

RESEARCH REPORT

Rehabilitation access for individuals with cognitive-communication challenges after traumatic brain injury: A co-design study with persons with lived experience

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ABSTRACT

Background: Adults with traumatic brain injuries (TBI) frequently experience cognitive, emotional, physical and communication deficits that require long-term rehabilitation and community support. Although access to rehabilitation services is linked to positive outcomes, there can be barriers to accessing community rehabilitation related to system navigation, referral processes, funding, resource allocation and communications required to ensure access.

Aims: This study aimed to identify barriers to accessing insurer funding for rehabilitation and healthcare services, for adults with TBI injured in motor vehicle collisions (MVCs).

Methods: We used a co-design approach to collaborate with persons with lived experience to design a survey of adults who sustained a TBI in an MVC. The survey examined access to insurer funding for rehabilitation services and was disseminated through brain injury networks in Ontario, Canada.

Results: Respondents ($n = 148$) identified multiple barriers to accessing rehabilitation services through insurer funding, including delays of more than 2 years (49%), mandatory duplicative assessments (64%) and invasion of privacy (55%). Speech-language therapy and neuropsychological services were denied most frequently. Negative experiences included insurers' poor understanding of TBI symptoms, denials of services despite medical evidence demonstrating need and unsupportive insurer interactions. Although 70% of respondents reported cognitive-communication difficulties, accommodations were rarely provided. Respondents identified supports that would improve insurer and healthcare communications and rehabilitation access.

Conclusion & Implications: The insurance claims process had many barriers for adults with TBI, limiting their access to rehabilitation services. Barriers

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were exacerbated by communication deficits. These findings indicate a role for Speech-language therapists in education, advocacy and communication supports during the insurance process specifically as well as rehabilitation access processes in general.

KEYWORDS

automobile insurance funding, brain injury, cognitive-communication, communication supports, rehabilitation access, speech-language therapy

WHAT THIS PAPER ADDS

What is already known on this subject

- There is extensive documentation of the long-term rehabilitation needs of individuals with traumatic brain injury (TBI) and their challenges in accessing rehabilitation services over the long term. It is also well known that many individuals with TBI have cognitive and communication deficits that affect their interactions in the community, including with healthcare providers, and that SLTs can train communication partners to provide communication supports to individuals with TBI in these communication contexts.

What this study adds

- This study adds important information about barriers to accessing rehabilitation, including barriers to accessing SLT services in the community. We asked individuals with TBI about challenges to accessing auto insurance funding for private community services, and their responses illustrate the broader challenges individuals with TBI face in communicating their deficits, conveying service needs, educating and convincing service administrators and self-advocating. The results also highlight the critical role that communication plays in healthcare access interactions, from completing forms to reviewing reports and funding decisions, to managing telephone calls, writing emails and explaining to assessors.

What are the clinical implications of this work?

- This study shows the lived experience of individuals with TBI in overcoming barriers to accessing community rehabilitation. The results show that best practices in intervention should include evaluating rehabilitation access, which is a critical step in patient-centred care. Evaluation of rehabilitation access includes evaluating referral and navigation, resource allocation and healthcare communications, and ensuring accountability at each step, regardless of model of service delivery or funding source. Finally, these findings show the critical role of speech-language therapists in educating, advocating and supporting communications with funding sources, administrators and other healthcare providers.

BACKGROUND

Traumatic brain injury (TBI) is a global health priority, with an estimated 69 million new cases annually (Dewan et al., 2018). Adults with TBI can present with chronic cognitive and communication deficits that affect their independence, social participation, academic and vocational success and quality of life (Andelic et al., 2021; MacDonald, 2017; Shiner et al., 2022). While the vast majority of TBIs are mild or moderate (Dewan et al., 2018), TBI of any severity can result in these chronic deficits (Canceliere et al., 2023; LeBlanc et al., 2020; Norman et al., 2022), underscoring the critical need for rehabilitation beyond the acute stage after injury. Community rehabilitation services are critical for the recovery process and are linked to positive outcomes such as return to independence, community participation, social participation and return to work (Andelic et al., 2021; Donker-Cools et al., 2016; Elbers et al., 2015; McQuiston et al., 2016). To achieve these benefits, however, people with TBI must be able to access rehabilitation services in their community.

Difficulties with access to rehabilitation services

Barriers to accessing rehabilitation services have been reported internationally, including delays or lack of referral to services; failure of referring providers to detect or address subtle cognitive, communication, or emotional sequelae; lack of knowledge on the part of referral sources; service system complexities and navigation difficulties; limitations in funding or resources; and insufficient frequency or duration of services (Andelic et al., 2021; Chan et al., 2022; Knollman-Porter et al., 2021; Shiner et al., 2022). These challenges in rehabilitation access appear to apply to most healthcare contexts and can be grouped according to three themes: system navigation and referral processes, funding and resource allocation and healthcare communications.

Difficulties with system navigation can be a barrier to accessing rehabilitation, particularly in community settings. Most individuals with mild TBI do not seek or receive hospital care, and many patients with moderate or severe TBI who are admitted to hospital do not receive inpatient rehabilitation (Rao et al., 2018). As a result, most people with TBI seek rehabilitation and support in the community (Grauwmeijer et al., 2012; Kohler et al., 2020; Spitz et al., 2012; Watanabe, 2013; Whyte et al., 2013), where system navigation can be more challenging. Services may be fragmented, individuals may require multiple types of rehabilitation services offered in differ-

ent locations and systems, and those with TBI may be unfamiliar with healthcare systems and funding processes (Andelic et al., 2021; Fuentes et al., 2018), especially in regions without case coordination. Referral patterns also suggest a tendency for providers to prioritise physical concerns and activities of daily living over more subtle but frequent and debilitating emotional, cognitive and communication concerns (Andelic et al., 2021; Chan et al., 2022; Knollman-Porter et al., 2021).

Identifying services is only the beginning of the process for many individuals with TBI. The largest challenge can be finding funding for those services. Funding and resource allocation for rehabilitation varies by geographic region and healthcare system; some regions, such as countries in Europe, provide government-funded interventions across the care continuum; and some provide acute and post-acute rehabilitation through a combination of government-funded programs and private insurance, with some countries relying more on the former versus the latter (e.g., more private insurance in the United States vs. more government-funded programs in Canada). Analysis of these various types of rehabilitation funding suggests that more important than source of funding is the process for fair and equitable access to resources to address individual needs. For example, Lequerica et al. (2023) analysis of funding systems in the United States found that patients with private insurance funding (e.g., via automobile insurance or worker's compensation programs) had longer inpatient lengths of stay (i.e., more rehabilitation hours) and better functional outcomes than patients with government insurance schemes. Other researchers have reported systemic barriers to accessing rehabilitation services through nongovernmental sources, particularly in relation to income and racial disparities (Gao et al., 2018; Patel et al., 2015; Vargo et al., 2016). Vargo and colleagues (2016) found that individuals with concussion who had private insurance were more likely to be referred for rehabilitation than those with no insurance, including being more than four times more likely to be referred for speech-language therapy services; and Patel and colleagues (2015) found that type of insurance influenced access to post-discharge rehabilitation for adults with moderate-severe TBI, which in turn predicted their quality of life. Unmet rehabilitation needs have also been identified in regions that provide a full range of government-funded services, including need for cognitive and communication therapy (Andelic et al., 2021; Shiner et al., 2022). These findings suggest that, rather than type of funding source, our focus should be on supporting access to fair, timely and comprehensive services that includes the full range of rehabilitation services (e.g., occupational, speech-language and physiotherapy) that meets the long-term needs of adults with TBI.

Whether funding is provided by government healthcare budgets, private health insurers, motor vehicle insurers or worker's compensation schemes, allocation of funding and resources requires comprehensive assessment, patient and family demonstration of need, and sufficient TBI knowledge on the part of "gatekeepers" to identify appropriate services and supports for that person (Andelic et al., 2021; Knollman-Porter et al., 2021). Relatively little is known about how individuals with TBI experience this process. Previous research indicates that individuals with TBI feel a general lack of support in the chronic phase, including difficulties communicating, receiving acknowledgement of their deficits and obtaining referrals for services (Hoepner & Keegan, 2022). Particular concerns with rehabilitation access can occur when individuals are injured in motor vehicle collisions (MVCs) and must negotiate funding from automobile insurers to cover the cost of community-based rehabilitation. Two studies in MVC-related populations revealed themes that might apply to those with TBI. Murgatroyd and colleagues (2011) elicited comments from adults with MVC-related upper- or lower-limb fractures, who met in focus groups to discuss their experiences after injury. Of 34 participants, 21 had injuries that were eligible for compensation. The study was completed in Australia, where there were several injury-compensation schemes (e.g., Workers Compensation, Compulsory Third-Party payments). Themes that emerged from grounded theory analysis included that the claims process was 'adversarial and stressful, particularly communication and treatment approvals' (p. 224); medico-legal assessments were 'universally disliked' (p. 224) and there was 'disbelief by insurers and some health professionals about their injuries' (p. 225). The experience for survivors with or without compensation could be summarised by this statement by one participant: 'You've got to go through a different type of trauma, mentally and emotionally when they go through your life' (p. 225). The authors excluded individuals with moderate-severe TBI from their sample, however, and as diagnoses were not provided, it is not clear that individuals with mild TBI were included.

In a second Australian study, Elbers and colleagues (2015) interviewed 417 adults who had sustained non-catastrophic injuries from MVCs in the preceding 3 months and re-interviewed a subset at 12 months ($n = 325$) and 24 months ($n = 289$). Adults with severe brain injury, acute spinal cord injury or injury requiring hospitalisation for more than 7 days were excluded. The first theme identified by qualitative analysis was problems communicating with insurers, including 'constantly' needing to be the one who initiated and followed up with the company and receiving mixed messages from different parties. A second theme was time and work needed to obtain compensation, including delays in receiving approval for procedures

and therapy, delays in receiving income replacement, pressure to settle early and frequency of assessments. A third theme was insurers' refusal to cover needed procedures and therapies 'without explaining why' (p. 6). The perspective of those with lived experience of TBI is critical not only to inform and guide others in similar situations, but also for advocacy and education of clinicians, insurers, referral sources and system 'gatekeepers'.

There may be additional barriers to rehabilitation access for individuals with TBI-related cognitive-communication deficits, as they may have particular difficulties with the type of healthcare communications required for service access (MacDonald, 2017). There is evidence that, as a group, adults with cognitive impairments use fewer healthcare services than those without cognitive impairments (e.g., Lu et al., 2022; Mejia-Arango et al., 2021), but research has focused mostly on how lack of access to healthcare funding can increase risks for cognitive impairment (e.g., via increasing risk of disease; (Mullins et al., 2021), rather than on how cognitive impairments can influence access to healthcare funding. The latter is particularly relevant for individuals with TBI, who are at high risk for cognitive-communication deficits (Togher et al., 2023). These barriers can be particularly challenging for individuals with cognitive-communication difficulties whose impairments in comprehension, expression, attention and recall, undermine the communication competence required to advocate for ongoing rehabilitation services in phone calls, forms completion, service research or communications with service providers (MacDonald, 2017). Speech-language therapists (SLTs) can support people with TBI in accessing services, but speech-language therapy services themselves can be challenging to access. Cognitive-communication challenges can be a lower priority than physical impairments at the time of discharge from acute care, so patients might not be referred for services at that time; and those who do receive services early after injury may be limited to a few weeks of therapy. Pathways to find and obtain speech-language therapy services in the community may be fragmented and difficult to navigate, especially for people with cognitive and communication challenges (McGill et al., 2020).

The rehabilitation context in Canada

Most Canadians with TBI access care in the community, outside of the hospital system (Rao et al., 2018). National statistics indicate that while 64% of Canadians with TBI access care through the emergency department, only 13% are admitted to hospital (Rao et al., 2018). Most individuals access the healthcare system in the community through follow-up with their family physician; however, the major-

ity of those surveyed at 1 year post injury (74%) were not receiving follow-up care from a health professional (Rao et al., 2018). Therefore, most individuals living with the effects of TBI, including the larger percentage who were never admitted to hospital and those admitted but discharged within 2 months, must seek privately funded services in the community, through either self-pay or private insurance. Publicly funded rehabilitation services delivered early post injury tend to prioritise physical recovery, return to activities of daily living and transition to home and community. The result is that most patients must access privately funded services to address goals related to cognition and communication in everyday life, patient and family counselling and support, vocational rehabilitation, academic reintegration, driving rehabilitation, and recreational, avocational, and social reintegration. Patients and families also must seek private funding for services related to self-management in the community, including information management for healthcare, legal, financial service transactions. Case management or navigation services are rarely government supported, leaving the person with a brain injury, their families and their primary-care physicians to sort out where and how to access privately funded services that vary in admission criteria, location and staffing.

MVCs are the cause of about 25% of TBI in North America (Dewan et al., 2018). In Ontario, drivers purchase mandatory auto insurance that is intended to provide community-based rehabilitation services, income replacement for injured earners and specified benefits for management in the home (e.g., attendant care). The methods of accessing these services are complex, as the injured party must meet criteria for financial and rehabilitation support and must undergo assessments dictated by the auto insurer. Our question was whether individuals with TBI were able to access these services, and how they experienced the insurance process.

Aims

This study explored the experience of individuals with TBI in accessing multidisciplinary community-based rehabilitation services funded through automobile insurance. Specifically, we aimed to examine rehabilitation access in terms of resource allocation (timing, type of service), aspects of navigation and referral (e.g., number of assessments to determine services) and aspects of healthcare communications when seeking rehabilitation (e.g., interactions, provision of communication supports). We asked about communication challenges specifically, as these were identified as barriers by participants in Murgatroyd et al. (2011) study and in other studies about speech-

language therapy service access (e.g., Hinckley et al., 2013; Hoepner & Keegan, 2022; Mahendra, 2012; McGill et al., 2020), and are widely known as barriers to healthcare access overall (Carrillo et al., 2011).

Relevance to other rehabilitation contexts

Although this analysis occurred in the context of auto insurance funding for rehabilitation in Ontario, Canada, we hope that many of the themes of rehabilitation access will be relevant to other funding and service contexts and certainly to those with similar features in service delivery, that is, services that are community based, with multiple entry points, gatekeepers to services, and funding constraints, and that require patients to navigate the system, communicate with gatekeepers, meet criteria for service eligibility and self-advocate.

METHODS

The study method was an anonymous survey designed using co-design methodology. Co-design methodologies are employed to incorporate the value of lived experience and collaboration to ensure that research related to service or system development is meaningful to end users (Moll et al., 2020). To motivate change to insurance claims related to rehabilitative needs of people with brain injury after an MVC, this study was designed in partnership between a group of SLT graduate students (Yvette Hou, Aileen Zhou, Laura Brooks and Daniella Reid), their professor (Lyn Turkstra), and a community-based SLT (Sheila MacDonald), and Acquired Brain Injury Survivor Solutions (ABISS¹), a community advocacy group composed of people who sustained a TBI from an MVC. ABISS members had discovered common experiences in navigating the auto insurance claims process, including duplicative, unnecessary, yet mandatory insurer examinations; the perception that insurers were starting from a basic premise of mistrust; and insinuations that non-injury-related life circumstances or history were responsible for their deficits or rehabilitation needs. The main aim of ABISS in this project was to improve the insurance claims system.²

As recommended by Moll et al. (2020), this co-design study established clear and equal roles from the outset of the research; communication practices to optimise fair and equal input; and a predefined set of research 'outcomes',

¹ ABISS members chose not to be listed as authors.

² ABISS members had been part of this system but were many years post injury at the time of this project, and no longer involved in rehabilitation or legal or insurance claims.

or potential impacts and pathways for change. One such outcome was the development and distribution of a report and knowledge-translation summary for distribution to key stakeholders. Consistent with co-design principles, the research team included diverse stakeholders in the co-design process (i.e., individuals with different injuries resulting from MVCs, socioeconomic status, gender, age, time post injury), had clearly delineated roles for participation, created a safe and collaborative space for research participation, and provided multiple opportunities for stakeholder input through a variety of methods.

To support successful collaboration with ABISS, the student researchers used cognitive-communication strategies (e.g., a written agenda, keywording to summarise discussion points, verbal comprehension checks, visual aids), invited reflection on communication supports and strategies and adapted study methods based on input from ABISS members. To enhance opportunities for participation, the group met regularly in person with options to join via phone or video call. To ensure communication and collaboration were supported within meeting timeframes, student researchers had designated roles (e.g., timekeeper, scribe, summariser of key points). These roles facilitated efficient meetings, where participants had the appropriate time and support to be able to share their lived experiences.

The study was reviewed and approved by the Hamilton Integrated Research Ethics Board.

The rehabilitation and funding context

This study was designed in Ontario, Canada. In Ontario, the public healthcare system funds care provided by the emergency department, acute hospital care, inpatient rehabilitation, some limited short-term home care services as well as some follow-up care provided by physicians (Chen et al., 2012, #8957). For people with MVC-related TBI, all other care—including longer-term rehabilitation—is provided by private automobile insurance through a provincially mandated system, or by fee-for-service private companies or providers hired by individuals with TBI themselves.

Survey development

In consultation with ABISS, we identified five key experiences reported by their peers with MVC-related TBI in accessing insurance coverage for rehabilitation services after their collision, and these became the basis of the survey: (1) enduring numerous repetitive and redundant insurer examinations; (2) delays, denials and reductions for income replacement; (3) funding delays and denials

for rehabilitation services, impacting timeliness of therapy; (4) violations of personal and family privacy; and (5) a lack of consideration of cognitive and communication challenges and minimal support in communications. The survey had seven sections with multiple-choice questions and rating scales: (1) background, (2) insurer examinations/independent assessments/insurer evaluations, (3) privacy, (4) timely access to treatment, (5) financial support and payment, (6) insurer communications and support, and (7) summary. It included one open-ended question at the end of the survey (see Appendix for complete survey).

We also asked respondents if their injuries were deemed *catastrophic* according to Ontario automobile insurance legislation (Financial Services Commission of Ontario, 2016b). This designation process involves multiple assessments to attain certain thresholds for funding. It is therefore possible for a claimant to have sustained a severe brain injury but not to have met the threshold for catastrophic injury designation. Insurance companies pay health professionals to determine severity of impairments and catastrophic status, and these professionals are meant to provide an objective and comprehensive evaluation of a claimant's health status (Financial Services Commission of Ontario, 2016a; Insurer Examination, 2015). These examinations are not conducted by the treating practitioners. Respondents were asked to provide an estimate of the total number of examinations required by their insurance company and the total number they attended.

Many people with TBI have cognitive-communication deficits that create difficulties with reading and understanding long and complex language (MacDonald, 2017). Language demands can increase the risk of bias due to question wording and question order (Boynton & Greenhalgh, 2004; Schwarz, 1999). To minimise the cognitive-communication demands of our survey, we consulted with ABISS members to ensure the survey had neutral unbiased language, clear question formats and a visually appealing layout and design (Questionnaire design, 2015); and was accessible to individuals with TBI (Boynton & Greenhalgh, 2004; Petelin, 2010; Schwarz, 1999).

Recruitment

The survey was distributed via email to brain injury organizations, relevant professional associations and case management firms. Ontario-based healthcare professionals working directly with individuals with brain injury were also asked to disseminate the survey to those who met study inclusion criteria. Prospective participants received an email that explained the study purpose, methods and potential risks and benefits. Those disseminating the survey were asked to not be present during survey com-

pletion or discuss questions with potential participants, to minimise bias.

Participants

Participants self-identified as meeting the following inclusion criteria before completing the survey:

1. Sustained a brain injury as a result of an MVC, including individuals who were in a vehicle or on a bike, or were a pedestrian.
2. Age 18 years or older at the time of survey response. The MVC that resulted in TBI could have occurred prior to that.
3. A resident of Ontario. The MVC that resulted in a brain injury could have occurred elsewhere.

To mitigate against bias, ABISS members were excluded as survey respondents and personal experiences of ABISS were not included in analysis or interpretation of survey results.

Data analysis

Quantitative

To address the primary research question, we calculated the percentage of participants who experienced each of the following: (1) numerous, repetitive and redundant insurer examinations; (2) violations of personal and family privacy; (3) delays and denials of funding for rehabilitation services that impacted timeliness of therapy; (4) delays, denials and reductions in obtaining income replacement; and (5) a lack of consideration of TBI-related deficits and minimal support in communications.

Qualitative

One researcher (AZ) reviewed responses to the open-ended response question. To avoid confirmation bias, this researcher was not involved in the analysis of any quantitative data. The researcher utilised an inductive thematic analysis approach (Kiger & Varpio, 2020) to review all qualitative responses. Inductive thematic analysis was chosen to understand the true experiences and thoughts of the respondents, as the approach is designed to search for common or shared meanings without a pre-existing researcher-driven focus (Braun & Clarke, 2012). First, key ideas in each response were highlighted and sorted into a series of codes. Second, this process was repeated to

ensure that all key ideas in the responses were adequately and appropriately captured. Next, the researcher identified key ideas that expressed perspectives not otherwise captured by the quantitative components of the survey. Key ideas were then defined into themes, with direct quotations selected from the open-ended participant responses to illustrate each theme. Finally, the qualitative themes and their corresponding quotes were then circulated to all members of the research team, including ABISS members. The confirmability of these themes was verified through corroboration with the lived experiences of ABISS members.

RESULTS

Quantitative results

Complete survey responses were submitted by 148 participants (see characteristics in Table 1). Responses to each question are summarised herein.

Insurer examinations

The number of insurer examinations participants attended ranged from zero (3.38% of the sample) to more than 20 (26.35%), with most respondents (50.69%) attending at least 10 examinations (Figure 1). Auto insurance companies required 10 or more examinations for 30.41% of respondents, and 64.19% of participants indicated they were required to attend duplicate assessments. On a scale of 1–10 (1 = completely unsatisfied, 10 = completely satisfied), respondents reported a mean score of 4.56 (SD 3.18) for how satisfied they were with the knowledge their assessors had about brain injury, and 20.95% ranked their satisfaction with the professionals' expertise as 1 out of 10. Additionally, 59.47% of respondents reported that the assessments caused them to experience fatigue (75%), stress (74.32%) and increased symptoms (62.84%); required them to travel long distances (58.78%); made them feel they had to 'prove' their brain injury (58.78%); or caused them to put their lives on hold (47.30%). Only 6.08% of respondents reported none of the preceding negative effects.

Timely access to treatment

One third (32.44%) of respondents experienced a delay of up to 2 years for speech-language therapy funding, 48.89% for physical therapy, 43.84% for occupational therapy, 49.54% for psychology, 37.81% for neuropsychology

TABLE 1 Participant characteristics ($N = 148$)

	N	Percentage
Participants requiring assistance for survey completion		
Yes	18	12.16
No	107	72.30
No response	23	15.54
Sex		
Male	44	29.73
Female	85	57.43
No response	19	12.84
Number of participants with catastrophic designation		
Yes	62	41.89
No	39	26.35
I don't know	20	13.51
No response	27	18.24
Difficulty thinking due to TBI	123	83.11
Difficulty with emotions due to TBI	112	75.68
Physical injuries or impairments due to TBI	92	62.16
Difficulty communicating due to TBI	104	70.27
Number of participants requiring services from:		
Speech-language therapist	87	58.78
Physiotherapist	119	80.41
Occupational therapist	113	76.35
Psychologist	93	62.84
Neuropsychologist	87	58.78
Physician	117	79.05
Other	124	83.78

Mean age of the sample was 47.99 years ($SD = 14.60$), and mean age at the time of the MVC was 40.59 ($SD = 15.20$).

Abbreviations: MVC, motor vehicle collision; TBI, traumatic brain injury.

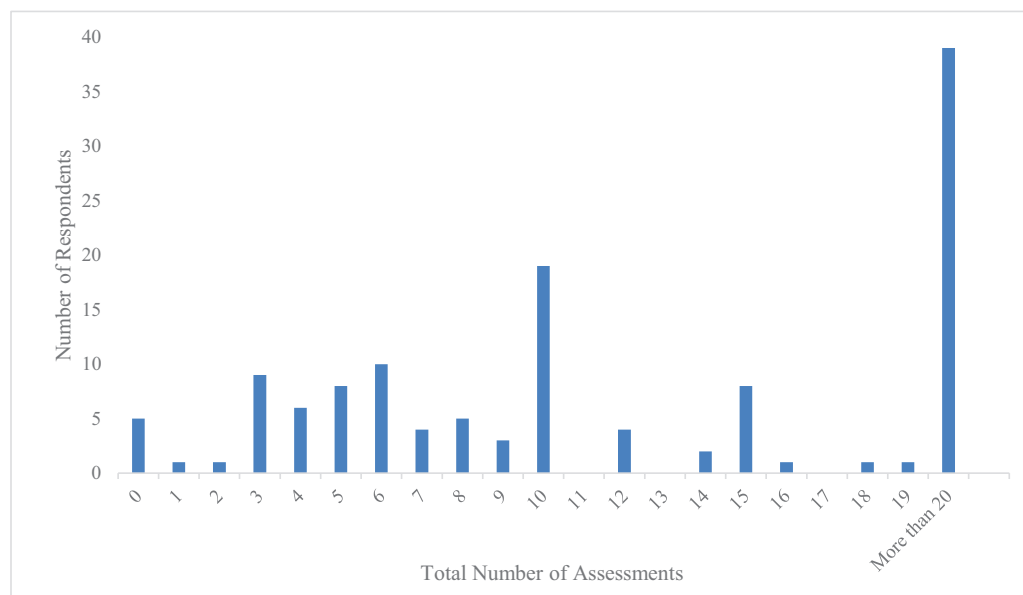


FIGURE 1 Total number of assessments that survey respondents reported attending. [Colour figure can be viewed at wileyonlinelibrary.com]

and 11.03% for physician services. Survey respondents were most commonly denied claims for speech-language therapy services (7.43%) and neuropsychology services (8.11%). Additionally, 40.54% of respondents reported facing financial barriers to accessing treatment.

Financial support and payment

More than half of respondents (50.67%) indicated they received income replacement, although delays in accessing this benefit were common: 64% of those receiving income replacement received their payments within 0–6 months, 13.33% received payments between 7 and 11 months, 17.33% received them between 1 and 2 years, 5.33% did not receive them until after 2 years, and 7.43% of respondents were denied income replacement claims completely. For 50.68% of respondents, a family member or friend reduced their working hours to assist the respondent.

Privacy

More than half of survey respondents (55.41%) felt they were questioned about information unrelated to their MVC. Respondents felt their personal history (22.97%), work history (15.54%), medical history (18.92%) or family medical history (12.84%) was shared without their consent. Many respondents also reported that they were unsure which information was ultimately shared, as they had to give blanket consent to insurers or risk halting the claims process altogether. In terms of insurer surveillance, 37.16% believed they were followed by someone hired by their insurance agency. When asked how they were informed about surveillance, most reported having been informed by their lawyers (43.92%) or by friends, family or others (16.89%); and a few (2.03%) stated they were informed by insurers.

Insurer communications and support

Overall, 57.37% reported that experiences with their insurance company worsened their recovery to some degree, with 7.43% feeling their insurance company completely supported their recovery. Respondents indicated that the following types of supports would have been helpful: repeating and clarifying key information (45.95%); consistency in staff (39.19%); faster response times (2.7%); and having supportive and non-judgemental adjusters (2.03%). As indicated in Table 2, such supports were reported to have been rarely provided by insurers.

Overall satisfaction

More than half of respondents reported they were unsatisfied with their insurance claims process (56.08%), with 24.32% saying they were not at all satisfied. Only 7.43% were completely satisfied. On a 5-point scale from Strongly Disagree to Strongly Agree, ratings for “Overall, I felt good with my insurance claims process” had a mean score of 2.27 (SD = 1.34), and 50% of respondents Disagreed or Strongly Disagreed with the statement.

Qualitative results

Eighty-seven respondents (59%) included an open-ended response. Analysis of these responses revealed seven major themes.

Lack of understanding of TBI symptoms

Respondents shared that professionals involved in the auto insurance process lacked understanding of TBI symptoms and prioritised physical injuries over psychological and cognitive difficulties. Respondents commented that insurer staff expressed beliefs that their injury should have been ‘cured’ within a certain time frame, despite TBI being a lifelong injury. Respondents described communication and environmental barriers, including lack of communication supports and the use of poor lighting during assessments. Respondent 143 explained, “It took me a month just to be able to fill out the application, and I have a cognitive-communication disorder that impacts my ability to speak on the phone, but am expected to constantly speak on the phone for my claim, otherwise I am labelled non-compliant.”

Perceived negative treatment by insurer staff

Overall, there was a general sense of dismay at the treatment of claimants. Respondents shared sentiments of feeling mistreated, disrespected and/or threatened by their insurance company, while having to deal with the profound aftermath of the injury. Several felt exploited by their insurer at a time when they were most vulnerable. Respondent 131 said “I was traumatised, lied to, manipulated and characterised as a lying cheat by my insurance company. They employed aggressive tactics (angry phone conversations, denying coverage, accusing me of lying, having me followed and invading my privacy and the privacy of those I was with) presumably to have me give up the case. It took

TABLE 2 Insurance company supports desired by and provided to respondents

Insurance support	Respondents who felt this would have been a helpful support		Respondents for whom this support was provided	
	N	%	N	%
Assigning a case manager	46	31.08	42	28.38
Consistency in staff	58	39.19	21	14.19
Allowing a support person to be present in a meeting	45	30.41	19	12.84
Quiet room	43	29.05	8	5.41
Larger print	30	20.27	0	0.00
Extra time	49	33.11	12	8.11
1-to-1 discussion	41	27.70	8	5.41
Repeating and clarifying key information	68	45.95	15	10.14
Funded transportation to and from therapy appointments	55	37.16	53	35.81
Funded transportation to and from non-therapy appointments	47	31.76	30	20.27
Other				
Better response times to inquiries	4	2.70		
Supportive and non-judgmental insurance adjuster	3	2.03		
No response	15	10.14	15	10.14

years, repeated invasive and upsetting assessments, and a drawn out legal process before I was given reasonable care and a settlement.”

Concerns regarding insurance adjusters

Respondents described mixed experiences with insurance adjusters who are responsible for managing their claim and access to rehabilitation and medical benefits. Those who shared positive experiences of supportive adjusters expressed nervousness about possible changes in adjusters. Some expressed concerns with treatment by insurance adjusters, including frequent staffing changes that furthered delays in treatment approvals or ‘impersonal’ treatment leading to a feeling of being “just a file number that each adjuster managed” (Respondent 9).

Delays and denials despite medical evidence

Many respondents reported delays and denials despite medical evidence of sustaining a brain injury and/or recommendations and approvals by therapists. Respondents described feeling cheated by their insurance companies: they were denied access to funds to which they were entitled, as they had paid insurance premiums for the promise of these services. One respondent (Respondent 64) expressed their disbelief at the unreasonable denials: “How can medical evidence be repeatedly denied by

numerically trained adjusters? This is killing and starving the most vulnerable in this province.”

Claims process as a roadblock to recovery

For some respondents, the stress of constantly fighting delays and denials and proving their injuries served as a roadblock to recovery that worsened their health. Respondent 79 wrote, “If they had just given me the treatment I needed, that’s all I wanted—to get my life back and move forward—they would have saved a ton of money and I would have gotten on my feet years sooner... it was hands down the worst experience of my life. Not the accident itself, the recovery and trying to deal with the insurance company.”

Auto insurance industry as a broken system

Many expressed a sense of disbelief and dismay toward the auto insurance system, describing it as ‘inhumane’ or ‘a human rights breach’. Respondent 78 wrote:

... a book could be written on the inefficiencies of time, money, staff in the world of auto insurance. It is absolutely incredible and unbelievable what they have put me through and what they get away with... What we aren’t told is that the disbursements of our funds are based on an adjudicator’s opinion or protocol, or whatever other shady system they have going... It is a terrible broken sys-



tem, especially for people with a brain injury and/or post concussive symptoms.

Advocacy: Need for change

Some respondents discussed the need for large-scale change in the auto insurance system. Suggestions included having adjusters collaborate with therapists, and mandatory training on TBI and how to communicate with TBI survivors. Institutional-level changes were also suggested, such as transitioning auto insurance from a private, business-run service to a public, government-run model with strict regulations. Respondent 71 wrote “A statistical snapshot of acquired brain injury & its effects on survivors and caregivers.” Institutional-level changes were also suggested, such as transitioning auto insurance from a private, business-run service to a public, government-run model with strict regulations.

DISCUSSION

The aim of this collaborative research was to identify barriers to rehabilitation access for adults with TBI by examining the experiences of persons injured in motor vehicle collisions when accessing insurer funding for rehabilitation and other healthcare services. Overall, results were consistent with reports from ABISS members and showed the negative experiences many individuals with TBI endured throughout their insurance claims process. Although this study focused on the insurance process in Ontario, Canada, the problems are unlikely to be specific to our context, particularly given evidence linking insurance coverage to outcomes in multiple countries (McQuiston et al., 2016).

Most survey respondents reported having to attend 10 or more insurer examinations. Consistent with previous research (Murgatroyd et al., 2011), this requirement was found to be arduous. The duplicative assessments were perceived as an effort by insurance companies to disprove the existence of an injury and its sequelae, leaving participants to question the knowledge and integrity of insurer-hired medical professionals. Similarly, the qualitative results echoed previously described feelings of being exploited while vulnerable, assessed only for the purpose of finding a reason to deny the claims and further traumatised (Elbers et al., 2015).

Previous research has described a feeling of being watched during the claims process and the sense that every action could be interpreted as proof that their injury did not really exist (Murgatroyd et al., 2011). The invisible nature of cognitive-communication difficulties associated

with TBI raises questions about the validity of surveillance methods used by insurers. Privacy violations were also of concern as most respondents reported that they were questioned about information unrelated to their collision, and many felt that information was being shared without their consent. Previous research has commented on how the invasiveness of the claims process can cause stress and anxiety, especially when all aspects of one's life, and not only those related to the collision, are under investigation (Elbers et al., 2015).

Quick claims resolution and access to therapy following brain injury have been demonstrated to result in better recovery outcomes (Cassidy et al., 2004, 2000; Feinstein et al., 2001). Unfortunately, many survey respondents experienced a delay of up to 2 years for speech-language therapy, physical therapy, occupational therapy, psychology and neuropsychology services.

This research reiterates previously reported findings of financial strain after brain injury (Gabbe et al., 2014; *The OBIA impact report 2012: A statistical snapshot of acquired brain injury & its effects on survivors & caregivers, 2012*); a burden that is exacerbated by lengthy insurance claims processes (Murgatroyd et al., 2011). Respondents reported facing financial barriers to accessing treatment and the need for carers to reduce working hours to support them. Previous research has found that the claims process compounded the burden of what was already a very traumatic event (Murgatroyd et al., 2011) and further strains family members who, in addition to caring for the person with TBI, have the administrative burden of managing the claims process (Florian et al., 1989).

Our results suggest that survey respondents experienced more difficulty advocating for their cognitive injuries than their physical injuries throughout the insurance claims process. Previous research found a tendency for brain injury misunderstanding due to its invisible nature relative to physical injuries (Donker-Cools et al., 2018; Harder, 2009; McClure, 2011; McClure et al., 2008). Importantly, our findings also revealed how the lengthy claims process delayed therapy and even worsened respondents' condition. This issue of fair access to auto insurance claims for individuals with acquired cognitive and communication impairments has wider implications when viewed in terms of disability rights and diversity.

Clinicians have an ethical obligation to detect and remediate departures from just behaviours; patients and families are not likely to be able to do so alone (Montgomery Jr, 2021). Clinicians and health administrators could better support individuals with TBI by developing standards and ensuring accountability for rehabilitation *access* in the same way we ensure standards for rehabilitation *interventions* once service is successfully obtained. Accountability standards for referral and system naviga-

tion could include criteria for education of referral sources, access to multidisciplinary services that address the full range of potential deficits (e.g., cognitive, communication, emotional, physical), and provision of patient and family navigation supports. Standards regarding funding and resource allocation could be developed, applied and audited for all funding and models of service delivery. These might include criteria for determination of resource allocation to be made based on clinical pathways, objective clinical assessment of need, single assessments rather than duplicative and with criteria for education of system gatekeepers regarding TBI (e.g., insurers, administrators), as well as standards of ethical practice regarding dignity, autonomy and privacy in rehabilitation access processes. Such standards should be co-designed with persons with lived experience of TBI challenges in rehabilitation access.

When the breaches in fair practice relate to barriers to communication access and denial of cognitive supports, SLTs and other therapists have a particular role to play in detecting and righting such injustices. Basic standards for healthcare communications could be developed, taught and applied that include such practical cognitive-communication supports as: allowing a support person to be present for meetings and calls; allowing extra time in communications, providing supports for document completion, providing options for communications (written materials, in-person or virtual meetings instead of telephone), providing plain language materials about processes and using communication supports such as key word writing, repetition, clarifying and verifying key information.

Limitations

There were several limitations to this research study. First, the participant recruitment process and the study's sampling frame were limited to those who could be reached through email. As there is currently no directory of individuals in Ontario who have sustained TBI as a result of an MVC, participants were recruited through relevant organizations and professionals, and thus could have been biased towards those who were connected to services or organizations. Inclusion of individuals with fewer supports might have increased the proportion of negative comments, as those individuals might have been unsuccessful in obtaining rehabilitation funding.

Second, the online survey format may have excluded individuals with financial, environmental, physical or cognitive barriers to accessing technology. We also asked respondents to complete the survey without the help of an individual who could have biased their responses, which further could have excluded individuals with those bar-

riers. Exclusion of individuals with more severe injuries could have under-represented the number of individuals designated with catastrophic status, who would have obvious deficits and thus could have had more success accessing funding. Our anecdotal experience suggests that even these individuals encounter barriers to rehabilitation funding, but future research is needed to determine if this is the case.

Third, there was a risk of self-selection bias, which occurs when respondents have possessed different characteristics, perspectives and opinions than those who chose not to participate (Wright, 2005). In this case, individuals who chose to respond were likely to be those who had a negative experience with insurance, while those with a positive experience might have been less likely to agree to participate. The study had a relatively large number of respondents, however, and they were dealing with over 39 auto insurance companies. This sample was substantial and diverse enough to warrant further investigation into the auto insurance claims process for claimants with TBI. The findings also revealed systemic, rather than insurer-specific, problems, which supports the generalizability of results.

Finally, the auto insurance company behaviours revealed may not be exhaustive. Our survey questions were developed based on the experiences of ABISS, which is one group of individuals with TBI following an MVC in southern Ontario. To mitigate the risk of question selection bias, an open-ended question at the end of the survey allowed respondents to comment on additional experiences. We recognise, however, that inclusion of an open-ended question may not fully address this limitation.

Future research directions

Further research of this area is warranted, including studies on perspectives of stakeholders such as family members and clinicians. It also is critical to examine rehabilitation access and funding issues in a broader range of groups such as those of different ages, in different funding contexts and geographical regions, and in persons from racialised and ethnic minority populations who have been shown to be less likely to access rehabilitation services (Gao et al., 2018). Future research should include collaboration with stakeholders who do not have insurance coverage. There is evidence that TBI outcomes are better in regions with government-funded schemes such as the Ontario no-fault system than in regions with a conventional fault-based systems (e.g., Harrington et al., 2015). Individuals without insurance access also are a critical group to engage in collaborative research and are often from racialised and low-income communities with multiple health risks (Ase-

mota et al., 2013; McQuiston et al., 2016). Addressing barriers specific to vulnerable populations is critical for equitable rehabilitation access.

CONCLUSION

Results of a survey of adults with TBI revealed many barriers to receiving rehabilitation after TBI due to MVCs. For most survey respondents, the claims process was stressful and harmful, in large part because it did not consider the unique characteristics and needs of people with TBI. Study results provide novel insights into the lived experience of people with TBI who are seeking rehabilitation to return to meaningful life roles and helped identify specific strategies to overcome access barriers. The most immediate strategy is to involve rehabilitation specialists in the claims process, in both the design and delivery of information and direct treatment of adults with TBI. Individuals with lived experience of brain injury also should be involved in the design of insurance processes. Finally, all professionals involved in the insurance claims process should be provided with education to increase their understanding of brain injury, cognitive and communication challenges and the necessity of supports and expedited processes. These changes will help ensure fair and accessible insurance claims processes for people with brain injury and equitable and timely access to rehabilitation services for all.

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CONFLICT OF INTEREST STATEMENT

The authors have no conflicts to declare.

DATA AVAILABILITY STATEMENT

Data are available by contacting the first author at yvette.y.hou@gmail.com.

PATIENT CONSENT STATEMENT

All research participants provided informed consent for their participation in the study.

PERMISSION TO REPRODUCE MATERIAL FROM OTHER SOURCES

All research is referenced and there is no inclusion of materials from other sources.

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APPENDIX

A Survey of Access to Rehabilitation Insurance Coverage for Adults With Brain Injury Caused by Motor Vehicle Collision

Background:

1. Someone is helping me complete this survey:
 - a. Yes
 - b. No
2. I identify as a _____
 - a. Male
 - b. Female
 - c. Other
 - d. Prefer not to answer
3. What year were you born?
 - a. Drop-down list
4. How old were you when you were in the collision that caused your brain injury?
 - a. Drop-down list
5. Were your injuries deemed catastrophic?
 - a. Yes
 - b. Yes, but it was difficult to get this designation
 - c. No
 - d. I don't know
6. My brain injury resulted in (please click all that apply):
 - a. Difficulty thinking
 - b. Difficulty with emotions
 - c. Physical injuries or impairments
 - d. Difficulty communicating
7. I needed services from (please click all that apply):
 - a. Speech-language pathologist/speech-language therapist
 - b. Physiotherapist
 - c. Occupational therapist
 - d. Psychologist
 - e. Neuropsychologist
 - f. Physicians
 - g. Other: _____
8. Who was your insurer?
 - a. Drop-down list, including prefer not to answer and I don't know options.
9. At some point in my claims process, I had legal representation/help from a lawyer.
 - a. Yes
 - b. Yes, but not right away
 - c. No
 - d. I don't know
 - e. Not applicable
10. Overall, how satisfied were you with your insurance claims process?
 - a. Scale from 'not at all satisfied' to 'very satisfied' (1-10)

Insurer Examinations/Independent Assessments/Insurer Evaluations

11. Overall, how many assessments or examinations did you attend? (Please provide your best estimate).
 - a. Drop-down list of numbers
12. To your knowledge, how many assessments or examinations were required by your auto insurance company? (Please provide your best estimate)
 - a. Drop-down list of numbers
13. I was asked to attend the same type of assessment or examination more than once
 - a. Yes
 - b. No
 - c. I don't know
 - d. Not applicable
14. Overall, how satisfied are you that the people assessing you for insurance examinations were knowledgeable about brain injury.
 - a. Scale of 'not at all satisfied' to 'very satisfied' (1-10)
15. I felt these assessments were:
 - a. Scale of 'not at all convenient' to 'very convenient' (1-10)
16. Due to these assessments, I (please check all that apply):
 - a. Experienced fatigue
 - b. Experienced stress
 - c. Had to travel long distances
 - d. Had to put my life on hold
 - e. Had to prove my brain injury
 - f. None of the above

Privacy

17. Do you believe you were followed by someone hired by your insurance agency?
 - a. Yes
 - b. No
 - c. I don't know
 - d. Not applicable
18. Who, if anyone, told you that you might be followed for insurance purposes? (please click all that apply):
 - a. My insurer
 - b. My lawyer
 - c. Other: _____
 - d. None of the above
 - e. Not applicable
19. I felt that I was questioned about information unrelated to my motor vehicle collision.
 - a. Yes
 - b. No
 - c. Not applicable

20. I felt that the following information was shared without my consent: (check all that apply)
- Personal history
 - Work history
 - Medical history
 - Family medical history
 - Other
 - None of the above
21. I felt that the information that was shared about me was accurate.
- Scale from 'none of the time' to 'all of the time' (1-10 scale)

Timely Access to Treatment

22. Did insurer decisions about funding delay your access to:
- Speech-language pathology: (scale of 0 months, 1-2 months, 3-4 months, 5-6 months, 7-8 months, 9-10 months etc., ending in greater than 2 years, option for I don't know, option for my claim was denied)
 - Physiotherapy: (above scale)
 - Occupational therapy: (above scale)
 - Psychology: (above scale)
 - Neuropsychology: (above scale)
 - Physician: (above scale)
23. Were finances a barrier to accessing treatment?
- Yes
 - No
 - I don't know
 - Not applicable

Financial Support and Payment

24. Did your insurance company initially offer you a cash settlement?
- Yes, within 0-3 months
 - Yes, within 4-6 months
 - Yes, within 7 months - 1 year
 - Yes, more than 1 year
 - No
 - I don't know
 - Not applicable
25. My income replacement claims were received within:
- 0-6 months
 - 7-11 months
 - 1-2 years
 - More than 2 years
 - I was denied
 - I don't know
 - Not applicable
26. A family member or friend reduced their working hours to support me after my brain injury.

- Yes
- No
- I don't know
- Not applicable

Insurer Communications and Support

27. My experiences with my insurance company impacted my recovery by:
- Scale of 1-10 from 'worsening my recovery' to 'completely supporting my recovery'
28. Did your insurer provide any of the following supports? (please select all that apply)
- Assigning a case manager
 - Consistency in staff
 - Allowing a support person to be present in a meeting
 - Quiet room
 - Larger print
 - Extra time
 - 1-to-1 discussion
 - Repeating and clarifying key information
 - Funded transportation to and from therapy appointments
 - Funded transportation to and from non-therapy appointments
 - Other: _____
29. Please indicate the supports you feel would have been helpful to have during the insurance claims process. (please select all that apply)
- Assigning a case manager
 - Consistency in staff
 - Allowing a support person to be present in a meeting
 - Quiet room
 - Larger print
 - Extra time
 - 1-to-1 discussion
 - Repeating and clarifying key information
 - Funded transportation to and from therapy appointments
 - Funded transportation to and from non-therapy appointments
 - Other: _____

Summary

30. Overall, I felt good with my insurance claims process.
- Scale of 1-10 (10 points)
31. Based on your personal experiences, please share any additional comments.