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Original Article

Aging Concerns, Challenges, and Everyday Solution Strategies (ACCESS) for adults aging with a long-term mobility disability

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ABSTRACT

Background: There are growing numbers of adults aging with long-term mobility disabilities. Very little is known about the challenges this population experiences with everyday activities, and such challenges are likely to be greater and more complex than those of older adults who experience mobility declines later in life.
Objectives: The current manuscript presents in-depth insights on the specific activity challenges experienced by older adults with long-term mobility disabilities, and the response strategies they employ to overcome those challenges.
Methods: In-depth, structured interviews designed to assess challenges and response strategies for a range of daily activities were conducted with sixty older adult participants (ages 60–79) who self-identified as having a mobility disability for a minimum of 10 years. A coding scheme was developed to classify emerging themes. We identify the most common challenges and responses reported across all 6 broad categories as well as for a single activity category as an exemplar of an in-depth activity analysis.
Results: A needs taxonomy revealed challenges and response themes in relation to the most difficult activities identified by the participants. Frequently reported challenges included physical limitations and accessibility challenges. Common response strategies (e.g., utilizing tools or technologies, obtaining assistance from others, or modifying the approach to the task) were successfully mapped onto the Selection, Optimization, and Compensation model.
Conclusions: Findings reveal the unique challenges individuals face when engaging in everyday activities, and the potential of affordable and effective supports to promote aging-in-place, functional independence, and community engagement for adults aging with long-term mobility disability.

Introduction

Worldwide, there has been rapid growth in the number of older adults with disabilities.[1,2] In the U.S., mobility difficulty, defined as "serious difficulty walking or climbing stairs", is the most prevalent disability among all older adults (ages 65+), affecting over 15% of older adults (ages 65–74), 26% of those ages 75–85, and 48% of those ages 85+.[3,4] A growing subset of individuals with mobility impairments acquired early to mid-life are aging with disability.[5] Their specific activity challenges and support needs are understudied, but are likely to be more complex compared to individuals who experience mobility disability in later life due to normative, age-related changes (i.e., aging into disability).[6,7]

Adults aging with long-term mobility disabilities are subject to the interactive effects of age-related declines (e.g., in vision, hearing, memory) and conditions (e.g., arthritis, hypertension) on top of pre-existing mobility disability. Moreover, such age-related declines have been found to occur earlier and progress more rapidly among people aging with physical disabilities, a phenomenon known as "accelerated aging."[8] People aging with physical disabilities are at risk of developing secondary conditions related to their primary disabling condition (e.g., pain, weight gain).[9] Thus, people aging with mobility disabilities are likely to experience more activity challenges and have greater unmet service needs.[10] Technology holds great potential to support continued

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engagement in activities of daily living among people aging with mobility disability.[11,12] To effectively design technologies that support these individuals, we must have an in-depth, contextual understanding of their unique activity support needs.[13,14]

An archival analysis of large-scale studies exploring activity challenges faced by individuals aging with functional limitations demonstrated that challenges were most commonly associated with ambulation and mobility.[15] This existing literature focused on select Activities of Daily Living (ADLs; e.g., bathing, dressing) and Instrumental Activities of Daily Living (IADLs; e.g., housework, grocery shopping), but failed to capture Enhanced Activities of Daily Living (EADLs; e.g., hobbies, exercise, attending an event) in which older adults spend a large proportion of their time.[16]

To explore the potential range of activity challenges among people aging with mobility disability, we interviewed Subject Matter Experts (SMEs) who had personal and/or professional experience working with this population.[17] SMEs identified a number of challenges such as: the availability and affordability of assistance and/or home modifications; usability and privacy concerns with technology; limited opportunities for exercise; and lack of transportation. Findings from the SME interviews shed light on potential challenges to anticipate among this population and led our efforts in selecting specific activity categories and corresponding activities. Understanding the contextual details of the challenges can only be fully realized through in-depth exploration among people aging with long-term mobility disabilities.

The Aging Concerns, Challenges, and Everyday Solution Strategies (ACCESS) study is a large-scale, mixed-method study investigating user needs of individuals aging with disability. The objectives of the ACCESS study were two-fold: 1) to identify the nature and distribution of task performance problems with everyday activities for older adults with long-term vision, hearing, or mobility disability, and 2) to explore the strategies for responding to these challenges. The design of the ACCESS study was guided by the Selection, Optimization, and Compensation (SOC) Model, a model of successful aging that provides a broad-based theoretical perspective from lifespan developmental psychology to understand how people aging with mobility disability respond to activity challenges.[18,19]

The SOC model described how individuals adapt to developmental challenges throughout their life span. *Selection* describes an individual choosing to pursue certain activities (*elective selection*) or no longer engaging in a task that they are unable to successfully complete (*loss-based selection*). Through strategies of *optimization*, an individual may continue to invest time and energy into activities deemed important or significant, despite the task perhaps taking more effort or time to complete, but without bringing in any new means to assist. *Compensatory* behaviors involve utilizing new means or processes, such as getting assistance, or using a technology to maintain engagement in a task. Although defined separately, selection, optimization, and compensation behaviors are not mutually exclusive and can be employed in concert with one another. For example, consider a woman with long-term mobility disability who uses a manual wheelchair and is experiencing challenges with community mobility. She may employ *selective* strategies, such as prioritizing certain activities to minimize the number of times she must leave home. She may also use *compensatory* behaviors, such as using a portable ramp to access the homes of her friends who have entrances with stairs.

Researchers have applied the SOC model to classify behavioral strategies for managing daily activities[20] and home management tasks.[21] More recently, the SOC model was used to classify how older adults with long-term mobility disability respond to challenges with ADLs and IADLs.[22] The participants reported actively adapting their behaviors to preserve engagement in daily activities, and confirmed the need to more comprehensively explore the source of, and responses to, activity challenges among this population.

The purpose of this study was to identify the specific, activity-related challenges and response strategies employed by adults aging with a long-term mobility disability, regardless of their specific impairment. The research questions were as follows:

RQ1: What is the nature and distribution of challenges with task performance in everyday activities?
RQ2: What are the response strategies for dealing with the challenges, and how are they classified according to the SOC model?

The structured interviews provided the basis of a taxonomy of everyday support needs in the form of a comprehensive coding scheme for challenges and response strategies. The most frequently reported challenges and responses within one exemplar activity category (Basic Daily Activities) are presented in detail to reveal in-depth insights on a specific activity category. Challenges and response strategies are then presented across all six activity categories to represent broader trends. Response strategies are classified according to the SOC model.

Method

Overview

The ACCESS study consisted of questionnaires (e.g., demographics, functional limitations) and an in-depth structured interview designed to assess specific challenges with a range of daily activities and current responses to those challenges, including strategies for overcoming them.[29] This study was conducted at the University of Illinois, Urbana-Champaign, and the Georgia Institute of Technology with Institutional Review Board (IRB) approval from each university. The ACCESS study included 60 individuals in each of three disability groups: vision, hearing, mobility). The focus of the present paper is the mobility disability group.

Participants

Eligible participants were aged 60–79 and self-identified as having a mobility disability (having serious difficulty walking or climbing stairs)[23] that began prior to the age of 50. Participants were excluded from the study if they were outside of the required age range, had acquired the disability after the age of 50 years, or did not identify as having 'serious difficulty walking or climbing stairs'. Table 1 provides the details on characteristics of participants, who included a total of 60 community-dwelling adults (mean age 69, $SD = 5.4$). Average age of disability onset was 19 ($SD = 16$), ranging from birth to age 49, with 55 years being the average duration of mobility disability ($SD = 15.4$). Participants were recruited through a variety of both local and national disability organizations, flyer distribution, social media posting, participant registries, and word-of-mouth referrals.

Procedures. A brief, scripted telephone screening determined eligibility. Eligible participants were scheduled for an interview and sent questionnaires to complete in advance. Interviews lasted approximately 60–90 min and took place remotely by phone or in-person (e.g., on campus, at home) based on preference. All interviews were recorded and transcribed verbatim. All participants provided informed consent and were compensated $30.

Interview. The structured interviews were designed to elicit conversation about challenges with everyday activities, as well as to identify strategies employed to overcome those challenges. The

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Table 1
Participant demographic and descriptive data.

Variable	Categories	N	%
Gender	Female	35	58.3
	Male	25	41.7
Education	< High school	2	3.3
	High school graduate / GED	6	10
	Vocational training	1	1.7
	Some college / Associate's degree	10	16.7
	Bachelor's degree	11	18.3
	Master's degree	20	33.3
	Doctorate degree	10	16.7
Race	White	52	86.7
	Black/African American	5	8.3
	Other	2	3.3
	No answer	1	1.7
	Do not wish to answer	4	6.7
	Unknown	1	1.7
Marital Status	Single	14	23.3
	Married	26	43.3
	Separated	1	1.7
	Divorced	13	12.7
	Widowed	6	10
Income	<$25,000	12	20
	$25,000-$49,999	13	21.7
	$50,000-$74,999	11	18.3
	>$75,000	19	31.7
	Do not wish to answer	4	6.7
	Do not know for certain	1	1.7
Perceived Health	Poor	4	6.7
	Fair	10	16.7
	Good	32	53.3
	Very good	11	18.3
	Excellent	2	3.3
Cause of Mobility Impairment	Polio	30	50
	Neurological condition (e.g., cerebral palsy)	11	18
	Accident or event	10	17
	Congenital condition (e.g., spina bifida)	4	7
	Spinal cord injury (SCI)	4	7
	Other (adverse drug reaction)	1	1

interviews covered six categories: Activities Outside the Home; Activities Around the Home; Shopping and Finance; Transportation; Managing Health; and Basic Daily Activities. For each category, participants were asked about 5–8 specific activities (see Table 2), using lists developed by the research team that were guided by previous study results.[17] Participants rated how difficult it is for them to do each activity using a 3-point scale (1 = *not at all difficult*, 2 = *a little difficult*, 3 = *very difficult*, or N/A = *not applicable*). Interviewers instructed

Table 2
Activity categories and activities discussed in the ACCESS interview study.

Activities Outside the Home	Activities Around the Home	Shopping & Finance	Transportation	Managing Health	Basic Daily Activities
Doing activities with a group or organization	Contacting others	Applying for financial resources	Arranging for transportation (taxi, Uber, Lyft)	Accessing health information	Bathing, showering, or grooming
Going to entertainment events	Doing hobbies at home	Going shopping in person	Driving	Caring for others	Dressing
Participating in religious services	Housekeeping	Managing finances	Flying on an airplane	Exercising	Eating or feeding self
Visiting family & friends	Noticing alerts	Paying and signing for things	Getting a ride from friend or family member	Getting help in case of emergency	Moving around in the home
Working, volunteering or participating in other civic activities	Repairing and maintaining home	Shopping online	Riding train or subway	Going to healthcare appointments	Toileting
			Taking a bus	Managing diet and nutrition	Transferring
			Walking	Managing medications	
			Wayfinding	Monitoring health	

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Table 3
Coding scheme for challenges and responses.

Challenges Codes & Subcodes	Response Codes & Subcodes
Accessibility Challenges	Devices, Tool, Technology
Access to assistive devices	Use tools, tech
Access to information	Don't use tools, tech
Physical access	
Assistance from Others	Own Methods
Can't Do/Don't Do the Task	Home modification
Cognitive/Knowledge Limitations	Perseverance/patience/assertiveness
Communication Challenges	Planning ahead/prioritizing
Device, Tool, or Technology Challenges	Redesign/unconventional use
Emotional/Social Challenges	Relying on familiarity, organization, learning, repetition, experience
Environmental Challenges	Negative emotional response
Physical Challenges	Assistance from Others
General Health/Physical Limitations	Does get assistance
Mobility Limitations	Does not get assistance from other
Physical Strength/Endurance Limitations	
	Response to Causes Issues/New Challenge Introduced
Safety/Pain Challenges	
Transferring Challenges	Previous, Proposed, or Other Person's Response to the Challenge
Transportation Challenges	
Not accessible	
Not available	Task Not Done

Note. The list of codes and subcodes presented reflect only those identified among the mobility disability subgroup of participants, and does not represent the comprehensive coding scheme for the ACCESS study.

participants to give ratings based on the way that they currently performed the activity, including any help from others, or assistive tools/technologies utilized. For each category, participants were asked follow-up, open-ended questions about the activity they rated most difficult. These questions inquired about the specific aspect of the activity that creates the most challenge; and how the participant handles the challenge, including utilizing tools or technologies; obtaining assistance from others, or coming up with their own methods or strategies.

Data analysis

Development of the Coding Scheme. A content analysis was conducted to extract meaning from the qualitative data through both categorization of responses based on previous research findings (deductive)[15–17,22] and identification of emergent themes (inductive).[24] The coding scheme was iteratively developed to analyze challenges and response themes, focusing on participant responses to the follow-up questions for the activity(ies) identified as 'most difficult'. Challenge and response codes, subcodes, definitions, and examples were discussed among the research team and revised until complete consensus was reached.

Coding. The finalized coding scheme (Table 3) was uploaded into a qualitative software program (MAXQDA; VERBI Software, 2017). Four researchers independently coded the same transcript until the independent coding yielded a sufficient agreement and reliability among them ($r = 0.85$). This process was repeated for four additional transcripts to ensure reliability across coders, iteratively adjusting definitions and adding examples to improve clarity of the coding scheme, as needed. All transcripts ($N = 60$) were then randomized for coding by the four researchers.

Analytic approach. We present a series of analyses that demonstrate how the ACCESS dataset can be used to understand the depth and breadth of activity challenges and response strategies among the sample. First, we present the finalized coding scheme. Next, as an exemplar, we focus on the results from Basic Daily Activities, highlighting the most commonly reported difficult activities, challenges, and responses strategies, mapping on illustrative quotes that reveal in-depth insights on the context of these challenges and current strategies. We calculated the number of coded segments for each activity, identifying the most difficult activities that were ultimately discussed in-depth, as well as the relative proportions of the difficult activities within the Basic Daily Activities category. We then identified the frequency for challenge and response codes and provide examples from the transcripts. We followed this same process of identifying the most difficult activity(ies) and most frequently reported challenge and responses for each activity category and present the most common challenges and responses across all six activity categories.

Results

The results include the finalized coding scheme, which captures both challenge and response themes, used to code all transcripts for the activity identified as the most difficult within each category. Frequently reported challenges and response codes for all five categories and the corresponding activities can be found in the Supplemental Material. The coding scheme reflects the nature and distribution of the challenges with task performance in everyday activities (RQ1), as well as the response strategies, classified according to the SOC model, for dealing with the challenges (RQ2). In this paper we provide in-depth results for one category (Basic Daily Activities) including the distribution of difficult activities along with frequently reported challenges and responses, and then provide the most commonly reported challenge and response themes across all activity categories.

Needs taxonomy

Table 3 depicts the finalized coding scheme, which provides a taxonomy representative of the range of challenges and responses discussed (see Supplemental Material for the complete coding scheme for the mobility disability group). Challenge themes are in line with prior research included those related to cognitive, perceptual, motor, physical, external, and general health limitations,[16] as well as technology use, accessibility, and transportation

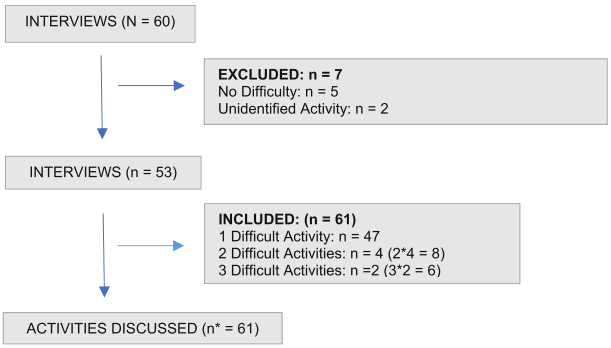

Fig. 1. Total activities coded (n*) based on the number of most difficult activity(ies) identified per participant for Basic Daily Activities.

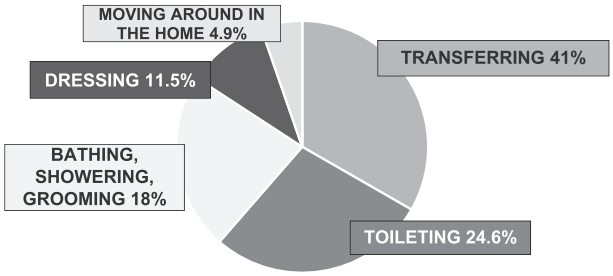

Fig. 2. Percentage values for the most difficult activities within the activity category of Basic Daily Activities.

challenges.[17] Emergent challenge themes included those related to finances; safety/pain; negative emotions or social challenges (e.g., embarrassment); environmental difficulties (e.g., the weather); and physical limitations related to strength or endurance, or other health issues.

Response themes were mapped onto the interview questions: utilizing assistive devices, tools, or technologies; assistance from others; or task abandonment. Participants frequently reported engaging in their own methods, such as displaying perseverance or patience; modifying the home; or relying on previous experience. Although not representative of active responses, sometimes participants responded with a previous strategy, one they had heard of someone else using, or a hypothetical new idea for a behavioral response to the challenge. The coding scheme provides the structure for understanding themes of challenges and responses in the context of the activity category.

Basic Daily Activities

Next, we demonstrate how the ACCESS dataset can be used to gain in-depth insights on challenges and response strategies within a specific activity category, by focusing on Basic Daily Activities as an exemplar. The most frequently reported challenge and response codes along with examples for all remaining five activity categories can be found in the Supplemental Material. Fig. 1 shows the total number of activities discussed within the activity category of Basic Daily Activities. Transferring was identified as most difficult activity for the largest proportion of the sample (41%), followed by using the toilet (24.6%), then bathing/showering/grooming (18%) (see Fig. 2). The most challenging aspects of these activities included the actual act of transferring (30%), followed by other physical challenges (24.9%) such a loss of balance, fall concerns, or difficulty standing. Participants responded to these challenges by utilizing devices or technologies (e.g., grab bars), reported by 28.6%; or coming up with their own methods (26.4%), such as redesigning the home. Table 4 provides participant quotes regarding frequently reported challenges and responses for Basic Daily Activities. For this activity category, a total of 84 challenge codes and 296 responses codes were identified.

Challenge themes across activity categories

Herein, we provide an overview of common challenges across all activity categories, followed by common responses in the next section (RQ1). The detailed data and examples specific to each activity category are presented in the Supplemental Material..

Physical challenges. Physical challenges in the form of limitations with mobility, physical strength, endurance, or health in general were the most frequently reported (25.6%) across all activity categories representing ADLs, IADLs, and EADLs. Mobility limitations included difficulty with fine motor movements (e.g., buttoning a shirt, signing documents) and gross motor limitations (e.g., walking, balancing, standing, or reaching). Mobility limitations were often associated with a fear of falling as well as specific activities such as walking on uneven ground (e.g., grass or gravel). Limited range of motion, particularly in the shoulders, was a challenge for activities that require transferring, sliding, or reaching.

Declines in endurance, strength, or stamina were also common. Many participants expressed concerns about fatigue and not being able to finish tasks. Activities with tasks that required physical strength, such as carrying groceries, were reported as the most difficult. Participants reported a variety of other health limitations as the source of their challenge. For example, exercise was difficult for many due to symptoms of post-polio syndrome or multiple sclerosis (e.g., fatigue, muscle weakness). Decline in shoulder functionality among manual wheelchair uses was also common.

Accessibility. Accessibility challenges were second most frequently reported (22.9%). Challenges associated with physical access to public or private spaces were mentioned for nearly all activity categories. Participants reported barriers to visiting family and friends due to inaccessible features of the home (e.g., stairs, narrow doorways). In public spaces, challenges accessing restrooms or buildings with non-automatic doors were also noted. Accessibility challenges with shopping were common, including difficulty reaching objects, navigating around obstacles, and avoiding other people. Housekeeping tasks that involved reaching overhead or into low places (e.g., top loading washer) or using mobility aids on uneven surfaces (e.g., lawn care) also created accessibility challenges.

Participants reported numerous accessibility challenges with transportation. Flying on airplane was a common challenge due to difficulties getting through security, transferring on and off the plane chairs, and not being able to access the restroom in-flight. Other transportation-related accessibility challenges included difficulty using public transportation due to restrictions on the number of wheelchair patrons served at any given time on buses and trains, or the limited availability of para transit services.

Assistance from others. Relying on assistance from others to engage in certain activities was common (6.2%). Participants reported difficulty finding someone who was able or willing to help, or able to complete the job in a trustworthy or thorough manner. Concerns about financial constraints, safety, and feeling comfortable with the person assisting with more personal tasks such as bathing and showering were common.

Response strategy themes across activity categories

The SOC model provided a framework to categorize the response strategies associated with ADLs, IADLs, and EADLs. Across

Table 4
Frequently reported challenges and responses for Basic Daily Activities.

Challenge Codes (n=84)	**Examples**
Transferring 30.0%	*"Getting my chair seat close enough to the seat of whatever I'm trying to transfer on to is the biggest challenge…"* *"Transferring to something that's a different height from the chair I'm sitting in."* *"As my weight has gone up since I was younger and not able to exercise after I had the shoulder surgery and couldn't move around as much. That made the weight go up more and made it harder to transfer."*
Physical Challenges 24.9%	*"I think maintaining my balance so I don't fall to the floor."* *"Just the fact that my shoulders have been damaged and I don't have the strength or flexibility I used to."* *"Standing to groom my hair, to blow-dry it is difficult."* *"Putting on my pants very difficult. As far as putting a t-shirt on… I'm not able to button things, I'm still not able to do that due to loss of dexterity in my hands."*
Other Challenges 12.0%	*"Well if I stumble getting down from a chair or getting up from a chair or any kind of a seat. I feel, if there's anybody around, I feel kind of awkward. It's a personal embarrassment issue."* *"Time required, help required, liability."* *"Well maybe getting dressed can be a hassle sometimes because things just fit a lot differently than they used to and my body is a very, has very weird dimensions… and it just takes a long time…"*
Assistance from Others 8.2%	*"I can't do it myself. My fingers don't work buttons anymore…I'm not completely independent as I once was and it's the loss of independence that is a problem for a lot of people, myself included."* *"I have to be lifted out of my wheelchair. I can't do it alone."*
Response Codes (n=296)	**Examples**
Use Device, Tool, or Technology 28.6%	*"… grab bars or pull bars… if you don't have anything in your shower it would be impossible for me to get out."* *"… in our home we have a ceiling lift that's on a track that straps under my knees and under my arms that then I have a remote that I can lift me up and over to wherever I'm going."* *"I suddenly realized I can use that four-footed cane, and I can use a shower chair."* *"I have a raised toilet seat. And from the standpoint of urination, I use catheters."*
Own Methods 26.4%	*"So when I built my home… I made sure that the doors were wide everything was very accessible the shower is big and so that I can just pull up to it and transfer from the wheelchair to the stool."* *"Sometimes going down the steps I go backwards so that I'm not facing forward."* *"I also buy things that are baggier… I buy elastic waist slacks rather than things with buttons and zippers. I minimize the numbers of buttons on my tops and sweaters."*
Assistance from Others 24.2%	*"Someone has to help me. So it's either a family member or a hired caregiver…"* *"Yes, I cannot do that one by myself. I need someone to help."* *"I do. Hired care providers and family members."*

Note. For the category of Basic Daily Activities, 84 challenge codes and 296 response codes were reported.

all activity categories, *elective selection strategies with compensation or optimization* were the most commonly reported, followed by *loss-based selection with compensation,* and then *loss-based selection strategies* (RQ2).

Elective selection with compensation. Response codes classified as *elective selection with compensation* include receiving assistance from others such as family members (e.g., spouses, children, service dogs), friends, or professionals to assist with a variety of activities inside and outside of the home. Participants reported using items such as portable ramps and reachers for physical accessibility challenges; transfer boards, raised toilet seats, and portable lifts for transfer challenges; arm ergometers and resistance bands for engaging in exercise; handheld showerheads, quad walking canes, or shower chairs for bathing; and rolling carts or trays to help carry objects. Other tools and technologies included mobility aids and equipment (e.g., power wheelchairs, wheelchair accessible vehicles, ceiling lifts), dressing aids (e.g., sock slider), medical devices (e.g., catheters), as well as communication technologies (e.g., smartphones, tablets, and the Internet).

Elective selection with optimization. Many *elective selection with optimization* responses involved relying on previous experiences, routines, or organizational strategies. For example, one participant organized her kitchen so that frequently used items (e.g., cooking pots and pans) were stored on the first two lower level shelves and infrequently used dishes (e.g., Thanksgiving dishes) were kept on the upper shelves. Similarly, one participant mentioned keeping her pills in a location where she would see them every day to help her remember to take them. Another common response was perseverance, specifically displaying patience or planning ahead for longer activities. For instance, to manage challenges related to flying, participants reported reducing food/drink intake prior to eliminate the need to use a restroom. Participants also reported doing advance research on venues, such as restaurants, to ensure accessible seats or elevators prior to leaving home. Another example involved researching the location of desired items at a grocery store to reduce time spent wandering the aisles.

Loss-based selection. The response strategy of *loss-based selection,* or total task abandonment, most frequently emerged when describing challenges associated with activities outside the home, such as visiting family and friends, or flying on an airplane. Participants also reported utilizing a *loss-based* response to challenges associated with working or volunteering because of an inability to engage in such activities, despite expressing desire to remain an active employee at work or to engage in civic activities.

Loss-based selection with compensation. Outsourcing, where the task or activity is carried out by someone else, was classified as *loss-based selection with compensation*, and was reported less frequently. Several outsourced activities had become impossible for participants to complete on their own, even with assistive devices or other people. Most commonly outsourced tasks were related to home maintenance, such as cleaning, particularly in hard to reach places (e.g., bathtub or shower floor). Participants expressed difficulties shopping in-person and opted to outsource shopping tasks instead, asking someone to do it or utilizing a grocery delivery service.

Additional responses. Other response strategies emerged that were not classified according to the SOC model. Participants discussed previously utilized solution strategies that were at one time useful and effective, but no longer appropriate because of other

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age-related changes (e.g., muscle weakness) to themselves or family members. Participants also reported solutions that they had not personally utilized but had heard from other people. Additionally, new solution strategies were reported as many participants had ideas to solve the reported activity challenges. For example, participants were eager to propose solutions for airline travel, including modifying the airplane aisle chair and developing mobile airline chairs that could accommodate a person onto a plane without the need to transfer. Negative emotions (e.g., embarrassment, anxiety) also emerged as a common response to challenges, particularly in visiting unfamiliar venues or using public transportation.

Discussion & implications

Individuals with long-term mobility disabilities are living longer lives and the population of older adults aging with mobility disability is expected to grow.[2] However, very little is known about their unique needs and the barriers they encounter when engaging in various daily activities.[15] Thus, the overall aim of the ACCESS study was to identify activity-specific challenges, and the subsequent response strategies employed to address the challenges among people aging with mobility disability. The qualitative approach allowed us to more deeply explore the challenges and responses strategies associated with the specific activity context. The results inform the design of effective supports to meet the unique needs and challenges for this growing population.

Challenges

To address the first research question, we utilized inductive and deductive qualitative coding methods to identify the nature and distribution of challenge themes from the data. In line with prior research, challenges were most commonly attributed to difficulties with physical limitations, namely mobility and ambulation.[15] These results are not surprising, given that participants are subject to the cumulative effects of having mobility disability for a prolonged period of time and are likely to have other co-morbid conditions.[25] The design of the ACCESS study revealed lesser known challenges among this population, such as those related to relying on assistance from others due to issues with reliability of the assistants, financial strain, or fear of inconveniencing others. Collectively, challenge themes indicate the need for interventions in multiple domains, particularly health management activities such as exercising, health monitoring, or managing diet to maintain physical function and promote independence for this population as they age. Technology innovations in the areas of tele-health, tele-exercise, and health monitoring systems offer great promise to overcome health self-management barriers and reduce caregiving needs.

Despite great advances in setting accessibility standards in public spaces mandated by the Americans with Disabilities Act,[26] challenges accessing public buildings, spaces, and transportation persist for many people aging with mobility disabilities. Accessibility challenges for these individuals can be even greater in private spaces, such as in homes of friends and family, or even within rooms of their own home. Collectively, such barriers can lead people aging with mobility disabilities to withdraw from community activities and limit their life space, which can ultimately lead to depression and social isolation.[17,27] In addition, although perhaps not considered the most critical activities of daily living, EADLs such as participating in group organizations, or going to entertainment events, can be an important component in one's quality of life.[28]

Response strategies

To address the second research question, we identified response themes from the data, and utilized the SOC framework to categorize participant response strategies to better understand the methods used for dealing with the reported challenges. Similar to the findings from previous studies[20–22] *elective selection with compensation* strategies were most common, within which getting assistance from others was most frequently reported. The results confirmed the high demands for assistance among people aging with mobility disability. Effective technologies, designed with input of stakeholders, hold great potential to reduce caregiving needs for these individuals and ultimately the workload for their caregivers.

Participants reported using a wide array of devices, tools, or technologies to overcome activity challenges, including assistive technologies specifically designed for people with disabilities and other mainstream technologies. Solutions included a mix of low-tech tools and high-tech devices with sophisticated operating systems. Cost of assistive tools and technologies was frequently reported as a barrier to utilizing many of the currently available supports. Previous solutions, particularly those involving abandonment of technology, shed light on the specific attributes that created barriers to technology adoption and continued use. Participants also offered other people's responses to challenges, which highlight the importance of "peer reviewed" solutions among this population.

Participants shared other response strategies that did not fit within any of the components of the SOC framework, including proposing new or previously utilized solutions, or response strategy ideas used by others. Their proposed solutions underscore the importance of including stakeholders in problem solving steps (e.g., assistive device design) to address activity challenges. Adults aging with mobility disability have experience gained over the years in adapting to activity challenges based on their first-hand experiences. Such information is valuable for individuals assisting (e.g., airport personnel), and for those developing public or private spaces to ensure accessibility. There is a critical need for broad knowledge dissemination about supportive solutions for people with disabilities. Sharing data more broadly to stakeholders through informal means (e.g., fact sheets, social media, assistive technology databases) holds potential. Furthermore, other groups are likely to benefit from the existing supports, such as younger individuals with disability, or older adults aging into disability.

Limitations & future research directions

As with any research study, there are limitations that must be acknowledged and addressed in future research. Out sample was highly educated, Caucasian, and higher income individuals. There are known health disparities for minority populations and individuals with low education and activity challenges for these individuals may be even greater.[30] Moreover, half of the sample was individuals with polio/post-polio syndrome. We cannot conclude that the challenges noted by our participants would generalize to a specific condition, nor to all older individual with mobility disabilities. Nevertheless, the types of challenges reported, and the contexts and details of the challenges provide valuable guidance for the development of solutions. Future research is needed with more inclusive samples in terms of education, income, racial/ethnic background, as well as with a range of etiologies.

Another limitation is the activity categories that were included, and the method we used to have people select their most difficult activity to elaborate on in the interview. We were constrained by the length of the interview and potential fatigue of our participants.

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Future research efforts could consider other activities (e.g., more about technology interactions; a broader array of health tasks) as well as in-depth information about every activity within a category, rather than the most difficult.

The qualitative interview format is a strength of the study, but also a weakness in the scope of what we were able to cover as well as the number of participants. These data can be used to develop supplements for large-scale nationally representative surveys. The findings provide insights into the type of challenge, the source of the challenge, and the response to the challenge, which could guide the survey design to directly assess the generalizability of the findings.

Conclusion

The ACCESS study explored challenges and support needs of the understudied population of older adults with long-term mobility disabilities using a novel and effective approach. Findings from the current study illuminate the need for understanding the complex challenges and needs of people aging with mobility disability. Many of the challenges reported are solvable with targeted design efforts. The variety of response strategies employed to combat the challenges show the resilience and creativity of this population and can be shared more broadly to help others. Additionally, the findings demonstrate the importance of assessing a range of activities in the home and the community and highlight the participants' desire to maintain engagement in everyday activities over outsourcing or complete task abandonment. Continued engagement in these home and community-based activities contribute to an individual's ability to age-in-place, maintain functional independence, and support quality of life.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.dhjo.2020.100936.

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