

ORIGINAL PAPER

A profile of community navigation in adults with chronic cognitive impairments

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Abstract

Primary objective: This study sought to identify navigation patterns and illuminate the barriers to and possible solutions for independent community travel in people with chronic cognitive impairments as a result of acquired brain injury.

Research design: Two investigative methods were used to explore navigation in the population of interest: Study 1 was a field study and study 2 convened a series of focus groups with relevant stakeholders.

Methods and procedures: For study 1, each week during a 4 month period, researchers administered a navigational survey and structured interview to a typical case sample of six participants in order to catalogue all trips taken outside the assistive living facility. Study 2 convened six focus groups to access perspectives on navigational issues for individuals with cognitive impairments (CI) from a number of stakeholder groups including individuals with CI, care providers for this population and public transportation workers.

Conclusions: The results of both studies were consistent and indicated that community access is severely restricted for individuals with CI. The majority of trips that were taken tended to be routine and assisted. The variety of travel was limited; participants ventured to the same set places with the same people. Participants described barriers accounting for these problems and suggested a number of strategies to minimize problems.

Keywords: TBI, brain injury, community integration transportation, navigation, cognitive impairment

Introduction

Research clearly documents the community integration restriction experienced by persons with acquired brain injury (ABI) [1–3]. The independent use of transportation has been identified as one of the key skills required for people with disabilities to be integrated within their communities [4, 5]. A study of patterns of community integration 2–5 years post-discharge from brain injury rehabilitation revealed that a high percentage of people who had received severe injuries fell into a ‘poorly integrated’ group, characterized in part by the absence of shopping or leisure activities outside the home [6].

Damage to brain regions needed for orientation and route finding is a frequent consequence of ABI. Patients with bilateral damage to the parietal lobes [7],

right temporal lobe involvement [8] and/or frontal lobe lesions [9] have all been shown to have difficulty with the skills necessary for navigation. One study showed that a measure of route finding (the Executive Function Route Finding Task) was the one executive task that differentiated people with chronic impairments due to closed head injuries from non-injured controls [9]. These authors concluded that people with brain injury, particularly when they have frontal lobe damage, rely more heavily on externally provided cues and have difficulty with daily tasks such as route finding because the activities do not inherently provide sufficient structure.

A known barrier to community navigation occurs when people can no longer drive [10]. Although the

effects of driving cessation in the disability population are not well specified in the literature, this restriction in community participation is often listed as a primary concern for those with ABI [10, 11]. One study of people with dementia revealed that, after losing their license, the vast majority of people depend upon informal support systems such as rides from family; they find it difficult to access destinations for social and recreational purposes because rides tend to be provided for destinations perceived to be more urgent such as medical appointments [13]. Alternative modes of transportation such as using public bus systems [5] or navigating on foot or by bicycle [7] have not provided widespread solutions to driving cessation following brain injury.

In spite of the importance of independent navigation to community integration and the documented difficulty in this domain experienced by people with all ranges in severity of brain injury, very little research has been devoted to developing solutions. A literature search revealed fledgling work in three domains with relevance to reducing navigation barriers to the brain injury population. The first is a model community programme designed to provide safety back-ups when people become lost in the community due to cognitive impairments. *Safe Return* (SR) for people with cognitive impairments who wandered and become lost provides recommendations to communities to minimize wandering and determine effective methods for locating lost individuals [14]. Secondly, there are several large research centres devoted to developing navigation systems or devices for people with cognitive impairments. For instance, the *CLever project* has studied the use of PDAs for displaying route information [15]. The Assisted Cognition project has used data collected from a PDA to infer the destination of traveller's within the community [16]. The hope is that the eventual fruits of this work will be accessible by people within the cognitively-impaired population as they take real trips within the community. The third potential solution area is direct intervention to teach navigation skills to people with cognitive impairments. For example, success was reported for teaching functional skills, including use of public transportation, in a group therapy context for people with chronic mental health issues [17]. Only one intervention study was found, however, dealing with transportation training and brain injury. Newbigging and Laskey [5] reported favourable outcomes using *in vivo* route training supplemented by daily planning sessions to teach one individual with brain injury to use a transit system to travel independently to and from work.

The lack of intervention research is inextricably tied to the lack of information on the nature of

navigation difficulties in the ABI population. It is not possible to develop solutions when there is not a clear understanding of the problem. The current study was conducted to advance understanding of community navigation in adults with brain injury who are no longer able to drive with the hope of shaping future intervention research. The authors know of no other longitudinal evaluation of community navigation in adults with cognitive impairments.

Purpose of study

This study sought to identify the actual navigational patterns and illuminate the barriers to independent community travel in people with chronic cognitive impairments as a result of acquired brain injury. Specifically, this study attempted to increase understanding of the types of destinations, modes of transportation, frequency of travel, level/type of transportation support and problems encountered by people living in the community with moderate-to-severe impairments in attention, memory and/or executive functions as a result of acquired brain damage. This study was also interested in learning about the places where people wanted to go, but were unable to travel to and their ideas for solutions to navigational issues. An additional research question was to learn what strategies and/or devices might be helpful to decrease navigational barriers. Two investigative methods were used to explore these questions: (1) a field study to document navigational patterns in a group of individuals over a 4 month period; and (2) a series of focus groups with relevant stakeholders.

Study one: Qualitative longitudinal study of navigational patterns

Methods: Participants and living facility

Study participants consisted of a typical case sample [18] of six individuals with severe acquired brain injuries. Each of the participants had chronic moderate-to-severe memory and/or executive function impairments documented by medical records. All of the individuals lived in a supported living facility designed for people with acquired brain injuries. All six participants were males between the ages of 22–54 years ($M = 37.7$). Aetiologies for brain injuries included four closed head injuries, one brain tumour and one anoxic event. Time post-onset ranged from 31 to 3 years ($M = 16.1$ years). See Table I for a summary of relevant characteristics of study participants.

Table I. Participant characteristics.

Participant	Gender	Age	Education	Aetiology	Time post-onset	Primary cognitive impairment	Physical impairment
B	Male	24	Special education programme	CHI (fall)	22	Severe impairment in attention, new learning and planning	Poor fine motor control with tremor in both hands
J	Male	25	Completed 12th grade	Frontal brain tumour	4	Severe impairment in attention, new learning and planning	Right hemiplegia
K	Male	50	1 year college	CHI (MVA)	31	Severe impairment in attention, new learning and planning	Right hemiplegia
P	Male	51	Completed 12th grade	Anoxia	21	Severe impairment in attention, new learning and planning	None
S	Male	54	Completed 12th grade	CHI (assault)	16	Low initiation and severe impairment in new learning	Left visual neglect and right sided weakness requiring walking with a cane
T	Male	22	Completed 11th grade	CHI (MVA)	3	Low initiation and severe impairment in new learning	Double vision and right-ear hearing loss

All of the participants were able to live in their own apartments and prepare their own meals. They received variable support for management of medication and budget. The facility was selected because it houses only residents with brain injuries and, other than driving residents on scheduled trips in the facility van, no specific transportation training was provided by the paraprofessional staff. Further, the facility was located in a mid-sized city on a main bus route providing an opportunity to study the use of public transportation. The single dwelling apartments had access to a common dayroom. There was an adjoining staff office. There were scheduled trips taken to the grocery store and selected recreational outings; however, if residents did not show up at the departure time, they were left behind.

Researchers explained the purpose of the proposed study to facility staff, all of whom concurred the study would provide useful data. The staff announced the opportunity to participate in a research project requiring recording community navigation patterns to all residents at a regularly scheduled group meeting. All residents indicated interest in participating, thus an existing memory support group that was held weekly was turned into the navigational study group. It was felt that using an existing group time would increase participation and reduce reaction effects to attending a new group. There were 12 individuals who came regularly to the group; the six that the staff indicated were most 'typical' in their community access patterns were selected for the present study although all the others attended the group and filled out the data charts. All participants in the group were consented by the researchers in accordance to university human subject compliance protocol.

Research design/data collection and analysis

Two field researchers and their assistants met with the group of study participants in the facility dayroom for 1 hour each week over the course of 16 weeks. Each week, the researchers administered a navigational survey designed to catalogue every trip taken outside the facility that week by each group member. The group began with a circle discussion about where people had ventured that week and the associated successes and problems they encountered. Group members were then paired one-on-one with the field researchers to be interviewed. The researcher completed a survey form using the responses from the interview soliciting information about the destination and purpose of each trip, mode of transportation, other people that accompanied the participant, navigational barriers and places the participant would have liked to travel but could not. The navigational barriers and desired destinations were solicited by open questions—no attempts were made to structure or categorize these responses and they were transcribed as given. Following each group session, one of the field researchers met with the programme staff to verify the survey information. When there were discrepancies in reporting, the data provided by the programme staff were utilized.

Survey and interview data were compiled to form navigational profiles on each of the six participants.

Results

Destination profiles displaying the number and types of community trips taken outside the facility over the 4 months are shown in Figure 1. In every case, the most frequented destination was the grocery store. For three of the participants, other errands (e.g. going to the mall or bank) was the second most

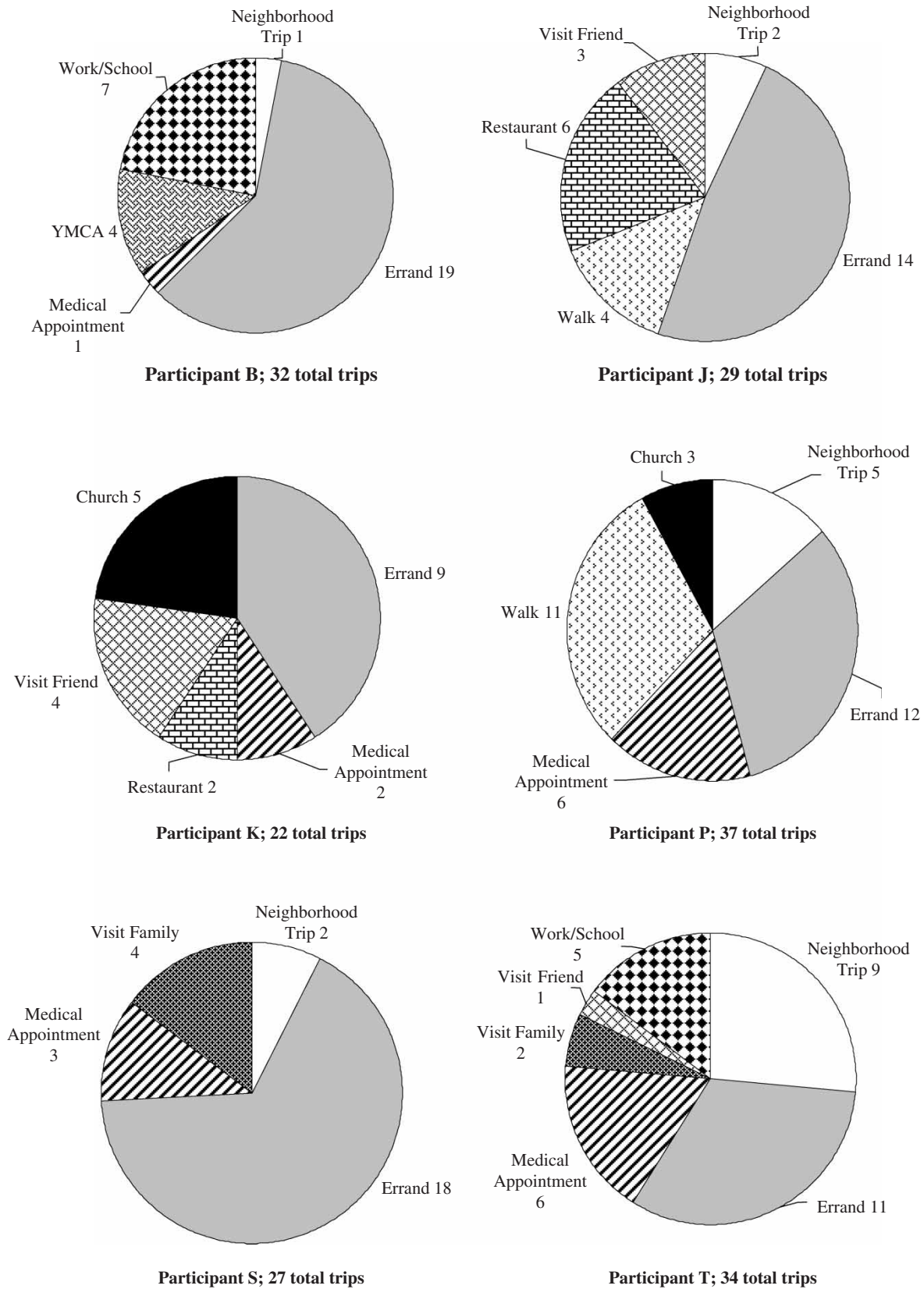


Figure 1. Number and types of destinations traveled by the participants. * Neighbourhood trips occurred within five blocks of the facility (e.g. local basketball court and corner market); ** Errands included trips to a large shopping mall, supermarkets and the bank.

frequent trip purpose (participants T, S and B). For the other three participants, recreational or social trips were the second most frequent trip purpose. Table II shows the weekly average of discrete trips taken outside the facility. The number of trips ranged from 3.4 (participant T) to 2.07 (participant J).

All of the participants utilized at least two modes of transportation as shown in Table III. The most restricted profile was participant S who utilized a taxi service or ride from a relative for all but two trips over the course of the 12 weeks; for two trips he walked to a local store. Participant K also primarily utilized a taxi service or took the facility van that provided transportation to a grocery store. Of the remaining participants, three of them (B, T and J) used all modes of transportation including walking, taxi service, city bus and facility van. Participant P used all modes but the city bus. High levels of assistance during trips was a consistent theme across participants. Four of the participants (P, B, K and S) were accompanied by a non-injured person who helped them navigate for the majority of their outings. Out of 29 total trips, participant J was accompanied on 15 trips by an assistant, nine by a peer with brain injury; five trips were unaccompanied walks in the neighbourhood. Participant T was

unaccompanied on 16 of his 34 trips; these trips involved either a walk in the neighbourhood or a taxi ride to a medical appointment.

Navigational problems or issues experienced by each participant are summarized in Table IV. The reported problems were revealed by the programme staff not the actual participants in response to open interview questions each week asking about barriers or issues that occurred. The most frequently reported problems were forgetting to initiate a trip and meet the bus (or taxi or facility van) at the scheduled time (participants K, P, J and T); forgetting the trip purpose or destination along the way (participants K, B and J) or having difficulties using written directions that were provided (participants B, P and T). Significant anxiety and fear of getting lost was also reported to be a barrier that prevented participants from attempting to venture out in the community by three of the participants (S, B and T).

A list of destinations not accessed but desired by each participant is presented in Table V. Thirty per cent of all of the desired destinations could be categorized as social or recreational. Errands to specific stores or a volunteer job/school constituted the remainder of the desired destinations. Three of the participants mentioned desired destinations that would involve venturing outside the city limits (participants S, P and J). Of note, in a 4-month period, only one of the participants (S) reported taking a trip outside of the city.

Table II. Average number of trips per week outside of facility.

Participant	Average no. trips per week
B	2.91
J	2.07
K	2.44
P	3.08
S	2.25
T	3.40
Average across six participants	2.69

Table III. Mode of transportation and level of independence for community navigation.

Participant	Walk	Chauffeured by car/taxi	Bus	Facility van
Independent trips				
B	1	0	3	0
J	6	0	3	0
K	0	0	0	0
P	16	0	0	0
S	2	0	0	0
T	14	0	0	0
Assisted trips (accompanied by staff or non-injured support person)				
B	0	6	13	9
J	2	2	9	7
K	0	12	2	8
P	5	1	2	13
S	0	24	1	0
T	0	12	0	8

Summary

Although each of the participants managed their own meals and kept their own apartments, their independence in community navigation was quite limited. They took very few trips outside their own apartments. The majority of trips that were taken tended to be routine and assisted. The variety of travel was limited; participants ventured to the same set places with the same people. The participants who used a variety of modes of transportation did not generalize transportation modes across different locations. For example, participant B utilized the city bus to go to the gym, the mall and a volunteer destination. He was trained to use the bus to travel to these places, but did not generalize using it to any other destinations. Memory impairment and concomitant confusion was a frequent cause of navigational problems with participants forgetting to initiate their trips or not recalling the destinations. Although the participants had co-occurring physical impairments, it was the cognitive difficulties that prevented their community access. These problems appear to cause anxiety in this population. Another strong trend was the desire to venture out for recreational and social purposes.

Table IV. Navigational problems reported by facility staff.

Participant	Source of problem	Staff reports
B	Psychosocial	Scared to leave facility without his family; usually calls mom to get help and relies on others to take him places
	Cognition/strategy use	Although he received extensive training to use written directions to go to target places, he still gets confused and has been unable to generalize using written directions for other destinations
J	Cognition/memory	Missed 50–75% of scheduled trips every month (e.g. forgot three planned shopping excursions and three medical appointments); Got off at the wrong bus stop at least twice weekly and either walked to the destination or stayed on the bus; forgot the trip purpose and destinations at least three times per week
K	Cognition/memory	Forgot to meet for scheduled facility van trips at least once per month even with 1–2 reminder phone calls; Forgot the purpose and destination of trips at least three times per week
P	Cognition/memory	He forgot trip appointments several times each week due to confusion with the date and time
	Cognition/strategy use	He was able to use written cue cards with directions to stores and pick up his medicine, but this has not generalized to other destinations
S	Psychosocial	Feels disoriented, resulting in extreme fear of going out in community unless accompanied
	Sensory/vision	Visual neglect makes it difficult to walk in the community
	Cognition/memory	Learned to use bus, but forgot procedures when he did not go out in the community due to fear and anxiety
T	Psychosocial	Expresses extreme anxiety about getting lost, thus he only goes to familiar routine places in spite of expressing desire to venture to new destinations; he can use his palm pilot to remind him to go to routine places but is too fearful of getting lost to try new destinations
	Cognition/executive functions	Did not initiate going to at least four medical appointments

Table V. Desired destinations not currently accessed.

Participant	Navigation 'wish list'
B	Wal-Mart, Fred Meyer, go out more often with other people
J	Family's house, a volunteer job, YMCA, movie theatre, sightseeing, festivals
K	Shopping mall, more frequent visits to family's house, restaurant, support groups, a volunteer job
P	Travel to other towns within the same state, movie theatre, restaurant
R	More visits to family's house, physical activities (e.g. mountain climbing and bike riding), school, places where he could meet people his own age
S	Coast, fishing, shopping mall, restaurant, a volunteer job, natural history museum, sister's house

Groceries and errands constituted the majority of trips.

The results of this longitudinal qualitative study logging navigational behaviours of people felt to be typical of the brain injury population suggest that individuals with moderate-to-severe memory and executive impairments are partially housebound. The study participants had a limited repertoire of destinations that they wished they could expand. For these individuals, living in a facility located on a major bus line, with access to a facility van, is not sufficient support for optimizing access to the community.

Caution is warranted in interpreting the results of this study. One cannot generalize from six individuals to an entire population. It is also possible

that the social attention provided to the participants during the study produced inflated or deflated values for the variables under study. The findings from this study are useful for encouraging future research that might inform the development of navigational assistive devices or training and public transportation systems for individuals with significant impairments in memory and/or executive functions.

Study two: Focus groups

Methods: Participants

In order to access perspectives on navigational issues for individuals with cognitive impairments (CI) from a number of stakeholder groups, six focus groups

Table VI. Focus group participants and locations.

Group	Number of participants	Participant description	Location
1	8	Individuals with mild/moderate CI living independently	Small city A
2	3	Individuals with severe CI living in a supported facility	Small city A
3	5	Individuals with mild/moderate disabilities living independently	Rural area
4	4	Bus operators	Small city A
	1	ADA specialist for transportation district	
	1	Supported employment job coach	
5	6	Care providers	Large city
	1	Individual with moderate CI living with spouse	
6	7	Individuals with moderate/severe CI living in supported facility	Small city B

were convened over a period of 5 months. Participants included (1) individuals with CI of various degrees of severity, (2) care providers for this population and (3) public transportation workers. Table VI shows the composition and location of each focus group. Individuals with CI and care providers were recruited from assisted living facilities and brain injury support groups. Participants for group 4, public transportation workers and a supported employment counsellor, were recruited by asking the local public transit authority to engage in a discussion about the challenges serving individuals with CI who ride the bus.

Data collection and analysis

Focus groups were composed and conducted according to procedures suggested by Morgan [19] to maximize participation of those attending and to encourage open discussion of challenges and strategies. For example, groups were composed of four-to-ten individuals with comparable degrees of cognitive impairment and individuals with CI were given the option of attending with a care provider or on their own. One group consisted entirely of care providers and another of public transit employees so that they could speak frankly about the challenges for individuals, families and transit systems related to navigation. The focus groups were conducted by a facilitator with experience in conducting focus groups with individuals with CI and their families and other care providers. Members of the research team also attended the focus groups to demonstrate a prototype navigational device. Researchers also asked questions to clarify comments made by focus group participants.

The groups began with a general discussion of participants' activities and how they get around in the community. Participants were also asked about the challenges they face and strategies they engage when they want to go to new destinations. Transportation workers were asked to describe common situations that arise for individuals with

CI who travel by bus and how the drivers and transit system deals with those issues. Participants examined a prototype device and gave feedback on appearance, ease of use, usefulness of displays and prompts and other features. They also suggested features that would tailor the device to their personal needs.

Each focus group lasted ~1.5 hours and was tape recorded for analysis. Participants were paid \$10. Several individuals with CI from group 1 called or emailed the focus group facilitator or researchers in the weeks following the focus group to comment on how pleased they were to have participated in the discussion and to reiterate their support for the navigational device concept. Following group 3, several participants wrote lists of specific features they would like the device to incorporate.

Analysis

Focus group transcripts were coded by topic, location, living situation and speaker profile, e.g. individual with CI with mild/moderate disabilities, individual with severe disabilities, care provider or transportation worker. This coding scheme made it possible to compare perspectives on navigation and mobility across and within groups. Code categories included navigational patterns and destinations, challenges encountered, strategies for addressing challenges, advantages and disadvantages of these strategies and suggestions for features to include in a navigation support device.

Coded segments were sorted by topic and speaker, using NVIVO, a software program to facilitate analysis of text-based data. The second author grouped similar comments from different groups to identify common themes. Perspectives particular to certain groups of participants were also noted. The results of the analysis are reported in the next section.

Results

Table VII shows the primary travel modes, challenges, strategies and device features suggested by

Table VII. Travel modes, challenges, strategies and suggestions for device features by group.

Participants	Preferred travel modes	Challenges	Strategies	Device features suggested
Severe CI, urban	Foot, group van, bus, taxi	Fear of getting lost Forgetting purpose of trip Getting lost in community Getting lost in large buildings Expense of taxi Hard to ask friends for rides	Written directions from staff Show directions to bus driver Use signs, landmarks Ask directions Go with group	Prefer short, written directions Features to protect device, avoid loss of device Beeper to locate companions
Mixed CI, rural	Foot, ride with family, senior bus	Limits on independent travel Senior bus is expensive and destinations are limited	Avoid/limit travel Go with family	Same
Mild CI, urban	Drive self, bus, ride with family	Getting separated from companions Forgetting destination Bus schedules and changes Bus drivers unhelpful Fear of asking strangers for help Landmarks could be from previous trip Finding items in a store	Use landmarks, maps Stick to routine destinations Ask directions Get directions on cell phone palm pilot Detailed written directions Ask bus driver Stay in place if lost, separated	Ability to add personalized landmarks, notes Oral directions for drivers Repetition of oral directions Ability to back track Save option for repeat trips Options for low vision Help button
Mixed CI, rural	Drive self, senior bus, ride with family	Getting separated from companions Forgetting destination Landmarks could be from previous trip Following maps while driving Forgetting where car is parked	Use landmarks, maps Stick to routine destinations Ask directions Get directions on cell phone, Palm pilot Detailed written directions Stay in place if lost, separated	Same as above plus: Refer to freeway exits by number and name
Care givers		Concerns about safety, whereabouts of person with CI Memory/navigation issues impact whole family	Maintain cell phone contact	Repeat directions often Link to support person Audio/visual option Features to protect device, avoid loss of device Address device appearance, bulkiness Ability to personalize directions Provide training for device use
Transit workers		Communication Memory impairment Confusion Confidentiality	Transit hosts at bus station Drivers monitor individuals who may need help Policies and procedures for dealing with lost riders	Provide location updates Alert rider when to get off bus Link with bus system GPS Track riders who are in the system Make route corrections mid-route Provide driver with medical, emergency information

each of the sub-groups that participated in the focus groups. Reflecting the highly individual nature of acquired cognitive impairments, there was a wide range of travel modes employed across participants, from independent driving and bike riding to restriction to the living facility unless accompanied by a care provider. Rural participants in this study did not have access to a bus system but could use the 'senior bus' to travel to specific destinations.

Challenges

In spite of the wide range of cognitive abilities, in all groups that included individuals with CI, these participants spoke of similar challenges related to getting around their communities. Individuals with severe CI expressed more global concerns, e.g. fear of getting lost, that kept them from venturing out, while those with milder degrees of impairment discussed challenges related to problem-solving while en route. However, the more cognitively impaired group showed more acceptance of limitations to mobility and less frustration with navigational issues than people with less severe cognitive impairments. The more severely impaired individuals did, however, discuss a number of destinations they would like to travel to if they were able, including museums, libraries, shopping malls, post office and friends' homes. As a result of these challenges, participants in all groups said they have difficulty taking care of medical issues and business matters and miss out on social and other opportunities. For example, one participant said she turned down an opportunity to have her music recorded because of concerns about finding her way around an unfamiliar city.

Spouses and other care providers reported that navigational issues of the individual with CI affect the whole family. Problems included forgetting where the car is parked, getting lost in airports, dropping off children at the wrong location and forgetting where the children were dropped off. Care providers also worry about loved ones who take the bus alone or go skiing or hiking. However, care providers also felt it is important to give people with CI the 'dignity of risk—let them figure out some things for themselves'.

Bus operators indicated that communication and memory impairments are the most difficult challenges they encounter in individuals with CI. Speech and language impairments may make it difficult for the individual to give information about the destination or to ask for help. Riders with memory impairments may forget where they are going or forget to get off when their stop is announced. Operators were also frustrated by

riders who give a business name rather than an address or cross streets when asking for help.

Strategies

When asked how they would proceed if they wanted to get to a new destination, strategies again reflected differences in degree of cognitive impairment. Some individuals with severe impairments said they would never try to go somewhere new without a care provider, while some participants with mild impairments said they would rely on directions programmed into their palm pilots. However, most participants with CI said they would plan for the trip by getting directions in some form from friends or care providers. There was general agreement that written directions are most helpful and that they must be detailed and specific, including landmarks and street names. Some participants reported that landmarks are not helpful because they cannot remember whether they passed a particular landmark on the current trip or a previous trip. Some found maps helpful if they are detailed enough, but for others maps are confusing.

Most focus group participants with CI reported that, in addition to planning and written directions, they need back-up strategies if these pre-trip strategies fail. Repeatedly asking for directions during the trip was the most common problem-solving strategy. Some individuals, especially those who drive, use cell phones to report their locations and receive instructions from family members on how to proceed. On foot, participants said they ask people walking by, in businesses along the route or working in their yards. Those who ride the bus said they ask the drivers to tell them whether they are on the right bus and when to get off. Most participants reported that drivers are helpful, although a few said that some drivers seem annoyed by requests for help.

Bus operators in the focus groups indicated that they expect requests for help from a substantial portion of passengers and that they try to assess who may need help as riders board the bus. They find it helpful if these riders sit near the front of the bus where the driver can cue them to listen for automated announcements of stops.

Care providers of individuals who are able to get around the community independently report that cell phones are helpful in keeping track of the individuals' whereabouts, as long as they remember to turn the cell phone on.

Tools for navigation

When focus group participants were given the opportunity to examine and provide feedback on

prototype navigation devices, they all expressed support for the concept. However, many participants said the device would need to have specific features in order to be useful and safe for a wide range of users.

For example, directions provided by the device should be short, precise and clear. Both potential users and care providers wanted the ability to program the device to include personal notes and meaningful landmarks. To address memory issues and the problem of not hearing directions because of ambient noise, participants suggested frequent repetitions of directions or a reminder button they could push to repeat the directions. Participants noted that the device should provide directions auditorily, especially for drivers, and in written format, with accommodations for individuals with visual impairments. They also wanted the ability to program routes not just from home to different destinations but from one destination to another, and to save frequently travelled routes.

Many of the comments from individuals with mild CI related to using the device to correct navigation errors. They suggested features that would allow users to retrace their footsteps (or driving route) back to a landmark where they could get back on track. Even with such a feature, several individuals with CI and care providers felt that the device should provide a way to link with a support person. Suggestions included a help button that provides a phone number or automatically dials a call to a care provider. Several individuals with CI and care providers indicated that the device should also provide a feature to find a missing travel companion or for the care provider to use to locate the device user.

Some participants and care providers noted that users would need training in order to use navigational devices effectively and independently. Individuals with CI expressed few concerns about the appearance of the device, especially those with more severe impairments who said that carrying the device in a back pack and wearing headphones to receive audio instructions would not be a problem. Several potential users across severity levels expressed concerns about their ability to keep track of the device. They worried that devices might be stolen, lost, left on the bus or that they might simply forget to use them.

Bus drivers supported the concept of personal navigational devices for individuals with CI who use public transportation. They noted that such devices could provide the kind of information that riders with CI ask for most often, i.e. reminders about where the bus is going and updates on where it is on the route. They also suggested that the device could issue alerts such as 'Get off at the

next stop' and 'You passed your destination'. The latter message would be followed by a signal to go see the driver. The device might then suggest a way to correct the route without going back to the station, something that drivers currently do not have time to do.

Drivers suggested that personal devices could link to the GPS system on the bus without calling undue attention to the user by scanning the rider's fare card. This would also allow the driver to identify the rider as someone who might need assistance. Drivers also welcomed the idea that the device could help locate someone who is in the system who is lost, as well as provide medical and emergency contact information for riders who may have health emergencies.

Drivers also expressed some concerns. They noted that routes change and that unanticipated deviations from route because of construction and accidents are inevitable. Such changes would cause the device to alert the user, who might be anxious and confused. Drivers were also concerned about what happens when riders get off the bus. This concern seems to be related to individuals who currently rely on support from care providers suddenly travelling independently with navigational devices that might not be accurately programmed and for which the user is not adequately trained.

Concerns about confidentiality were also raised. Carrying a navigational device and linking it with the bus GPS system would identify the user as having a disability. Care providers and potential users were not as concerned about this issue, noting that individuals would need to decide whether it is more important to get around independently or to avoid the potential stigmatization of carrying a device. Most seemed to think that it would be less stigmatizing to carry a device than to get lost or repeatedly ask for help. As one care provider put it 'To think that there would be a device that could be made simple enough for someone who has a really severe cognitive issue, to give them freedom would be the greatest gift you could give that man'.

Discussion

The results of the field and focus group studies were consistent; both indicated that community access is quite restricted for individuals with CI. The focus group study included participants with a wider range of ability and suggested that the level of restriction depends somewhat on an individual's extent of impairment, but navigation was affected to some degree for all participants with memory and/or executive function impairments. Navigation problems and concerns about getting around independently appear to cross severity levels, living situations and locations.

Restricted community access affects family, other care providers and public transit systems. All of the focus group participants endorsed that community navigation problems affect their ability to carry out their responsibilities.

The field study suggested that people with moderate-to-severe CI need more direct support in order to optimize community access. Living on a bus line or having access to taxi or rides on a facility van did not result in trip frequency or range of destinations that either the participants or the paraprofessional staff found acceptable. The focus group study suggested a number of strategies that might be implemented to increase navigational independence in the CI population.

All groups endorsed the potential of a personal navigation device to increase transportation abilities across domains—from foot travel to driving to taking the bus. There was agreement among care providers and drivers that, regardless of the type of assistive device, it would need to link to a human help system. Suggestions were provided for other features that would make the device useful to individuals and to their support systems. Finally, safety of the device user was a concern for drivers, care providers and some individuals with disabilities.

The results of this study illustrate the restricted community access experienced by people with cognitive impairments and highlight navigational barriers. It is hoped these results will spawn further investigation of needs and solutions included the development of assistive navigational devices usable by people with reduced memory and executive function abilities.

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