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To cite this article: William D. Kearns, Adam J. Becker, John P. Condon, Victor Molinari, Ardis Hanson, William Conover & James L. Fozard (2019): Views of wheelchair users and caregivers regarding a passive safety monitoring system for electric powered wheelchair operators with cognitive impairment, *Assistive Technology*, DOI: [10.1080/10400435.2019.1689537](https://doi.org/10.1080/10400435.2019.1689537)

To link to this article: <https://doi.org/10.1080/10400435.2019.1689537>



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Views of wheelchair users and caregivers regarding a passive safety monitoring system for electric powered wheelchair operators with cognitive impairment

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ABSTRACT

The opinions of cognitively intact current wheelchair users and their professional caregivers were solicited to explore acceptability of the concept of a passive electric wheelchair-mounted movement monitor to track driving safety and cognitive impairment. Two focus groups of electric wheelchair users (N = 9), and two focus groups of staff caregivers (N = 8) were conducted at a congregate care facility. Participants also completed a questionnaire examining their perceptions of the concept. The results indicated most wheelchair users and staff caregivers were receptive to the idea of a passive safety monitoring system for wheelchairs to detect cognitive impairment. Three main and interrelated themes emerged regarding how the device could promote safety, how such a system might infringe upon the users' autonomy, and how and to whom the cognitive state information should be communicated. Legal, training, and marketing issues reflected similar concerns over balancing autonomy with safety issues. If successfully addressed, it appears there would be support for the device's use not only for older adults in institutional settings, but perhaps also among community living younger and older adults. A passive safety monitoring system for wheelchairs is acceptable to wheelchair users and can be successfully marketed if developers balance autonomy and safety concerns.

ARTICLE HISTORY

Accepted 30 October 2019

KEYWORDS

assistive technology design; dementia; electric powered wheelchair; fractal dimension

Introduction

Prevalence and importance of wheelchair use



Mobility impairments occur in people of all ages (Okoro, Hollis, Cyrus, & Griffin-Blake, 2018; Reid, Laliberte-Rudman, & Hebert, 2002), however, the majority of Americans using wheelchairs are elderly (Gell, Wallace, LaCroix, Mroz, & Patel, 2015; Iezzoni, McCarthy, Davis, & Siebens, 2001). In 2010, an estimated 3.7 million Americans used wheelchairs, 15% of which were electric powered wheelchairs. The wheelchair user population has been increasing by 5.9% per year (Torkia et al., 2015) and many users will have comorbid conditions and reside in institutional care settings. For example, it is estimated that as of 2016, 1-in-9 individuals aged 65+ were afflicted with Alzheimer's disease (AD) – approximately 5.2 million individuals (Alzheimer's Association, 2016). This number is expected to increase to 13.8 million by 2050 (Hebert, Weuve, Scherr, & Evans, 2013). AD is the most common form of dementia, accounting for 60% to 80% of all cases (Alzheimer's Association, 2016).


Power mobility offers a wide range of potential benefits. For some users, power mobility offers independence within a facility and/or community, enhances functional capability, offers increased access to the local environment, and increases opportunities for socializing (Mortenson, Miller, Backman, & Oliffe, 2012). However, physical, visual, and cognitive impairments

make driving an electric powered wheelchair potentially unsafe. Upper-body physical impairments (ataxia, bradykinesia, dystonia, weakness/fatigue, spasticity, tremor and paralysis), visual impairments (low vision or blindness, limitations in head, neck or eye movement, visual field loss and visual field neglect) (Simpson, LoPresti, & Cooper, 2008) are often the focus of mobility research. However, *cognitive impairments* (executive function deficits, impaired attention, agitation, or impulse control problems) also can result in serious mobility limitations and safety concerns (Webber, Porter, & Menec, 2010). The focus of our research, therefore, was to determine the feasibility of the concept of a passive monitoring system for detecting cognitive impairment in electric powered wheelchair users.

Powered mobility & cognitive impairments

Operating a wheelchair, whether manual or powered, is a complex task requiring skills in navigation, planning, and problem solving (Simpson et al., 2008). Wheelchairs can be potentially dangerous to the user and others in the environment and their successful navigation requires the driver's control of their impulses and emotions. Impairments in cognitive function can lead to difficulty constructing or remembering a path to a destination due to visual-spatial problems; difficulty maintaining concentration on wheelchair navigation

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 Supplemental data for this article can be accessed on the [publisher's website](#).

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due to executive dysfunction; dividing attention between wheelchair navigation and some secondary task; or intentionally colliding with obstacles or people due to disinhibition (Simpson et al., 2008). The compounding of age-related sensory impairments with cognitive problems has deleterious effects on the general functioning of older adults and mobility in particular (Blaum, Ofstedal, & Liang, 2002; Koroukian, Warner, Owusu, & Given, 2015; Pinto et al., 2017).

Cognitive impairment-related navigational errors can be due to poor executive function including reasoning and planning, diminished attention, and memory difficulties (Moffat, 2009). The cognitive impairment may be tonic, the result of structural and long-term functional changes related to a disease process, or phasic, as in short-term delirium related perhaps to a subclinical urinary tract infection (UTI) whose resultant cognitive impairment might be alleviated by antibiotic treatment (Balas et al., 2012). Nevertheless, driving an electric powered wheelchair while cognitively impaired, irrespective of reason, increases accident risk (Wang, Holliday, & Fernie, 2009). Unfortunately, a short-term bout of delirium can potentially bar one from using powered wheelchairs indefinitely. This may result in severe independent mobility limitations if symptoms are misattributed to long-term dementia-related functional changes when in fact they are phasic (Mortenson et al., 2006, 2005). There may be an expectation that caregivers will prevent all power-mobility accidents causing personal and property damage, fostering 'risk management concerns' (Townsend, 1998). The caregivers' predicament of promoting autonomous client-centered practice, allowing clients to participate in acceptable risk-taking (Mortenson et al., 2006) while also ensuring safety of users and others in the vicinity, reflects countervailing ethical principles of autonomy versus beneficence/non-maleficence.

Several standardized power mobility assessments have been developed, such as the Power Mobility Indoor Driving Assessment (PIDA) (Dawson, Chan, & Kaiserman, 1994) and the Power-Mobility Community Driving Assessment (PCDA) (Letts et al., 2007; Letts, Dawson, & Kaiserman-Goldenstein, 1998), and the Wheelchair Skills Test, Power Mobility version 4.1 (WST-P, Mountain, Kirby, Smith, Eskes, & Thompson, 2014). However, these skills tests are not designed to determine if a person is, or will be, a safe driver (Mortenson et al., 2006). Instead caregivers must resort to personal or clinical judgment to: 1) police existing electric powered wheelchair users for safe operation, 2) determine the root cause of any incidents, 3) intervene to address safety concerns and prevent future incidents, and 4) ensure corrective measures are implemented (Mortenson et al., 2006) and maintained. To address power mobility safety issues, many facilities have developed guidelines and tools to aid decision-making. Despite significant effort, it has been reported that these power mobility safety measures have been poorly operationalized, applied arbitrarily, inconsistently, and in ways that fail to reflect the perspectives of electric powered wheelchair users, contributing to the view that the tools are ineffective (Mortenson et al., 2006).

We explored the acceptability of the concept of a passive safety movement monitoring system for electric powered wheelchair operators that could potentially advise the user

and caregivers if, and when, hazardous wheelchair driving is detected due to cognitive impairment. To do so, a convenience sample was used to solicit the opinions of currently cognitively intact wheelchair users and their professional caregivers about the usefulness and limitations of using a wheelchair mounted passive safety movement monitoring device to track driving safety and cognitive impairments.

Our research aim was to obtain feedback from those persons with intimate knowledge of the use of electric powered wheelchairs in order to improve the design of the wheelchair and to make it safer, user-friendly, and marketable to older adults. We therefore required wheelchair users who could conceptualize about whether they themselves or others who resided in the same living environment and who may have cognitive impairment might find the concept acceptable. The electric wheelchair users were therefore chosen to be relatively cognitively intact (as reflected by an independent living administrator's judgment) to participate in this phase of passive wheelchair safety monitoring concept development.

Methods

Approval for the conduct of this study was obtained from the University of South Florida Institutional Review Board (IRB). Administrators of a 'retirement and rehabilitation community' located just south of the Tampa Bay area, which offers both independent and assisted living, were contacted about the purpose and methodology of the study and recruited participants for our focus groups and questionnaire. The only requirements for inclusion for the wheelchair users were that they live in the facility, use a wheelchair, and the administrators believed that the users were sufficiently cognitively intact to participate in a focus group. The only requirement for the professional caregivers was that they provide paid caregiving services to the older residents of the same retirement community and had firsthand experience caring for residents with dementia. The parameters of the timing of the study made recruitment of family caregivers prohibitive.

We used a mixed methods approach, with both focus groups and questionnaires, to determine the acceptability of the concept by analyzing the details of oral and written evaluative comments stated by wheelchair users and professional caregivers. Focus group research allows researchers to obtain multiple perspectives and shared insights from respondents. All respondents have a specific life experience or opinion on the topic, an explicit interview guide is used, and the subjective experiences of the respondents are explored vis-à-vis the predetermined research questions (Merton & Kendall, 1946).

The focus group questions were based on what elements the authors believed to be the salient information needed from focus group participants to inform the continued product development and refinement. These included 1) participant knowledge of autonomous wheelchair technologies, 2) ideal wheelchair design to assist with navigation, 3) discussion of strengths and weaknesses of the prototype, and 4) how to market the device. Questions were embedded in a printed focus group facilitator guide, developed by the authors. The two focus group facilitator guides were developed for the wheelchair users and the caregivers. The guides consisted of

the following seven sections: Pre-focus group checklist; Introduction of the purpose of the study; Brief discussion of wheelchair technology; Definition of the concept of a semi-autonomous powered wheelchair; Ideal product questionnaire; Demonstrating the prototype; and Marketing questions. Please see Procedures section.

In addition, the authors used a nine-question Participant Post-Focus Group Questionnaire (PPFGQ), developed specifically for this study about the proposed passive monitoring wheelchair system, which consisted of four quantifiable questions and five open-ended questions (See [Supplemental material A](#)). The question format and content were modeled from previous focus groups addressing other proof-of-concept development products. The open-ended questions were designed to capture additional responses from the focus group discussions.

Respondents

Nine electric wheelchair users (i.e., use either a powered wheelchair or powered scooter) and 8 caregivers (professional staff who helped the older residents at the retirement and rehabilitation community where the study was conducted) were recruited. The wheelchair users group was comprised of 3 men and 6 women; the caregivers' group was comprised of 1 man and 7 women. Two wheelchair users did not complete the post-focus group questionnaire.

Data collection

Two sets of focus groups were held with participants over a 3-week period. Each session lasted between 60 and 90 minutes. Two sessions were held with wheelchair users (2 users in one session; 7 users in the other) and two sessions with caregivers (2 caregivers in one session; 6 caregivers in the other). In addition to the focus groups, participants in each group also completed the nine-question PPFGQ

Procedure

Focus groups were run by the group leader (WC) and observer (VM) who are authors of this paper. The focus group leader (an engineering student) was trained by the observer, a licensed psychologist with experience in the conduct of focus groups; the observer also monitored a trial focus group conducted by the student.

The focus group leader and the observer first obtained informed consent, by discussing the study in detail and the requirements for focus group participation. It was explained that the focus group sessions would be audio-recorded for data quality purposes. The informed consent procedure was explained in simple terms to ensure each participant understood the intent of and requirements for the study before they signed the informed consent. All participants were told that they could forego participation at any time. No mental status exams were administered to screen for cognitive impairment for the wheelchair users. Given that the study addressed the use of a new technology, the focus group leader and observer monitored participant comments to ensure the participants

were able to understand the questions and to provide appropriate feedback.

The focus group leader asked questions to stimulate discussion while the observer took notes. Then, the focus group leader explored participants' opinions on current practices, safety monitoring, and available technologies. The focus group leader was careful not to ask leading questions that might bias the findings by using a supportive approach. He specifically noted that the study team needed to know what the participants truly believed versus what they guessed those who commissioned the study wanted to hear. The focus group leader queried about whether participants had additional opinions they would want to include that may have differed from the opinions they earlier expressed throughout the focus groups and at the final summary.

Next, the overarching goal of the project was presented, and the users/caregivers were asked to define their "ideal" system. The proposed concept was introduced, feedback was solicited on its strengths and weaknesses, and possible improvements to features were explored. Focus groups lasted between one hour and one hour and a half. At the close of each group, the focus group leader summarized main points, and asked participants if they wanted to volunteer additional insights. The observer noted key points and included verbatim comments from the focus group participants. At the end of the group, participants also were asked to complete the nine-question PPFGQ, and were given a \$20 store gift card.

The only deviation in the data collection procedure was whether a wheeled toy model was shown to the participants. In the first two focus groups, a toy model was described to one group of wheelchair users and one group of caregivers at the end of the focus group after the questions were completed. In the other two focus groups, the wheeled toy model was presented at the beginning of the focus group. It was used to demonstrate graphically the concept and to try to ensure to the greatest degree that the wheelchair users understood the concept.

The dataset for the qualitative analysis was comprised of the focus group data (transcripts; focus group leader notes; and observer notes) and qualitative data from the PPFGQ (questions 4–5, 7–9). Focus group interviews were transcribed and loaded into ATLAS.ti. A thematic analysis was conducted on the focus group interview transcripts and on five of the questions from the PPFGQ. The quantitative data was comprised of the four remaining PPFGQ questions (1–3, 6). Answers were quantified regarding whether they would recommend the product (# endorsing 'Yes/No'); estimates of the price (range and mean for endorsing 10 categories from \$100-\$1000); likelihood of purchase at the price you want (# endorsing 4 categories from 'Definitely Would – Definitely Would Not'); and purchase if one thing were corrected (# endorsing 5 categories: 'Definitely more likely – Not Likely').

Thematic analysis

Thematic analyses were conducted on the focus group data and PPFGQ questions (4–5, 7–9). The goal of a thematic analysis is to identify patterns in the data and use these themes to interpret and *make sense* of the research question(s) (Clarke & Braun, 2013). Following Braun and Clarke's (2006) six-step iterative framework

Table 1. Braun and Clarke's six-step iterative framework for thematic analysis.

Step 1: Become familiar with the data	Step 4: Review themes
Step 2: Generate initial codes	Step 5: Define and name themes
Step 3: Search for themes	Step 6: Producing the report

for thematic analysis (see Table 1), the team examined the data for both semantic and latent themes. Semantic themes focus on the explicit or surface meanings of the data, while latent themes identify underlying assumptions or beliefs that shape the semantic content of the data (Braun & Clarke, 2006).

Becoming familiar with the data. Audio recordings of focus groups first were transcribed to ensure the reliability of data and then analyzed by three investigators for content validation. Verbal content alone was transcribed because how the respondents made sense of the questions asked was important. Other elements, such as latched or overlapping speech or pauses, were not coded as the team was not conducting a discourse analysis.

Generating initial codes. Since the purpose of the study was to address specific research questions, a theoretical thematic analysis was followed, rather than an inductive analysis. Each segment of data that was relevant to or captured something interesting about the research questions was coded. Codes are labels assigned to segments of documents (i.e., words, phrases, sentences, or paragraphs) to catalogue concepts essential to the research question (Miles, Huberman, & Saldaña, 2019). Since we are working with talk, context on how a word or phrase is used is also important. Coding also captures the context in which these concepts occur.

Open coding was used as the codes were developed and modified as the study team worked through the coding process. In addition, the team used Atlas.ti to identify specific segments of data as codable, which were then collated as themes. Team members examined the transcribed data, developed a preliminary set of codes, and reached consensus agreement regarding discrepancies in codes and themes (Crabtree & Miller, 2000). Initial codes identified content: *MARKETING*, *WHO GETS DATA*, *TRAINING*, *REPAIRS*, *PLACEMENT*, and *CONCERNS* (see Table 2). Notetaker data was not placed in quotes as it represented indirect reported speech (i.e., summarization of the respondents' comments). Respondent comments are enclosed within quotes as it represented direct reported speech.

Searching for themes. A theme captures significant or interesting information in the data or related to the research question that is a part of a pattern. A small data set, such as the one that was generated by this study, may have large overlap between the coding stage and the identification of the preliminary themes. As the team worked through the codes, preliminary themes were developed based on the coding and user data. Table 2 shows the preliminary themes and codes from the focus groups written by the note-taker.

Reviewing themes. At this point, the team reviewed the initial themes and reread the data to determine if the themes supported the data and properly contextualized the data set

within the individual focus groups and across all the focus groups. After rereading the transcripts, focus group notes, and the qualitative questions from the PPFQ, the original themes – *MARKETING*, *WHO GETS DATA*, *TRAINING*, *REPAIRS*, *PLACEMENT*, and *CONCERNS* – were determined to be too broad. The data and coding appeared to capture different elements and user concerns. Although each of the coders had coded first for explicit (semantic) themes, not all the coders recoded a second time to address implicit (latent) themes of the participants.

Table 3 shows 11 themes identified by a member of the team from the WCU FG1 data. The theme, *NOISE*, is an example of explicit coding. Of the three elements coded, the team agreed that *NOISE* could be themed as *SAFETY* as well as *AUTONOMY*, since the intent of the device is to increase the ability of a person to remain independent and increase their personal safety. However, these statements are also pertinent to *DESIGN*.

Define and naming themes: Generating final themes and subthemes. The overarching research question the team decided to address thematically was “what specific elements are the respondents using to frame their understanding of a passive safety movement monitoring system for electric powered wheelchair?” Themes were predominately descriptive, in that they described explicit and implicit patterns in the data relevant to the research question. Three decision points regarding the themes were considered: 1) did the themes make sense within the context of the data, 2) were overlapping themes really separate themes, and 3) if there are themes within themes (subthemes), how do they relate to the main theme(s).

Ideas that were most salient and related to each other were recategorized as final themes or subthemes. For example, discussions regarding the speed and hazards of the device were labeled under the ‘safety’ theme, while questions regarding who would receive the monitoring information and what the display would show to others were categorized under the ‘privacy’ theme.

The coded themes were matched with evidence supportive for that theme. All the data was analyzed, with similar comments on a distinct topic justifying categorization as a theme. In addition, affiliative discursive markers by participants were used to signify importance of a theme/code for the group; the data in ATLAS.ti was reviewed to quantify the frequency with which themes presented. Explanations or elaborations made by the moderator were not analyzed. Affirmative discursive markers or ‘fillers’ (e.g., okay, yeah, um, uh) by the moderator were not included in the analysis.

A more granular review of each of the focus group transcripts, the note taker themes, and the qualitative questions from the PPFQ led the team to re-theme. For example, within the *SAFETY* theme, four subthemes were identified: *Personal safety*, *Safety of others*, *Design*, and *Autonomy* (shown in Table 4). However, from a parsimonious perspective, it made more sense to move certain subthemes into their own categories to increase understanding of how the participants framed *their* issues and concerns regarding the use of this new technology. *SAFETY: Design* appeared to address ergonomic and mechanical concerns of how the device

Table 2. Initial themes from note-taker at the focus groups.

Marketing	Who gets Data
Safety device may motivate administrators to allow powered wheelchairs	Data given to administration "to take away subjectivity"
TV; internet;	Print it out, alert caregiver
\$2000-3000 [Price point]	Daughter
Weather-proofed; spill-proofed	Someone in the nurses' station
Automatically lowers speed	Someone in authority (administrator) to review information???
Small size; make it portable	Continuous record that could be reviewed by a third party (Physical therapy) reviews the information!!
Universal port	Uses
Should be able to be used anywhere in facilities, hospitals, house	Improved safety, reduce injuries
\$50	Used by people who are cognizant, can legally make decisions
Perhaps put on new wheelchairs	Backing out of elevators
Just something basic, simple- if it's too complicated then it's uncomfortable	Wide enough sweep to make it into the room
People need to believe in its effectiveness	Cruise control
What it's telling me "has to be straightforward"	
Should be a vital part of the machine- should not be bought separately from the wheelchair	
Small size as possible for transport	Training
Doubt if this device would be bought individually unless covered by insurance	Patient & management should be trained
App should ping	Week for caregivers; more for wheelchair users
Light weight; shock absorbent; what it's made up of; not too loose to lose connectivity; deeply embedded	Will prevent burnout
Comfort	Make sure you know how to use it
Just blend in	
Accessible	Repairs:
Full monitoring system	Caregivers don't want to repair, limited for liability reasons
Safety	Concerns: if resident is stubborn, won't use it
Whole concept is embarrassing to older adults who need to be monitored	Independent person to maintain the device
Can go anywhere, used in all facilities	Should be dependable
Advertised online, mobility stores	"not me"- someone in the building who knows how to use computer
Sell on Amazon, Medical Equipment company	Concerns:
Make sure it's not a safety hazard; shouldn't make it uncomfortable	Not much practicality
Shut down if it keeps malfunctioning	Don't like 'big brother'
Make sure it's safe	Not hard to use
Should be able to be used anywhere in facilities, hospitals, house	Not embarrassing
Market it to families or facilities	Not prone to malfunction
Placement:	Can't see the value
Not hanging off; not near motor; not accessible; not close to battery	Focus on operator not the machine
Device embedded into wheelchair should be separately monitored	I don't see much use for it- better for golf carts
Partner with the wheelchair company or monitoring organization	Equivalent to what is currently in place- person asked to stop driving if they fall, hurt others, damage walls, scuff marks
Easy access	Should be powered like a wheelchair
Not hanging off; not near motor; not accessible; not close to battery	If person can access it, may keep it from being reliable
Device embedded into wheelchair should be separately monitored	Could be things that need to be navigated around which might affect the readings
Partner with the wheelchair company or monitoring organization	Invasion of privacy
Have it built in vs more stuff on wheelchairs	If hurricane comes you need back-up solar power
Bottom; back, fit in bed of truck	Afraid of false readings Automatically lowers speed
Put in back of wheelchair	Use correctly
Easy access	Only those who need it- don't promote laziness
Weather-proofed; spill-proofed	Need an evaluation- Perhaps age cut-off or dementia
They know about it but don't have access	

needed to function. SAFETY: *Autonomy* implicitly addressed issues surrounding the legal/ethical issues of autonomy and privacy, as in being able to continue to live independently, making decisions, not having to face the stigma of others in the use of a monitoring device. Hence, *Design* and *Autonomy* also were moved to Theme status, as coded strings were identified as different contextually from a broader grouping. Final themes are shown in [Table 4](#).

Results

The results section is broken into two parts. The first part of this section examines the qualitative thematic analysis based upon the responses from the focus groups, written notes from each of the sessions, and the qualitative answers from the PPFQ. The second part of this section examines the analyses of the quantitative questions of the PPFQ.

Table 3. Themes and data from 1 wheelchair user focus group.

Theme: Safety	Theme: Use of the device	Theme: User Privacy	Theme: Legal issues
"Improved Safety"	"recognize when it changes surfaces, like if it's going to go up and down a slope"	"how is that data being given to people?"	"some sort of waiver and they have to make sure they know they're not hurting someone else or damaging property."
"Reduce injury	"limit people from increasing speed"	"[data] should go to the administration because then what you're really doing is just providing them with solid objective data"	"know that they are liable, they are liable"
"hurting themselves or running into something or anybody else"	"it disengages the engine and just stops it"		"damage to property"
"people have neck and back pain ... how quick and the forces with the stopping."	"knowing when there's an obstacle"	"Invading my privacy"	"we have guidelines"
"they are gonna need some sort of restraint to keep them from coming out of the chair"	"hit or brake really hard, like a seat that absorbed it"	"You'd be in big brother people"	"Whoever is the POA, it's a power of attorney thing"
"a resident who is in her room and uses her scooter, I feel like that's when she's the most unsafe is within her room."		"it would be a difficult conversation to have with these residents that we're going to be monitoring you"	
"would alert caregiver"		"Who else might review the data?"	
Theme: Training	Theme: Marketing	Theme: Autonomy	Theme: Cost
"need to have some degree of training for safety"	"electric power"	"The executive director of the facility ... it has to go to them through approval"	"if it's like offered a monthly service, a trial of like a deposit kind of thing, security deposits"
"I like the print outs that we get"	"It would surprise me if there would be a personal market for that"	"family member, it probably depends on that person's budget or their financial situation."	"is this covered by my insurance?"
"it can be like some animated thing"	"if it's an industry standard, then it just is what it is."	"if we're going to implement it, it's going to be everybody."	
"like a safety drivers list that everybody gets"	"Mobility stores. Their catalog of safety items."	"it would be a difficult conversation to have with these residents that we're going to be monitoring you"	
Theme: Noise	Theme: Understanding	Theme: Setting	
"worried about the vibrations, a dinging around and making it loose"	"people that are somewhat cognitive"	"we're not allowed to do repairs or alter anybody's devices"	
"She needs to be, they need to be able to hear"	"I don't know how it's going to detect that we're doing something unsafe"		
"should draw attention .. like a beeping noise"	"I can't picture what this is going to say."		
	"I just can't get my head around what kind of technology thing needs because to me it's all in the driver"		
	"let me call my grandchild. They'll tell me."		

Table 4. Final themes and sub-themes.

Theme: Safety
Subtheme: Personal safety
Caregivers don't want to repair [devices], limit for liability reasons
Subtheme: Safety of others
"hurting themselves or running into something or anybody else"
"I feel like that's when she's the most unsafe is within her room."
Subtheme: Design
"people have neck and back pain ... how quick and the forces with the stopping."
"need some sort of restraint to keep them from coming out of the chair"
Make sure it's not a safety hazard
Shouldn't make it uncomfortable
"worried about the vibrations, a dinging around and making it loose"
"should draw attention . like a beeping noise"
Subtheme: Autonomy
"Whoever is the POA, it's a power of attorney thing"
Don't like 'big brother'
Not embarrassing
"Invading my privacy"
"She needs to be, they need to be able to hear"
Used by people who are cognizant, can legally make decisions

Qualitative data: Thematic analysis

The findings from each of the user focus groups were combined with the qualitative responses from their PPFQ. Data from the wheelchair user focus groups (WCU FG) were combined with their qualitative responses from the PPFQ. Data from the caregiver user focus groups (CG FG) were combined with their qualitative responses from the PPFQ.

The thematic analyses from the combined data determined five major themes -SAFETY, DESIGN, COMMUNICATION, LEGAL/ETHICAL ISSUES, and MARKETING (Table 5).

Theme 1 – Safety

Both sets of participants, the wheelchair users and caregivers, believe safety is a major issue, both in terms of the device making wheelchair use safe (*Personal use*) but also not injuring anyone when it is in use (*Safety of others*). A major emphasis for the WCU FGs centered on how the device would assist the user (driver) in ensuring the personal safety of the driver and the safety of other people around them. The WCU FGs were very focused on elements to monitor or assist the driver and saw the value of monitoring the driver (themselves) during the safety discussion, in that monitoring would allow them to continue to use the wheelchair, maintain their mobility, and continue living independently. The WCU FGs definitely wanted to avoid "hurting themselves or running into something or anybody else".

Theme 2 – Design

Both groups agreed that such a device needed to be simple, unobtrusive, easy to use, weatherproof, and reliable. Both groups also echoed the importance of safety in their design suggestions, which focused on data display and ergonomics (subthemes). They wanted users to be notified if there were any problems with their driving (e.g., audio prompt or video display), or an emergency call button if the wheelchair had problems. WCU FGs were particularly concerned about any increases in the size, shape, and weight of their wheelchair, as it may restrict their mobility or use of the wheelchair within the facility or on public transport. In addition to recognizing

changing surfaces, obstacles, and other environmental factors that may affect effective use, CG FGs thought such a device should also monitor the shock absorption system and driver's use of fall restraints. If this device were to be added to wheelchairs, then they believed it should be an industry standard.

Theme 3 – Legal/ethical issues

This category had three subthemes: *Privacy*, *Autonomy*, and *Liability*. *Privacy* was a major concern. WCU FGs were particularly concerned about who would receive the data generated and transmitted by the device and how that data would be used. They wanted a clear set of rules governing the communication of the data and training in the proper ways of interpreting the data so that they would not feel like 'big brother' was trying to control them. WCU FGs also introduced concern over the display (interface) during larger conversations on privacy as well as design.

Autonomy was a consistent theme and subtheme. WCU FGs mentioned their concerns that a family member or a person with power of attorney may misuse this information to reduce their autonomy and mobility. Both groups were especially concerned about the legal ramifications of using the data to prevent wheelchair users from operating their powered wheelchair. A solution voiced by both CG and WCU FGs was to require it to be an industry standard or a facility requirement, i.e., that such a device be placed on all wheelchairs. This also addressed privacy concerns raised by the WCU FGs on how to avoid embarrassment that they were singled out for using such a device.

Liability (individual and/or facility) issues were either plainly stated as above or contextualized around cognitive status and safety. CG FGs suggested that a person's cognitive status should be considered as a mitigating factor in the use of a machine when considering facility liability for resident safety. If the device was an industry standard, then liability could be addressed more easily. WCU FGs did not want to be concerned about repairs, which they said should be the responsibility of the manufacturer or professionals knowledgeable in repair.



Table 5. Final themes and sub-themes.

<p>Theme: SAFETY</p> <p>Subtheme: Personal safety</p> <p>"need some sort of restraint to keep from coming out of the chair"</p> <p>"I feel like that's when she's the most unsafe is within her room"</p> <p>Operator knowledge key</p> <p>Call button</p> <p>Monitoring driver</p> <p>Subtheme: Safety of others</p> <p>hurting themselves or running into something or anybody else</p> <p>Monitoring driver</p> <p>Should be an industry standard</p>	<p>Theme: LEGAL/ETHICAL</p> <p>Subtheme: Autonomy</p> <p>Invasion of privacy</p> <p>Data given to administration "to take away subjectivity"</p> <p>"Facility should say the device needs to be on wheelchair or person who has power of attorney"</p> <p>If cognitively intact, person makes choice</p> <p>Used by people who are cognitizant, can legally make decisions</p> <p>"that's why we're for independent living"</p> <p>"we need our independence",</p> <p>"everything I see is from the thriving standpoint, the person doing it right"</p> <p>"it would have to be a good enough that you can rely upon it upon its ability"</p> <p>Subtheme: Liability</p> <p>"Independent person to maintain the device"</p> <p>Caregivers don't want to repair</p> <p>Limit for liability reasons</p> <p>"some sort of waiver and they have to make sure they know they're not hurting someone else or damaging property"</p> <p>Used by people who are cognitizant, can legally make decisions</p> <p>"Should be an industry standard"</p> <p>Subtheme: Mandated use</p> <p>"we have guidelines"</p> <p>"Whoever is the POA" [power of attorney thing]</p> <p>"It would be for newer residences. We wouldn't be able to do it in our older ones."</p> <p>Subtheme: Privacy</p> <p>"Don't like 'big brother'"</p> <p>Not embarrassing</p> <p>"Invading my privacy"</p> <p>Third party maybe okay</p> <p>"Family members could know"</p> <p>nurses' station</p> <p>person in authority</p>	<p>Theme: COMMUNICATION</p> <p>Subtheme: Training</p> <p>"need to have some degree of training for safety"</p> <p>Physical therapists, dealer, sales source</p> <p>Learning curve</p> <p>"I like the print outs that we get"</p> <p>"it can be like some animated thing"</p> <p>"like a safety driver's list that everybody gets"</p> <p>Audio and/or visual display maybe flashing light or beeping</p> <p>Use letters 'slow down'</p>
<p>Theme: DESIGN</p> <p>Subtheme: Data display</p> <p>"would alert caregiver"</p> <p>simple, unobtrusive, easy to use</p> <p>Computer should just stay on not be taken off and on</p> <p>Audio and/or visual display maybe flashing light or beeping</p> <p>"Use letters 'slow down'"</p> <p>Subtheme: Ergonomics</p> <p>"Shouldn't make it uncomfortable"</p> <p>"Reduce injury"</p> <p>weatherproof, reliable</p> <p>"cruise control"</p> <p>Reliability</p> <p>"people have neck and back pain ... how quick and the forces with the stopping."</p> <p>Power battery or solar or plug it in</p>	<p>Theme: Marketing</p> <p>Advertise online, mobility stores</p> <p>Sell on Amazon, Medical Equipment company</p> <p>"if it's like offered a monthly service, a trial of like a deposit kind of thing, security deposits"</p> <p>"is this covered by my insurance?"</p> <p>Cost – don't know. More justification for facility use not private home</p> <p>Market it to families or facilities</p> <p>"Should be an industry standard"</p>	

Theme 4 – Communication

A number of practical issues for both the WCUs and the CGs, such as how rules would be communicated, how liability was framed, and who was responsible for maintenance and assistance, were identified. However, questions on how the monitoring device would communicate to the user also were raised. From a contextual perspective, the WCU FGs were concerned that how the device might communicate with them would cause them embarrassment (privacy) and affect operational safety (audible or visual distractions). More importantly, there was agreement that all users “need to have some degree of training for safety.”

The Communication sub-theme *Training* showed the need for training was a critical component for the use of this device. Participants were concerned with who would be the trainers and the type of instruction. Dealers and facility staff were the most common choices for the provision of hands-on training. The WCU FGs mentioned physical therapy staff as the best choice since ‘everyone’ interacted with the physical therapy staff. Other areas that were implied in both the focus groups addressed different levels of and needs for training for residents, professional staff, and administrators. Basic wheelchair training for residents should include backing up, turning around, and other navigational and operational concerns. Additional areas outside of operational training for professional staff and administrators would probably address liability, reportability, accountability, etc. Both groups agreed there should be no training on maintenance; an outside contractor or sales vendor should do repair and upkeep.

How training would be conducted included suggestions for hands-on, face-to-face training, with manuals written in large type that are easy to handle. WCU FGs also expressed a desire to have more than one session of training, and possibly yearly update sessions. However, WCU FGs also were concerned that training may drive up the cost of the device.

Theme 5 – Marketing

In the discussion on marketing this device, discussions incorporated a number of themes (i.e., Safety, Design, Communication) and subthemes (i.e., Safety, Autonomy). Both the WCU FGs and the CG FGs emphasized safety as a way to market the use of the device to residents, administrators, and family members or persons with power of attorney. Both groups also stressed marketing the device through mobility stores, catalogs of safety items, medical equipment stores, online stores (e.g., Amazon), and advocacy groups (e.g., AARP). Both groups also wanted the device covered by insurance, and as mentioned in Design and Legal/Ethical Issues, the device should not be sold separately but as a regular part of the wheelchair or industry standard. Both groups preferred a ‘straightforward’ advertising approach, talking about user safety and independent living.

A subtheme in this category was Cost. Each group was willing to recommend the device if it were developed, but CG FGs were willing to pay significantly more for it than wheelchair users. CG FGs were more likely than WCU FGs to say that they would purchase the device if it were developed even if private insurance did not pick up the tab; however, comments throughout the focus groups suggested that both

wheelchair users and caregivers thought that the best way for it to be marketed was for insurance to pay for it.

Responses to the structured questions (see below) also supported a number of the main findings of the thematic analyses of the focus group data. PPFQ responses also mirrored concerns regarding safety, design, and autonomy.

Participant post-focus group questionnaire analyses

The Participant Post-Focus Group questionnaire on the Passive Safety Monitoring Wheelchair System consisted of nine questions geared to wheelchair users or caregivers. Two of the wheelchair respondents did not turn in their questionnaires, and not all the wheelchair respondents answered some items. As noted above, questions 4–5 and 7–9 provided qualitative responses, which were coded as part of the thematic analysis. The themes are identified within this section of the findings.

The first question was “Would you recommend the use of, or want to use, the Passive Safety Monitoring Wheelchair System evaluated by the group?” 8/8 caregivers and 5/7 wheelchair users said that they would recommend the system.

The second question was “If the Passive Safety Monitoring Wheelchair System evaluated by the group was available for purchase today, what do you think its price should be?” Caregivers were variable in their responses, indicating prices ranging from the lowest (\$100) to the highest (\$1000), with a mean of \$450. Wheelchair users endorsed decidedly lower end prices with an average of \$185.

The third question was “If the Passive Safety Monitoring Wheelchair System evaluated by the group was available at the price you selected in Question #2, but NOT paid for by third party insurance, how likely would you be to purchase it out of pocket or recommend its purchase to another?” Six caregivers endorsed ‘Probably’ and two caregivers said ‘Probably Not’. The responses were much more variable among the wheelchair users, with 2 respondents indicating ‘Definitely’, 2 indicating ‘Probably’, 2 indicating ‘Probably Not’, and 1 indicating ‘Definitely Not’.

The fourth question was “What would be critical circumstances that would make you decide to recommend the use of, or want to use, the Passive Safety Monitoring Wheelchair System?” The majority of the caregivers (N = 5) indicated safety, but two gave responses suggesting need for autonomy (“A person who struggles to walk but still wants to have the independence to do things”). The majority (N = 5) of wheelchair users focused much more on declining health circumstances (e.g., “failing mental capacity”, “stroke”, etc.).

The fifth question was “If you had one thing you could change about the Passive Safety Monitoring Wheelchair System, what would that be?” Design issues were predominant. The caregivers were quite variable in their recommendations, suggesting pressure sensors on seats “to track where they actually go”, the need to make it mandatory, the placement of the device and its cost, and insurance coverage. Some of the wheelchair users’ suggestions regarded the device’s “visibility”, “simplicity”, and the desirability of it producing little noise.

The sixth question was “If that one thing (referring to the answers to question #5) was corrected to your satisfaction,

how much more likely would you be to purchase the monitoring system?” For the caregivers, 3 said ‘Little’, 2 ‘More Likely’, 2 ‘Much More Likely’, and 1 ‘Definitely’. The wheelchair users were less likely to change their mind even with the item corrected to their satisfaction, with 2 ‘Not Likely’, 1 ‘Little Likely’, 2 ‘More Likely’, and 1 ‘Definitely’.

The seventh question was “What will you need from the developers of the monitoring system to understand what the safety monitor says?” Clearly, communication and training were important to both the CG FGs and the WCU FGs. Caregivers focused on printouts, graphs and a manual, while wheelchair users emphasized easy directions, large type, instructions, verbal commands, and automatic stopping of the wheelchair if needed.

The eighth question was “If the monitor on the wheelchair indicates that the wheelchair user whom you care for is no longer able to safely use a powered wheelchair, will you need help to prevent continued unsafe wheelchair use? If so, what type of help will you need?” Legal/ethical issues and training were identified as factors by both the CG FGs and the WCU FGs. Four caregivers answered “No” to this question. The remaining caregivers answered, “Way for person to know unsafe”, disability feature, driving course for violators, and “personal choice”. For the wheelchair users, 2 didn’t know, while the others said professional advice, explanation, “take it away”, “leave it to the family”, and “shut it down”.

The ninth question was “Do you have any further comments or design suggestions about the Passive Safety Monitoring Wheelchair System that you did not mention during the discussion but would like to volunteer? Marketing, Design, and Legal/ethical issues were central. Caregivers replied, “Go to all ALFs”, “pressure sensor on seat for safety”, and an App for caregivers/administrators; wheelchair users suggested cost-effectiveness, and that circumstances should dictate where and when the device is used.

Discussion

Mobility devices, such as wheelchairs and scooters, allow individuals to engage and participate more actively within their communities (Mortenson et al., 2012; Smith, Sakakibara, & Miller, 2016). However, such devices need to meet users’ needs, function reliably, and be useful in a variety of settings (Hammel et al., 2008; Whiteneck & Dijkers, 2009). This is particularly true in the case of persons with cognitive impairments (Arthanat, Nochajski, & Stone, 2004; Rocha, Marques, Pinto, Sousa, & Figueiredo, 2013).). Most importantly, decision-making on the use of or improvements for mobility devices should incorporate the best available evidence, as well as clinical/caregiver expertise, preferences, and circumstances.

Quantitative and qualitative analyses

Regarding the acceptability of the concept of a passive monitoring system for electric powered wheelchairs, this study found concerns over a number of issues, including privacy, loss of autonomy, liability, and the non-maleficent need for safety for both wheelchair users and those in their path across

all participants (wheelchair users or professional caregivers). This suggests that psychosocial benefits, physical benefits, and use for daily life activities were important considerations for many, if not all, of the participants. Hence, a major factor in the adoption and use of a passive monitoring system for electric powered wheelchairs is the successful resolution of these issues from the two interrelated stakeholder perspectives – personal and institutional. In their systematic review of the literature, Yusif, Soar, and Hafeez-Baig (2016) found privacy, functionality of technology, suitability for daily use, stigma, loss of autonomy, and lack of training as serious concerns for older adults in the adoption of assistive technologies or “gerontechnologies” (p.112) designed specifically for older adults.

It appears that participants in both the WCU FGs and the CU FGs struggled to resolve these issues. They tried to strike a balance across a number of concerns to create a safe and discreet system that allows residents to continue to live more independently. This is reflected within all of the transcripts. Phrases, such as “that’s why we’re for independent living”, “we need our independence”, “everything I see is from the thriving standpoint, the person doing it right”, and “it would have to be a good enough that you can rely upon it upon its ability”, illustrate the desire to remain as autonomous as possible yet also have a sense of safety in a reliable and functional product.

Training is an essential component in the use of new technologies (Peek et al., 2016), as well as to ensure a standard knowledge of operating powered mobility devices. Studies have shown the importance of training to reduce injury rates, increase confidence with wheelchair use, and increase participation within social groups (Kirby et al., 2015; MacGillivray, Sawatzky, Miller, Routhier, & Kirby, 2018). There was consensus that clear communication was key – whether it addressed procedural rules, safety or device training, or data. Study participants were clear – training and manner of training were important. Effective training would increase their knowledge of and comfort level with the use of this technology. It appears that the only way such a device would be successfully marketed to wheelchair users or accepted by them is if the rationale for its use is justified to promote safety while at the same time assuring autonomy. Wherton, Sugarhood, Procter, Hinder, and Greenhalgh (2015) emphasize the importance of customization and adaptability of technologies for both the user and, by implication, the institution.

To encourage non-users to adopt technology, there is a need to remove barriers at personal, technological, and linguistic levels and reduce stigma or discriminatory perceptions. Effective marketing should use language that promotes successful and positive aspects of services and assistive technologies (Lancaster, 2002; Ward, Fielden, Muir, Holliday, & Urwin, 2017). Clearly, the WCU FGs and CG FGs emphasized how independence can be promoted by using the device appropriately (perhaps alert health care professionals to resolve an incipient delirium) so that the person *retains autonomy in the long term*, rather than advertising it as a means to alert others that the person is unfit to use a wheelchair. Indeed, one wheelchair user made the point that it would be useful if it could be marketed to administrators who previously did not allow powered wheelchair use;

however, in the light of the added safety feature, they may reconsider and permit use of enhanced powered wheelchairs. Further, the manufacturer of such wheelchairs should keep safety, reliability and dependability in mind, and it was almost uniformly voiced that neither wheelchair users nor caregivers should be responsible for repairs.

Another important element in the development of such a device is affordability. The request that this device be considered standard wheelchair equipment or even perhaps an industry standard by both groups suggests a belief that this could be a very useful tool to maintain autonomy and ensure safety. Power-operated vehicles (scooters), walkers, and wheelchairs are durable medical devices (DMEs) provided by specific suppliers approved by Medicare Part B for an individual's home and residential long-term care facilities (Centers for Medicare and Medicaid Services, 2019). The concept of a passive safety monitoring system is viable and deserving of further research attention, specifically regarding development of an ethical and effective communication system satisfying wheelchair users' concerns over infringement of autonomy, and caregivers' concerns for safety. The details of constructing such a system that is safe, reliable, and marketable should be the focus of future research efforts. Such a system should include an 'instruction manual' that addresses the legal and ethical issues that must be addressed by institutions that adopt this technology. Informed consent will need to be a mainstay of such implementation, whereby wheelchair users must be given detailed information about how the safety data will be used, which family members or administrative staff (if used in a facility) have access to the data, and how their privacy/autonomy may be affected.

Comparisons with other studies

Some of the themes identified in the present study were also reported in other studies that used questionnaires and interviews to assess user attitudes and preferences for partially or fully automatic powered wheelchairs in older electric powered wheelchair users with documented MMSE scores in the mild to moderate dementia categories (Foley, Viswanathan, Zambalde, & Mihailidis, 2016; Mortenson et al., 2005; Viswanathan et al., 2017). One recurring theme in these studies was a preference for partial operator control of the powered wheelchair, the usefulness of the partial automated options being "dependent on the situation." Other themes concerned training and safety.

Although the proposed system concerns the use of a machine-based monitoring system to assess safety concerns rather than the observer-based evaluation approaches described in the introduction, the two approaches are not mutually exclusive. By understanding how the participants framed their understanding of the system and its possible value to them, several elements not considered initially by the researchers were discovered. One significant element is the use of an industry standard as a way to enlarge the market for such a device. Another is how this device may mitigate liability and increase autonomy within the safety context. Finally, most if not all user evaluations of powered wheelchair safety focused on modification of aids for speed, object avoidance, and braking. Additional mixed methods studies that

combine an information-motivation-behavior model and user experience elements for studying interactions between users and products will generate useful data to address design, implementation, and use decisions.

Study limitations

Some limitations of this study should be noted. The data was generated on a convenience sample of just 17 participants, all of whom either worked or resided at a single congregate facility. Some of our findings therefore might be location-specific in terms of being valid for congregate retirement facilities but perhaps not for other settings. No attempt was made to control for variables regarding age, cognitive ability, functional/mobility status, or ethnicity. It would have been helpful to gather more demographic data regarding ages of the wheelchair users and years of experience of the professional caregivers. Inclusion of family caregivers may have provided a different perspective.

Due to validity of response concerns regarding the concept of an electric wheelchair passive safety monitoring system, the wheelchair users in the focus groups were chosen not to be significantly cognitively impaired, so we were unable to ask questions of those individuals who were the target audience for the device.

A passive monitoring system is a technologically advanced concept. Some wheelchair users had a difficult time understanding the concept of a passive monitoring system. Even with the introduction of a simple three-dimensional plastic physical model during the last focus groups to show its basic operation, a few wheelchair users seemed not to grasp what the device might be able to do for them.

The questionnaire used for the written comments was developed specifically for this study by the authors, and its reliability and validity were not assessed. Finally, despite their efforts to the contrary, the status of the group leader and observer may have biased the group discussion to favorably dispose the participants toward this passive safety monitoring system. Regardless of our attempts to evaluate the data in an unbiased rigorous manner by adhering to established qualitative methodology, it cannot be determined how the authors' preconceptions and preferences influenced the evaluation of the qualitative data.

Conclusion

In summary, wheelchair users and caregivers are accepting of the concept of a passive safety monitoring system if it balances safety, autonomy, and privacy needs; if it is inexpensive and/or covered by insurance; and if it is reliable and not prone to need repairs. Showing how the features of the passive safety monitoring system can lead to greater independence of wheelchair users rather than punitive consequences for them will be the challenge for developers, researchers, and marketers.

Disclosure statement

Professors Kearns and Fozard are co-inventors of US Patent #7978085-1 "Human and Physical Asset Movement Pattern Analyzer", which is described in this research.

Funding

This research was supported by the NIH National Institute on Aging under grant # 1R43AG058331-01 “A Passive Safety Monitoring System for Electric Powered Wheelchair Operators with Alzheimer’s disease (AD) and Cognitive Impairments”.

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