder system to help him take his medications as prescribed. D1 highlighted connectivity issues with Video Relay Interpreting (VRI) which could be improved in future development and refinement of the system. M1's trouble identifying whether or not a building is wheelchair accessible might be addressed through a website or mobile application that utilizes crowdsourced information on the presence or absence of accessible features within community venues. Regardless of what potential technology solutions might be appropriate, and whether such a solution currently exists, the interviews honed in on participants' user needs that are not currently being met.

IV. DISCUSSION

Older adults with long-term sensory and mobility impairments are likely to experience challenges beyond those that accompany the normative aging process. There is a need for in-depth research that explores not only the activity challenges experienced by this population, but also the specific components of the task that create problems and could ultimately result in disability [8]. The ACCESS study is the first large-scale interview study exploring user needs among older adults with long-term vision, hearing, and mobility impairments. The interview was strategically designed to explore difficulty across a broad range of activities, while also probing for each participant's insights on activities that are particularly challenging for them. By incorporating a number of accommodations, including the training of Deaf interviewers to conduct interviews with Deaf older adult participants, the ACCESS study serves as a novel method to capture the perspectives of older adults with sensory and mobility impairments.

These case study examples (n = 3) convey the potential depth and breadth of insights on technology user needs of older adults with long-term sensory and mobility impairments that can be realized through this study. Interviews suggest that challenges experienced by these individuals are complex, and are subject to a variety of factors related to the person (e.g., capabilities and limitations, financial resources, support) and their environment (e.g., housing, community infrastructure, transportation). Moreover, it is clear that age-related declines and other co-morbid conditions are contributing to activity challenges among this population. This finding leads to the hypothesis that older adults with long-term impairments are not only likely to experience more challenges than non-impaired older adults, but also more than younger cohorts of people with the same types of impairments. The complexity of challenges revealed among just 3 individuals confirms the need to extend this research with a larger, more diverse group of individuals. Researchers continue data collection and analysis for the ACCESS study with the goal of developing a taxonomy of everyday support needs for individuals aging with impairment. Detailed user needs insights can ultimately guide the development of supportive and accessible technology solutions for individuals with impairments across the lifespan.

TABLE I.   PARTICIPANT CHARACTERISTICS AND EXAMPLES OF ACTIVITY CHALLENGES MENTIONED IN THE INTERVIEW

	Vision - V1	Deaf - D1	Mobility - M1
Participant characteristics	Gender: male Age: 60 Age of impairment onset: birth Cause of impairment: Right eye not fully developed at birth Nature of impairment: No vision in right eye; able to read large print with left eye Use of visual supportive aids: Reading magnifier, scanners, optical character recognition (OCR) Chronic conditions: Arthritis, cancer, cardiac arrhythmia, depression, heart failure, hypertension, high cholesterol, overweight	Gender: female Age: 69 Age of impairment onset: 1 Cause of impairment: unknown Nature of impairment: impairment in both ears; even with use of hearing aid, cannot hear well enough to have a spoken conversation Use of hearing supportive aids: hearing aid, interpreter services, TTY, video phone Chronic conditions: High cholesterol, overweight	Gender: female Age: 70 Age of impairment onset: 6 Cause of impairment: multiple sclerosis and post-polio syndrome Nature of impairment: able to walk short distances with cane Use of supportive mobility aids: cane, manual wheelchair, scooter, knee brace, orthotic device Chronic conditions: asthma, arthritis, diabetes, hypertension, high cholesterol, overweight
Categories	**Examples of challenges from interview**		
Activities Outside the Home	It is challenging for him to participate with without getting short of breath or dizzy. (Working, volunteering or participating in other civic activities)	"If it is a group of all deaf people, it is fine. If there was some kind of activity with hearing people, then that would be difficult...I have to write with them and I hope they are patient writing with me." (Working volunteering or participating in other civic activities)	"I have to do a lot of pre-planning. I contact whoever is in charge to find out where it is, and if that place is upstairs, that is has an elevator. If getting there is a problem, I might have to use my wheelchair instead of my scooter, and then I have to find somebody to push it." (Doing things with a group or organization)
Things You Do Around the Home	He relies on his high-powered magnifier and sense of touch for fixing things around the home. It is hard because he can't see where a leak is coming from or what type of screw is needed. (Repairing and maintaining the home)	"When I scrub the floor, I notice now I find that my knee hurts. Maybe this is getting older" (Housekeeping)	She is no longer able to climb on a chair or get down on the floor so many home cleaning tasks have become difficult. (Housekeeping)
Shopping and Finances	He is unable to read most printed store receipts, so he always asks someone to read it aloud and keeps a copy to review at home with his magnifier (Paying and signing for things)	No challenges mentioned.	She often has to wait to use the handicap dressing room because "everyone wants it." (Going shopping in-person)
Transportation	"I leave that up to the drivers. I don't try to plan a trip and decide what roads I want to be on". He is no longer able to drive due to progressive vision loss and the number of medications he is taking. (Wayfinding)	She nearly missed a flight because they she was unaware of a gate change announcement made over the intercom. "I just wish that they would make those announcements on some kind of visual display, but you never see that." (Travel)	"There are times were I just can't go where I want to because the vehicle we are using isn't really accessible. (Getting a ride from others)
Managing Your Health	He is unable to read prescription labels, so relies on wife to set up containers. "After having brain surgery last year, my medication went from 6 or 8 pills a day to over 25 pills a day... the hardest part is remembering to do it in the proper time period" (Managing medications)	Her doctor's office provides Video Relay Interpreting (VRI), but sometimes there are connection issues and it is hard to see the interpreter if the screen is blurry. One visit, she stopped using the VRI and instead tried to communicate with the doctor by writing and doing a thumbs-up or thumbs-down. (Going to healthcare provider appointments)	"I would like some help in managing the pills. Sometimes I forget. Even though I'm using a checklist and all that, I'm just not sure of myself. I have to check my blood sugar eight or ten times a day." (Managing medications)
Basic Daily Living Activities	"I'm able to shave. I'm able to brush my teeth. I'm able to do those things but with my memory, sometimes I forget that I didn't do it. (Grooming)	Sometimes she gets vertigo and loses her balance. (Moving around the home)	"I injured one of my legs worse, and had to use the scooter to get into the bedroom and that took planning. I had to get a longer ramp installed. (Movement around the home).

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