

ORIGINAL RESEARCH

Cognitive support technologies for people with TBI: current usage and challenges experienced

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Abstract

Purpose: We investigated the current use of off-the-shelf cognitive support technologies (CSTs) by individuals with traumatic brain injury (TBI), the challenges they and their caregivers face when using these technologies, the functional areas where support is needed, and their current experience in learning new technologies. *Method:* We conducted two focus groups with participants with TBI and their caregivers. Focus group interactions were captured using recordings and a court reporter. Transcripts were analyzed qualitatively. *Results:* We identified three core themes – consumer and caregiver self-reported needs for support, how support is used on a daily basis and consumer and caregiver attitudes towards the use of support by types of support. We also inferred implications for design of CSTs. *Conclusions:* Individuals with TBI use consumer available technologies to support cognition. The design of most of these devices is not targeted to meet the needs of people with TBI, and they can be challenging to use independently, but individuals and their caregivers still benefit from their use by embedding technology as one type of support within a broader support network that includes personal assistance.

Keywords

Assistive technology, caregiver, cognitive support technology, psychosocial, support systems, traumatic brain injury

History

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► Implications for Rehabilitation

- People with traumatic brain injury (TBI) are attempting to use a wide range of consumer available technologies to support cognition, although not always successfully. One important role for rehabilitation providers could be helping people with TBI use these technologies with more accuracy and success.
- People with TBI note that an important element in adopting new technology is good training in its use.
- Cognitive support technologies (CSTs) are one part of broader network of supports. People with TBI and their caregivers desire independence but do not want to lose the human element that can be provided by a caregiver. New technologies should be implemented with an understanding of an individual's broader support network.
- Psychosocial aspects of TBI need to be considered when designing and implementing CSTs. In particular, rehabilitation providers need to address the anxiety that many people with TBI experience, including fear about forgetting and their need for early, repeated reminders so they can prepare for upcoming events.

At least 1.7 million people sustain a traumatic brain injury (TBI) annually in the United States. Of these, about 52 000 die, 275 000 are hospitalized, and 1.4 million are treated and released from an Emergency Department [1]. In a study of prevalence of long-term disability resulting from TBI in the U.S. civilian population, Zaloshnja, Miller, Langlois, and Selassie [2] found that 3.17 million individuals were living with long-term disability as a result of a TBI. The high mortality and morbidity associated with these injuries is compounded by the fact that TBI occurs primarily among previously healthy young people, who must deal with the associated disabilities for the rest of their lives [3].

For military members serving in war zones such as Iraq and Afghanistan, the incidence of TBI accounts for a larger proportion of casualties than in any other recent US conflict. Prevalence of TBI among returning Iraq/Afghanistan soldiers is reported as high as 73 000 [4]. Undiagnosed cases of TBI are estimated at more than 7500 [5]. Improvements in combat protection such as Kevlar helmets and body armor have resulted in fewer penetrating injuries and increased survival rates [6,7]. However, “most brain injuries are being caused by IEDs, and closed brain injuries outnumber penetrating ones among patients seen at Walter Reed, where more than 450 patients with TBI were treated between January 2003 and February 2005” [6]. Evaluations of all admitted soldiers who have survived a blast injury indicate that 59% receive a diagnosis of TBI; of these, 56% are considered moderate or severe, and 44% are mild [6,7].

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TBIs may have an impact on all major areas of functioning, including cognitive executive functions such as planning and memory, social cognition, social functioning and motivation [8–10]. Depending on the severity of injury, these impairments may leave persistent residual deficits that can hinder or prevent the injured person from resuming activities of everyday life [11–16]. These consequences are of the utmost importance to the person injured, his/her family, and society at large.

Even mild traumatic brain injury is associated with long-term cognitive deficits [17,18]. Among veterans with mild TBI blast injuries, long-term effects include high rates of sensory impairment, pain issues, and polytrauma [19].

Individuals with TBI have a diverse range of challenges and cannot be characterized in a reductionist way; however, deficits in executive function are common. Executive function includes important aspects of learning and remembering; prospective memory; regulation of impulsivity and behavior; accurate self-awareness or apperception; psychosocial judgment; initiation of activity, and temporal sequencing; planning and organizing; and the ability to navigate or plan travel. Mateer [20] has categorized executive function deficits as follows (Mateer's original points are in quotation and exemplified based on our clinical experience and case study research):

“Problems of starting”, where individuals have a difficult time initiating activity or knowing which activity to begin. For example, an office worker with TBI with three or four tasks on the desktop might have difficulty beginning work on one task without cues or prompts.

“Problems of stopping”, where individuals persevere at an activity. For example, during a work-related conversation, a young adult survivor of TBI might fail to recognize social cues to end the conversation and continue perseverating about the topic.

“Difficulties in making mental or behavioral shifts”, where individuals cannot change behavioral or cognitive responses when the existing set is no longer productive. For example, an individual with TBI working in sales might continue talking about seeking bids when his colleagues had moved on to discuss new sales. These difficulties in making shifts may also be related to reduced sensitivity to social and environmental cues, another set of executive deficits.

“Problems with attention”, include distractibility, difficulty with selective or divided attention (e.g. focusing on one set of stimuli from the field, or multitasking), and reduced working memory capacity. For example, a student with TBI might report that he could not listen to the lecture and take notes – that when he began notetaking, he would completely lose track of what the lecturer was saying.

“Problems with awareness of self and others”, may include reduced apperception or ability to see oneself as others do, a reduced understanding of the impact of oneself on others, difficulty accurately discerning the motivation of others, and reduced empathy. For example, an employee with TBI may not recognize the critical subtext of his employer with respect to job performance, or an adolescent may completely miss the sarcasm in a fellow student's communication, taking the comment literally.

Prospective memory is particularly difficult for people with executive function deficits [21]. Prospective memory involves remembering and implementing plans for the future. For example, an individual might commit to memory a plan to attend a medical appointment but not remember on the day of the appointment. Even if the appointment was written in an appointment book, the individual might fail to consult the book. Often, however, if the individual were given a cue or prompt, such as, “what is on your schedule this morning?”, he or she would be able to recall the appointment.

These deficits in executive function are often a barrier to participation in all areas of life, including employment and education [22,23] and lead to reduced participation, economic marginalization [24], and lower reported quality of life [23].

Cognitive support technologies (CSTs)

Clearly, people with TBI would benefit from support in remembering, planning, and initiating activities of daily living. Support systems consist of three components: personal assistance, assistive technology, and adaptive strategies [25]. All three are necessary and important and no single component can provide an individual with adequate support alone, rather, these three components work in synergy together. In this article, we focus our investigation on the use of technology by individuals with TBI.

CST are devices and services intended to reduce the impact of disability for individuals with functional deficits in cognition. These technologies are often referred to as assistive technology for cognition (ATC) or in some cases as “cognitive prosthetics” or “cognitive orthotics”. A number of reviews (both systematic and non-systematic) written over the last decade have evaluated the development of CSTs [26–30]. In their recent, comprehensive systematic review, Gillespie and colleagues summarize the research on CSTs. Of 91 research studies, they found that 23% targeted individuals with TBI. Studies addressed a broad range of cognitive functions including attention, calculation, emotion, experience of self and time, memory and executive function. The majority of studies addressed time management, organization and planning using technologies that provided reminders and micro-prompting and described technologies that provided support in managing daily routines. They found moderate to good evidence for the effectiveness of CST systems and devices that shift attention, provide context-free cuing, provide biofeedback to reduce autonomic arousal, and that support organization and planning.

In our study, we wanted to build on the current state of the science in CSTs for individuals with TBI. Specifically, we wanted to learn more about the current use of off-the-shelf CSTs by individuals with TBI, the challenges they and their caregivers face when using these technologies, the functional areas where support is needed, and their current experience in learning new technologies.

Methods

Protection of human subjects

Application was made to the University of Washington Human Subjects Division in the Office of Research for approval to conduct this research. Approval was granted. Subjects were consented using the IRB approved format.

Sample

We chose to include caregivers and survivors of TBI together in each focus group because we expected the interaction between them as well as individual narratives to inform our investigation. We do not report demographics to preserve anonymity of our subjects, but all informants were between the ages of 21 and 65. Subjects were recruited from our TBI Model Systems project and were a sample of convenience. Our first focus group included four individuals with TBI (all male) and two caregivers (both female). Caregivers included a mother and a partner, both providing unpaid support. Our second focus group included three individuals with TBI (two female, one male) and two caregivers (both female). Caregivers included a spouse and a paid care provider. Individuals with TBI were four to 17 years post-injury.

Data collection

Participants came to the university for a 2-h session, were told that we were interested in finding out about their experiences and the issues they face every day, that there were no right or wrong answers, and that we were interested in the full range of experiences, so they should feel free to share their point of view even if it differed from what others said.

Two faculty members with experience with people with TBI, CST, and conducting focus groups facilitated the discussion. Discussion was transcribed by a court reporter with digital recording for backup. We asked participants a series of open-ended questions to help identify needs for support, types of support currently used, identification of supports that might be useful and barriers and use of technology for support. Our questions included:

- (1) What types of support, if any, do you need to perform everyday tasks (including at home and work)?
- (2) What is it about a task you need help with?
- (3) How do you accomplish these tasks now? What works well, what doesn't?
- (4) What additional types of support or accommodations would be helpful, if available?
- (5) Current use, comfort and familiarity with technology.
- (6) What technology was tried and failed and why?
- (7) What concerns do you have about the reliability of technology? What if software or services stop working?
- (8) Where do you fall on the spectrum of wanting technology for independence versus wanting assistance from a caregiver?

Analysis

We analyzed the data using standard qualitative methods [31]. Specifically, the transcripts from the focus groups were analyzed in two ways. First, we identified the range of responses in certain categories. For example, we identified the different types of technologies used by participants. For these categories, we just reported what participants told us. Second, we analyzed the transcript qualitatively looking for themes that cut across categories. For example, participants frequently talked about psychosocial factors that affect their decision making and use of cognitive supports (e.g. anxiety, frustration).

Results

We identified three core themes: consumer and caregiver self-reported needs for support, how support is used on a daily basis, and consumer and caregiver attitudes towards the use of support by types of support. Figure 1 graphically represents these three core themes and the subthemes identified in our study. We have used pseudonyms below to identify subjects for ease of reading.

Needs for support

Our participants described their daily challenges and the types of support needed to perform everyday tasks. The most commonly reported problems are related to short-term memory loss and difficulties with organization. For example, all our participants with TBI reported having difficulty adhering to their medication schedules. They either forgot to take the medicine at the scheduled time or became confused about whether or not they had taken it. Usually, they needed to take different types of medications at different times of the day or on different days. To cope with the difficulty of remembering to take the medication, our participants with TBI depended on some kind of reminder, such as the timer bottle or refrigerator door. Connie says, "I take medication three times a day . . . what I was finding myself doing was, did I take it or didn't I take it? (so now) I have timer bottles. Because I forgot

at night. I was forgetting at night". Chelsea has her medications packaged in bubble wrap by the pharmacist: "I have basically three sheets of bubble pack . . . one for the medication at night, and then one for morning. And I take something at noon so that's separate out of the bubble pack".

To help take the correct medication at the right time, several participants developed memory-prompting strategies that rely heavily on routine. Connie relies on a set routine and Martin routinizes his medication schedule by putting his "pills in different parts of (the) house so I know I go to this location in the morning, and this location in the afternoon, and this location in the evening". Keeping appointments and a daily schedule was another big challenge for our participants. The most commonly used strategy is to keep notes of what needs to be done in various calendaring systems, such as a Daytimer. Other forms of commonly used calendaring systems include white boards and wall calendars, on which either the individual with TBI or the caregiver write the tasks that need to be done for the day or the important appointments. However, a major limitation to this type of support is recognizing what had been written. Connor told us that he has "a pad of paper – with stuff that I scribble on it. But sometimes I can't even tell what I've written". Another problem with textual calendaring systems is forgetting to check the calendars or any other notes. The difficulty in complying with the schedule is closely related to time management. Elaine explains, "There is no time. It's days, dates, anything. So even like [Bob] has to get on the bus every day. I call him every half hour". "Bob, the bus is coming in a half hour; remember to get on the bus. He'll forget to get on the bus, he'll forget".

Both caregivers and participants with TBI described frustration and anxiety resulting from difficulties with time management. "He gets so worried about forgetting probably because I make him anxious too by calling that he stands in the kitchen and waits (Elaine)"

One consistently reported issue is difficulty in initiating an activity. Most participants with TBI had the experience of avoiding a task even when they knew it needed to be done. Martin described how he struggled with paying his bills and dealing with other financial matters. He kept putting the task off, "I'll do it tomorrow, I'll do it tomorrow (but) with no time and nobody coming and saying did you pay, I ended up getting dinged quite a bit. It's not on purpose". Managing personal finances presents a challenge to many of our participants and their caregivers. "I want to throw out about the bill paying thing. It has taken me months to straighten out stuff because of all that time when I didn't have a memory. I got taken advantage of. . . we lost money they didn't have". Elaine has "taken everything over. [Bob] used to do it and he did it for a while after his brain injury. But I've taken it over and I've tried to get him back to that but he's not comfortable yet".

In addition to bill paying, managing income and keeping records for both business and tax purposes is especially challenging. For example, Carl, who was an electrician for years, kept the receipts of people who he did work for around the park with their names, and stuck the receipts on a board until he got paid. In this way, he kept a record of his services and income.

Our participants reported that their short-term memory impairment severely affects their ability to carry out daily tasks. They reported difficulty completing a task with multiple steps because they would forget what had just been done and tended to repeat the same steps. They reported trouble remembering a task that had been started and was left unfinished. For instance, more than one participant reported leaving the stove or oven on while cooking and forgetting about it. Problems with navigation and way finding were also reported. Participants reported that they frequently got lost without support from others. A one caregiver

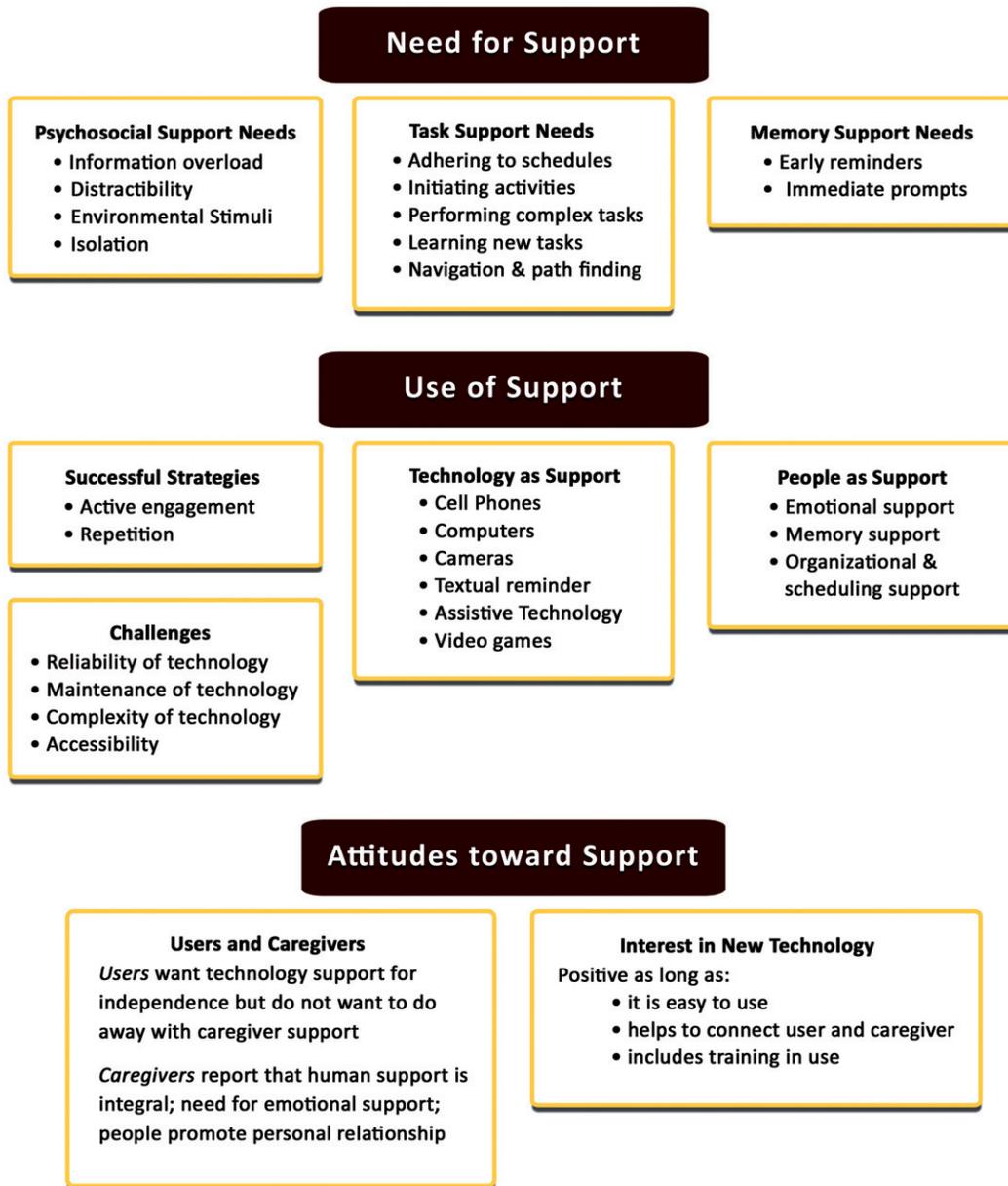


Figure 1. Need, use and attitudes toward support.

stated, “a lot of times they don’t know where they are and they’re trying to figure it out themselves”.

Perhaps related to this were reports of distractibility. One participant talked about daydreaming at the bus stop and being unaware that the bus had gone by. Connie reported that she would “follow a bird or follow an owl and I’ll tumble down a slope”.

New tasks or tasks that happen infrequently require additional support. Participants differentiated between tasks that were routine or habitual and those that were not. Connie describes her routine task, “I call it my ‘cow path’ – [tasks] that I do constantly every day. Feed my dogs, things like that. But for anything off my so-called cow path, I have to write it down. Otherwise it’s gone”. While developing their own strategies of coping with the various problems in daily living, the needs for various exterior prompting supports, that is, verbal cues from people or devices, is very important. As noted previously, our participants reported that verbal prompting is more effective than visual prompts, such as a written note. For a planned event, a series of prompts that start early are preferred to avoid surprises and to allow adequate time for preparation. Many participants

explained that they didn’t like surprises because it made them feel pressured. This is particularly true of the appointments or tasks that require planning time. “Giving notice – is what we – is what I really want. I want as much notice as possible for anything I’m responsible for. [...] Like, I don’t like to find out today that I have to go to a doctor today. It has to be two or three days so that I can prepare myself, I got to go to the doctor in a couple days” (Martin).

In addition to feeling anxious, our participants with TBI discussed feeling overwhelmed when information was delivered too quickly or there was too much information relayed at one time. “That’s a big thing is the overwhelming. It’s like if you have blinders... if someone says getting me that pencil and before I can get that pencil they say, where’s your glasses, it scrambles everything in my head. And I can’t – I get frustrated because I – my head says, get this pencil, now you’re asking me to get this glass, I can’t do it”. Therefore, for participants with TBI, the size and number of tasks that need to be accomplished really matters. One participant discussed strategies for dealing with becoming overwhelmed at work by dividing a large task into

smaller ones and then getting each of the smaller pieces done one by one.

Environmental stimuli, such as light, smell, or sound, are another cause of the stress that is reported by our participants. For example, participants with TBI discussed their experience of trying to avoid places with florescent lighting, or store areas where there are a lot of candles and scents. Participants report using different strategies to relieve the stress or anxiety. For example, some go to a safe, quiet place where they can be alone and calm down. Some report using a soothing sound such as the sound of running water. Connie finds that having her dog around is a tremendous help.

All of our participants with TBI reported feeling isolated and experiencing low self-confidence because of their disabilities. “And I’ve become anti-social with everybody. Because if I have a thought, I get anxious to say it because I think if I don’t get it out I’ll forget it, and that frustrates me. And if people around me don’t understand my disability, then my patience is very short”.

Use of support

Based on our analysis, participants are using a wide range of strategies for cognitive support; the two most important resources are technology and people.

Cell phones are considered the most important technology to the majority of our participants. They use cell phones for calling others, texting, and setting alarms or reminders. Some caregivers used the phone for location tracking. Although cell phones are a commonly used technology, our participants used only limited features on their phone; the more advanced features were found to be too complicated for them to use.

Personal computers are also commonly used, to varying degrees by participants. For one participant, e-mail served as a good reminder system but for others e-mail was not reliable because they didn’t check it frequently. Some participants reported using productivity software, such as spreadsheets, to help manage finances, or a Google calendar for scheduling appointments. Others mentioned using the computer to find information on the World Wide Web or entertainment (e.g. watching TV online). Only one participant reported using a computer for work. Computer access can be a problem for individuals with TBI, who often have comorbid impairments such as visual impairments and print disabilities. More than one participant had difficulty with inputting into a computer or phone using their hands or reading texts from the screen.

There were other types of technology in use. For example, video games provided a source of entertainment and escape to some of our participants. Cameras, including cameras on phones were found to be useful as a form of pictorial memory prompt. Sam uses his camera, “a lot for, like, say I’m working under a kitchen sink and something, I got to go to Home Depot. I’ll take a picture and when I go to Home Depot it will help me to remember what I needed to get and do”.

All of our participants receive some level of support from family members, friends, caregivers, or other professionals such as a banker. People provide support in almost all aspects of daily living, attending to needs including maintaining a schedule, managing finances, traveling, and various kinds of memory support. Connie describes, “. . . on a good day is when like I have a friend that comes over and has coffee with me, and she’ll make a list of things for me to do. And those are great days because I get a lot of stuff done on those days”.

However, participants do recognize this was a lot to expect from friends and families. Sam told us that, “I’m polite when I ask my wife to help me remember something because I know it’s not her job”.

Attitudes toward support

Most of our participants strongly valued independence and wanted to use technology as much as possible to support independence: “I would rather – the more independent I could be, the better I would feel about it” (Martin). They noted that reliance on people made them “feel(s) like a burden” and they “feel so bad about asking people all the time” (Shawn). Also, human support was not always available, “Sometimes people are there and sometimes they’re not. So if I was able to have something with me all the time, I would – it would be more reliable, and then I would be more independent . . .” (Shawn).

Generally, our participants are positive toward using a technology as long as it is affordable and they can receive adequate training and support in using the device. However, they did note that they didn’t want to do away with human support. They felt technology could fail and “a real life person backup is always going to be important”. Caregivers confirmed this. They felt that individuals with TBI could benefit from the use of technology but stressed the need to continue to include caregivers in the support network, particularly for emotional support. Our participants told us that they would like technology that is “smart”, “simple”, and “easy to use”. Technologies that can help connect individuals with TBI and their caregivers were particularly appreciated. Caregivers wanted to be more aware of the individuals’ schedule, status and whereabouts, and participants wanted to know where their caregiver/support person is going to be, especially when they are living apart. A coordinated calendar that can be shared and accessed to both from different locations would be great help. Another valuable piece of technology of this kind is the localization technology that helps to report the location of the individual to the caregiver.

Barriers to using technology for support

Our participants also identified several challenges with current supports, including the reliability of technology, usability, accessibility and cost. Participants talked about the importance of the technology that they rely upon. “I lost my phone once and I had to go that night and get a new one. And it showed up the next day, but I couldn’t even focus without it”. Also, the technology needs to be used consistently and constantly because “the technology doesn’t do you any good if you don’t remember to turn it on”. Another problem that prevents the effective use of technology is the complexity of a device. For example, many participants reported difficulty with using a smart phone: “He also has a smart phone. I mean, it’s pretty sophisticated even for me to use. So I put in everybody’s phone number. And then one day he deleted them all and he didn’t know how he did it. So it works, and it doesn’t work” (Eileen).

Another challenge involved in the technology design is to improve the devices’ accessibility for different users. As noted above, people with TBI may have comorbid impairments that affect their ability to use technology (e.g. blurred vision, fine motor impairment). Finally, most participants expressed their concerns about the cost of obtaining the needed support. As a result, participants cannot afford a new device, such as a smart phone, an iPad, or a laptop, and the cost of its service. Neither were they able to meet the expense of human support. More than one participant shared the experience of losing their helpers (e.g. the caregiver, the banker, or the computer technician) due to budget cuts.

Discussion

Participants identified several effective strategies that can inform the design of new technologies. Active engagement in setting

a reminder is helpful: “It helps in my experience if I write it myself. You know, because then it’s – it puts a little chip in my head” (Martin). Participants found that putting things in the same place every time helped them to remember where they were. Adhering to a daily schedule and following a routine is the most effective way to ensure the completion of daily tasks. Although one participant did wish he “could be spontaneous”, he saw the risk that “change can elicit failure”. So instead of being spontaneous, he chose to “do the same thing every day. It feels comfortable. It’s safe”. Finally, a few participants noted that mnemonic strategies were helpful, “When I get going for the day, it’s wallet, watch, those two are W, that’s good. Eyeglasses, sunglasses, and camera. And cell phone” (Shawn). Designing technology supports should be designed to integrate into individuals’ routines.

Verbal prompts are more effective than written prompts

Most participants with TBI talked about avoiding tasks that were either too demanding or aversive, such as paying bills. They described putting off these tasks even when it was well scheduled and written down on a board or calendar. They also agreed that they would be more likely to do the task if they heard others saying “you need to do this”. Based on our analysis, there are several explanations for the effectiveness of a verbal prompt. First, visual or textual reminders are useless if you forget to check it or have difficulty reading what is written. Participants with TBI often need a prompt from their caregiver to remind them of an appointment that is written on a board or calendar. Second, verbal prompts can be given in close proximity to the event, reducing the need to rely on short-term memory. Technology may be designed or configured to provide verbal prompts.

Earlier, repeated prompting helps participants to avoid surprises and allow for preparation time

Prompts that are administered immediately prior to a desired behavior are particularly useful for compensating for the short-term memory deficits which affect the ability to perform a complex task. Compared with the use of immediate prompts, which have been studied by many prompting systems, earlier prompts were reported to be of particular importance by all participants. For example, one participant talked about his need to know about an upcoming doctor’s appointment two or three days in advance. Another participant reported that her way to prepare for an outdoor activity several days in advance was by moving things into a cart near the front door. In these cases, our participants need prompts well ahead of time so they get ready both behaviorally and psychologically, and reduce the likelihood of feeling anxious or overwhelmed by unexpected events. “Pressure” is the word that comes up most frequently when the participants described their feelings when something happened too quickly and they did not have enough time to prepare. Prompting well in advance is important for avoiding such “surprises”.

People with TBI may have comorbid disabilities that need to be taken into consideration when designing technology

Common comorbid disabilities include visual impairment, diminished fine motor skills, and reading impairments. All of these aspects of an individual’s cognitive, physical, and sensory capabilities should be taken into account in creating new technology or applying existing technology supports. For example, Shawn reported issues both with dexterity and with spelling: “. . . spelling names, that’s hard because you got to press

two times for this letter and two times for that letter, so at that point, I’ve had it!” Six participants asked for a device with speech recognition: “. . . to me that would be the ideal thing because I could tell it . . . I don’t type quickly anymore” (Connie).

People are an important part of the broader support network in which technology fits

Even though they strongly value the independence supported by technology, participants with TBI did not want to do away with human support. The reliability of technology is an important consideration; participants felt technology devices could fail or get lost. People can be more reliable and they can provide emotional support, such as positive feedback. Also, people promote developing personal relationships while technology, instead, may result in greater isolation even with access to social networking technology. One participant talked about his experience of spending so much time on Facebook that he found it very “isolating”.

Technology is not only designed for individuals with TBI

People are an important part of our participants’ lives and technology design should not only involve them but also the people around them who provide the day-to-day support. Participants from both focus groups expressed their interest in technologies that can help to connect them to their caregivers. Both caregivers and individuals with TBI share the need to be aware of other one’s whereabouts, activities, or schedules, especially when they are living apart.

Shared technology can be useful in multiple situations. When location is activated on a smartphone, for example, the caregiver could potentially be available to assist an individual who has become lost. Eileen, Ben’s spouse, told us that she has “. . . a thing on my phone because I’m always worried (Ben) is going to get lost and I track his phone. So I know where he is all the time”.

To a large extent access to technology comes down to cost

Participants responded positively to using technology that is smart, simple to use, and most importantly, affordable. To a large extent, access to technology comes down to its cost. Individuals with disabilities, including TBI, are far more likely to experience financial hardship, which makes purchasing and using new devices burdensome. Connie stated that not only could she not afford new technologies, such as a smartphone or a replacement for her computer that is “on life support”; she also cannot afford the monthly internet or data plan service fees.

Limitations

The limitations associated with qualitative research in general apply to this project. This was a hypothesis seeking study. No attempt was made to recruit a representative sample and no inferences to a larger population can be made. We have made recommendations about potential implications for design and deployment of technologies to support cognition, but we have not tested these.

Conclusion

In this study, we used a qualitative methodology to gain an initial understanding of the perspectives of people with TBI and caregivers with respect to CSTs. CSTs, especially existing off-the-shelf technologies, may facilitate increased independence and participation for individuals with TBI. The availability of training in using features of the device and the cost of purchasing

the device were critical considerations reported by our participants. Technology, however, should not replace the role of the caregiver in providing support. Rather, CSTs should be viewed as an opportunity to increase independence while providing a way to communicate support needs on an as-needed basis. It is worth noting that though various advanced technologies are available, most participants used lists or other textual reminders as a form of memory support in one way or another. However, they reported multiple disadvantages, such as keeping paper notes organized.

There are clearly implications for future research including formal usability studies of the use of CSTs with people with TBI and caregivers, as well as pilot intervention studies where CSTs are deployed with explicit instruction and support. The findings of our current study may inform such research.

Declaration of interest

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