



Patient perspectives on quality and access to healthcare after brain injury

Kristen Dams-O'Connor, Alexandra Landau, Jeanne Hoffman & Jef St De Lore

To cite this article: Kristen Dams-O'Connor, Alexandra Landau, Jeanne Hoffman & Jef St De Lore (2018) Patient perspectives on quality and access to healthcare after brain injury, *Brain Injury*, 32:4, 431-441, DOI: [10.1080/02699052.2018.1429024](https://doi.org/10.1080/02699052.2018.1429024)

To link to this article: <https://doi.org/10.1080/02699052.2018.1429024>



Published online: 01 Feb 2018.



Submit your article to this journal [↗](#)



Article views: 25



View related articles [↗](#)



View Crossmark data [↗](#)



Patient perspectives on quality and access to healthcare after brain injury

Kristen Dams-O'Connor^a, Alexandra Landau^a, Jeanne Hoffman^b, and Jef St De Lore^c

^aDepartment of Rehabilitation Medicine, Icahn School of Medicine at Mount Sinai, New York, NY, USA; ^bDepartment of Rehabilitation Medicine, University of Washington, Seattle, WA, USA; ^cDepartment of Neurological Surgery, University of Washington, Seattle, WA, USA

ABSTRACT

Primary objective: To gather information about brain injury (BI) survivors' long-term healthcare needs, quality, barriers and facilitators.

Research design: Qualitative content analysis of data gathered in focus groups using semi-structured interviews.

Methods: Forty-four community-dwelling adults participated at two clinical research centres in Seattle, Washington and New York, New York. Participants were asked open-ended questions about their experiences with healthcare in the community with regard to care needs, utilization, access, barriers and facilitators to health management.

Results: Central themes emerged across three categories: 1) barriers to healthcare access/utilization, 2) facilitators to healthcare access/utilization, and 3) suggestions for improving healthcare after BI. The importance of communication as both a facilitator and barrier to care was mentioned by most participants. Compensatory strategies and external tools were identified as key facilitators of medical self-management. Finally, improving clinicians' knowledge about BI emerged as a potential solution to address health needs of individuals with chronic BI.

Conclusions: Additional efforts need to be made to improve access to appropriate healthcare and increase the ability for individuals to successfully navigate the healthcare system. Findings suggest several specific, low-cost modifications to healthcare delivery and strategies for improving medical self-management that can maximize long-term health maintenance for BI survivors.

ARTICLE HISTORY

Received 3 August 2016

Revised 21 July 2017

Accepted 14 January 2018

Published online 1 February 2018

KEYWORDS

Traumatic brain injury; acquired brain injury; chronic health; qualitative research

Introduction

Each year in the USA, more than 3.5 million people develop an acquired brain injury (1). Brain injury (BI) is defined as an injury that occurs after birth as a result of external force (e.g. traumatic brain injury (TBI)) or due to non-traumatic processes (e.g. stroke, brain tumour, encephalitis). BI can result in temporary or permanent deficits in cognitive functioning, mood, behaviour and overall functional ability. Recent estimates suggest that well over 6 million people in the USA are living with a BI-related disability (1–4).

BI has been conceptualized as an isolated event, but in recent years there is a growing consensus that BI may be better understood as a chronic health condition given the enduring sequela experienced by many long-term survivors. Evidence suggests that individuals with TBI experience increased rates of seizures, sleep disorders, neurodegenerative diseases, neuroendocrine problems, psychiatric diseases, genitourinary conditions and systemic metabolic conditions that may evolve for months or years after injury (5,6). Findings from smaller studies suggest older adults with TBI report more metabolic and endocrine problems, in addition to more neurologic symptoms (i.e. headache, sensory changes), than age-matched uninjured peers (7), indicating that survivors of BI experience greater medical comorbidity as they age (8–11). While a proportion of individuals who have sustained

a moderate-to-severe TBI continue to improve in terms of global functioning even many years post-injury, a substantial proportion (20–30%) experience functional decline over time after injury (12). Moreover, a large body of literature indicates an increase in mortality and reduction in life expectancy of 6–7 years among individuals who survive at least 1 year after BI compared to the general population (13–18). Interestingly, a recent comparison of functional trajectories of individuals who received inpatient rehabilitation for moderate-to-severe TBI suggests that those who died within the study period had distinct functional trajectories (worse functioning at baseline and a steeper rate of decline over time than survivors), which may suggest that there are missed opportunities to identify and prevent premature death (19). The mechanisms for medical comorbidity following BI are speculative at this point. Possible contributors include medical (e.g. prolonged inflammatory, immune, and metabolic responses that impact multiple organ systems (5)), physical (e.g. decreased physical activity), cognitive (BI-related impairments that impact health maintenance behaviours) or life circumstance or lifestyle factors (e.g. substance use, reduced income leading to dietary changes and/or reduced access to healthcare) that over time impact health (5,6).

Given the increased medical needs and rates of medical comorbidity after BI, in combination with the lasting functional impairments seen in some individuals with BI, it has

been suggested that a chronic disease management approach may be appropriate for improving the long-term health and life quality in this group (20). Such an approach may involve structured long-term medical management overseen by healthcare providers, a supported health self-management programme or some combination of the two that is geared towards: a) long-term health maintenance and b) prevention of secondary complications and comorbidities.

Very little is known about the healthcare usage patterns of individuals with BI, the extent to which they are able to manage their medical care effectively or the barriers that may prevent effective medical self-management. Some qualitative studies have examined the healthcare experiences and service utilization of individuals with BI (21–23). These studies suggest that individuals with BI have difficulty accessing outpatient services, especially specialist services (e.g. TBI specialists, mental healthcare), as early as 1 year after discharge from acute care. However, BI survivors' personal experiences with healthcare access and quality of services have not been examined.

The purpose of this study was to learn about the experiences individuals with BI have in seeking and accessing healthcare (both primary and specialty care), from the 'patient' or insider perspective, in order to better understand how providers and health systems can improve care for their patients with BI. Qualitative research methods were employed to provide a comprehensive and nuanced exploration into specific factors that contribute to the care and health management of individuals with BI.

Methods

Participants

Focus groups were conducted in Seattle, Washington and New York, New York with individuals who survived a BI and/or their caregiver. 45 adults (44 individuals with BI, one caregiver) participated in seven focus groups conducted across the two locations. Four focus groups were held in Seattle and three in New York. Each group was composed of four to nine participants (mean(SD) = 6.43(1.59)). This convenience sample was recruited through posted flyers and email invitations to the TBI Model System Advisory Board at University of Washington Medical Center, Brain Injury Research Center at Mount Sinai, and local Seattle and New York-area BI support groups. All participants sustained a BI more than 6 months ago, or identified as a caregiver for an individual with BI. All data were collected in accordance with participating academic institutional review boards.

Demographic information about the 44 individuals with BI is provided in Table 1. 27 individuals participated in Seattle and 18 participated in New York. Participants with BI ranged in age from 23–72, were primarily female, white, college educated, unmarried and currently unemployed. Most participants rated their physical health as good, very good or excellent and most had health insurance coverage. Average time since injury was 13 years and among those with TBI, most sustained an injury that would be classified as moderate to severe based on duration of post-traumatic amnesia and/or loss of consciousness.

Interview methods

Focus groups lasted approximately 60–90 minutes and were facilitated by licenced clinician researchers (JH and KD). Groups were asked a series of open-ended questions about their experiences with healthcare after BI. The semi-structured group format included broad questions about what qualities they value in their medical providers, the types of care providers they have seen, how they determined when to seek care, what they felt their doctors needed to know about BI to provide good care, whether they shared their BI history with their providers, and what barriers or facilitators impacted their ability to access and manage their healthcare. Research staff audio-recorded the group discussions and took field notes to aid in accurate transcription. A de-identified written transcription of focus group content was created either by an on-site stenographer or via professional transcription of the audio-recorded sessions.

Analysis

In order to ensure accuracy and completeness of data, the transcripts were reviewed and cross-checked with the audio recordings and field notes. After preliminary review of the transcribed data, the research team developed a codebook to organize participant responses into three broad categories that best reflected the information provided throughout the transcripts. These categories included: barriers to healthcare access/utilization, facilitators to healthcare access/utilization, and suggestions for improving treatment. All members of the research team reviewed the transcripts and came to a consensus on the categories and their definitions.

The transcripts were then uploaded into Dedoose, a secure online application for analysing qualitative and mixed-methods research (24). Two members of the research team (JS and AL) independently read over the transcripts and coded the data according to the three general categories. After all transcripts were coded, disagreements in coding were identified. There were few disagreements, and each was discussed by all four authors and a consensus was reached on the appropriate coding.

To further characterize the data, each of the four authors independently reviewed the coded data, made notes of recurring patterns, and identified common themes that surfaced from the data. Each author created a list of the most common themes they noticed and chose examples of each theme using direct quotes from the transcribed data. The authors met to discuss their observations and agreed upon a set of common themes that best characterized participants' responses within and across each coded category.

Results

Here we present BI survivors' experiences with healthcare as captured in this qualitative study. We have organized the data according to the three categories identified in the first round of review: 1) barriers to healthcare access/utilization, 2) facilitators to healthcare access/utilization and 3) suggestions for improving health after TBI. In each category, we have listed

Table 1. Demographics of focus groups.

	Seattle	New York	All
Participants	27	18	45
Age (years) (mean (SD))	52.8 (13.1) N = 26	53.5 (15.9) N = 18	53.1 (14.1) N = 44
Range (years)	23–72	24–71	23–72
Gender			
Female	16 (59%)	10 (56%)	26 (58%)
Male	11 (41%)	8 (44%)	19 (42%)
Married			
Never	9 (33%)	8 (44%)	17 (38%)
Married	8 (30%)	3 (17%)	11 (24%)
Divorced/separated/widowed	6 (22%)	6 (33%)	12 (27%)
Other	2 (7%)	1 (6%)	3 (7%)
Unknown	2 (7%)	0	2 (4%)
Ethnicity			
Hispanic	1 (4%)	4 (22%)	5 (11%)
Not Hispanic	23 (85%)	14 (78%)	37 (82%)
Unknown	3 (11%)	0	3 (7%)
Race			
White	22 (82%)	13 (72%)	35 (78%)
Non-white	5 (4%)	5 (11%)	10 (22%)
Type of Brain Injury			
TBI	18 (67%)	17 (94%)	35 (78%)
Non-traumatic BI	9 (33%)	1 (6%)	10 (29%)
Years since first injury (median(IQR))	11.3 (28.3)	15.8 (12.5)	12.8(21.0)
Range (years)	.8–46.2	1.4–66.3	.8–66.3
Insurance			
Private	7 (26%)	4 (22%)	11 (24%)
Medicare	3 (11%)	6 (33%)	9 (20%)
Medicaid	4 (15%)	3 (17%)	7 (16%)
Both Medicare and Medicaid	6 (22%)	2(11%)	8 (18%)
Other	7 (26%)	3 (17%)	9 (20%)
Education			
High school graduate or below	2 (7%)	2 (12%)	4 (9%)
Up to 4 years of college	13 (48%)	8 (45%)	21 (47%)
Graduate school (Master's, PhD, MD, etc.)	13 (44%)	8 (45%)	21 (46%)
Employment – current			
Full time	0	4 (22%)	4 (9%)
Part time	3 (11%)	3 (18%)	6 (13%)
Not employed	22 (82%)	11 (61%)	33 (73%)
Missing	2 (7%)	0	2 (4%)
Employment - before injury			
Full time	12 (44%)	9 (50%)	21 (47%)
Part time	5 (19%)	4 (22%)	9 (20%)
Not employed	7 (26%)	5 (28%)	12 (27%)
Don't know/Missing	3 (11%)	0	3 (6%)
Physical health – current			
Fair	7 (26%)	5 (28%)	12 (27%)
Good	9 (34%)	6 (33%)	15 (33%)
Very good	6 (22%)	3 (17%)	9 (20%)
Excellent	3 (11%)	4 (22%)	7 (16%)
Don't know/refuse	2 (7%)	0	2 (4%)

the themes that were identified by author consensus as best representing the participants' responses. The themes described here emerged across the broad categories, and several themes are used to illustrate the participants' experiences across multiple categories as shown later. We describe each category and associated themes, and we have included comments from participants in quotations that best illustrate the themes. Throughout this article, an ellipsis within a quoted passage (i.e. '...') is used to signify omitted content, and square brackets are used to insert words omitted by the speaker. These edits were made to remove unrelated content such as repeated words, stutters or crosstalk, and to focus on key content and increase readability.

Barriers to healthcare access/utilization

As described earlier, the interviewers across all focus groups used a common script that began with a general introduction

to the project followed by a preliminary question about the type(s) of clinical care providers the participants see for their healthcare. Our goal in starting with this broad question was to help facilitate recall among participants of the various providers they see and to cue recall about recent interactions they've had with the healthcare system. Across the groups, this preliminary question was met with a litany of responses about doctors and other clinicians from whom participants wanted to seek care but had been unable to. The specific barriers to care varied a great deal across participants, but common themes were readily identifiable. Common themes in this category included: health system-wide barriers, provider-specific factors, unidentified BI, external barriers and BI-related impairments. Participants alluded to barriers to care access, utilization and health self-management quite frequently in response to several of the interview prompts and these themes emerged throughout and across the focus groups at both locations.

Health system-wide barriers

Barriers to healthcare access are by no means unique to individuals with BI, and many of the problems our participants reported are relevant to most consumers of healthcare. However, several of these barriers, such as gaps in care, limited availability of speciality services, restrictions based on insurance coverage and financial strain, seemed to have a particularly detrimental impact on patients with BI and their families. In the context of a sudden life-altering injury that commonly results in impaired cognition and myriad long-term medical care needs, lack of information and poor care coordination seemed to present considerable challenges for many of our participants.

'... the discharge people were explaining to my wife a little bit about the next steps... we have this inpatient or outpatient rehabilitation. And we have all this stuff set up. And then [my wife] says that sounds awesome, but we have [Health Insurance Carrier]. And he says well, pretty much disregard everything I just said. We can't help you anymore. All those things you just heard, disregard'.

'I was in the hospital about 10 days... we maxed out our insurance. And then I came home. And I didn't see any doctors. And I had all kinds of problems then'.

'Once my brain bleed went away, they focused on my facial reconstruction. And, once that was done, they were, like, all right, great; you're stable, you're young, you're healthy. We've got to get you out of here, right? That's protocol. I get it'.

'Since there are so many components to a brain injury you really need all the healthcare team members working together on a specific patient. The lack of communication and collaboration I think is such a huge problem'.

Discharge from the hospital, whether from an emergency room, acute care hospital, rehabilitation unit or nursing facility, was frequently identified as a time when participants felt that their BI diagnosis, or the implications of that diagnosis, was not explained. Several participants indicated they were given insufficient information or poorly timed information.

'Especially when it's such a traumatic time, people's heads aren't in the right place. They don't know they have a TBI. There needs to be... just a couple bullet points of what you need to know. Here's what you need to do. Here's my number. Please follow up with us... But I think it's really critical to make sure that the information doesn't just go to a person, that it goes to the right person'.

'In [the hospital], my wife was away for a moment when the nurses were doing their rounds, but my mom was there. And they gave her a bunch of handouts... And I think they may have explained a little bit about brain injury. But my mom wasn't quite in the head-space to remember all of it at the time. And so we got a handout about my brain injury...I think it's really important that they make sure that for a piece of information that's that critical, that...the primary caretaker [receives the information]'.

The importance of access to speciality care came up in several focus groups. Some participants indicated that providers with specialized knowledge of BI (such as physiatrists and neuropsychologists) were central to their long-term care, but many participants reported not having access to specialized services after the first few weeks or months after the injury. Even among participants who sought speciality care,

lack of insurance and/or financial barriers kept them from continuing treatment or seeing the specialists they needed.

'She [a neuro-ophthalmologist] was the person that diagnosed me with having nystagmus and disconvergence. [My] ophthalmologist and neurologist, they just missed it. And so, I waited for like four hours to see her and then she told me about this and it was... sort of a lightning strike moment. And then [the treatment] was working... I felt very fortunate to see her, and I felt like that diagnosis was incredible. And...then now not being able to see her, you know sucks... Especially because it's my insurance company saying, "No, you can't"'.

'So if I didn't have specialty doctors, I wouldn't be thriving, I wouldn't be able to work, I wouldn't have friendships and relationships. I would be scary, I really would be... So I was really lucky, more than once'.

Provider-specific factors

Certain characteristics of healthcare providers were identified as barriers to care when they caused a loss of trust or confidence in a given provider. Some participants said they were less likely to return to a provider for follow-up care if they did not believe the provider was willing or able to address their health concerns. Several focus group members felt that their primary care physicians showed a lack of empathy about BI, or had a tendency to dismiss or downplay the effects of the injury.

'And, he asked how I hurt my hip and I told him that I had a traumatic brain injury and during the accident that's when the hip [injury] happened but before I could even finish he said, "I don't care about your traumatic brain injury, tell me about your hip"'.

'I am [a member of healthcare system] and they wrote off my traumatic brain injury. They said, "We don't have anything else for you and we are not going to pay for anything outside of our system"'.

'And, I mean, the last guy I went in to, I told them what my priority was. And they didn't agree, so my priority didn't even get addressed'.

Others felt that their physicians overall demonstrated a lack of knowledge about BI. Some participants felt that their BI-related health problems were not understood by their provider (e.g. interpreting a participant's description of cognitive fatigue as being the same thing as physical fatigue or sleepiness) or that the provider was not equipped to manage brain-injury-related problems. It seemed that particularly when providers seemed unwilling to learn or to try to understand more about BI, some participants reported that they chose not to seek further care at all. There was a sense of disillusionment or weariness that for some participants seemed to impact their willingness to seek medical care at all.

'I feel like I've spent a lifetime educating providers about a TBI... Most of the time I've done it unsuccessfully'.

Unidentified BI

Given that most of our focus group participants sustained what would be considered clinically significant BIs, we were somewhat surprised to hear that several people reported not

having been told they sustained a BI during acute care, or in some cases went years before being diagnosed with a BI. A variety of factors seemed to have contributed to these issues, such as a person sustaining multiple traumatic injuries that required urgent interventions and perhaps overshadowed the BI during early hospitalizations, a lack of follow-through with healthcare professionals after hospital discharge, and/or limited access to speciality care.

'He never diagnosed the TBI. It wasn't until six months later that I was actually diagnosed. So I would say, number one, when somebody has a concussion, take it seriously. Don't tell them they're just getting old and that's why they're forgetting things'.

'I was confused all the time... very scared. I went back to work thinking that I would begin to feel normal but it wasn't happening... and then I decided to cover up things. And then I went to see my – I keep talking to my doctor about it and he just does not pay attention; he just keeps saying, "Oh, your blood pressure is 280 over 170". But then... somebody told me I should go and see a neuropsychologist. I thought she said psychiatrist so I was thinking maybe she thinks I'm crazy. So I hesitated. After one year I went and then [the psychiatrist] told me that I'm not really supposed to see him, I'm supposed to see a neuropsychologist... So I spent 6 years in total confusion before I found a neuropsychologist... and when I did go... they found out that I have traumatic brain injury'.

We asked the focus groups whether they routinely told their doctors about their BI, and across groups usually at least half of the participants indicated they felt it was important for their providers to know about their BI. Others felt their injuries were self-evident and had not considered the need to tell their providers. Still others indicated that previous interactions with healthcare professionals led them to believe there was little to be gained by sharing this information, and subsequently chose not to report their injury history.

'I don't tell any of my doctors that I have a brain injury. [Several other participants asked why not?] Why? What for? They're not gonna treat me different. He doesn't care. He doesn't want to know about it'.

Financial and logistical factors

Several focus group members reported a variety of logistical barriers to accessing care or maintaining their health. Financial concerns were frequently mentioned, as many participants reported major changes to their economic status that resulted from extended time away from work, working only in a reduced capacity or inability to return to work at all after their BI. Some participants are unable to drive or have difficulty navigating public transportation independently, so transportation to medical appointments was often cited as a barrier. Several participants mentioned that they relied on ambulance services to transport them to medical appointments. However, these services often arrived late to pick them up, at times dropped them off at appointments so late that they were not seen by the provider, and that services that transported multiple passengers often meant spending an entire day getting to and from a single medical visit.

'Just getting there takes an inordinate amount of energy. Will there be traffic? Will there be parking? All of those things'.

'You know, you're all talking to a roomful of people who have high need medical lives. And that [expletive] ain't cheap. We require a lot of care, and it's expensive'.

'Right now, I'm having physical therapy...but my copay is 30 dollars a visit. So if I go three times a week [as prescribed], that's 90 dollars a week. I can only afford [to go once a week]. The doctor wants me to go for 2 months, and so that's a lot of money. Especially when you are on a fixed income'.

Due to factors such as financial expense and insurance coverage limitations, many participants felt that these barriers (rather than healthcare providers) ultimately determined the medical care they were able to get. Additional external barriers included things like changes to insurance carriers that resulted in gaps of care or discontinuation of care when a person's healthcare providers were not covered by the new insurance or when medications were not covered by the new plan. Limited access to speciality providers was also commonly mentioned, whether due to insurance-related restrictions, cost, transportation barriers or geographic proximity to specialists.

BI-related impairment

Common symptoms and sequela of BI were almost universally identified as barriers to accessing and using appropriate medical care. Cognitive impairment was frequently cited as a barrier to making, keeping and following through with medical appointments and medical directives. Difficulty with distractibility, slowed information processing, organization and verbal communication seemed to pose specific challenges during office visits. Others reported problems with prospective memory, or remembering to do things at specific times – which caused missed healthcare appointments or limited ability to follow through with doctors' recommendations, including medication compliance. Even getting routine physicals and preventative healthcare was a challenge for people with cognitive impairments.

'I couldn't remember when I went to a doctor. Did I go 4 years ago; did I go a year ago? ...My concept of time is all messed up'.

'And a lot of times they are rushed for time, so if you don't write down your questions before you visit, and you have the tendency to forget what you're there for, they just rush out'.

One caregiver who participated in the focus groups shared similar concerns about the extent to which cognitive impairments can impact medical care:

'I didn't realise until I started going to appointments with him how easy it was for his doctors not to understand. It was partly because [my husband was] just happily telling them everything's fine and kind of making stuff up. And I was just like: Oh, my God. This is not good'.

For some participants, BI-related physical and cognitive impairments impacted their health self-management skills, posing barriers to maintaining an overall healthy lifestyle, such as keeping up with an exercise routine and eating healthy foods. Physical symptoms that were mentioned consistently included vision changes (depth perception, double vision), poor balance, headaches and fatigue.

'If I am trying to make food for myself, it is so many steps than going to the store. First of all – you can't do it... Being in the store [is a challenge] even though I have a list. Being able to get through the list which that doesn't always happen. I didn't eat fruit for ages because it was at the end of my list'.

'I think it just feels like work for him to remember to brush his teeth, and eat, and, you know, change his clothes'.

Given the preponderance of physical and cognitive impairments across our brain-injured participants, these challenges were alluded to in response to nearly all questions and throughout all groups. Several system-wide barriers such as complicated insurance-related procedures (e.g. preauthorization, doctors' changing participation in insurance panels, dealing with unexpected bills), lack of communication between healthcare providers, poor continuity of care from the hospital to the community and time-limited visits with doctors were all discussed in the context of being especially challenging for people with BI-related cognitive or physical problems.

'And because I know I only have this amount of time. And I, oh, damn, I forgot to write down some of my concerns and what's going on. Because [people with] brain injury, we have those definite memory deficits. I will later on go back and it's like oh, shoot, I forgot to ask about this or I didn't express my concerns about something. And it's just getting worse'.

It was clear that injury-related impairments also served to exacerbate financial and logistical barriers such as transportation and insurance authorization. Overall, BI-related impairments seemed to have a mutually exacerbating effect on healthcare utilization and health self-management among our participants.

'I get really bad headaches, and it's hard for me to keep track of my medicine and calling the pharmacy and calling to make sure the insurance company is going to cover it and making sure the doctor's going to order it...with my brain injury it is virtually impossible. It's too taxing to keep track'.

'But I think, I can do that when I am not worried about money. If I am worried about money, everything else falls to pieces... When I have all of the things to support me, then I can do self-care. When I was trying to work, self-care went out the window because I was just trying to show up'.

Facilitators to healthcare access/utilization

We anticipated that our focus group participants would readily identify barriers to healthcare access and self-management, so we included in our interview script questions to help elicit factors that make it easier to manage one's health. Participants identified a variety of facilitators, including good communication with certain providers, environmental accommodations and strategies they used to compensate for injury-related impairments that would otherwise pose barriers to care and provider knowledge about BI.

Good communication

Communication was a common theme across several of the care facilitators that participants identified. Communication seemed to be important at two levels: communication between members of a treatment team, and communication

between the clinician and the patient/family. Several focus group members cited examples of times when problems were solved after medical providers collaborated on a care plan, discussed a patient's medication needs, or referred to specialists who maintained regular contact with the referring provider. When participants were asked what quality or skill stood out with their favourite medical provider, good communication skills and overall interpersonal rapport were among the most commonly cited contributors across groups. Good communication involved listening to the participant and explaining diagnoses/treatment in terms that they could understand. Interactions with medical providers that were significant to the participants usually included the clinician remembering personal facts about their interests and/or family so that the participant felt like the provider saw him/her as not just a patient with a disease or as 'a number', but as a person. Some participants named non-physician providers such as neuropsychologists or rehabilitation therapists as their most important or favourite providers; this seemed to be attributable at least in part to the rapport, communication, and awareness of BI-related challenges demonstrated by these providers.

'He just asks better questions. He listens. And if I tell him that we need to have follow-up information in writing, he will do that, which is quite amazing. And he's clear speaking; he speaks in a way that we can understand'.

'But I think one thing that's really, really helpful, that kind of exists more in the metasphere, is the rapport you have with your doctor is crucial to you wanting to go back'.

'My neuropsychologist is excellent and is very aware, and informed of all the different conditions that a person with a brain injury may have or experience and suggest different ways that I could target whatever challenge I'm having'.

Environmental accommodations

Participants also mentioned several accommodations made by providers or providers' office staff that made it easier for them to make and keep appointments and follow-through with doctors' recommendations. While some of these accommodations are common in clinical practice regardless of the patient population being served (e.g. providing appointment reminders), others appeared to be targeted to address the cognitive or physical symptoms commonly experienced by individuals with BI.

'There's no sense of rush; the office is low lighting; it is quiet and calm. Appointments are on time'.

Nearly all participants indicated that having sufficient time with the provider was essential to a successful patient-provider interaction (i.e. not being rushed, having time to ask questions):

'I have a wonderful primary care doctor and she listens and gives me a routine 20 minutes because that is how long it takes to get the story out'.

Accurately documenting recommendations, treatment plans, details for referrals (e.g. written down names and contact information) and other information that is central to care was deemed vital for most participants.

'A better doctor is somebody that, yeah, does write things down or gives you time so that you can write things down so that you can remember when you get home'.

Self-implemented compensation strategies

Finally, participants described strategies and external tools that they or their caregivers have used to make it easier for them to manage their healthcare. Participants said that physical reminders in their homes helped them keep track of appointments, medications and other important health-related tasks in their lives. Some used electronic devices (i.e. smart phones, electronic calendars) while others wrote notes on paper or used large whiteboards in their homes. Others found success when family, medical providers and/or other caregivers were able to remind participants of appointments with phone calls and/or emails. Several people said that they always brought someone with them to medical appointments to help them describe recent symptoms, remember what was discussed or follow-through on recommendations.

'I bring my sister with me who knows the medical terminology'.

'I have a caregiver, a wife...she generally goes to the, makes the doctor appointments with me. Most of the doctors...major ones, they go with you. Someone there who helps cover with some notes maybe you didn't do yourself. If you've got a caregiver, a spouse, a friend, boyfriend, or an animal that can write... just bring them, and it helps'.

Many participants also developed their own unique systems to stay on task and to keep their environment safe so that they can engage in activities that were viewed as being important for their overall health (e.g. cooking at home as opposed to ordering takeout, exercising).

'That's the key thing that got me through; it was just the calendar on my computer and I would have to write every day: exercise, do this or do that, or call this person or do that. And I would have to make long lists of things to do. Now it's not as much like that, but following the head injury it laid out my life for me and that got me through it'.

'One other quick trick I learned is, when you cook, put the ceiling fan on. So, when you leave the room, the fan is still running. So either you left it on or something else is going on the stove'.

Provider knowledge about BI

As indicated before, several participants reported that access to specialists has been essential to their recovery and health maintenance. These statements implied that it is important for many BI survivors to receive care from providers with specialized knowledge of BI-related impairments. We were interested to also learn about participants' experiences with general practitioners such as primary care physicians and family medicine doctors. Among participants who had a primary care doctor who knew about their BI, it became evident that knowledge of, or at least interest in, BI and its impact on their patient, was viewed as a tremendously valuable contributor to health maintenance. Additionally, awareness of appropriate referrals for specialized services was frequently cited as an important attribute of general medical providers.

'He doesn't specialise in [brain injury]. But, because I'm a patient, what he did is learned a whole bunch about it. He bought three

books and read them all and stuff. And I just thought that was awesome. I came in once morning. And he said, "Hey, I learned a lot about your injury that you have, your brain injury"... And I thought that was pretty cool. So I thought that he was a doctor to keep right there'.

'He tries to understand and kind of come at it from a survivor perspective of idiosyncrasies that are present for a [person with brain injury], things we have to consider...But at the same time, he treats me just like any other patient, you know...I have the confidence to know that he was considering the other factors'.

One participant described a family practice physician who helped him set and achieve health self-management goals as his recovery progressed and he became better able to manage his health independently:

'He's young and very green, but he's very good in that he's all about focusing on your recovery. And he takes it very serious. And he's very diligent in everything that's to be done. And if it doesn't work, we keep trying. And making sure it's fit correctly for my needs and where I am at in my points at that time in my recovery and my life... He makes sure I'm moving forward in a healthy way and my choices are good ones'.

Suggestions for improving treatment

Throughout and across all focus groups, participants spontaneously provided suggestions for how healthcare systems, providers, and patients and caregivers themselves can better manage and maintain health after BI. We also included an open-ended question asking participants to tell us things they thought healthcare providers should know about BI in order to provide the best care to patients with BI. We organized participants' input according to several themes, as described later.

Educating providers about TBI

When asked what providers needed to know to best help their BI patients, overwhelmingly, participants responded that their doctors needed to know at least some basic information about BI, such as common symptoms, and the impact of BI on one's health and quality of life. Participants didn't unanimously think their providers needed to already have this knowledge, but most felt that providers should be open to learning about BI so they could provide appropriate care to individuals with BI. There were also some things participants felt would be important for providers to keep in mind when treating patients with BI, such as the invisibility of the injury and the importance of personalized care.

'Some person, somewhere needs to write something so it can be incorporated into medical school training and also in rehab medicine training. It is not taught, believe me'.

'I think primary care physicians need to understand that brain injury is not visible... So when you walk into a doctor's office, maybe you're looking nice. But there's a lot of other things going on'.

'It's not an event, it's a chronic illness that we have'.

'It is an invisible disease! And you only see it when you try to function'.

While participants lauded providers who knew about BI (or who proactively tried to learn more about BI), they also felt it was important for providers to know that every BI survivor has a unique constellation of injury-related sequela that may present differently across each individual.

'To know no two head injuries are the same. Not assume that, you know, you come in with a head injury and that we have the same stuff going on'.

'...what do they need to know? That we're humans first with a brain injury. We're not a walking brain injury. That we're still human beings that grew up, that had an unfortunate accident that changed our lives forever. That's what I think they need to know'.

Database of BI information

Consistent with the overall desire for information reiterated across several themes earlier, participants reported wanting to have easier access to information about BI. These ideas came up in the context of patients' and families' desire for more information during the acute and chronic stages of recovery, the need for information about community resources for people with BI and also when discussing the importance of BI awareness among general medical providers. Specific information that participants wanted greater access to included information on potential symptoms related to their BI, expectations for recovery and local resources for BI rehabilitation specialists. Given the difficulty many participants had with finding and accessing speciality providers, another specific suggestion was to create a database and/or website of medical providers (of all specialties) who have experience and comfort treating and working with this population.

'There should be a centralised information system. It shouldn't be secret. It should be universal database, right there. Like my dating profile. If it can be with a dating profile, why isn't that happening?'

Accommodations for clear communication

There were several specific suggestions for how communication related to treatment and care services could accommodate cognitive or physical impairments commonly experienced by individuals with BI. The most universal request was to have more time with providers so visits could be less rushed and there would be more time to ask and answer questions, verify understanding and address all health concerns in a given visit. With the understanding that most healthcare providers are unable to make accommodations that could interfere with efficient and productive care delivery across all patients, minor changes to the mode of information delivery (e.g. writing down instructions instead of simply stating them out loud) could be beneficial. Increasingly widespread use of technology was evident in some of the participants' suggestions which included having instructions emailed, printing medication dosage information from the medical record, and text reminders for follow-up appointments. A more general suggestion was that providers working with individuals with BI could ask the patient how they best receive information and what communication tools work best for them, and use that format to document treatment/care

instructions, referral information and follow-up appointments.

'It would help me if my doctor always gave me in writing what they're saying to me. So I don't have to write it, jot down, and listen. [My] hands don't work right'.

'I have found that I have made some huge cognitive errors in the last few months... it is almost like I need somebody to ask me to paraphrase back to them what I think I've heard to see if it actually went in. Because I think I got it and looks like I got it and low and behold I didn't get it. I don't even know what is going on'.

Support groups

Managing BI-related symptoms and dealing with the medical community's perceived lack of knowledge about BI has left many participants across our focus groups feeling alone and frustrated by their circumstances. Peer networks were frequently mentioned as a way to access basic information about what to potentially expect from a BI (short- and long-term symptoms), learn about local resources and even learn strategies from one another. Support groups for individuals with BI were specifically mentioned as an important platform for individuals to process their feelings and to identify resources. In addition, participants noted that caregiver support groups, whether formal or informal, could be helpful for these same reasons.

'And I think having an actual physical group of other people that are going through it is better than just having that [pamphlet]'.

'Perhaps it's not about a condition that is treatable by medication, but some support. I get, we get, confused. And how about a support group or some guidance on how to structure your life so you don't get confused sometimes? And just some systematic ways that we can improve our quality of life? I don't have that...'

Discussion

The current study provided both poignant and important insights into the experiences of individuals with BI and the challenges and successes they face with respect to their healthcare encounters. Interestingly, individuals with BI living on opposite coasts of the USA reported similar experiences and ideas about the barriers, facilitators and strategies that impact their engagement with healthcare. Findings from our study are consistent with other projects that have examined the experience of individuals with BI and their utilization of care services (21,23,25). Barriers to services such as financial struggles, gaps in the continuity of care and limited availability of speciality services are commonly reported in individuals with chronic diseases (26).

The notion that the quality of communication, care continuity and the strength of the patient-clinician relationship can have a measurable impact on health outcomes is not novel; these factors are well documented contributors to long-term health among many clinical groups (27) and individuals with chronic diseases (28,29). Practitioners may lack a full appreciation of the day-to-day challenges faced by individuals with multiple chronic conditions, including depression or anxiety. Targeted interventions may help facilitate communication and improve patient outcomes (30). However, some

studies suggest that satisfaction with primary care providers is particularly low among individuals with disabilities (31,32), which is at least partly attributable to a lack of disability-specific knowledge among general practitioners (31,33).

Few studies have examined the perceived competencies and attitudes of healthcare professionals with respect to caring for individuals with BI, but there is some evidence that a lack of knowledge and even misinformation about BI may be present among providers. One study reported that qualified healthcare professionals may have negative attitudes towards individuals who they viewed as being responsible for their TBI, and these attitudes were negatively associated with helping behaviours (34). Specific misconceptions about TBI among less experienced health professionals include a tendency to attribute patients' undesirable actions to their personality rather than to injury-related neurobehavioural impairments (35). Other studies suggest that non-expert medical professionals may overestimate the cognitive abilities of those with 'invisible' impairments (36,37) which may allow them to downplay the significance of injury-related symptoms (38); at the same time, health professionals who are not experts in BI may regard those with clear impairments as being mentally ill or learning disabled (37). A clinician's self-reported knowledge, confidence and attitudes towards individuals with dementia has been found to impact care; for example, physicians who lacked confidence in diagnosing and managing patients with dementia were less likely to engage in open communication and care planning with the patient and caregiver (39).

The current study adds to a growing body of research which suggests that poor communication and lack of knowledge about specific disability groups among general practitioners may place individuals at risk for unsatisfying or even harmful interactions with the healthcare system. This may be particularly true for individuals with disabilities involving cognitive and neurobehavioural impairment which may not be readily 'visible' to the clinician.

The information provided by participants in the current study suggests that some of the strategies recommended for health management among individuals with other chronic diseases may similarly be useful for individuals with BI. In particular, specific efforts on the part of the clinician such as asking open-ended questions to learn about barriers and anticipated challenges to health management, setting specific and measurable goals as a part of a personal action plan, linking patients to community-based self-management resources, regular clinician-initiated follow-up to monitor adherence, and scheduling planned visits of longer duration (e.g. 30–45 minutes) can help support health self-management (40–42). Other studies emphasize that informational materials, action plans, and technological aids are most effective when they are used in addition to (never instead of) face-to-face interactions with health professionals (43).

Self-management skills training protocols have been developed for individuals with early or preclinical dementia (44), many of which emphasize the importance of caregiver involvement (45), and may also be useful in accommodating the cognitive impairments that many of our focus group participants identified as key barriers to health maintenance. A small

focus group study of individuals with aphasia and their caregivers found that consumers preferred when their providers used 'disability-specific' communication strategies (such as visual aids and writing down key words) which the providers rarely used (46). The authors' conclusion that clinicians should routinely inquire about patients' communication preferences and then utilize patient-centred communication strategies (46) seems entirely relevant to individuals with BI as well.

Results of the current study suggest that some participants felt that their providers were unwilling to work with them or acknowledge their BI. However, others were fortunate to have experienced providers who were willing to share information with their team of healthcare providers (typically facilitated by the individual or their family members). It appears that many individuals with moderate-to-severe BI require a team of healthcare providers over time and communication amongst providers and between the providers and the patient/caregivers may be critical for allowing individuals with BI to get the most from their healthcare experience.

Limitations and future studies

The current study was limited by sample size and a large range of time since injury. Given that the sample included self-selected individuals with BI and a caregiver recruited from hospital and support group settings, these results may not generalize to the experiences of others with BI. In addition, those who are closer to injury may have different experiences with healthcare compared to those many years out which was not able to be evaluated given the current sample size. The focus group methodology relied on open-ended questions and group discussion in which the discussion at times veered off the research questions and some time was spent on irrelevant topics. Further, it is possible that some participants may have been compelled to give responses in agreement with others' ideas due to the interactive group methodology used here. However, responses from focus group participants were consistent across groups and locations (Seattle, New York City).

Conclusion

The increasing awareness of BI as a chronic condition with potentially lifelong consequences is gaining growing support in the scientific literature and among clinicians experienced in working with individuals with BI. Results from our focus groups suggest that additional efforts need to be made in order to improve access to appropriate healthcare and to increase the ability for individuals with BI to successfully navigate the healthcare system. Specifically, improved educational efforts are warranted to allow general practitioners and other health professionals to become more familiar with the symptoms, daily challenges and health sequela experienced by individuals with BI. Increasing access to specialized providers as well as access to compensatory tools and supports within healthcare settings may help individuals with BI to maximally benefit from the care that they receive.

Declaration of interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of this article.

Funding

This work was supported by Grants from the National Institute on Disability, Independent Living, and Rehabilitation Research (Grant Numbers 90DP0038-02-00 and 90DP0031-01-00), and by a Grant from the National Institutes of Health, National Institute of Child Health and Development (Grant Number K01HD074651-01A1).

References

- Brain Injury Association of America. Brain injury statistics. Vienna, VA: Brain Injury Association of America; 2015. [accessed 2016 July 15]. <http://www.biausa.org/LiteratureRetrieve.aspx?ID=104992>
- Selassie AW, Zaloshnja E, Langlois JA, Miller T, Jones P, Steiner C. Incidence of long-term disability following traumatic brain injury hospitalization, United States, 2003. *J Head Trauma Rehabil.* 2008;23(2):123–31.
- Thurman DJ, Alverson C, Dunn KA, Guerrero J, Sniezek JE. Traumatic brain injury in the United States: a public health perspective. *J Head Trauma Rehabil.* 1999;14(6):602–15.
- Zaloshnja E, Miller T, Langlois JA, Selassie AW. Prevalence of long-term disability from traumatic brain injury in the civilian population of the United States, 2005. *J Head Trauma Rehabil.* 2008;23(6):394–400.
- Masel BE, DeWitt DS. Traumatic brain injury: a disease process, not an event. *J Neurotrauma.* 2010;27(8):1529–40.
- Masel BE. The chronic consequences of neurotrauma. *J Neurotrauma.* 2015;32(23):1833.
- Breed S, Sacks A, Ashman TA, Gordon WA, Dahlman K, Spielman L. Cognitive functioning among individuals with traumatic brain injury, Alzheimer's disease, and no cognitive impairments. *J Head Trauma Rehabil.* 2008;23(3):149–57.
- Breed ST, Flanagan SR, Watson KR. The relationship between age and the self-report of health symptoms in persons with traumatic brain injury. *Arch Phys Med Rehabil.* 2004;85(4 Suppl 2):S61–S67.
- Flanagan SR, Hibbard MR, Riordan B, Gordon WA. Traumatic brain injury in the elderly: diagnostic and treatment challenges. *Clin Geriatr Med.* 2006;22(2):449–68.
- Flanagan S, Gordon WA, Hibbard M. Diagnostic issues in TBI in the elderly. *Brain Injury Professional.* 2005;2(2):22–24.
- Flanagan SR, Hibbard MR, Gordon WA. The impact of age on traumatic brain injury. *Phys Med Rehabil Clin N Am.* 2005;16(1):163–77.
- Corrigan JD, Hammond FM. Traumatic brain injury as a chronic health condition. *Arch Phys Med Rehabil.* 2013;94(6):1199–201.
- Hannerz H, Nielsen ML. Life expectancies among survivors of acute cerebrovascular disease. *Stroke.* 2001;32(8):1739–44.
- Harrison-Felix C, Pretz C, Hammond FM, Cuthbert JP, Bell J, Corrigan J, Miller AC, Haarbauer-Krupa J. Life expectancy after inpatient rehabilitation for traumatic brain injury in the United States. *J Neurotrauma.* 2015;32(23):1893–901.
- Brooks JC, Strauss DJ, Shavelle RM, Paculdo DR, Hammond FM, Harrison-Felix CL. Long-term disability and survival in traumatic brain injury: results from the national institute on disability and rehabilitation research model systems. *Arch Phys Med Rehabil.* 2013;94(11):2203–09.
- Brown AW, Leibson CL, Malec JF, Perkins PK, Diehl NN, Larson D. Long-term survival after traumatic brain injury: a population based analysis. *NeuroRehabilitation.* 2004;19:37.
- Ventura T, Harrison-Felix C, Carlson N, Diguiseppi C, Gabella B, Brown A, Devivo M, Whiteneck G. Mortality after discharge from acute care hospitalization with traumatic brain injury: a population-based study. *Arch Phys Med Rehabil.* 2010;91(1):20–29.
- Harrison-Felix C, Whiteneck G, Devivo MJ, Hammond FM, Jha A. Causes of death following 1 year postinjury among individuals with traumatic brain injury. *J Head Trauma Rehabil.* 2006;21(1):22–33.
- Dams-O'Connor K, Cantor JB, Brown M, Dijkers MP, Spielman LA, Gordon WA. Screening for traumatic brain injury: findings and public health implications. *J Head Trauma Rehabil.* 2014;29(6):479–89.
- Malec JF, Hammond FM, Flanagan S, Kean J, Sander A, M S, Masel BE. Recommendations from the 2013 Galveston Brain Injury Conference for implementation of a chronic care model in brain injury. *J Head Trauma Rehabil.* 2013;28(6):476–83.
- Pickelsimer EE, Selassie AW, Sample PL, W Heinemann A, Gu JK, Veldheer LC. Unmet Service Needs of Persons with Traumatic Brain Injury. *J Head Trauma Rehabil.* 2007;22(1):1–13.
- O'Callaghan AM, McAllister L, Wilson L. Experiences of care reported by adults with traumatic brain injury. *Int J Speech Lang Pathol.* 2010;12(2):107–23.
- Toor GK, Harris JE, Escobar M, Yoshida K, Velikonja D, Rizoli S, Cusimano M, Cullen N, Sokoloff S, Colantonio A. Long-term health service outcomes among women with traumatic brain injury. *Arch Phys Med Rehabil.* 2016;97(2 Suppl):S54–S63.
- Dedoose Version 5.0.11. Web application for managing, analyzing, and presenting qualitative and mixed method research data. Los Angeles, CA: SocioCultural Research Consultants, LLC; 2014. <http://www.dedoose.com>
- Rotondi AJ, Sinkule J, Balzer K, Harris J, Moldovan R. A qualitative needs assessment of persons who have experienced traumatic brain injury and their primary family caregivers. *J Head Trauma Rehabil.* 2007;22(1):14–25.
- Bellinger JD, Hassan RM, Rivers PA, Cheng Q, Williams E, Glover SH. Specialty care use in US patients with chronic diseases. *Int J Environ Res Public Health.* 2010;7(3):975–90.
- Kelley JM, Kraft-Todd G, Schapira L, Kossowsky J, Riess H. The influence of the patient-clinician relationship on healthcare outcomes: a systematic review and meta-analysis of randomized controlled trials. *PLoS One.* 2014;9(4):e94207.
- Cabana MD, Jee SH. Does continuity of care improve patient outcomes? *J Fam Pract.* 2004;53(12):974–80.
- Bayliss EA, Ellis JL, Shoup JA, Zeng C, McQuillan DB, Steiner JF. Effect of continuity of care on hospital utilization for seniors with multiple medical conditions in an integrated health care system. *Ann Fam Med.* 2015;13(2):123–29.
- Wittink MN, Yilmaz S, Walsh P, Chapman B, Duberstein P. Customized care: an intervention to improve communication and health outcomes in multimorbidity. *Contemp Clin Trials Commun.* 2016;4:214–21.
- Kroll T, Beatty PW, Bingham S. Primary care satisfaction among adults with physical disabilities: the role of patient-provider communication. *Manag Care Q.* 2003;11(1):11–19.
- Bowers B, Esmond S, Lutz B, Jacobson N. Improving primary care for persons with disabilities: the nature of expertise. *Disabil Soc.* 2003;18(4):443–55.
- DeJong G, Frieden L. It's not just managed care; it's the larger health care system say researchers. *National Rehabilitation Hospital Research Update* 2002; Spring Supplement:1,4-7,9.
- Redpath SJ, Williams WH, Hanna D, Linden MA, Yates P, Harris A. Healthcare professionals' attitudes towards traumatic brain injury (TBI): the influence of profession, experience, aetiology and blame on prejudice towards survivors of brain injury. *Brain Inj.* 2010;24(6):802–11.
- McClure J, Buchanan S, McDowall J, Wade K. Attributions for behaviours of persons with brain injury: the role of perceived severity and time since injury. *Brain Inj.* 2008;22(9):639–48.
- McClure J, Devlin ME, McDowall J, Wade K. Visible markers of brain injury influence attributions for adolescents' behaviour. *Brain Inj.* 2006;20(10):1029–35.
- Swift TL, Wilson SL. Misconceptions about brain injury among the general public and non-expert health professionals: an exploratory study. *Brain Inj.* 2001;15(2):149–65.

38. Giles GM, Manchester D. Two approaches to behavior disorder after traumatic brain injury. *J Head Trauma Rehabil.* 2006;21(2):168–78.
39. Turner S, Iliffe S, Downs M, Wilcock J, Bryans M, Levin E, Keady J, O'Carroll R. General practitioners' knowledge, confidence and attitudes in the diagnosis and management of dementia. *Age Ageing.* 2004;33(5):461–67.
40. Wagner EH, Austin BT, Davis C, Hindmarsh M, Schaefer J, Bonomi A. Improving chronic illness care: translating evidence into action. *Health Aff (Millwood).* 2001;20(6):64–78.
41. Coleman MT, Newton KS. Supporting self-management in patients with chronic illness. *Am Fam Physician.* 2005;72(8):1503–10.
42. Schulman-Green D, Jaser S, Martin F, Alonzo A, Grey M, McCorkle R, Redeker NS, Reynolds N, Whittemore R. Processes of self-management in chronic illness. *J Nurs Scholarsh.* 2012;44(2):136–44.
43. Coulter A, Ellins J. Effectiveness of strategies for informing, educating, and involving patients. *Bmj.* 2007;335(7609):24–27.
44. Quinn C, Toms G, Jones C, Brand A, Edwards RT, Sanders F, Clare L. A pilot randomized controlled trial of a self-management group intervention for people with early-stage dementia (The SMART study). *Int Psychogeriatr.* 2016;28(5):787–800.
45. Quinn C, Toms G, Anderson D, Clare L. A review of self-management interventions for people with dementia and mild cognitive impairment. *J Appl Gerontol.* 2016;35(11):1154–88.
46. Morris MA, Clayman ML, Peters KJ, Leppin AL, LeBlanc A. Patient-centered communication strategies for patients with aphasia: discrepancies between what patients want and what physicians do. *Disabil Health J.* 2015;8(2):208–15.