

Survey of Auto Insurance Claims Process for Individuals with Communication Disorders After
Traumatic Brain Injury

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Introduction

In Canada, it is estimated that 452 people suffer an acquired brain injury (ABI) every day. This number translates into one individual sustaining an ABI every 3 minutes (Brain Injury Canada, 2014). While the term ABI refers to any disruption of normal function to the brain, including stroke, traumatic brain injury (TBI) is a subset of ABI that refers to a brain injury caused by a bump, bolt, jolt to or penetration of the head. Importantly, statistics show that motor vehicle collisions (MVCs) are one of the leading causes of TBI (Andriessen et al., 2011). Individuals with TBI often present with cognitive, emotional, physical, and communication deficits, and often require rehabilitation therapy (MacDonald, 2017).

Brain injury is an invisible and often misunderstood injury, as the associated deficits are not always apparent in the same way as bodily injuries, such as a broken limb (Donker-Cools et al., 2016; Harder, 2009; McClure et al., 2008; McClure, 2011). The deficits associated with brain injury often restrict participation in life activities, including, but not limited to, day-to-day and vocational tasks. Brain injury can create significant financial burdens for the individual and their family as it often results in a change in employment status (Gabbe et al., 2014; Ontario Brain Injury Association, 2012), which can make rehabilitation therapy financially inaccessible. A lack of access to therapy can impede recovery and may consequently further delay or prevent return to work and other daily activities (Shames, Treger, Ring & Giaquinto, 2007). Therefore, insurance compensation is crucial for the recovery of many individuals with brain injury.

Acquired Brain Injury Survivor Solutions (ABISS) is a group of Ontarians who have sustained a brain injury from a MVC. Through conversation, they discovered a number of common experiences with insurance claims processes that seemed to have a significant impact on their recovery. Many of the members experienced breaches of privacy; a sense that insurers were starting from a basic premise of mistrust (i.e., that they were lying about their injury until

proven truthful); inappropriate or unfair questioning from insurers, examiners, and insurer-hired medical professionals; duplicative and unnecessary, yet mandatory, insurer examinations; and insinuations that non-injury related life circumstance or history was responsible for their deficits or rehabilitation needs. The discovery of these common experiences led the group to question whether these barriers in the insurance claims process were universal among those with brain injury following MVC.

Interestingly, the experiences of ABISS group members are comparable to the findings of a qualitative study by Murgatroyd, Cameron, & Harris (2011). These authors interviewed 34 adults with TBI from MVCs and found that the claims process was stressful due to a strong sense of injustice, an inability to move on with their lives during the claims process, and an extreme dislike of insurance examinations. According to Murgatroyd et al. (2011), all participants found the recovery process difficult; however, the recovery process was particularly stressful for participants who were claiming compensation, which they found was a burdensome and negative experience. Interestingly, many of the experiences highlighted by Murgatroyd et al. (2011) were similar to that of the ABISS members, despite the fact the study occurred in Australia, where insurance schemes are likely different from those in Ontario, Canada. This highlights the potential commonality of negative experiences despite country of residence when claiming financial compensation with a brain injury.

To our knowledge, Murgatroyd et al. (2011) is the only recent qualitative study of the lived experiences of those with TBI due to MVCs in accessing insurance compensation. Quantitative studies have identified the broad indicators of claiming compensation, such as claim type and duration, and their impact on the recovery process of individuals with brain injury (Cassidy et al., 2000; Cassidy et al., 2004; Feinstein et al., 2001). These studies have not, however, identified the specific effects of seeking compensation on the recovery process. The negative experiences reported by the ABISS members and the participants from the Murgatroyd et al. (2011) study, as well as the potential adverse effects of those negative experiences on

recovery, warrant a study investigating the specific factors of the insurance claims process that affect the lives of those with TBI from a MVC in Ontario, Canada. Moreover, with limited existing qualitative research, it would be beneficial for future research to be informed by persons with lived experience of TBI due to MVC.

To facilitate the development of a study rooted in the experiences of people with brain injury in navigating their insurance claims, we used a Participatory Action Research (PAR) approach. Participatory Action Research is an approach that encourages *partnership* with people with lived experience in research (Baum, MacDougall, & Smith, 2006). Baum and colleagues (2006) defined PAR as a process in which researchers and participants collaboratively develop goals and methods, collect and analyze data, and implement results; in an effort to encourage relevant change that will impact the lives of those involved. In other words, PAR encourages engagement of people with lived experience across every stage and step of the research process. PAR approaches allow for more relevant research that is informed by, and therefore more useful for, those impacted by its results (Baum et al., 2006; Ehde et al., 2013; Kidd & Kreal, 2005). Additionally, PAR supports 'conscious-raising', which influences greater change based on research results (Kidd & Kreal, 2005).

PAR has previously been encouraged for use in rehabilitation-related research (Ehde et al., 2013; Hassouneh, Alcalá-Moss, & McNeff, 2011; Kelly, 2005; White, Suchowierska, & Campbell, 2004). Although PAR has been used in TBI research (e.g., Carozzi, Tulskey, & Kisala, 2011; Gauld, Smith, & Kendall, 2011), to our knowledge, no PAR studies have explored the experiences of those with TBI following MVCs. Embracing a PAR approach in the exploration of brain injury and insurance claims allowed us to ensure that our study was informed by people with brain injury and grounded in what was relevant and meaningful to them.

In this study, researchers partnered with ABISS group members to develop project goals, create and disseminate a survey, and develop knowledge-sharing materials for future advocacy. The ABISS group were considered to be a good group for PAR as they were an advocacy group with lived experience of auto insurance claims after brain injury, but no longer in active therapy, and had no active insurance claims, lawsuits or pending financial settlements. The decision to use a survey as the research method was made in consultation with the ABISS group and was selected to efficiently collect data from a large sample of Ontarians with brain injury following MVC. The overarching aim of the project was to gain a better understanding of the experiences of Ontarians in obtaining insurance funds for medical and rehabilitation benefits and for income replacement following a TBI due to a MVC. Our primary research question was: How often do people with TBI due to MVCs have negative experiences with insurance claims processes? Our findings provided insight into the pervasiveness of negative experiences with insurance claims processes in Ontarians who have sustained a TBI due to MVCs. With a better understanding of such experiences, the ABISS group will continue to provide the brain injury community with information that may lead to further advocacy for more fair and equitable insurance policies for this population in the province of Ontario.

Methods

Survey Development

The present study was reviewed and approved by the Hamilton Integrated Research Ethics Board (HiREB). Our survey was developed in partnership with ABISS members and a speech-language pathologist in the community, who provides facilitation to the ABISS group and acted as a research supervisor on this project. In meetings with all group members, we identified five key experiences of individuals with brain injury due to MVC in accessing insurance coverage for rehabilitation services after their collision: (1) enduring numerous repetitive and redundant insurer examinations; (2) violations of personal and family privacy; (3)

delays and denials of funding for rehabilitation services that impact timeliness of therapy; (4) delays, denials, and reductions in obtaining income replacement; and (5) a lack of consideration of deficits and minimal support in communications. These five key experiences became the basis of the survey.

The survey consisted of seven sections: (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. The survey consisted of a combination of multiple-choice questions and rating scales, with a total of 31 questions. There was also space at the end of the survey for participants to share any additional comments regarding the survey and/or their experiences. The complete survey can be found in Appendix A.

In the background section, respondents were asked whether their injuries were deemed catastrophic. A catastrophic injury is a designation given to individuals who have a serious disability or life-threatening injury and this designation of catastrophic injury is determined by meeting established criteria that are set out in Ontario automobile insurance legislation (Financial Services Commission of Ontario, 2016b). The definition of catastrophic injury has changed, most recently on June 1st, 2016 (Financial Services Commission of Ontario, 2016a). Determination of catastrophic injury is a complex process whereby an individual undergoes multiple assessments to determine if they meet an established threshold for physical, mental, and/or behavioural impairments. Adults with brain injury diagnoses are not automatically declared to have sustained a catastrophic injury and must be assessed to determine whether their persistent deficits meet the threshold. That is, it is entirely possible for a claimant to have sustained a severe brain injury and not meet the definition of catastrophic impairment.

For the insurer examination section, respondents were asked to provide their best estimates on how many total examinations they attended and how many examinations were required by their insurance company. Insurer examinations are completed to assess a claimant's health status (Financial Services Regulatory Authority of Ontario, 2019). An insurer examination is meant to be an objective and comprehensive evaluation completed by a healthcare professional (AssessMed, 2020). These insurer examinations may be referred to as insurer assessments, insurer evaluations, independent medical examinations, etc. For the purposes of this paper, these assessments of an individual's deficits following their brain injury will be referred to as insurer examinations.

Many people with brain injury have cognitive-communication deficits, including reduced working memory, attention, and executive functioning (MacDonald, 2017). These deficits can make it difficult for respondents to read and understand long and complex sentences or complicated language and wording (MacDonald, 2017). Confounding variables like language demands can increase the risk of bias due to question wording and question order (Boynton & Greenhalgh, 2004; Schwarz, 1999). To minimize the cognitive and communication demands of our survey, researchers worked closely with ABISS members to ensure question wording and order met ABISS members' specifications for accessibility, using neutral and unbiased language, question format, and question order. To encourage survey participation, specific measures were taken to ensure the layout and design of the survey was visually appealing (Statistics Canada, 2015) and accessible to individuals with brain injury (Boynton & Greenhalgh, 2004; Petelin, 2010; Schwarz, 1999). For example, ABISS members with visual impairment provided input on optimal readability in terms of font type, size, and spacing.

Recruitment

Prospective participants were recruited through collaboration with relevant community stakeholder groups. The groups included, but were not limited to, Ontario-based healthcare professionals (e.g., physiotherapists, occupational therapists, speech-language pathologists, neuropsychologists), and brain injury support and advocacy groups (e.g., Brain Injury Association of Waterloo Wellington, Ontario Brain Injury Association). These community stakeholder groups were identified through collaboration with ABISS. A complete list of organizations and professionals contacted for survey distribution can be found in Appendix B.

Each community group was contacted through email to request their assistance in distributing our survey to their email lists and through social media. Along with the request, community groups were also provided with an ethics-approved email with a link to forward to individuals on their email lists and post on social media. Ontario-based healthcare professionals working directly with individuals with brain injury were also asked to email this information to clients who may fit our inclusion criteria. All prospective participants received the same email correspondence that explained the study purpose, data collection, and potential risks and benefits.

Participants

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

1. Sustained a brain injury as a result of a MVC, including individuals who were in a vehicle, on a bike, or were a pedestrian when the collision occurred.
2. Over the age of 18 years at the time of survey response; however, the MVC that results in a brain injury could have occurred prior to that.

3. A resident of Ontario; however, the MVC that resulted in a brain injury could have occurred elsewhere.

While ABISS members were involved in the construction of the survey, their consultations were independent from survey results. No ABISS members responded to the actual survey; personal experiences of ABISS members were not included in the data analysis of our survey results

Data Collection

All participant data were obtained through a secure, online survey program approved for use by McMaster University. Data were stored on a secure network and only downloaded onto password-protected computers. Prior to sharing data with the ABISS group, the data were de-identified and aggregated in Microsoft Excel.

Data Analysis

Quantitative analysis.

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

Qualitative analysis.

An open-ended response question was included at the end of the survey, allowing respondents to provide additional comments based on their personal experiences with the auto

insurance claims process. An objective (i.e., not affiliated with ABISS) researcher reviewed these responses to extract additional information that were not captured in the quantitative data. To avoid confirmation bias, this researcher was not involved in the analysis of any quantitative data. To analyze the qualitative data, this researcher reviewed all qualitative responses in three stages. First, key ideas in each response were highlighted and sorted into a series of nodes. As the researcher read the responses, the frequency of each key idea was tallied. Next, the process was repeated to ensure that all key ideas in the responses were adequately and appropriately captured. Finally, key ideas that expressed perspectives not otherwise captured by the quantitative components of the survey were identified. These nodes were translated into themes, which were further organized into sub-themes. Select quotes that encapsulate each of these themes and sub-themes are included in the results.

Results

Survey Distribution

The survey was distributed to brain injury organizations, relevant professional associations, and case management firms. ABISS members also reached out to any personal professional contacts they believed would be interested in distributing the survey. Although attempts were made to contact as many relevant organizations throughout Ontario, not all organizations responded to survey distribution requests. A complete list of organizations contacted and those who confirmed survey distribution can be found in Appendix C.

Participants

In total, 172 people accessed and initiated the survey. Of these 172 responses, 126 surveys were fully completed, 22 were partially completed, and 24 were left blank. Blank surveys were excluded from the analysis, resulting in a final survey sample size of 148. The

characteristics of the survey sample population, results for each survey domain, and overall satisfaction with the auto insurance claims process are described below.

Demographics

29.73% of survey respondents identified as male and 57.43% identified as female. The remainder of participants selected 'Other' or 'Prefer not to answer'. The mean age of survey respondents was 47.99 ± 14.60 and the mean age at the time of their collision was 40.59 ± 15.20 . In terms of severity of injury, survey respondents were asked whether their injuries were deemed catastrophic. 41.89% of survey respondents reported that their injuries were deemed catastrophic. Of those who were deemed catastrophic, 32.25% of those individuals reported it was difficult to achieve this designation. 13.52% of respondents were unsure whether they were given a catastrophic designation. The survey respondents were asked at the beginning of the survey if someone else was supporting them in completing this survey and 12.16% of survey respondents reported having assistance.

In order to better understand the impact of their brain injuries, survey respondents were asked specific questions as to the type of cognitive, emotional or physical difficulties they experienced. Survey respondents reported difficulty thinking (83.11%), difficulty with their emotions (75.68%), physical injuries or impairments (62.16%), or difficulty communicating (70.27%) as a result of their brain injury. They reported needing the following services following their collision: Physiotherapy (80.41%), Physicians (79.05%), Occupational therapy (76.35%), Psychology (62.84%), Speech-language pathology/Speech-language therapy (58.78%), and Neuropsychology (58.78%). Several respondents indicated they also received services from Massage Therapists (15.54%), Osteopaths (9.46%), Chiropractors (8.78%), Vision Therapists (7.43%), and Social Workers (6.76%). A full list of additional services can be found in Appendix D in Table D1. Although 70.27% of respondents indicated they had difficulty communicating

following their brain injury, only 58.78% reported they needed services from Speech-language pathology/Speech-language therapy.

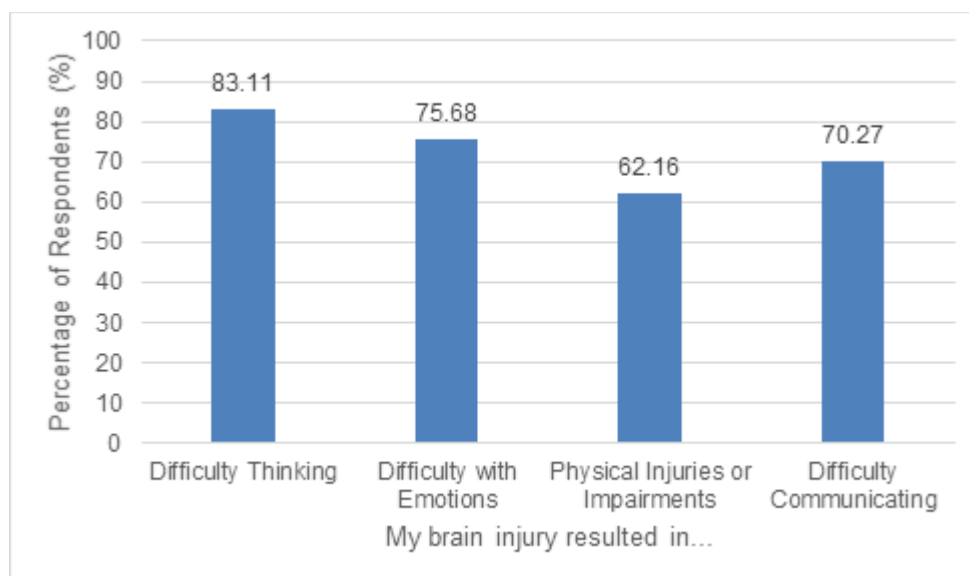


Figure 1. The percentage of respondents that experienced difficulty thinking, difficulty with emotions, physical injuries or impairments, and difficulty communicating as a result of their brain injury.

There were a variety of different insurance companies reflected in the sample population, with the most common being Aviva Insurance Company of Canada (8.11%), Certas Home and Auto Insurance Company (7.43%), Economical Mutual Insurance Company (7.43%), Co-operators General Insurance Company (6.76%), and Intact Insurance Company (6.08%). A complete list of insurance companies can be found in Appendix D in Table D2.

The majority of survey respondents reported having legal representation at some point during their claims process (83.78%), but 25% of respondents did not have this representation from the start.

Insurer Examinations

Survey participants were asked how many total assessments they had attended after their injuries. Overall, survey respondents attended anywhere between zero (3.38%) to more than 20 (26.35%) assessments. The majority of respondents (50.69%) attended at least 10 assessments. An overview of total assessments attended by respondents can be found below in Figure 2. Next survey participants were asked to report how many of these assessments were required by their *auto insurers*, that is, how many total assessments were insurer assessments conducted as part of the insurance claims process rather than for rehabilitation. 30.41% of respondents reported that 10 or more insurer examinations were required by their auto insurance company and 7.43% reported they were required to attend more than 20 insurer examinations.

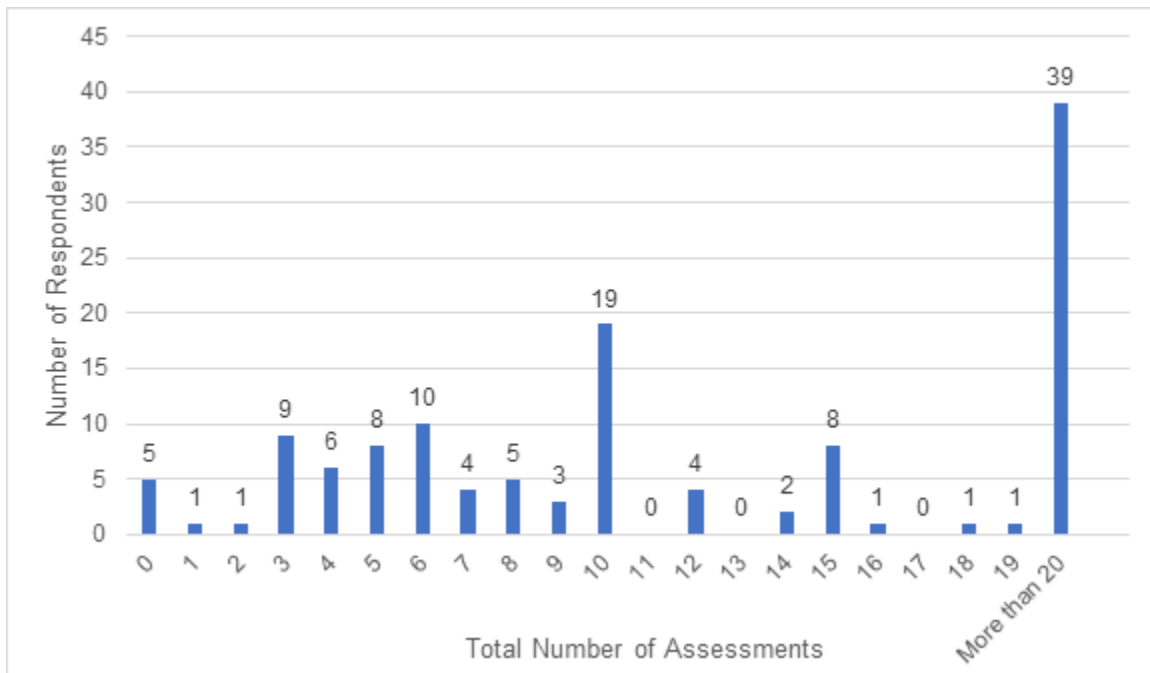


Figure 2. Total number of assessments that survey respondents reported attending.

Survey respondents were asked if they were required to attend the same type of assessment more than once and 64.19% indicated they were required to attend duplicate assessments. On a scale from one to 10, with one being 'Not at all satisfied' and 10 being

'Completely satisfied', respondents reported a mean score of 4.56 ± 3.18 for how satisfied they were with the knowledge their assessors had about brain injury. In fact, 20.95% ranked their satisfaction with the professionals' expertise as a one out of 10, or 'Not at all satisfied'.

Additionally, respondents reported that these assessments were inconvenient, with 59.47% of respondents selecting scores of five or below on a scale of one to 10, indicating feeling inconvenienced by assessments. To better understand the impact that insurer examinations had on respondents, the survey asked respondents to select different circumstances that arose as a result of their assessments. Overall, respondents reported experiencing fatigue (75%), stress (74.32%), increased symptoms (62.84%), traveling long distances (58.78%), feeling they had to 'prove' their brain injury (58.78%), and putting their lives on hold (47.30%). Only 6.08% of respondents indicated that they did not experience any of the above circumstances.

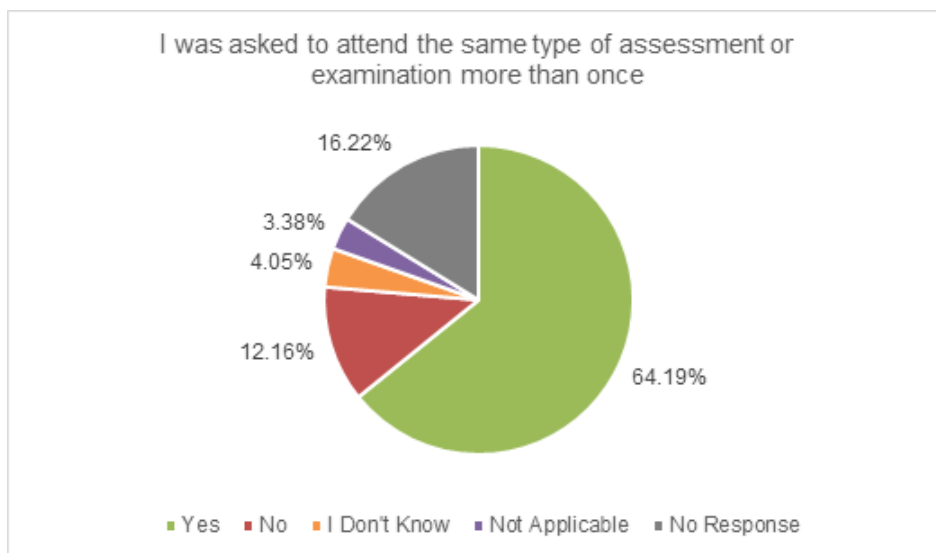


Figure 3. The percentage of respondents that were asked to attend the same type of assessment or examination more than once.

Privacy

Out of all survey respondents, the majority (55.41%) felt they were questioned about information unrelated to their MVC. Additionally, respondents reported that they 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. Overall, participants rated the accuracy of the information shared about them as 5.31 ± 2.66 on a scale of 1 to 10, with 1 being none of the time and 10 being all of the time.

In order to better understand surveillance practices by insurance companies, survey respondents were asked questions related to their experience with being followed for insurance purposes. 37.16% of survey respondents believed they were followed by someone hired by their insurance agency. 43.92% reported that their lawyer informed them they may be followed for insurance purposes with only 2.03% reporting being informed by their insurers themselves. A group of survey respondents also indicated that they were informed of this general practice of possibly being followed by their insurance company by friends, family, and other people with brain injury. Many respondents also expressed that they were unsure what information was ultimately shared because they had to give consent to the insurers as part of the insurance claims process or risk halting the claims process all together.

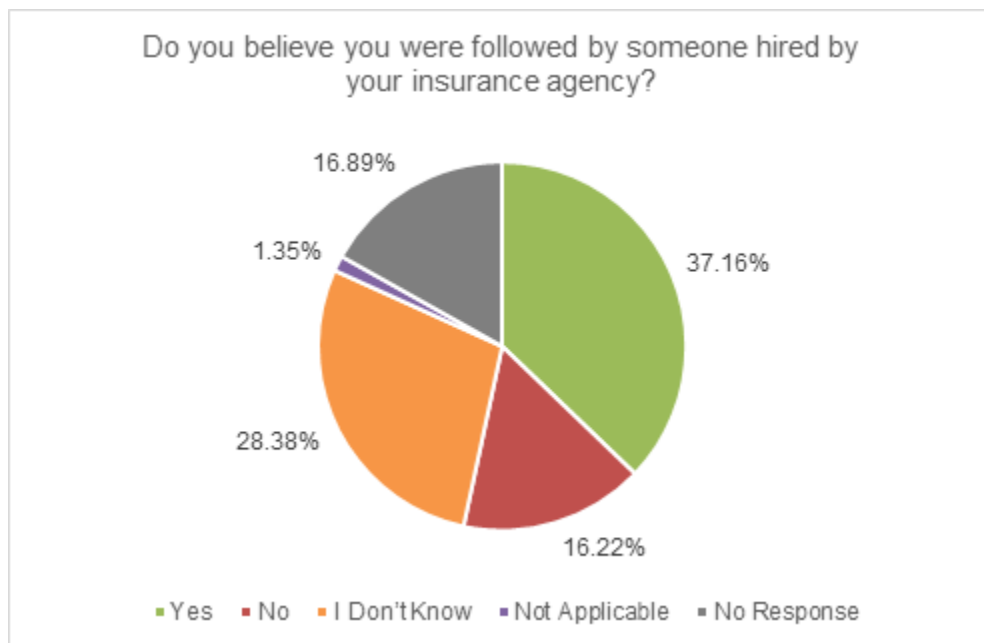


Figure 4. The percentage of respondents who believed they were followed by someone hired by their insurance agency.

Timely Access to Treatment

The survey respondents were asked to report whether insurer decisions about funding delayed their access to SLP, PT, OT, Psychology, Neuropsychology, or Physician services. 32.44% of respondents experienced a delay of up to two years for SLP, 48.89% for PT, 43.84% for OT, 49.54% for Psychology, 37.81% for Neuropsychology, and 11.03% for Physician services. In terms of claim denials, survey respondents were most commonly denied claims to SLP and Neuropsychology services at 7.43% and 8.11% respectively.

Table 1

Reported Wait Time Between Brain Injury and Access to Health Services in Percentages

| | 0 mos | 1-2 mos | 3-4 mos | 5-6 mos | 7-8 mos | 9-10 mos | 11-12 mos | >1 year, <2 years | >2 years | I don't know | Denied | No Response |
|----------------------------------|-------|---------|---------|---------|---------|----------|-----------|-------------------|----------|--------------|--------|-------------|
| Speech Language Pathology | 16.22 | 9.46 | 5.41 | 4.73 | 2.70 | 0.68 | 1.35 | 5.41 | 2.70 | 7.43 | 7.43 | 36.49 |
| Physiotherapy | 27.70 | 20.00 | 9.46 | 3.00 | 2.70 | 1.00 | 1.35 | 8.00 | 3.38 | 13.00 | 4.05 | 31.00 |
| Occupational Therapy | 25.68 | 11.00 | 4.73 | 7.00 | 2.70 | 4.00 | 2.03 | 9.00 | 3.38 | 14.00 | 5.41 | 38.00 |
| Psychology | 14.86 | 10.00 | 4.05 | 9.00 | 3.38 | 4.00 | 2.03 | 11.00 | 6.08 | 13.00 | 4.73 | 49.00 |
| Neuropsychology | 14.86 | 7.00 | 1.35 | 3.00 | 2.70 | 4.00 | 3.38 | 13.00 | 3.38 | 15.00 | 8.11 | 56.00 |
| Physician | 50.00 | 4.00 | 0.00 | 2.00 | 0.00 | 1.00 | 0.00 | 2.00 | 2.03 | 8.00 | 0.00 | 54.00 |

Additionally, 40.54% of respondents reported facing financial barriers to accessing treatment.

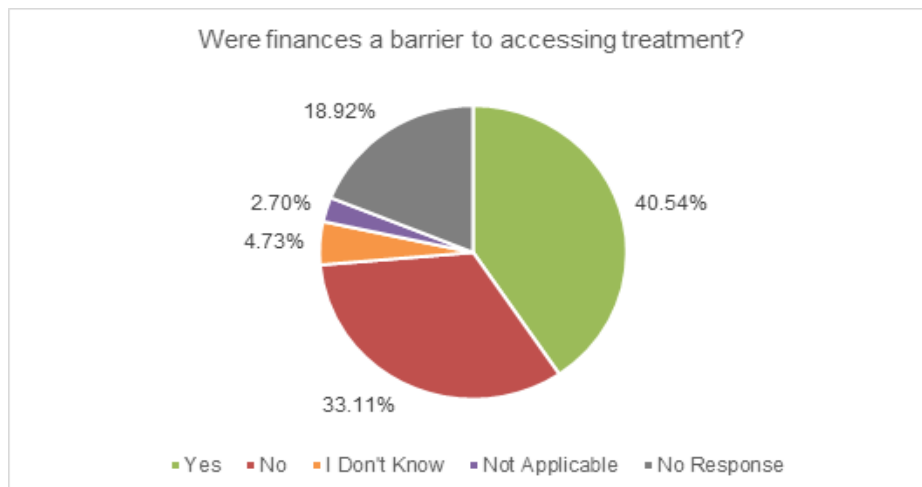


Figure 5. The percentage of respondents that indicated finances were a barrier to accessing treatment.

Financial Support and Payment

The majority of respondents (50.67%) indicated that they received income replacement. Although 32.43% of respondents received their income replacement within 0-6 months, 18.24% experienced delays of more than 6 months, with waits of 7-11 months (8.78%), 1-2 years (2.70%), and more than 2 years (7.43%). In order to better understand how having a brain injury as a result of a MVC impacts family and friends, survey respondents were asked whether a family member or friend had to reduce their working hours to support them after their brain injury. It was found that 50.68% of respondents had a family member or friend reduce their working hours.

Survey respondents were asked if they were offered a cash settlement. 21.63% of respondents reported being offered a cash settlement, with 16.89% being offered a cash settlement after more than a year into their claims process. The majority of respondents (50.67%) indicated that they received income replacement. 32.43% of respondents received their replacement within 0-6 months, 6.79% received it between 7-11 months, 8.78% received it between 1-2 years, and 2.70% received it after 2 years. 7.43% of survey respondents were outright denied income replacement claims.

Insurer Communications and Support

Overall, 57.37% reported that the experiences with their insurance company worsened their recovery to some degree, with only 7.43% feeling their experiences with the insurance company completely supported their recovery. On a scale from 1 to 10 with 1 being 'Worsening My Recovery' and 10 being 'Completely Supporting My Recovery', the mean score was 4.17 ± 3.02 . Survey participants were asked to comment on the type of support that would have assisted them in the claims process and whether their insurer provided those supports. Many respondents expressed that little to no support was provided by their insurer. An overview of

supports along with the percentage of respondents who were provided and believed that support would have been helpful can be found in Table 2. From the supports listed, the most commonly stated supports that respondents felt would have been helpful were 'Repeating and clarifying key information' at 45.95% and 'Consistency in staff' at 39.19%. However, only 10.14% of respondents reported receiving 'Repeating and clarifying key information' and 14.19% reported having 'Consistency in staff'. There was an 'Other' option at the end of this survey question that allowed respondents to type an additional support they were provided with or would have liked during their claims process. The most common supports listed in 'Other' that survey respondents felt would have been helpful during their claims process were better response times to inquiries (2.70%) and having a supportive and non-judgmental insurance adjuster (2.03%).

Table 2

Insurance Company Supports Provided to and Desired by Respondents

| Support | Respondents that felt this would have been a helpful support | | Respondents for whom this support was provided | |
|---|--|------------|--|------------|
| | Count | Percentage | Count | Percentage |
| 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 | | | | |
| <ul style="list-style-type: none"> Better Response Times to Inquiries | 4 | 2.70 | | |
| <ul style="list-style-type: none"> Supportive and Non-judgmental Insurance Adjuster | 3 | 2.03 | | |
| No Response | 15 | 10.14 | 15 | 10.14 |

Overall Satisfaction

For overall satisfaction, survey respondents most commonly reported they were not satisfied with their insurance claims process (56.08%) and 24.32% of these respondents were not at all satisfied. However, 7.43% reported they were completely satisfied. The mean of satisfaction scores was 4.39 ± 3.03 indicating that there were more survey respondents who were unsatisfied with their claims process compared to those that were satisfied.

At the end of the survey, respondents were asked to rate the statement “Overall, I felt good with my insurance claims process” on a 5-point Likert scale from Strongly Disagree to Strongly Agree. 50% of respondents Disagreed or Strongly Disagreed with the above statement. The mean of these scores was 2.27 ± 1.34 .

Qualitative Findings

Eighty-eight out of 148 (59%) respondents included an open-ended response commenting on their personal experiences with the insurance claims process, revealing novel

experiences not captured within the quantitative data. Major themes included the perception that there was a general lack of knowledge of TBI symptoms amongst professionals involved in the process, concerns regarding insurance adjusters, the perceived negative treatment by insurer staff, unfair delays and denials of services despite medical evidence, the insurance claims process serving as a roadblock to recovery, a general dissatisfaction of the auto insurance system as a whole, and advocacy for the need for large-scale change in the auto insurance system.

Lack of knowledge of TBI symptoms.

Respondents commented that insurer representatives and insurer assessors expressed a belief that their injury should have been cured or recovered within a certain timeframe. One respondent wrote, “My therapists all had difficulty dealing with the last adjuster who indicated she felt, at six years post BI, that I should be cured” (Respondent 9). Another respondent expressed how these faulty beliefs benefit insurance companies, saying: “The lack of knowledge from medical professionals is a burden that being used in the advantage of the insurance company” (Respondent 132).

Several respondents expressed that they felt there was a biased focus on physical injuries and a neglect for mental health/cognition-related difficulties, which are cornerstones of TBI that are often invisible. For example, one respondent described an assessor who focused most of the assessment on physical abilities, despite the fact that his file clearly showed his challenge was with cognition. Another respondent contrasted their most recent car accident, which resulted in a brain injury, with previous car accidents that resulted in physical injury:

All my previous accidents had affected me more physically... than cognitively... and yet I recovered back to my “new normal” after each one. This accident has been different, this time, my concussion injury is what has been debilitating. Losing my cognitive function, difficulty with my vision, experiencing light sensitivity and noise sensitivity, head heating

up, nausea, and the feeling of being lost and unconnected is what has been most challenging. On top of all my symptoms ... I had to deal with an insurance adjuster who did not return phone calls in a timely manner ... and who never addressed any of my concerns whether in writing or verbally... This has been a very emotionally draining experience. (Respondent 159)

Other respondents described communication barriers to their success in navigating the insurance claims process with the cognitive-communication deficits associated with a brain injury:

I hate that I have a brain Injury yet they ask me endless questions that I may or may not answer correctly due to my brain injury, my memory or other thoughts that may be on my mind. My answers are not consistent. It is a struggle to navigate the insurance system and be treated as a suspect. (Respondent 94)

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 labeled non-compliant. (Respondent 143)

Several respondents also alluded to a general lack of knowledge on the symptoms of TBI in highlighting the lack of support and modifications provided by their insurers during communications and assessments. One respondent commented on the environmental barrier of fluorescent lighting, which made the insurer examination process more difficult to navigate due to his brain injury:

This system is so broken it is crazy. I spent 1 hour and 45 minutes doing paperwork in a room with florescent lighting, I had to shut off the lights and open the door to get some light in and fill in my forms with my phone light. No assistance offered. (Respondent 42)

Perceived negative treatment by insurer staff.

Several respondents described feeling like they were taken advantage of by their insurance companies at a time when they were most vulnerable. In expressing their vulnerability, several respondents described feeling like they were consistently on trial of having to prove their injury. One respondent wrote:

You are assumed to be a fraud even though you have evidence of an injury. ... These companies treat you like crap when you are vulnerable. One moment in mediation they are saying you are a liar and you were at fault, then they settle and wish you a speedy recovery. (Respondent 101)

Another respondent echoed similar sentiments in their comment, while expressing gratitude for having a lawyer to advocate on their behalf: "When you are injured, confused because of a brain injury, in pain and afraid of what is happening, the insurance company is terrible. They take advantage of you. My lawyer became my advocate for treatments" (Respondent 66).

A large number of respondents commented on feeling mistreated, disrespected, and/or threatened throughout the insurance claims process. One respondent wrote:

I was traumatized, lied to, manipulated and characterized 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 years, repeated invasive and upsetting assessments, and a drawn out legal process before I was given reasonable care and a settlement... " (Respondent 131)

Overall, there was a general sense of dismay at the treatment of claimants during the insurance claims process in the majority of the open-ended responses. One respondent expressed their alarm at the cruelty of their treatment on top of having to deal with the profound aftermath of their brain injury:

As someone who survived a near death experience, then a brain injury and then having to constantly prove that to certain people so they can give me the compensation I justly deserve? Is there anything more cruel? ... I lost my job, I lost my working status, I lost my identity. It wasn't just a brain injury, it was a life injury. (Respondent 123)

In describing how they dealt with the perceived negative treatment, one respondent alluded to the benefits of keeping a positive attitude and accepting that the unpleasant behaviour of the insurance company is the standard and therefore not to be taken personally: "I had a positive attitude and demonstrated integrity throughout the process, which "paid off" at the end... I accept that this is how the insurance system works with intimidation, mind-games and not taken personally" (Respondent 80).

Concerns regarding insurance adjusters.

A common comment involved the level of satisfaction with insurer staff. Respondents described mixed experiences with adjusters. The term "supportive" was frequently used to distinguish between positive and negative experiences with adjusters. One respondent described her negative experiences with her adjuster in the following:

I feel like my adjuster did not support me in my recovery. I was in an MVA¹, the other driver was charged, yet I was treated with complete disrespect and distrust when all I wanted was to heal. I still struggle every single day due to not receiving the services I need. (Respondent 114)

In contrast, those who shared positive experiences with their adjusters described them as supportive of their recovery. One respondent expressed gratitude for having a supportive adjuster, alongside nervousness of possibly losing that support with a recent switch in adjusters:

I was lucky to have a very good adjuster once I became catastrophic. Just recently,

¹ Motor Vehicle Accident

however, my adjuster has been switched so I don't have a rapport yet with my new adjuster. I am a little nervous that moving forward the process will be more challenging than it has been." (Respondent 82)

The challenges of having a constant change in insurer staff were commonly mentioned. One described feeling like the process was very impersonal due to such change: "I had 4 different adjusters. It was during that time I didn't feel I had a face or a name... just a file number that each adjuster managed" (Respondent 9). Another respondent commented on how a change in staff led to further delays in approval of treatment plans.

Delays and denials despite medical evidence.

Many respondents commented on delays and denials despite medical evidence of sustaining a brain injury. Several also commented on delays and denials of services despite those services being recommended and approved by therapists. Respondents described feeling cheated by their insurance companies, explaining that they were denied access to funds to which they were entitled based on what was included in their insurance premiums. One respondent expressed her disbelief at the unreasonable denials of insurance adjusters: "How can medical evidence be repeatedly denied by numerically trained adjusters. This is killing and starving the most vulnerable in this province" (Respondent 64).

A frequently mentioned factor was the indispensable support of their legal representation and healthcare providers in fighting the delays and denials. Although some described having a lawyer who worsened their experience, most described feeling thankful for having had a good lawyer, without whom the process would have been impossible. One respondent wrote, "I truly believe if we have had to deal on our own with the insurance company and not have a personal injury lawyer working for me from the very beginning the process would have been very difficult to navigate" (Respondent 90). Many also commented on the immense help they received from their medical professionals, who advocated for services that they needed. One respondent

described feeling “blessed” by their medical team.

Claims process as a roadblock to recovery.

A recurring theme was the added stress related to the constant battle of fighting delays and denials and proving their injury, which served as a roadblock to recovery. One respondent wrote, “The whole thing has been a sham where all I wanted was to get the help I needed nearly 6 years ago. I want this solved so I can go on with my life” (Respondent 140). Another respondent described wanting to recover so they would no longer need services. They shared, however, that the insurance system seemed to be counterproductive to that aim, with unnecessary assessments, denials, and delays:

I was treated like I was on trial the entire process. I never asked for anything above and beyond what was recommended by specialists, and even pushed to return to work/school as soon as I could. I was TRYING to get my life back, not stay on disability or collect money. They still followed me, denied all my claims unless I pushed back, and paraded my unrelated personal life in front of everyone at discoveries, and focused on as a main point by insurance assessors - including counselling records for completely unrelated childhood abuse - in order to intimidate and bully me. I had to hire a lawyer just to protect myself and make sure I got the treatment I needed... 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. I hated it. Still hate it. Although I've finally returned relatively to normal, 9 years later, it was hands down the worst experience of my life. Not the accident itself, the recovery and trying to deal with the insurance company. (Respondent 79)

Moreover, many described the insurance claims process as an experience that has actually worsened their condition. One respondent wrote about a sense of hopelessness after having to continuously self-advocate for her rights on top of dealing with symptoms of their brain

injury, fighting through a system that resulted in the deterioration of their mental health:

I have had to advocate very hard to access essential services that I've needed. As someone who already deals with several symptoms from my brain injury, it felt that it was unfair that I had to carve out mental energy to advocate for myself. The delay in coverages led to a major depressive and suicidal episode that led to a week-long stay at a psychiatric hospital. My experience has been hell, very painful, and frustrating, that it was very difficult to find hope throughout the recovery process. (Respondent 139)

Auto insurance industry as a broken system.

Some respondents provided general comments on the insurance system as a whole. A recurring theme in such comments included a general sense of disbelief and dismay at the auto insurance system. One respondent wrote:

I feel like 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. My accident was 0% my fault and the other driver was charged and pled guilty to careless driving. Still, I have been treated like a scammer since the day after my accident. People believe they have medical coverage for a certain amount following an accident. 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. I am quite certain that their primary goal is to make the process as difficult and as stressful as possible so people will cave in and just suffer in silence. It is a terrible broken system, especially for people with a brain injury and/or post concussive symptoms. (Respondent 78)

When describing the auto insurance system, the idea that the insurance claims process was a "human rights breach" or "inhumane" was prevalent. One respondent wrote:

The current insurance process in Ontario is a giant human rights breach. They are

pushing people onto OHIP/ODSP/PPP² and not paying out health claims in a timely manner. I have been repeatedly gaslit, followed, maligned and shamed by the insurance company. (Respondent 63)

Another respondent shared similar sentiments, describing a sense of shock and disappointment at the auto insurance system, despite having worked in the industry and taken precautionary steps to ensure a smooth process:

I am also unique in that I worked in the insurance industry at the time of my accident, so I am familiar with the system and advocated for myself right from the get-go: however, my insurance experience has still been awful! ... It's an awful, inhumane system that seems to be unfairly stacked against folks with brain injury. (Respondent 143)

Advocacy for the need for change.

Some respondents included an explicit statement regarding the need for a large-scale change in the auto insurance system. These comments were complementary to the issues described about the various aspects of experiences in previous sections. One respondent commented on the adversarial nature of the insurance system against MVC survivors, suggesting that adjusters work with, rather than against, therapists: "I think that the car insurance system in Ontario is based on survivors "needing to prove that they are injured... adjusters should work WITH therapists to support recovery, rather than behaving antagonistically ." (Respondent 71)

In writing about their frustrations dealing with insurer-selected assessors who seemed to have a poor understanding of the lived experiences of brain injury, one respondent suggested that professionals involved with the auto-insurance field have mandatory training specifically for working with brain injury survivors. Similarly, another respondent expressed frustrations about

² Ontario Health Insurance Plan; Ontario Disability Support Program; Canadian Pension Plan

the lack of emphasis on mental/cognitive health aspects of the injury, which are often overshadowed by the prioritization of physical injuries. This respondent suggested that, particularly in the early stages of recovery, greater focus be placed on the more covert signs and symptoms of brain injury: “Some type of head injury and mental health support (or at the very least education/info) is critically necessary those first few months, when all everyone is talking about is all of your many physical injuries” (Respondent 127).

Other respondents suggested changes at the institutional level, expressing a perceived need for the transition of the auto insurance industry from a private, business-run to public, government-run model. One respondent compared the insurance system in Ontario to that of other provinces, suggesting that auto insurance rates be strictly controlled and that the permissible behaviours of insurance companies be closely regulated. This respondent wrote:

Insurance as a for-profit business is bordering (if not engaging) in criminality and fraud and should be stopped. Mandated insurance such as we have in Ontario should be run by the government as it is in other provinces and rates should be strictly controlled. In the alternative, for-profit insurance companies should be much more closely monitored and stiff penalties should exist for the kinds of behaviours I was subjected to.

(Respondent 131)

Discussion

The results of this study appear to mirror the experiences of those in the ABISS group who consulted on the research and survey design. It was important to the group to understand how experiences of the greater population of Ontarians with brain injury following MVC related to their experiences. In the following sections, we discuss the main themes of our results as they relate to findings of previous studies and the experiences that the ABISS group considered most pertinent in the development of the survey.

The ABISS group reported having to attend numerous and duplicative assessments during the insurance claims process. They explained that their auto insurance company ordered them to attend these assessments, during which they felt as though the goal was to disprove their injury. The ABISS group commented that, because the results of their brain injury were not immediately visible, they were doubted and made to continually prove the existence of their injury despite already receiving a diagnosis. These experiences were common among survey respondents, a majority of whom reported attending 10 or more insurer examinations required by their auto insurance company. Unsurprisingly, most participants found these numerous assessments to be inconvenient. The survey findings match that of participants in previous research, who also reported having to attend numerous and burdensome assessments (Murgatroyd, Cameron, Harris, 2011). Interestingly, participants in the study by Murgatroyd and colleagues (2011), as well as members of the ABISS group, reported that they were not confident in the knowledge or honesty of the medical professionals they saw by order of their auto insurance company. The current survey reported similar findings, with participants indicating general dissatisfaction with these assessors. Input from the ABISS group suggests that this lack of confidence in insurer assessors may stem from the sense that these professionals are trying to discredit their claim, rather than provide an objective evaluation. These experiences were echoed in the qualitative results, which outlined feelings of being taken advantage of while vulnerable, feeling that they were being assessed for the purpose of finding a reason to deny the claims, and being manipulated and further traumatized.

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 didn't really exist (Murgatroyd, Cameron, Harris, 2011). This experience was also reported by the ABISS group. Given the invisible nature of cognitive-communication difficulties associated with TBI, there is reason to question the validity behind the possible use of surveillance by insurers. Nevertheless,

over a third of survey respondents reported that they believed they were followed by someone hired by their insurance agency. In addition to impacting their privacy, a majority of 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 feels disruptive and violating, especially when all aspects of one's life, and not only those related to the collision, are under investigation.

ABISS members expressed concern regarding the delay in rehabilitative and medical service acquisition caused by delays in the insurance claims process. Quick claims resolution and access to therapy following brain injury has been demonstrated to result in better recovery outcomes (Cassidy et al., 2000; Cassidy et al., 2004; Feinstein et al., 2001). Unfortunately, a large proportion of survey respondents experienced a delay of up to two years for SLP services, PT, OT, psychology, and neuropsychology. It is possible that, as an invisible injury, respondents experienced more difficulty proving the legitimacy of their injury. Previous research has commented on the tendency for brain injury to be misunderstood due to its invisibility relative to more obvious physical injuries (Donker-Cools et al., 2016; Harder, 2009; McClure et al., 2008; McClure, 2011). The qualitative results suggest that survey respondents experienced more difficulty advocating for their cognitive injuries than their physical injuries throughout the insurance claims process. Importantly, the qualitative findings also commented on how the lengthy claims process delayed their therapy, and even worsened their condition.

Previous research has commented on the connection between brain injury and financial difficulty (Gabbe et al., 2014; Ontario Brain Injury Association, 2012). Additionally, research has suggested that financial strain adds to the burden experienced by people undergoing the insurance claims process (Murgatroyd, Cameron, Harris, 2011). In this survey, a large proportion of respondents reported facing financial barriers to accessing treatment for their brain injury. Further contributing to the financial strain, only 50% of respondents reported receiving

income replacement. Another 50% reported that their family or friends reduced their working hours in order to support their care. The support of family members who are willing to compromise their own work was also found to be a major theme in research by Murgatroyd, Cameron, and Harris (2011). Previous qualitative research has reported that the claims process adds additional stress and burden to people during their recovery from what may already be a very traumatic event (Murgatroyd, Cameron, Harris, 2011). Similar to the findings of Murgatroyd, Cameron, and Harris (2011), a majority of respondents reported feeling that their recovery was negatively impacted by experiences with their insurance company. The qualitative findings also suggested that the insurance claims process prevented them from recovering from their injury or returning to their regular life activities. Survey respondents expressed that their experience may have been improved with the provision of supports such as a consistent and supportive insurance adjuster.

Overall, most survey respondents were not satisfied with their insurance claims process.

Limitations

There were several limitations to this research study. First being the participant recruitment process and the study's sampling frame. There currently is no directory for every individual in Ontario who has a brain injury as a result of a MVC. Therefore, participants needed to be recruited through other means, namely relevant organizations and professionals. Even though many different organizations across Ontario were contacted to assist with distribution of the survey, there may have been certain subgroups of the target population that were unintentionally missed. Additionally, if these organizations were sending regular emails to their listserv, some individuals may not always check these emails consistently. If individuals receive multiple correspondences for surveys, potential survey respondents may experience negative associations towards surveys (Wright, 2005). This in turn may negatively impact response rates

and the responses themselves. There were also several organizations that refused to distribute the survey to their listserv and some organizations that requested a distribution fee, which was not feasible due to lack of funding. As a result, the survey may not have reached individuals who were solely associated with these organizations. Individuals in remote communities may not be adequately represented in the sample population due to limited access to reliable technology and internet services. More specifically, these issues have been known to be a challenge for remote Indigenous communities across Canada (Muttitt, Vigneault, & Loewen, 2004). The survey did not ask individuals to report their geographical location, which limits any judgements on the geographical representativeness of the responses within Ontario. As a result of the overall recruitment process, there is a risk for sampling bias where there may be specific characteristics in the target population that are under or overrepresented in the final sample (Johnson, Beaton, Murphy, & Pike, 2000).

While some organizations confirmed that they distributed the survey, others did not confirm their distribution and some refused to distribute the survey. Regardless, it is likely that many relevant prospective survey respondents and professionals were still included because specific brain injury associations distributed the survey to their listserv. The organizations that declined were general professional organizations for practice in all areas, rather than just brain injury. In terms of representation from individuals with limited technology access or internet services, the survey results may have underestimated issues associated with the auto insurance claims process. This may be especially true for individuals who may have severe persistent deficits following their MVC such that access to technology is limited. Furthermore, the survey may not have captured the perspectives of those with severely debilitating injuries who lack the required support to overcome the barrier of being unable to independently access and use technology (e.g., those in minimally conscious states, those with extreme fatigue). As a

result, it is possible the survey results actually underestimate how prevalent these insurer behaviours are.

Online surveys offer many advantages to researchers, such as access to unique populations, efficiency of distributing surveys to a wide audience in a short period of time, and low cost (Wright, 2005). However, the fact that this survey was completely online may be a limitation because it may have been more accessible for certain individuals to fill out a hardcopy survey or answer the survey questions verbally over the telephone. There is a possibility that the format of the survey unintentionally excluded a specific group of individuals who had a certain type of impairment following their MVC that made online completion impossible. However, this was difficult to track due to the nature of the recruitment process. There was no way to keep track of how many individuals actually received the survey invitation and link. There was no data available to calculate a non-response rate of this survey. As well, because the survey was completed online independently, respondents were not given an opportunity to ask for clarification on any of the survey questions. The involvement of ABISS in revising the wording of questions helped reduce some of the limitations with using an online platform. However, the non-response rate for each question ranged from 0.68% to 25%, indicating there may have been unresolved issues related to wording of questions. Alternatively, respondents may have chosen to skip certain questions as a result of fatigue from the cognitive demand of reading and completing the survey.

Moreover, due to the nature of the survey being online, there was a risk for self-selection bias, which occurs when prospective participants have the choice whether they would like to participate in the research study or not (Wright, 2005). The individuals who chose to participate in the study may possess different characteristics, perspectives, and opinions compared to those who chose not to participate. This would impact the generalizability of these study results and may not capture the experiences of individuals who chose not to participate. For the

present study, the majority of survey respondents identified as female (57.43%) and only 29.73% identified as male. This binary sex difference in survey responses reflects previous research that has shown women tend to be more likely to participate in surveys compared to men (Curtin et al 2000; Moore & Tarnai, 2002; Singer et al 2000). As a result, male perspectives may be underrepresented in the survey results. However, the analysis did not show significant binary sex differences on most of the insurer behaviour variables. Additionally, those with negative perceptions about the auto insurance process might have been more motivated to participate in the survey. As such, our results may represent a disproportionately negative profile of the auto insurance experience. However, our survey attracted the attention of 126 participants across Ontario with a wide range of insurance companies. Therefore, our sample size is substantial enough to warrant further investigation into the auto insurance claims process for claimants with brain injury. Our findings also bring light to a systematic, rather than insurer-specific, problem with the auto insurance industry in Ontario.

Another source of bias may have been response bias, where participants may respond how they think the researchers want them to respond or how they think other participants may respond (Summers, 1969). Throughout the development of this survey, many efforts were made to reduce the risk of bias due to the wording and ordering of questions. However, it is unlikely that all bias was eliminated because different individuals may naturally interpret questions differently. As a result, despite efforts to minimize bias, there is still an inevitable risk of response bias impacting the survey results.

Finally, all survey questions were developed in partnership with ABISS, which is one group of individuals who have a brain injury following a MVC in southern Ontario. There is a possibility that some auto insurance company behaviors may not have been fully captured or may be unique to these individuals. In order to mitigate the risks associated with this, an open-ended question at the end of the survey was provided to allow respondents to freely comment

on any additional experiences. Although the inclusion of an open-ended question may not fully address this limitation, it is noted that the results of the qualitative question revealed responses that were consistent with experiences originally expressed by ABISS.

Implications/Recommendations

Our results indicate a need for all individuals involved in the insurance claims process to become more aware of the characteristics and features of brain injury. Our findings reveal that individuals with brain injury are required to prove their injury during the insurance claims process, often despite medical evidence of injury. The process of proving their injury was described to have a substantial negative impact on their mental and physical health, which impeded and/or worsened their recovery. If professionals involved in the insurance claims process were more aware and knowledgeable about brain injury, factors that impede the recovery of brain-injured individuals could be eliminated from the process, including excessive and duplicative insurer examinations, violations of privacy, feeling taken advantage of, feelings of distrust for insurer professionals, unjust delays and denials to access treatment, and unjust delays and denials for financial compensation.

The harmonious statements from our findings, the study by Murgatroyd, Cameron & Harris (2011), and the members of ABISS suggest that the process of claiming financial compensation following a MVC is taxing on an individual with brain injury. Our results indicated that individuals with brain injury are expected to constantly self-advocate and prove the legitimacy of their injury. This indicates a need for professionals and clinicians to advocate for this population. Our results suggest that a role exists for clinicians to advocate for the needs of those who have sustained a brain injury from MVC with insurance agencies.

Our findings also indicate a unique role for speech-language pathologists. Cognitive-communication challenges are often common with brain injury, and fall within the scope of speech-language pathologists. Indeed, over 70% of this sample reported cognitive and

communication difficulties. As a result, speech-language pathologists should have an active role throughout the claims process. Specifically, speech-language pathologists should assist with communication between the brain-injured individual and the insurer. A speech-language pathologist is imperative to a just claims process as they are in a unique position to support the communication competency of individuals with brain injury, a skill which is instrumental to navigating the complexity of the auto insurance process. Likewise, a speech-language pathologist could also support the insurer to implement effective communication partner strategies and environmental modifications that facilitate fair communications with individuals with brain injury. Additionally, a speech-language pathologist's ability to support various areas of cognitive function can support individuals with brain injury after MVC to participate in the basic activities that make a just claims process possible. Such activities include, but are not limited to, following and contributing to conversations, participating in insurer examinations, and accurately filling out paperwork throughout the claims process.

Future Research Directions

Future research is warranted on investigating how insurance companies can implement brain injury education initiatives and supports (e.g., repeating and clarifying key information, providing large print, allowing a support person to be present) in order to facilitate a more satisfactory claims process for vulnerable claimants with brain injuries. Given the complexity of navigating the auto insurance and medical system with brain injury related cognitive-communication deficits, speech-language pathologists may have a unique role in supporting auto insurance companies to implement these supports. Therefore, future research exploring ways through which SLPs and/or other healthcare providers could support the implementation of such supports may be beneficial.

While this study used primarily quantitative methods, our qualitative analysis of the open-ended responses at the end of the survey revealed that there would be significant value in

a comprehensive qualitative research of this area in the future. Specifically, qualitative research using methods such as focus groups or interviews would allow us to learn more about the experiential aspects of being an auto insurance claimant following a brain injury. The experiential aspects introduced in the present study suggested significant psycho-emotional impacts that one may argue has brought into question the human-rights ethics of the current auto insurance claims process in Ontario. The described psycho-emotional impacts in the present study therefore provide the impetus for further research into the extent and frequency of such experiences, with the ultimate aim of minimizing the harm experienced by future auto insurance claimants with a brain injury due to automobile collision.

Additionally, the open-ended responses revealed that many individuals with brain injury following MVC have a keen interest in taking action to make concrete changes towards an improved auto insurance system in Ontario. Respondents provided input on some suggestions for improvement (e.g., having more regulations protecting claimants, mandating brain-injury specific training for professionals involved in the insurance claims process). These suggestions may be further explored and evaluated for feasibility and effectiveness in future research.

One method by which these suggestions may be further explored and evaluated is through the Experience-Based Co-Design (EBCD) approach. The EBCD approach uses PAR and user experience design tools to develop programs and procedures that support the health and well-being of vulnerable populations. Originally developed in 2005 in the context of head and neck cancer, it has since been effectively implemented in a variety of clinical settings with vulnerable populations around the world (Donetto, Tsianakas, & Robert, 2014). Consistent with PAR principles, EBCD involves gathering lived experiences of the vulnerable populations for which a project is intended (e.g., via observational fieldwork and in-depth interviews) and bringing all relevant members (e.g., staff, patients, caregivers) together to co-design that project to facilitate meaningful change (Bate & Robert, 2007a; Robert, 2013). To our knowledge, the use of EBCD has not yet been explored in the auto-insurance industry. However, the results

from the present study suggest that the implementation of EBCD in the auto-insurance industry may be a valuable future direction, as the majority of our respondents indicated that the insurance claims process had a significant negative impact on their health and recovery following their MVCs.

Finally, as previously mentioned, an inherent limitation of the present study is the selection-bias of its participants. To address this limitation, future research with an aim to gain a more complete understanding of the auto insurance claims process for TBI claimants from perspectives of both the insurers and claimants would be valuable. For example, future research may include collaboration with insurers on a quality-improvement study. In addition to providing a less biased perspective, inclusion of the insurers in such a study would also allow researchers to more easily reach all claimants associated with the involved insurance companies.

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Appendix A

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)
 - a. Personal history
 - b. Work history
 - c. Medical history
 - d. Family medical history
 - e. Other
 - f. None of the above
- 21. I felt that the information that was shared about me was accurate.
 - a. 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:
 - a. 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)
 - b. Physiotherapy: (above scale)
 - c. Occupational Therapy: (above scale)
 - d. Psychology: (above scale)
 - e. Neuropsychology: (above scale)
 - f. Physician: (above scale)
- 23. Were finances a barrier to accessing treatment?
 - a. Yes
 - b. No
 - c. I don't know
 - d. Not applicable

Financial Support and Payment:

- 24. Did your insurance company initially offer you a cash settlement?
 - a. Yes, within 0 - 3 months
 - b. Yes, within 4 - 6 months
 - c. Yes, within 7 months - 1 year
 - d. Yes, more than 1 year
 - e. No
 - f. I don't know
 - g. Not applicable
- 25. My income replacement claims were received within:
 - a. 0-6 months
 - b. 7-11 months
 - c. 1-2 years
 - d. More than 2 years
 - e. I was denied
 - f. I don't know
 - g. Not applicable

26. A family member or friend reduced their working hours to support me after my brain injury.

- a. Yes
- b. No
- c. I don't know
- d. Not applicable

Insurer Communications and Support:

27. My experiences with my insurance company impacted my recovery by:

- a. 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)

- a. Assigning a case manager
- b. Consistency in staff
- c. Allowing a support person to be present in a meeting
- d. Quiet room
- e. Larger print
- f. Extra time
- g. 1-to-1 discussion
- h. Repeating and clarifying key information
- i. Funded transportation to and from therapy appointments
- j. Funded transportation to and from non-therapy appointments
- k. Other: _____

29. Please indicate the supports you feel would have been helpful to have during the insurance claims process. (please select all that apply)

- a. Assigning a case manager
- b. Consistency in staff
- c. Allowing a support person to be present in a meeting
- d. Quiet room
- e. Larger print
- f. Extra time
- g. 1-to-1 discussion
- h. Repeating and clarifying key information
- i. Funded transportation to and from therapy appointments
- j. Funded transportation to and from non-therapy appointments
- k. Other: _____

Summary:

30. Overall, I felt good with my insurance claims process.

- a. Scale of 1-10 (10 points)

31. Based on your personal experiences, please share any additional comments.

If you would like to receive a summary of the results of this survey, please provide us with your email.

Email: _____

You can expect to receive a summary in July 2020.

Thank you for completing this survey. Please remember to click the 'submit' button.

Appendix B

Organizations

Brain Injury Support Groups

| | |
|----------------------|--|
| Southwestern Ontario | New Beginnings ABI & Stroke Recovery Association Brain Injury Association of London and Region Brain Injury Association of Waterloo – Wellington Brain Injury Association of Windsor & Essex Brain Injury Association of Sarnia-Lambton |
| Southcentral Ontario | Brain Injury Association of Niagara Brain Injury Association of York Region Hamilton Brain Injury Association Brain Injury Association of Peel & Halton Brain Injury Society of Toronto Brain Injury Association of Durham Region Brain Injury Association of Fort Erie Headwaters Acquired Brain Injury Group (HABI) |
| Northern Ontario | Brain Injury Association of North Bay & Area Brain Injury Association of Sudbury & District Seizure and Brain Injury Association (Timmins) Brain Injury Association of Thunder Bay & Area Brain Injury Association of Sault Ste. Marie & District |
| Eastern Ontario | Brain Injury Association of Peterborough Region Brain Injury Association of Ottawa Valley Brain Injury Association of Quinte District |

Groups of Regulated Health Professionals

- Ontario Rehabilitation Alliance (ORA)
- Acquired Brain Injury Professionals Network of Waterloo Wellington (ABPIN)
- Ontario Association of Speech-Language Pathologists

Other Community Groups

- Ontario Trial Lawyers Association

Appendix C

Complete List of Organizations/Associations Contacted Through Email for Survey Distribution

| Organization / Association | Received Confirmation of Survey Distribution |
|---|--|
| ABISS | Yes |
| Abilities Rehab | No |
| Acquired Brain Injury Professionals Network | Yes |
| Brain Injury Association of Durham Region | No |
| Brain Injury Association of Fort Erie | No |
| Brain Injury Association of London and Region | No |
| Brain Injury Association of Niagara | No |
| Brain Injury Association of North Bay & Area | No |
| Brain Injury Association of Ottawa Valley | No |
| Brain Injury Association of Peel & Halton | No |
| Brain Injury Association of Sarnia-Lambston | No |

| | |
|--|--------------------|
| Brain Injury Association of Sault St. Marie & District | No |
| Brain Injury Association of Sudbury & District | No |
| Brain Injury Association of Thunder Bay & Area | No |
| Brain Injury Association of Toronto | Yes |
| Brain Injury Association of Waterloo Wellington | Yes |
| Brain Injury Association of Windsor and Essex | No |
| Brain Injury Association of York Region | No |
| Brain Injury Association Peterborough Region | No |
| Brain Injury Services of Northern Ontario | No (email bounced) |
| Brian Injury Association of Quinte District | No |
| Complex Injury Rehab | No |
| Cronk and Associates | No |
| Dale Brain Injury Services | No |

| | |
|--|-----|
| DMAREhability | No |
| For Accident Insurance Reform (FAIR) | Yes |
| Funtionability | No |
| GLA Rehab | No |
| Hamilton Brain Injury Association | No |
| Headwaters Acquired Brain Injury Group | No |
| Independent Case Management | No |
| Innovative Case Management Inc. | No |
| Jusdanis Neuro Rehabilitation Consultants Inc. | No |
| Key Rehab | No |
| Knorr & Associates Inc. | No |
| MacGregor & MacGregor Rehabilitation Services | No |
| March of Dimes | No |

| | |
|---|---------------------|
| ModernOT | No |
| Neurological Rehabilitation Institute of Ontario | No |
| Neuro-Rehab Services Inc. | No |
| New Beginnings ABI & Stroke Recovery Association | No |
| North Bay Regional Health Centre | No |
| North Eastern Ontario ABI | No |
| Ontario Association of Speech-Language Pathologists | No |
| Ontario Brain Injury Association | Yes |
| Ontario Brain Injury Services (North Eastern Ontario) | No |
| Ontario Physiotherapy Association | Refused due to cost |
| Ontario Psychological Association | No |
| Ontario Rehabilitation Alliance | Yes |
| Ontario Society of Occupational Therapists | Refused |

| | |
|--------------------------------------|-----|
| Ontario Trial Lawyers Association | No |
| OSLA ABI Interest Group | No |
| Provincial Brain Injury Association | Yes |
| Provincial Neuro-Physiotherapy Group | Yes |
| Pursuit Health Management | No |
| Rehab First | No |
| Rehab Staff of Regional ABI programs | No |
| Rehabilitation Management Inc. | No |
| REHABilitation Planning Corp. | No |
| Renew Rehab | No |
| Seizure & Brain Injury Association | No |
| Swanson & Associates | No |
| Toronto ABI Network | Yes |

TRAC Group

No

Appendix D

Table D1

Overview of Services Needed by Survey Respondents

| I needed services from (please click all that apply): | Count | Percentage |
|--|--------------|-------------------|
| • Speech-Language Pathologist/Speech-Language Therapist | 87 | 58.78 |
| • Physiotherapist | 119 | 80.41 |
| • Occupational Therapist | 113 | 76.35 |
| • Psychologist | 93 | 62.84 |
| • Neuropsychologist | 87 | 58.78 |
| • Physicians | 117 | 79.05 |
| • Other | | |
| ○ Massage Therapist | 23 | 15.54 |
| ○ Osteopath | 14 | 9.46 |
| ○ Chiropractor | 13 | 8.78 |
| ○ Vision Therapy | 11 | 7.43 |
| ○ Social Worker | 10 | 6.76 |
| ○ Acupuncturist | 7 | 4.73 |
| ○ Neurologist | 6 | 4.05 |
| ○ Optometrist | 6 | 4.05 |

| | | |
|---|---|------|
| ○ Audiologist | 5 | 3.38 |
| ○ Ophthalmologist | 5 | 3.38 |
| ○ Rehab Support Worker | 4 | 2.70 |
| ○ Dentist | 3 | 2.03 |
| ○ Pain Clinic | 3 | 2.03 |
| ○ Psychiatrist | 3 | 2.03 |
| ○ Nutritionist | 2 | 1.35 |
| ○ Psychiatrist | 2 | 1.35 |
| ○ Rehab Assistant | 2 | 1.35 |
| ○ Rehab Therapist | 2 | 1.35 |
| ○ Surgeon | 2 | 1.35 |
| ○ Accessibility Office, Attendant Care, Case Manager, Cognitive Therapist, Colour Therapy, Counselor, Cranial and Sacral Therapist, Dietician, ENT, Float Therapy, Iridologist, Kinesiologist, Music Therapy, Oxygen Therapy, Podiatrist, Psychotherapist, Reflexologist, Skills Builder, Vestibular Rehabilitation | 1 | 0.68 |

Table D2

Overview of Insurance Companies used by Survey Respondents

| Who was your insurer? | Count | Percentage |
|--|--------------|-------------------|
| • AIG Insurance Company of Canada | 1 | 0.68 |
| • Allstate Insurance Company of Canada | 2 | 1.35 |
| • Aviva General Insurance Company | 4 | 2.70 |
| • Aviva Insurance Company of Canada | 12 | 8.11 |
| • Belair Insurance Company Inc | 4 | 2.70 |
| • Certas Direct Insurance Company | 2 | 1.35 |
| • Certas Home and Auto Insurance Company | 11 | 7.43 |
| • Chubb Insurance Company of Canada | 2 | 1.35 |
| • Co-operators General Insurance Company | 10 | 6.76 |
| • COSECO Insurance Company | 1 | 0.68 |
| • The Dominion of Canada General Insurance Company | 2 | 1.35 |
| • Echelon Insurance | 1 | 0.68 |
| • Economical Mutual Insurance Company | 11 | 7.43 |
| • Edge Mutual Insurance Company | 2 | 1.35 |
| • Gore Mutual Insurance Company | 2 | 1.35 |

| | | |
|--|---|------|
| • Heartland Farm Mutual Inc. | 1 | 0.68 |
| • Intact Insurance Company | 9 | 6.08 |
| • Jevco Insurance Company | 1 | 0.68 |
| • Liberty Mutual Insurance Company | 1 | 0.68 |
| • Pafco Insurance Company | 1 | 0.68 |
| • Pembridge Insurance Company | 2 | 1.35 |
| • Royal & Sun Alliance Insurance Company of Canada | 1 | 0.68 |
| • Security National Insurance Company | 2 | 1.35 |
| • TD Direct Insurance Inc | 1 | 0.68 |
| • TD General Insurance Company | 2 | 1.35 |
| • TD Home and Auto Insurance Company | 5 | 3.38 |
| • The Personal Insurance Company | 4 | 2.70 |
| • Tradition Mutual Insurance Company | 1 | 0.68 |
| • Travelers Insurance Company of Canada | 5 | 3.38 |
| • Unica Insurance Inc. | 3 | 2.03 |
| • Unifund Assurance Company | 3 | 2.03 |
| • The Wawanesa Mutual Insurance Company | 2 | 1.35 |

| | | |
|--------------------------------|----|------|
| • Western Assurance Company | 3 | 2.03 |
| • Zenith Insurance Company | 2 | 1.35 |
| • Zurich Insurance Company Ltd | 1 | 0.68 |
| • Other | 10 | 6.76 |