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UNIVERSITY OF TASMANIA

Knowledge of Traumatic Brain Injury in Informal and Professional Carers

Minette Janse van Rensburg

Supervised by: Dr Christine Padgett

A report submitted in partial requirement for the degree of Master of Psychology (Clinical) at

the University of Tasmania, 2023

Statement

I declare that this research report is my own work and that, to the best of my knowledge and belief, it does not contain material from published sources without proper acknowledgement, nor does it contain material which has been accepted for the award of any other higher degree or graduate diploma in any university.

Signature:

Acknowledgement

First and foremost, I would like to sincerely thank my supervisor, Dr Christine Padget, for her invaluable support, patient guidance, and dedicated involvement throughout this process. I would also like to acknowledge the work of the larger TBI MOOC team, and specifically Alex Kitsos and Tim Saunder for their assistance with data extraction. I would also like to thank the participants for their involvement in this study.

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Abstract

Traumatic Brain Injury (TBI) is a complex injury that often results in impairments in functioning that may be temporary, long-term, or permanent. Consequently, at least two-thirds of individuals who suffer TBI require support and assistance from carers to complete everyday tasks for at least some period after the injury. Despite the significant burden and ramifications associated with TBI, misconceptions and a general lack of knowledge about TBI is widespread among people with TBI, their family members and friends, and the broader community. The aim of the current study was to investigate the knowledge of TBI held by individuals involved in providing care for people with TBI. Six hundred and twenty-one individuals with TBI caring experience (informal carers $n = 113$, paid disability/support workers $n = 77$, paid health professionals $n = 431$), aged 18-81, completed a self-report measure, the Common Misconceptions of Traumatic Brain Injury (CM-TBI; Gouvier, Prestholdt, & Warner, 1988), to assess their knowledge of TBI across several domains. In line with predictions, health professionals demonstrated significantly more knowledge of unconsciousness and amnesia compared to informal carers and disability/support workers, however, this effect was not found for brain damage. Contrary to predictions, this study did not show informal carers and disability/support workers to have significantly more knowledge of brain injury sequelae, recovery, and rehabilitation, as compared to health professionals. The clinical and practical implications of these findings are considered and potential directions for future research are discussed.

Knowledge of Traumatic Brain Injury in Informal and Professional Carers

1.1 Traumatic Brain Injury

Traumatic Brain Injury (TBI) is characterised by damage to the brain and/or neural dysfunction that has developed following an external force to the head (Qadeer et al., 2017). Each year in Australia, it is predicted that 200, 000 individuals will experience TBI, with over 20, 000 of these individuals' requiring hospitalisations as a result of the injury (Feigin, 2013). In Australia, causes of TBI most commonly include falls (42%), transport accidents (29%) and assault (14%) (Jaimieson, Harrison, & Berry, 2008). There are several factors that place some individuals at increased risk of acquiring TBI compared to the general population (Roebuck-Spencer & Cernich, 2014). Firstly, age is an important factor of TBI incidence, as infants under the age of four and adults over the age of 65 have been found to be more likely to suffer TBI due to increased vulnerability related to mobility issues and therefore, increased susceptibility to falls (Faul et al., 2010; Harvey & Close, 2012). Additionally, adolescents aged between 15 and 19 also have a higher likelihood of experiencing TBI due to increased engagement in risk-taking behaviours (Asemota et al., 2013). Further, studies have universally reported greater prevalence of TBI in males than females (Biegon, 2021; Gupte et al., 2019), which is often attributed to the greater tendency demonstrated by males to engage in physical altercations, contact sports, and other risk-taking behaviours (Frost et al., 2012). Finally, Indigenous Australians have also been identified to be at higher risk of suffering TBI (Esterman et al., 2018; Jamieson et al., 2008).

TBI often presents as a complex injury with a broad range of symptoms, as severity of TBI ranges from mild to extremely severe (Corrigan, Selassie, & Orman, 2010; Pozzato et al., 2019). Depending on the severity of TBI suffered, ramifications following TBI may be temporary, long-lasting, or permanent (Roebuck-Spencer & Cernich, 2014). These ramifications may include impairments in functioning, including cognitive, behavioural, physical, and social (Fitts et al., 2019). For example, individuals who suffer TBI may develop

increased aggression and disinhibition, poorer self-awareness, and impaired social skills, all of which may adversely impact the individuals' interpersonal relationships (Roebuck-Spencer & Cernich, 2014). These impairments in functioning following TBI negatively impacts not only the individual with TBI, but also affects their family members, friends, and the community surrounding them (Douglas, 2019; Riley, 2016). Further, as the recovery process following TBI is often lengthy and incomplete, individuals who attempt to re-enter community, school, or work environments, while still learning to manage their deficits, may be expected to function at the same level as before the TBI (Guilmette & Paglia, 2004). As the impairments faced by individuals who suffered TBI may diminish their ability to successfully re-engage at previous levels of employment, return to work following TBI has been highlighted as one of the lowest areas of psychosocial outcome (Draper, Ponsford, & Schonberger, 2007). Therefore, TBI has been found to result in impairments that may significantly disrupt the ability to function effectively in everyday life (Barman, Chatterjee, & Bhide, 2016). Given the large number of TBIs that occur, and the insidious nature of symptoms, TBI has been deemed a 'silent epidemic' as the Australian community is generally unaware of the extent of the problem (Jagnoor & Cameron, 2014).

In addition to difficulty retuning to work or school, many individuals who have TBI face a loss of personal independence in completing everyday tasks, such as caring for themselves, driving, and leisure activities (Lieshout et al., 2020). This loss of independence following TBI can be due to changes in motor function, cognitive function, or a combination of both (Fujimoto et al., 2004; Wilson et al., 2021). Consequently, individuals may not have the ability to return to independent living settings following TBI and may need to live with family members or friends. Further, individuals who acquire moderate to severe TBI are more likely to require in-patient community-based placements, with care provided by formal carers (Eum et al., 2015). This study aims to explore the knowledge about TBI held by individuals involved in the care of people with TBI.

1.2 Carers of individuals with TBI

As TBI often results in impairment of functioning (Fitts et al., 2019), many individuals with TBI require long-term or life-long assistance to complete everyday activities and rely on carers for this assistance (Dillahun-Aspilaga et al., 2013). According to the Australian Bureau of Statistics (2007), at least two-thirds of people with TBI require assistance from a carer, at least for short term recovery; however, for many individuals with TBI, this assistance is required for longer or lifelong recovery. As individuals with mild to moderate TBI often return home shortly after suffering TBI, this carer role typically falls to family members and friends (Jackson et al., 2009). However, due to the social difficulties that arise following TBI, individuals may experience an absence of social relationships or challenges with their current relationships and therefore, informal care provided by family members and friends may not be possible (Douglas, 2019; Lefebvre, Cloutier, & Josee Levert, 2008). Even when informal care is provided, as impairments following TBI are often long-term, respite and additional care may be required (DeGraba et al., 2021; Lieshout et al., 2020). In this case, or for individuals who sustained more severe TBI and acute physical, cognitive and/or behavioural deficits, formal care arrangements, such as acute inpatient rehabilitation, may be utilised (Khan, Baguley, & Cameron, 2003).

Accessing formal care services is often dependent on people with TBI's perception of their own needs and their previous experiences with health services, along with their attitudes and beliefs of moving to supported accommodation, and receiving care from individuals who are not family members or friends (Gordon, Simpson, & Paasila, 2023). Furthermore, the carer's own beliefs about TBI may have an impact on decisions regarding support (O'Callaghan, McAllister, & Wilson, 2011). As such, knowledge about the nature of TBI can play an important role in decision making.

1.2.1 Informal carers. As there are limited suitable formal services available to individuals who suffered moderate to severe TBI, and the process of locating these options

tends to be demanding, extensive, and financially expensive, approximately two-thirds of the care provided to individuals' with TBI after discharge from hospital is provided by informal carers (Hopman, Tate, & McCluskey, 2012; Piccenna et al., 2016). Informal caregiving usually falls to family members or friends and often, due to the sudden and unexpected onset of TBI, these carers are thrust into their new roles with little to no time to prepare and adapt (Jackson et al., 2009; Lieshout et al., 2020). The challenge of adjusting to the role of caregiving is often further exacerbated by personality and behavioural changes that develop after TBI (McAllister, 2008). As such, previous research has found the adjustment to the caregiving role to be more arduous for spouses, as the relationship undergoes significant strain resulting from increased dependence and social isolation (O'Callaghan, McAllister, & Wilson, 2011). As deterioration of friendships and engagement in previously enjoyed leisure activities is prevalent following TBI, individuals with TBI often become progressively dependent on informal carers to fulfil their social needs (Douglas, 2019). This increases caregiver burden, as informal carers have limited opportunity to engage in their social networks, resulting in increased social isolation (D'Ippolito et al., 2018; McIntyre, Ehrlich, & Kendall, 2020).

1.2.2 Formal carers. Formal carers are characterised as individuals who are paid to provide services of care for individuals and have some level of training in caregiving, for example, health professionals or disability/support workers (Li & Song, 2021). Formal carers may be employed to deliver respite for informal carers to ease some of the pressure associated with caring (Behn et al., 2012). However, for individuals who acquire moderate to severe TBI, formal carers may also be employed to care on a more regular basis, either in individual or group settings. This long-term formal care often involves extensive support in coordinating ongoing care, re-engage in everyday life activities, and re-integration into workplace roles (Gordon, Simpson, & Paasila, 2023). While formal care settings for individuals with TBI are often facilitated by rehabilitation professionals, who provide care,

support, and advice to individuals with TBI and their families, these rehabilitation professionals may not have had the opportunity to undergo formal training specifically focusing on TBI and its effects (Swift & Wilson, 2001). For the purpose of this thesis, we have broadly classified formal carers into two groups: disability/support workers, and those in the allied health/health professions. Each is described in the following sections.

1.2.3 Disability/support workers. Disability/support workers play a vital role in supporting individuals with TBI to participate fully in society (Topping, Douglas, & Winkler, 2022). When providing care for individuals with TBI, disability/support workers often have a range of responsibilities, including assistance with everyday personal care, organisation of social leisure and recreational activities, management of finances, and facilitating skill development post TBI (Hewitt & Larson, 2007; Iacono, 2010; Redhead, 2010). Despite the various skills and depth of knowledge of TBI required for this caring role, previous research has found disability/support workers enter the workforce with widely diverse levels of education and training, ranging from secondary school education to university degrees (Dempsey & Arthur, 2002). Historically in Australia, a low percentage of disability/support workers have held formal qualifications (Cortis et al., 2013). Further, as there are no suggested formal qualifications or training requirements for disability/support workers prior to entering the workforce (Macdonald & Charlesworth, 2016; Ryan & Stanford, 2018), many are forced to learn and develop skills and competencies on-the-job (Cortis et al., 2013). As a result, disability/support workers may enter this role with a lack of knowledge or the necessary skills to competently provide care in this highly demanding, and often challenging, caring role.

1.2.4 Health and allied health professionals. For the purpose of this thesis, health and allied health professionals have been combined to acknowledge that both health professionals (e.g. nurses) and allied health professionals (e.g. physiotherapists, psychologists, speech pathologists, occupational therapists) may play a role in caring for

people with TBI, and will collectively be referred to as health professionals from hereon. Health professionals undergo rigorous training and education to obtain the formal qualifications required to enter the workforce (Grimmer-Somers, Milanese, & Kumar, 2012). For example, in Australia as part of their training requirements, health professionals complete work-integrated learning, where they undergo supervised work to gain experience, build competency and ultimately, prepare to work in their professions (Luders et al., 2021; Penman et al., 2023). Additionally, this training aims to provide health professionals with skills and knowledge to manage the various responsibilities of the role, including identifying and assessing difficulties, providing treatment, monitoring progress, and supporting individuals through recovery and rehabilitation (Houghton et al., 2012; Thomas, McLean, & Debnam, 2011).

1.3 Misconceptions of TBI

Despite the significant burden and ramifications associated of TBI, misconceptions and a general lack of knowledge about TBI is widespread among individuals with TBI, family members, and the broader community (Swift & Wilson, 2001), and even in health professions (Farmer & Johnson-Gerard, 1997; Hooper, 2006; Oyesanya et al., 2016).

Previous research has assessed individuals' misconceptions and inaccurate beliefs related to TBI using the Common Misconception of Traumatic Brain Injury (CM-TBI; Gouvier, Prestholdt, & Warner, 1988) questionnaire. This widely used, established, and well-researched self-report measure comprises of seven subtests that cover various domains related to TBI, including prevention of TBI, unconsciousness, amnesia, brain damage, brain injury sequelae, recovery, and rehabilitation.

Several studies have explored misconceptions of TBI held by the general population, with findings suggesting 50% of individuals have misconceptions of unconsciousness and 46% of individuals have misconceptions about amnesia, specifically the inaccurate belief that a second blow to the head could reduce amnesia and restore memories (Gouvier, Prestholdt,

& Warner, 1998). Additionally, a study by Hux et al. (2013) reported 93% of the general population held the inaccurate belief that an individual with TBI may have severe memory impairment but be normal in every other way. These misconceptions of amnesia may be a result of the portrayal of memory loss in the media (Block, West & Goldin, 2016; Baxendale, 2004). Studies have also found that the general population has misconceptions of the long-term ramifications of TBI (Willer et al., 1993) and hold the inaccurate belief that following a severe TBI, individuals can make a full recovery (Merz, Van Patten, & Lace, 2017). These misconceptions about unconsciousness, amnesia, brain injury sequelae, and the recovery process held by the general population may have significant ramifications for individuals with TBI, as lack of knowledge results in increased frustration related to unrealistic expectations, leading to more intensified deficits and therefore, potentially hindering recovery and re-integration into the community (Guilmette & Paglia, 2004). Further, these unrealistic expectations held by several invested parties may not align more generally with achievable outcomes or the expectation held by others.

Due to the sudden onset, many people with TBI and their family members lack adequate knowledge about TBI (Guilmette & Paglia, 2004). Although few recent studies have explored specific misconceptions held by family members, a study by Springer, Farmer, and Bouman (1997) found that similarly to the general population, family members of individuals with TBI held misconceptions regarding amnesia, unconsciousness, and the recovery process. More broadly, this study found family and friends of individuals with TBI lacked understanding that recovery from TBI is not determined by an individual's hard work but rather by the severity and extent of the TBI suffered. This lack of knowledge of TBI plays a crucial role in informal carers experience of distress and emotional, financial, and physical burden, all leading to carer burnout (Block et al., 2014). Further, feelings of inadequacy and frustration experienced by informal carers due to misconceptions may impact treatment outcomes of individuals with TBI; as reported by Awadh Bamatraf et al. (2021), recovery

time for an individual with TBI is closely linked to the level of stress and psychological burden experienced by carers. Providing informal carers with sufficient information about TBI improves preparedness and assists with better adjustment to the changes they are experiencing, consequently, reducing the risk for psychological distress, both for the carer and the person with TBI (Samartkit et al., 2010).

Despite the misconceptions held by informal carers, previous studies have found personal experience with TBI to be associated with accuracy of knowledge about TBI (Gouvier, Prestholdt, & Warner, 1988; Guilmette & Paglia, 2004) and tends to moderate some common misconceptions. Merz, Van Pattern, and Lace (2017) suggested that family members of individuals with TBI exhibited more knowledge about injury prevention, brain damage, and brain injury sequelae, while Springer, Farmer, and Bouman (1997) found family members caring for individuals with moderate to severe brain to have fewer misconceptions regarding the direct impact of brain injury and adverse effect on cognition as compared to individuals in the general population. While it is possible that family members in this study by Springer et al. (1997) may have different education levels to individuals in the general population, as education levels were not reported in the paper, this aspect remains somewhat unclear. Further research in the specific areas of TBI in which informal carers hold misconceptions will be beneficial in helping to alleviate their distress and supporting re-engagement in the community.

In addition to misconceptions about TBI held by family members and friends, studies have highlighted that misconceptions about TBI are also present in health care professionals involved in the care of individuals with TBI (Ernst et al., 2009; Farmer & Johnson-Gerard, 1997; Hooper, 2006; Oyesanya, Turkstra, & Bowers, 2016). For example, a study by Ernst et al. (2009) investigated pre-nursing and nursing major students' misconceptions of TBI by utilising a shortened version of the CM-TBI, which included subtests across five domains of TBI, including prevention, unconsciousness, amnesia, brain damage and recovery. Findings

of this study indicated that nursing students demonstrated high rates of misconceptions regarding recovery and amnesia, with percentages of incorrect responses in line with those of the general population (Gouvier et al., 1988) and family members (Springer et al., 1997). Additionally, this study also found nursing students demonstrated lower rates of misconceptions regarding brain damage and unconsciousness as compared to the general population. Concerningly, we were unable to find any specific research regarding TBI-related knowledge in disability/support workers, and as such it is uncertain whether there are specific areas in which disability and support workers might have misconceptions.

Despite the lack of literature regarding disability and support workers, there is research about TBI-related knowledge of health professionals. As health professionals often care for a multitude of individuals with a variety of different presentations and complex needs, Swift and Wilson (2001) found that medical professionals (e.g. doctors, nurses, occupational therapists, physiotherapists) who did not specialise in TBI also had several misconceptions of TBI, similar to those held by individuals in the general population. Their study specifically found that medical professionals held misconceptions about recovery time and the possible degree of recovery following TBI. Similarly, misconceptions and inaccurate beliefs about recovery from TBI have been identified in nurses (Ernst et al., 2009), psychologists (Hooper, 2006) and correctional health care professionals (Yuhazs, 2013). This is particularly pertinent given the shift in Australia of care being provided by professionals with a broad range of client presentations (Obembe et al., 2018).

While previous research reported similarities in their findings of misconceptions of TBI held by health professionals, some studies have reported contradicting findings. For example, Gurusamy et al. (2019) found second and third year nursing students held the highest rates of misconceptions in the domains of brain damage and brain damage sequelae, however, in contrast, Ernst et al. (2009) and Yuhazs (2013) found the brain damage domain to be the lowest scored misconception as compared to other domains of TBI, including

prevention, brain injury sequelae, unconsciousness, amnesia, recovery, and rehabilitation. As such, exploration into the specific areas of TBI in which common misconceptions are held by formal carers is crucial to help inform further training in these areas and consequently, improve the quality of care provided to TBI individuals.

1.3 Rationale, aims and hypotheses

Although preventing misconceptions in the community is a crucial element of the feedback process in caring for individuals with TBI, the potential lack of knowledge about TBI by formal carers may be passed onto family members and the general community, therefore affecting the quality of care the informal carers provide (Bryant et al., 2020). Further, as many formal carers suffer professional time constraints, they may be unable to thoroughly discuss all the potential impacts of TBI with family members and friends (Norman et al., 2021). As a result, formal carers are often faced with the decision of whether it is more pertinent to provide family members and friends with information about current deficits or longer-term outcomes following TBI (Springer et al., 1997). Even when family members and friends of individuals with TBI receive information from healthcare professionals, findings have indicated knowledge of brain injury sequelae remains poor (Guilmette & Palgia, 2004). It is essential for misconceptions about TBI to be identified and corrected within families and friends of individuals with TBI and within society, as these misconceptions ultimately result in poorer adjustment to the injury and difficulty re-engaging in the community.

There is a clear need for more research to be conducted in this area to establish differences in misconceptions and knowledge of TBI between different types of carers. While previous studies have focused primarily on misconceptions in the general population and health professionals, who have a significant function in the rehabilitation of individuals with TBI (Oyesanya et al., 2018), there is little to no research to our knowledge regarding misconceptions of disability/support workers. Therefore, the current study seeks to identify if

there are differences in knowledge of TBI between informal carers (family/friends), disability/support workers and health professionals, and to identify whether there are specific knowledge gaps for the groups in question.

This study proposed to investigate knowledge of TBI – specifically within family/friends, disability/support workers and health professionals caring for individuals with TBI. This comparison will furthermore add to the limited literature on the differences in knowledge of TBI in informal versus formal carers. Based on previous literature, it is anticipated that informal carers (family members and friends) will have better awareness, knowledge and understanding of the effects following TBI than disability/support workers and health professionals, as previous research suggested informal carers hold fewer misconceptions about brain injury sequelae (Merz, Van Pattern, & Lace, 2017). It is also possible that health professionals will have more knowledge of brain damage, unconsciousness, and amnesia than informal carers and disability/support workers, given that health professionals receive some level of training and education relating to TBI (Li & Song, 2019), and that both disability/support workers and informal carers caring for individuals with TBI will have more knowledge of rehabilitation and recovery than health professionals, as disability/support workers and family members/friends provide support and assistance on a day-to-day basis and therefore, may be more likely to seek information and educate themselves about recovery and rehabilitation. Therefore, the hypotheses are as follows:

Hypothesis 1: Informal carers will have more knowledge of brain injury sequelae (as measured by the CM-TBI) compared to disability/support workers and health professionals, who will not differ from one another.

Hypothesis 2: Health professionals will have higher scores on the brain damage, unconsciousness, and amnesia subscales of the CM-TBI compared to informal carers and disability/support workers, who will not differ from one another.

Hypothesis 3: Both disability/support workers and informal carers will have more knowledge of TBI related rehabilitation and recovery, as measured on the CM-TBI, compared to health professionals.

2. Method

2.1 Participants

Participants in this study were a convenience sample of formal and informal carers enrolled in the 2022 iteration of the Understanding Traumatic Brain Injury (TBI) Massive Open Online Course (hereafter referred to as the TBI MOOC). The TBI MOOC is a free six-to-eight-week course that is provided by the Wicking Centre at the University of Tasmania. TBI MOOC aims to improve awareness and knowledge of TBI to enhance rehabilitation outcomes for individuals who have suffered TBI. TBI MOOC is open to individuals worldwide, including health care professionals and family and friends caring for individuals who have suffered TBI. The sample included participants aged over 18 who agreed to voluntarily participate in the online survey prior to commencing the TBI MOOC. TBI MOOC participants were included in the study if:

1. They provided consent to participate in the research.
2. They identified themselves as informal, disability/support carers or health professionals with TBI caring experience in the demographics.
3. They completed the pre-course Common Misconception – Traumatic Brain Injury (CM-TBI).

The final sample consisted of 621 participants, with 113 participants in the informal carer group, 77 participants in the disability/support worker group and 431 participants in the health professional group. To determine whether there were differences in demographic or clinical characteristics between the carer groups, an ANOVA and chi square test was conducted (see Table 1). These tests showed that age differed across groups, such that the participants in the informal carer and disability/support worker groups were significantly

older than the participants in the health professional group. No other differences between groups were identified.

Table 1. Participant demographics.

Characteristic	Informal Carers (<i>n</i> = 113)	Disability/Support Workers (<i>n</i> = 77)	Health Professionals (<i>n</i> = 431)	<i>F</i> (2, 116) / χ^2	<i>p</i> -value
Sex <i>n</i> (%)				4.99	0.288
Male	17 (2.8)	6 (1.0)	67 (10.9)		
Female	94 (15.3)	68 (11.1)	358 (58.4)		
Other	1 (0.2)	1 (0.2)	1 (0.2)		
Age (years)				37.7	<.001
Mean (SD)	51.8 (13.9)	47.8 (11.1)	40.8 (12.7)		

2.2 Measures

2.2.1 Demographics. Demographic information, including age and gender, was collected from participants. Further, participants were required to identify their current occupation from a drop-down list.

2.2.2 Independent measures: Carer status. Participants reported their carer status using a drop-down menu prior to completing the pre-course survey and the TBI MOOC. Participants were identified as formal carers if they reported they were paid disability/support workers or health professionals who had experience providing care to an individual with TBI. In contrast, participants were identified as informal carers if they reported they provide any form of unpaid care to a friend or family member with TBI.

2.2.3 Knowledge of TBI. Common Misconceptions – Traumatic Brain Injury (CM-TBI; Gouvier, Prestholdt, & Warner, 1988) is a 40-item self-report questionnaire with seven subtests addressing the main domains of TBI, including prevention (4 items), brain damage (4 items), brain injury sequelae (9 items), unconsciousness (3 items), amnesia (4 items) recovery process (13 items), and rehabilitation (3 items). Further, as there is a general misunderstanding in the population of the severity of concussion and how these relate to TBI (Block, West, & Goldin, 2016), a concussion subtest (5 items) was added (See Appendix B

for all items). The concussion subtest is a newly developed measure currently undergoing validation procedures (C. Eccleston, personal communication, October 26, 2023).

For each item, participants utilised a 4-point Likert Scale ('*true*', '*probably true*', '*probably false*', and '*false*') to signify their agreement or disagreement with statements relating to TBI. A score of 2 was allocated for correct answers where the participant was sure (e.g. '*true*' or '*false*'), 1 for correct answers but where the participant is unsure (e.g. '*probably true*' or '*probably false*') and 0 for incorrect answers or '*don't know*' responses. Scores from the subtests are summed to generate a total score, with total scores ranging from 0 – 90, with higher scores showing greater knowledge of TBI. The CM-TBI, including the seven core subtests, has previously demonstrated good reliability and internal consistency ($\alpha=0.69$ to 0.84 ; Pappadis et al., 2011; Pretorius & Broodryk, 2013).

2.3 Procedure

This study was approved by the University of Tasmania Human Research Ethics Committee (24140 – see Appendix A). Prior to starting the TBI MOOC, and following informed consent, participants are invited to complete the demographic and occupation questionnaire and a pre-course survey, the CM-TBI scale, online via LimeSurvey.

2.4 Design and Analysis

This study employed a cross sectional between group design. A series of ANOVAs were conducted, with the independent variable (IV) being group (3 levels: informal carer, disability/support worker with TBI caring duties, health professional with TBI caring duties), and the dependent variables (DV) being the subscales of the CM-TBI scale (prevention, brain damage, brain injury sequelae, unconsciousness, amnesia, recovery process, and rehabilitation), with the additional concussion subtest. To detect statistically significance difference between groups ($\alpha = 0.05$) with power set at 0.80, a G-Power analysis (Faul et al., 2007) suggested a sample of 176 participants would be required for a medium effect size.

Significant effects were followed up with Tukey HSD post hoc analysis. All preliminary and primary analyses were performed using Jamovi Statistical Software. The percentage of incorrect responses for each subscale were also calculated in line with previous studies (Ernst et al., 2009; Gurusamy et al., 2019; Springer et al., 1997), as this allowed the findings of the current study to be compared with previous literature.

3. Results

3.1 Preliminary Analyses

A review of the skewness and kurtosis statistics and the histograms revealed normal kurtosis for all CM-TBI subtests except brain damage. The brain damage subtest revealed positive skews that fell outside -2 and 2, suggesting a deviation in normality. Further, Levene's test showed that the variances of knowledge of brain damage among carer groups was unequal ($F(2, 618)=5.74, p < .05$). Similarly, this assumption was violated for the subtests of amnesia ($F(2, 618)=3.66, p < .05$) and rehabilitation ($F(2, 618)=7.95, p < .001$). As Levene's test found that the homogeneity of variance assumption had been violated, hypothesis tests were based on unequal variances. Further, the Shapiro-Wilk test demonstrated that the distribution of all CM-TBI subtests departed significantly from normality. As suggested by Field (2000), it is a known difficulty that when using Shapiro-Wilk for assumption testing in a large sample size, it is highly sensitive to detecting even small deviations in normality.

Parametric (ANOVA) and non-parametric (Kruskal-Wallis) analyses were run with no significant differences. Given this, and as Uttley (2019) suggests the violation of normality assumption within a large sample size should not have a major impact on results if robust analyses methods are used, only ANOVA results are reported here.

3.2 Primary Analyses

Table 2 shows the descriptive statistics and percentage of incorrect responses for each group. ANOVAs were conducted to determine whether knowledge of TBI differed between the three carer groups for each of the eight subscales, and the total score. The overall ANOVA results are provided in Table 3.

For the first hypothesis regarding knowledge about brain injury sequelae, as can be seen in Table 3, there was a significant difference in knowledge of brain injury sequelae between the carer groups with a small effect size. However, contrary to the first hypothesis, post hoc analyses indicated that health professionals had more knowledge of brain injury sequelae than informal carers [$t(618) = 2.356, p_{\text{tukey}} = .049$] and disability/support workers [$t(618) = 3.048, p_{\text{tukey}} = .007$]. Additionally, results revealed that knowledge of brain injury sequelae did not differ significantly between informal carers and disability/support workers.

There was partial support for the second hypothesis, with the ANOVAs showing a significant difference in knowledge of unconsciousness and amnesia between groups, with a small effect size. Post hoc analyses revealed that as expected, health professionals demonstrated significantly higher knowledge than informal carers [$t(618) = 2.809, p_{\text{tukey}} = .014$] and disability/support workers [$t(618) = 2.378, p_{\text{tukey}} = .047$] on the unconsciousness subscale. A similar effect was found on the amnesia subscales [health professional – informal carers $t(618) = 2.925, p_{\text{tukey}} = .010$; health professional – disability/support $t(618) = 3.109, p_{\text{tukey}} = .006$]. However, contrary to the proposed hypothesis, there were no significant differences between any of the carer groups' knowledge of brain damage.

Contrary to the proposed third hypothesis that disability/support workers and informal carers would have more knowledge of recovery and rehabilitation than health professionals, results revealed the opposite. Post hoc tests suggest that health professionals had more

Table 2. Descriptive results for CM-TBI subscales and total scales.

CM-TBI subscales	Carer group	<i>M</i>	<i>SD</i>	% incorrect responses
Prevention	Informal Carers	3.32	0.63	17.0
	Disability/Support Workers	3.30	0.63	17.5
	Health Professionals	3.30	0.70	17.4
Concussion	Informal Carers	3.64	0.97	27.3
	Disability/Support Workers	3.48	1.03	30.0
	Health Professionals	3.75	0.91	25.1
Brain damage	Informal Carers	3.66	0.61	8.4
	Disability/Support Workers	3.71	0.51	7.1
	Health Professionals	3.77	0.52	5.7
Brain injury sequelae	Informal Carers	6.48	1.59	24.8
	Disability/Support Workers	6.30	1.36	26.4
	Health Professionals	6.83	1.35	21.0
Unconsciousness	Informal Carers	1.28	0.90	57.2
	Disability/Support Workers	1.29	0.97	57.1
	Health Professionals	1.56	0.91	49.1
Amnesia	Informal Carers	1.44	0.79	64.0
	Disability/Support Workers	1.39	0.69	65.3
	Health Professionals	1.66	0.68	58.5
Recovery	Informal Carers	9.41	2.45	27.6
	Disability/Support Workers	9.57	2.32	26.4
	Health Professionals	9.7	2.29	25.4
Rehabilitation	Informal Carers	2.17	0.86	27.7
	Disability/Support Workers	2.14	0.84	28.6
	Health Professionals	2.53	0.66	15.5
Total score	Informal Carers	33.0	5.67	
	Disability/Support Workers	32.6	5.15	
	Health Professionals	35.7	5.15	

Table 3. ANOVA results for CM-TBI subscales and total scales.

Measure	<i>F</i> (2, 618)	<i>p</i> -value	ω^2
CM-TBI subscales			
Prevention	0.03	0.975	-0.003
Concussion	2.90	0.056	0.006
Brain damage	1.93	0.146	0.003
Brain injury sequelae	6.35	0.002	0.017
Unconsciousness	5.77	0.003	0.015
Amnesia	7.74	<.001	0.021
Recovery	0.72	0.487	-0.001
Rehabilitation	17.9	<.001	0.052
Total score	20.4	<.001	0.059

knowledge of rehabilitation than informal carers [$t(618) = 4.787, p_{\text{tukey}} = <.001$] and disability/support workers [$t(618) = 2.372, p_{\text{tukey}} = <.001$]. Further, no statistically significant differences in knowledge of recovery were found between carer groups.

Results also revealed that health professionals scored higher on all subscales of the CM-TBI as well as the additional concussion subtest and consequently, health professionals demonstrated significantly higher overall knowledge of TBI than the other two groups. Finally, the results revealed that there was no significant difference in knowledge of prevention and concussion, as related to TBI, between the carer groups. The marginal means and confidence intervals for CM-TBI and concussion subscales can be seen in Figure 1 below.

3.3 Ancillary Analyses

Given the variation between subscales on percentage of incorrect scores, an exploratory analysis of the differences in knowledge of TBI collapsed into correct/incorrect categories across all groups was conducted to identify the ranking of knowledge in these areas. A repeated measures ANOVA using Tukey post hoc analysis revealed significant difference between all scales, with the exception of prevention and rehabilitation, with lack of knowledge being ranked in the following order (from least knowledge to most knowledge): amnesia, unconsciousness, concussion, recovery, brain injury sequelae, rehabilitation, prevention, and brain damage. However, given the number of items in each subscale varies, this result needs to be interpreted cautiously. The output for this ancillary analysis is in Appendix C. Figure 3 shows the mean percentage of knowledge and associated standard error.

Figure 1. Plots of marginal means and confidence intervals for CM-TBI and concussion subscales.

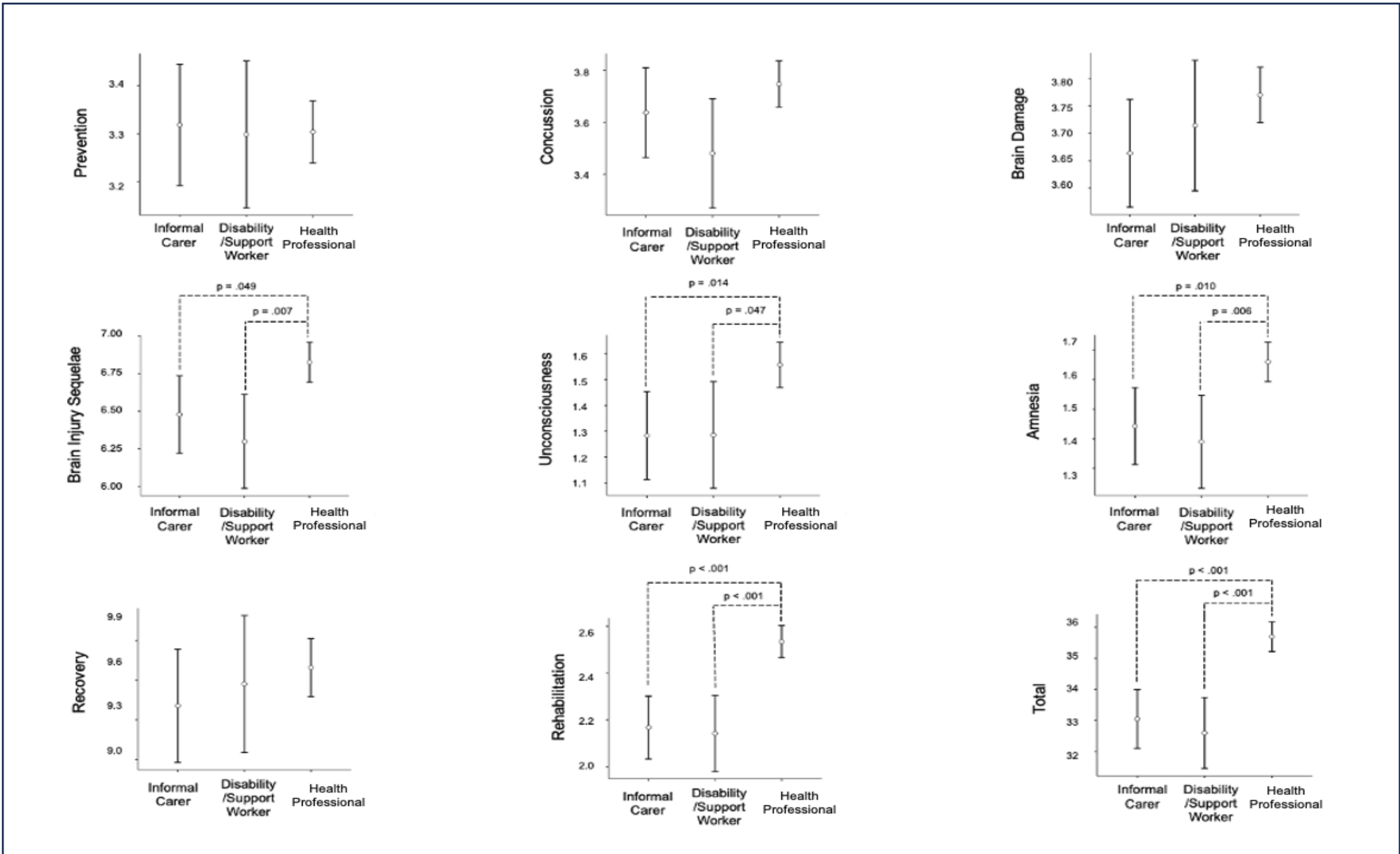
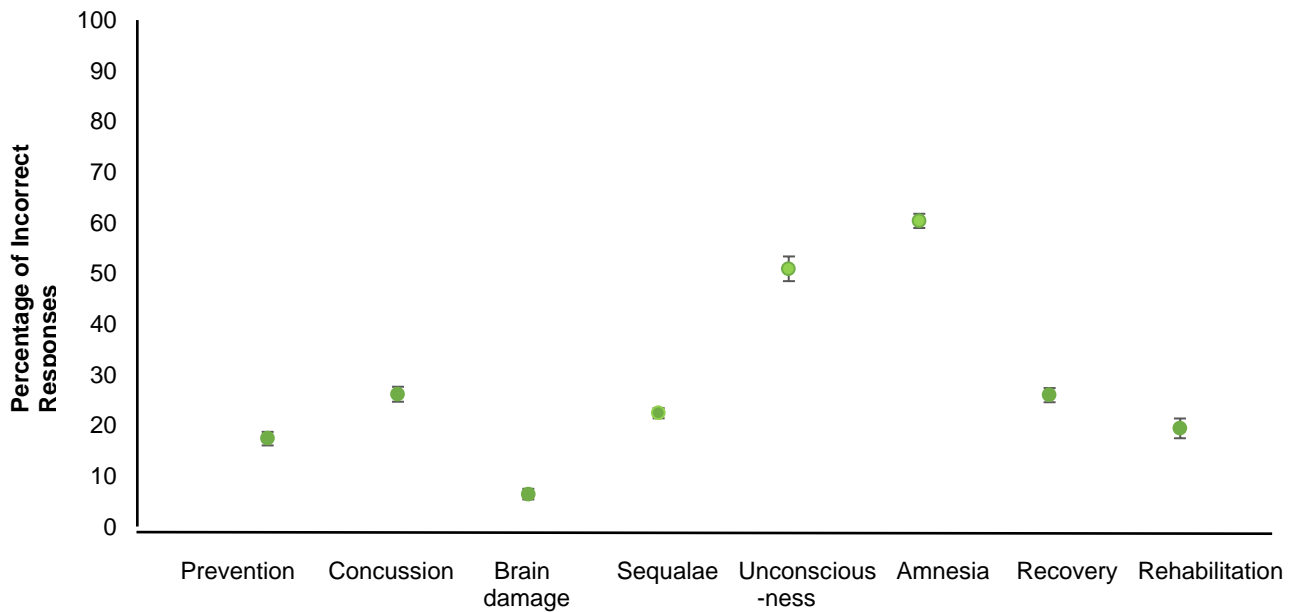


Figure 2. Percentage and standard error of incorrect responses for CM-TBI and concussion subscales across all groups.



4. Discussion

The present study investigated and compared the knowledge of TBI held by different types of carers: informal carers, disability/support workers and health professionals. The first hypothesis that informal carers would have more knowledge of brain injury sequelae, as related to TBI, compared to disability/support and health professionals, was not supported. Contrary to prediction, results of this study found health professionals had more knowledge of brain injury sequelae than informal carers and disability/support workers. The second hypothesis that health professionals would have more knowledge of unconsciousness, amnesia, and brain damage than informal carers and disability/support workers, was partially supported. As predicted, results revealed that health professionals had more knowledge of unconsciousness and amnesia than informal carers and disability/support workers, however, this effect was not found for brain damage. Next, the third hypothesis that informal carers and disability/support workers have more knowledge of recovery and rehabilitation following TBI than health professionals, was not supported, as no significant differences in knowledge of recovery was found between groups. Further, contrary to prediction, health professionals

demonstrated more knowledge of rehabilitation, compared to informal carers and disability/support workers. To better understand this, the following sections consider how the three carer groups might utilise or be exposed to each of the elements of knowledge. In addition to the primary hypotheses, we also found that misconceptions varied greatly across the CM-TBI subscales. The applications of this will be considered in the implications and future directions section.

- 4.1 Brain Injury Sequelae

As disability/support workers and informal carers provide day-to-day support to individuals with TBI, and personal experience with TBI has been linked with accuracy of knowledge (Gouvier, Prestholdt & Warner, 1988; Guilmette & Paglia, 2004), it was postulated that these carers would have increased awareness and understanding of the ramifications following TBI. However, contrary to prediction, findings of the current study suggest health professionals have significantly more knowledge of brain injury sequelae compared to disability/support workers and informal carers. Specifically, results indicate lower rates of misconception of brain injury sequelae for health professionals (21.0%), and higher rates of misconception for informal carers (24.8%) and disability/support workers (26.4%). This finding is surprising, given previous evidence suggested brain injury sequelae was the second highest scoring misconception for nursing students (74.7%; Gurusamy et al., 2019) and one of the lowest scoring misconceptions for family members of individuals with TBI (11.2%; Springer et al., 1997). However, as will be described in a subsequent section, the findings of Gurusamy et al. (2019) are notably different to findings of other researchers who also explored nurses' knowledge of other domains of TBI (e.g., Ernst et al., 2009), and therefore, should be interpreted with caution. As there are considerable differences in findings in the current study compared to previous research, further investigation of carers' knowledge of brain injury sequelae would be beneficial.

4.2 Unconsciousness

While the findings of the current study support the proposed hypothesis that health professionals demonstrate significantly more knowledge of unconsciousness compared to informal carers and disability/support workers, the rate of endorsement of misconceptions of unconsciousness remained high for health professionals caring for individuals with TBI (49.1%). These results are in line with previous findings that although nurses held fewer misconceptions of unconsciousness compared to family members and the general population, the rate of misconceptions was still substantial (Ernst et al., 2009; Gurusamy et al., 2019). One possible explanation for the high rate of misconception may be a result of the training received by health professionals in various roles, which may include inaccurate or conflicting information of unconsciousness, resulting in confusion and ultimately, the development of misconceptions of TBI-related unconsciousness. Additionally, these misconceptions of unconsciousness held by health professionals may be passed onto informal carers or disability/support workers, leading to increased carer burden and frustration. As findings of the current study suggest high rates of misconceptions in informal carers (57.2%), it may be important to consider the possible impact of optimism bias (Dolinski et al., 2021). As family members and friends are likely to have greater personal investment in the wellbeing of the individual with TBI, these informal carers may lean towards more optimistic viewpoints of TBI, resulting in inaccurate beliefs. For example, carers may hold the inaccurate belief that when unconscious, individuals with TBI have awareness of what is happening around them, as this may provide carers with hope that their loved ones' medical status following TBI is less severe.

4.3 Brain Damage

Contrary to prediction, no significant difference in knowledge of brain damage was identified between the carer groups. The percentage of misconceptions for the brain damage

domain was low across all carer groups in the current sample: health professionals (5.7%), disability/support workers (7.2%), and informal carers (8.5%). These results are in line with the findings of previous research with family members (6.7%; Springer et al., 1997), as well as American samples of nurses (6.6%; Ernst et al., 2009), but contrast dramatically with the rate of misconception of brain damage found in nurses from a more recent study by Gurusamy et al. (80.2%). One factor that may explain the substantial difference is that as the studies by Ernst et al. (2009) and Gurusamy et al. (2019) were conducted in different countries, the considerable difference in rates of misconception may be attributed to vast variations in the education and training received by health professionals. Therefore, until this study has been replicated, it is suggested that the results reported by Gurusamy et al. (2019) be treated with caution when comparing the findings to other studies.

4.4 Amnesia

Supporting the proposed hypothesis, results from the current study indicate that health professionals demonstrated significantly more knowledge of amnesia as compared to disability/support workers and family members/friends caring for individuals with TBI. This coincides with past research that approximately half of the general population exhibited an evident lack of accurate knowledge of amnesia, with many individuals holding misconceptions relating to memory loss prior to and following TBI and the impact of memory loss on general functioning (Gouvier et al., 1988; Guilmette & Paglia, 2004; Hux et al., 2013; Willer et al., 1993). Further, in the current study, the percentage of misconceptions for health professionals for the amnesia domain was relatively high (58.5%) and in line with the findings of a previous study of nurses (55.6%; Ernst et al., 2009).

One possible explanation for the findings of the current study is as health professionals are often faced with professional time constraints (Springer et al., 1997), rather than passing on knowledge of amnesia to informal carers, health professionals may choose to

spend the limited time post-discharge providing information of other aspects of TBI. However, if health professionals do choose to pass on their knowledge of amnesia to informal carers, the results of this study indicate as health professionals demonstrate high levels of misconceptions of amnesia, it is possible that this misinformation and inaccurate beliefs are transferred to informal carers. Persistent misconceptions of amnesia held by carers have been shown to result in stigmatisation of individuals with TBI (Poritz et al., 2019), further impacting on the wellbeing of both the carer and the individual with TBI. While research has shown the benefits of utilising interdisciplinary collaboration among health professionals when planning treatment for individuals with TBI-related memory deficits (Sander & Constantinidou, 2008), this finding suggests including disability/support workers and family members/friends in the treatment planning process would also be beneficial. This may provide an opportunity for health professionals to share their knowledge of broader aspects of TBI, including amnesia, with disability/support workers and family members/friends, and consequently may result in fewer misconceptions and more appropriate expectations of an individuals' functioning following TBI.

Another explanation for the misconceptions of amnesia held by disability/support workers and informal carers is the portrayal of memory loss and TBI in the media. As the media both informs and reflects public opinion, it plays a crucial role in shaping the general populations' perception of amnesia and overall understanding of TBI (Block, West & Goldin, 2016). For example, movies and television shows often dramatise and oversimplify the experience of amnesia, with individuals spontaneously regaining memories or making an immediate recovery (Baxendale, 2004), all of which may contribute to the misconceptions about the causes, symptoms, and ongoing ramifications of amnesia. Further, the persistence of misconceptions of amnesia following TBI may be a result of limited opportunities for the family members and disability/support workers to gain access to accurate information about

TBI, through public education or awareness campaigns. Therefore, future research may focus on the development of education initiatives that is accessible to the general population as well as carers providing support to individuals with TBI.

4.5 Rehabilitation and Recovery

In the current study, it was postulated that as individuals with TBI are often dependent on informal carers and disability/support workers to provide care and support on a day-to-day basis (Jackson et al., 2009; Piccenna et al., 2016), these carers may be more likely to seek out information and educate themselves, for example by enrolling in the TBI MOOC, about the process of recovery and rehabilitation following TBI. Therefore, it was hypothesised that informal carers and disability/support workers would have more awareness, knowledge, and understanding of rehabilitation and recovery, compared to health professionals. However, contrary to our expectations, the results of this study indicated that health professionals (15.5%) had fewer misconceptions of rehabilitation compared to informal carers (27.7%) and disability/support workers (28.6%). One possible explanation for this finding is that as health professionals often work as part of multi-disciplinary teams (Nowell et al., 2022), they may have more exposure and awareness of the process and different aspects involved in rehabilitation following TBI. Further, previous research suggested that individuals hold inaccurate beliefs that rehabilitation following TBI largely focuses on building motor gains (Khan, Baguley, & Cameron, 2003). Interestingly, in the CM-TBI, two-thirds of items in the rehabilitation subtest focus on physical abilities, further reinforcing the emphasis placed on physical rehabilitation, as opposed to cognitive, psychological, and emotional rehabilitation. Therefore, it is possible that we were unable to capture the full extent of knowledge individuals may have of the rehabilitation process.

While this study did not identify significant differences in knowledge of recovery between carer groups, the findings suggest approximately a quarter of carers endorsed

misconceptions about the recovery process following TBI. This is in line with previous research that healthcare professionals and the general population hold inaccurate beliefs that individuals with TBI fully recover within a short period of time or that recovery is complete when individuals with TBI are discharged from acute care (Ernst et al, 2009; Hooper et al, 2006; Swift & Wilson, 2001; Merz, Van Patten, & Lace, 2017; Yuhazs, 2013). One possible explanation for misconceptions of recovery may relate to the understanding of recovery as influenced by the phrasing of brain ‘injury’, compared to brain ‘damage’, which may imply that full recovery from TBI is possible (Swift & Wilson, 2001). As previous research has shown lack of knowledge of recovery leads to unrealistic expectations, feelings of frustration and helplessness, and ultimately, poorer outcomes for both carers and TBI survivors attempting to reintegrate into society (Awadh Bamatraf et al., 2021; Block et al., 2016; Guilmette & Paglia, 2004), this study reiterates the importance of addressing misconceptions across all carer groups to assist with managing expectations and ensuring the provision of comprehensive and sustained support throughout the recovery process.

4.6 Strengths and Limitations

There are several strengths that set the current study apart from existing TBI research. Firstly, this is the first study to investigate the knowledge and misconceptions of TBI held by disability/support workers who care for individuals with TBI. As previous research has shown that individuals who sustain moderate to severe TBI often require long term, extensive support from formal carers, such as disability/support workers, to engage in everyday activities (Dillahunt-Aspilaga et al., 2013; Khan, Baguley & Cameron, 2003), it is beneficial to gain a deepened understanding of disability/support workers’ knowledge of TBI. Additionally, this study examined and compared knowledge of TBI between informal carers, disability/support workers and health professionals, highlighting similarities and differences

in knowledge of TBI between groups and providing useful information that can inform future carer training.

Despite these strengths, there are some limitations. Firstly, the study was limited as a result of the proportions of females. There is no previous research to our knowledge that has specifically investigated whether there are differences in knowledge of TBI between genders. In the current study, 84.4% of participants were female, therefore, males were significantly underrepresented. Nonetheless, the higher percentage of female carers is congruent with most previous TBI literature (Juengst et al., 2022), suggesting that due to traditional gender roles, women are more likely to assume caregiving roles compared to men. This is also in line with previous research findings of carers across a broad range of disabilities and chronic health conditions (Perrin et al., 2015).

Furthermore, this study has some limitations as participants were a convenience sample, recruited as they had independently registered to participate in the TBI MOOC. As these participants demonstrated interest in learning more about TBI, there may be sampling bias, as these participants may have pre-existing knowledge or previous learnings about TBI or may have increased awareness of TBI and its impacts.

Additionally, in this study, professionals from various caring occupations (e.g., physiotherapists, occupation therapists, psychologists, nurses) were grouped together under the umbrella term of 'health professional'. As a result, the grouping of professionals in this study may have posed the potential risk of overlooking crucial contextual differences between professions, including areas of training and education, experience with specific client populations, or different clinical focuses or areas of expertise, all of which may influence knowledge of the different domains of TBI. Future research may explore knowledge of TBI for specific professions to identify any potential areas of misconceptions that may benefit from changes to training pathways.

Further, it is acknowledged that comparisons of findings of the current study were made with previous research (e.g., Ernst et al., 2009; Gurusamy et al., 2019), in which participants were nursing students. As nursing students are still in training, they may not have the same degree of knowledge or skill as a fully registered nurse, and therefore, this may be a limitation to consider when interpreting the comparisons of percentage of incorrect responses between the health professionals of the current study and the nursing students of previous studies.

Another limitation of this study may be due to study design. As the data collected was part of a larger study, there were no specific items gathering information about how long participants have been carers for individuals with TBI. However, previous research by Farmer and Johnson-Gerard (1997) demonstrated that there was no significant difference in misconceptions of TBI in rehabilitation workers based on the number of years they have cared for people with TBI or their level of experience with TBI. Further, as the term 'carer' is not clearly defined in the field of healthcare and individuals may have different understandings of what is meant by the 'carer' role (Dirik et al., 2020), this may have resulted in participants identifying themselves as carers, however, may not meet the criteria.

It is also important to note that in the current study, participants were broadly characterised as 'informal carers' if they reported providing any form of unpaid care to family members or friends. This broad classification should be considered when interpreting results, as informal carers in this study may possess diverse ranges of experience and knowledge. Future research could benefit from conducting a more detailed analysis of informal carers, specifically measuring their experience, for a nuanced understanding of how this may influence informal carers' knowledge of TBI.

Finally, measurement issues related to the scale used to assess knowledge of TBI may have impacted results. The CM-TBI is the most widely utilised scale in this area of

research with the most psychometric validation (Bennett & Sullivan, 2023; Bryant et al., 2020), however, it does appear to have some limitations. As mentioned earlier, the CM-TBI appears to excessively focus on motor function in relation to rehabilitation. Further, the double barrel nature of several of the statements in the CM-TBI (i.e. “Problems with speech, co-ordination, and walking can be caused by brain damage”, “Even after several weeks in a coma, when people wake up, most recognise and speak to others right away”) increases the statements complexity and also means that people may ascribe to one element of the item and not the other/s, which can result in difficulty in answering (Menold, 2020). This may provide an explanation as to findings of previous research demonstrating that participants completing the CM-TBI frequently opted for the “don’t know” response to statements (Linden, Braiden, & Miller, 2013). Further, with the exception of the rehabilitation subscale, many items on the CM-TBI focus on the psychological and cognitive aspects of TBI, and few focus on personality changes or motor impairments that may arise as a result of TBI. As the development of the CM-TBI was based on the clinical experience of Gouvier et al (1988), it may lack reference to the overarching theoretical and conceptual framework (Bryant et al, 2020). Therefore, important domains of TBI may have been missed in the scale, such as social recovery and concussion, however, these are crucial in gaining a holistic understanding of the experiences of people with TBI. Further, as the additional concussion subtest is currently undergoing validation procedures, it is important to consider the findings of this subtest as preliminary until the reliability and validity of this measure has been established.

4.7 Implications and Future Recommendations

This study has several clinical and practical implications. Firstly, the results of this study suggest that health professionals have more awareness, knowledge and understanding of TBI overall, compared to disability/support workers and informal carers. [This was despite the health professional group being significantly younger than the other two groups. This](#)

suggests training in the healthcare sector may be providing greater knowledge than the training offered in the disability support sector. Given the long-term support that individuals with moderate to severe TBI may require, the findings here could indicate further training in the disability sector is warranted. As previous research suggests that informal carers' need for guidance and ability to absorb information about TBI may present at varied stages of TBI care (Falk, 2013), it may be advantageous to provide family members and disability/support workers with training opportunities that they can engage in at a time more suited to their needs. Previous research posits that individuals are better able to understand and absorb information when it is provided in a calm environment (Fleming et al., 2009) without time pressure (Leibach et al., 2014). Based on this, it is recommended that health professionals provide more systematic follow up with informal carers and disability/support workers post discharge to provide adequate information on the multitude of symptoms and effects following TBI. Further research exploring the efficacy of providing carers with information about TBI at different stages of TBI care may be beneficial in reducing the risk of misconceptions impacting on TBI recovery and rehabilitation outcomes.

Second, the results suggest that health professionals have more knowledge of brain injury sequelae and rehabilitation following TBI, than informal carers and disability/support workers. This important finding may shift efforts towards providing disability/support workers and informal carers with more specific information about what to expect when caring for and supporting people with TBI post discharge. These findings also have implications for psychosocial care; previous research posits that lack of knowledge of TBI leads to increased carer distress and consequently, may negatively affect TBI recovery time (Awadh Bamatraf et al., 2021; Block et al., 2016; D'Ippolito et al., 2018; McIntyre, Ehrlich, & Kendall, 2020), and as such it is crucial to promote education of TBI for family member and friends. Therefore, the development of TBI-specific support groups may provide

informal carers with the opportunity to build social networks with individuals experiencing similar circumstances and access a wealth of information regarding TBI. These support groups may assist in reducing carer burden and isolation, while provide the opportunity to access resources needed while supporting the recovery of people with TB. Future research may benefit from investigating the efficacy of support groups in reducing carer burden and increasing knowledge of brain injury sequelae and rehabilitation.

The results did not provide support for the proposal that informal carers and disability/support workers would have more knowledge of recovery following TBI compared to health professionals. Previous research has produced varying findings as to the expected course of recovery for mild, moderate, and severe TBI, with limitations in research methods and heterogeneity across patients proposed as the major factors explaining these inconsistencies (Nelson et al., 2019). As a result, these inconsistent findings regarding the recovery process following TBI contributes to the misconceptions held by health care professionals and consequently, the general population. Further research involving large, prospective studies may increase our knowledge and understanding of the aspects that contribute to the recovery process, and therefore, may help enhance the support and care provided to people with TBI by carers.

While this study demonstrated that disability/support workers' knowledge was comparable to other's caring for people with TBI, it is crucial that more research is conducted to determine the knowledge of this profession, given the integral role they play in mid-to-long term care of people with TBI. Finally, given the differences in levels of misconceptions between the CB-TBI subscales across all groups, it is important that future studies identify where knowledge gaps might be, and that training and educational programs are designed to better provide information for these areas.

Lastly, future research could incorporate a measure of length of time caring for someone with TBI, and further explore whether specific aspects of knowledge develop at particular stages of the caring journey.

4.8 Conclusion

Misconceptions of TBI held by individuals providing care for people with TBI is a sorely under-researched area that would benefit from more attention, due to the significant burden and ramifications associated with lack of knowledge of TBI. This is the first study to our knowledge to investigate difference in knowledge of TBI between informal carers, disability/support workers, and health professionals providing care to individuals with TBI. This study presented evidence that health professionals have significantly more knowledge of unconsciousness, amnesia, rehabilitation, and TBI overall compared to informal carers and disability/support workers. Further, findings suggest no significant differences in knowledge of TBI between informal carers and disability/support workers. While this study offers preliminary findings to a growing body of research, future studies may aim to further understand the extent of the differences in knowledge of TBI between informal carers, disability/support workers, and health professionals, as this would be beneficial in developing appropriate educational initiatives and consequently, reducing caregiver burden and improving recovery outcomes for individuals with TBI.

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Appendices

Appendix A

Ethics approval letter



Ethics Approval Letter

31/03/2022

To: Dr Ziebell

Project ID: 24140

Project Title: Traumatic Brain Injury (TBI) MOOC

The amendment received in support of the above named project has been approved by the University of Tasmania Human Research Ethics Committee on 31.03.2022.

Approval has been granted for the changes to research personnel and the following documentation:

Removal of: Rachel Gates, Vlasti Broucek, Jay Borchard

Addition of: Minette Janse Van Rensburg, Marielle Prazak

Submission Document Name	Submission Document File Name	Submission Document Type	Submission Document Date	Submission Document Version
consent form screenshot	consent form screenshot.PNG	INVITATION TO PARTICIPANT	29/01/2021	v001
Enrolment Form	Enrolment Form.pdf	QUESTIONNAIRE	29/01/2021	1
enrolment screenshot	enrolment screenshot.PNG	INVITATION TO PARTICIPANT	29/01/2021	1
Knowledge survey participant invitation	Knowledge survey participant invitation.PNG	INVITATION TO PARTICIPANT	29/01/2021	1
Course Feedback Survey	Course Feedback Survey.pdf	QUESTIONNAIRE	29/01/2021	1
terms and conditions	terms and conditions.pdf	OTHER PROJECT-RELATED DOCUMENTATION	29/01/2021	1
Module 4 support networks	Module 4 support networks.PNG	OTHER PROJECT-RELATED DOCUMENTATION	29/01/2021	1
TBI_MOOC_ethics_project_plan v008_clean	TBI_MOOC_ethics_project_plan v008_clean.docx	PROTOCOL	21/03/2022	v008
TBI_MOOC_ethics_project_plan v008_marked up	TBI_MOOC_ethics_project_plan v008_marked up.docx	PROTOCOL (TRACKED)	21/03/2022	v008
TBI knowledge survey v003	TBI knowledge survey v003.pdf	QUESTIONNAIRE	21/03/2022	v003
TBI knowledge survey v003_highlighted	TBI knowledge survey v003_highlighted.pdf	QUESTIONNAIRE	21/03/2022	v003
Your background v003	Your background v003.pdf	QUESTIONNAIRE	21/03/2022	v003
Your background v003_highlighted	Your background v003_highlighted.pdf	QUESTIONNAIRE	21/03/2022	v003
Participant information sheet TBI MOOC with letterhead v005_clean	Participant information sheet TBI MOOC with letterhead v005_clean.pdf	PARTICIPANT INFORMATION AND CONSENT FORM	25/03/2022	5
Participant information sheet TBI MOOC with letterhead v005_marked up	Participant information sheet TBI MOOC with letterhead v005_marked up.docx	PARTICIPANT INFORMATION AND CONSENT FORM	25/03/2022	5

[\(remove site information if not applicable to amendment approval\)](#)

The University of Tasmania Human Research Ethics Committee has provided approval for the project to be conducted at the following sites:

Medical School Precinct (MSP)

Please ensure that all investigators involved with this project have cited the approved versions of the documents listed within this letter and use only these versions in conducting this research

project.

This approval constitutes ethical clearance by the University of Tasmania Human Research Ethics Committee. The decision and authority to commence the associated research may be dependent on factors beyond the remit of the ethics review process. For example, your research may need ethics clearance from other organisations or review by your research governance coordinator or Head of Department. It is your responsibility to find out if the approvals of other bodies or authorities are required. It is recommended that the proposed research should not commence until you have satisfied these requirements.

In accordance with the [National Statement on Ethical Conduct in Human Research](#), it is the responsibility of institutions and researchers to be aware of both general and specific legal requirements, wherever relevant. If researchers are uncertain they should seek legal advice to confirm that their proposed research is in compliance with the relevant laws. University of Tasmania researchers may seek legal advice from Legal Services at the University.

The University of Tasmania Human Research Ethics Committee (HREC) operates under and is required to comply with the National Statement on the Ethical Conduct in Human Research.

Therefore, the Chief Investigator's responsibility is to ensure that:

- (1) All investigators are aware of the terms of approval, and that the research is conducted in compliance with the HREC approved protocol or project description.
- (2) Modifications to the protocol do not proceed until **approval** is obtained in writing from the HREC. This includes, but is not limited to, amendments that:
 - (i) are proposed or undertaken in order to eliminate immediate risks to participants;
 - (ii) may increase the risks to participants;
 - (iii) significantly affect the conduct of the research; or
 - (iv) involve changes to investigator involvement with the project.

Please note that all requests for changes to approved documents must include a version number and date when submitted for review by the HREC.

- (3) Reports are provided to the HREC on the progress of the research and any safety reports or monitoring requirements as indicated in NHMRC guidance.

Guidance for the appropriate forms for reporting such events in relation to clinical and non-clinical trials and innovations can be located under the ERM "Help Tab" in "Templates". All adverse events must be reported regardless of whether or not the event, in your opinion, is a direct effect of the therapeutic goods being tested.

- (4) The HREC is informed as soon as possible of any new safety information, from other published or unpublished research, that may have an impact on the continued ethical acceptability of the research or that may indicate the need for modification of the project.
- (5) All research participants must be provided with the current Participant Information Sheet and Consent Form, unless otherwise approved by the Committee.
- (6) This study has approval for four years contingent upon annual review. A Progress Report is to be provided on the anniversary date of your approval. Your first report is due on the anniversary of your approval, and you will be sent a courtesy reminder closer to this due date. Ethical approval for this project will lapse if a Progress Report is not submitted in the time frame provided.
- (7) A Final Report and a copy of the published material, either in full or abstract, must be provided at the end of the project.
- (8) The HREC is advised of any complaints received or ethical issues that arise during the course of the project.
- (9) The HREC is advised promptly of the emergence of circumstances where a court, law enforcement agency or regulator seeks to compel the release of findings or results. Researchers must develop a strategy for addressing this and seek advice from the HREC.

Kind regards,

Ethics Executive Officer



Appendix B (pp 49-54) is based on the following article:

W. Drew Gouvier, Perry H. Prestholdt, Mark S. Warner, A survey of common misconceptions about head injury and recovery, *Archives of Clinical Neuropsychology*, Volume 3, Issue 4, 1988, Pages 331–343,
<https://doi.org/10.1093/arclin/3.4.331>

Appendix B

Common Misconception of Traumatic Brain Injury (CM-TBI) scale



Section A: Seatbelts/prevention

A1. User ID

A2. Stage

A3.

True Probably true Unsure Probably false False

You don't need seatbelts as long as you brace yourself before a crash ————

It is more important to use seatbelts on long trips than in driving around town ————

It is safer to be trapped inside a wreck than to be thrown clear ————

Wearing seatbelts causes as many injuries as it prevents ————

Section B: Concussion

B1.

True Probably true Unsure Probably false False

Concussion is a type of brain injury ————

To be diagnosed with a concussion, you have to be knocked unconscious ————



	True	Probably true	Unsure	Probably false	False
A concussion never results in long-term effects	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Concussion always causes damage to the brain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In adults, concussion symptoms usually go away in 10-14 days	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Section C: Brain damage

C1.

	True	Probably true	Unsure	Probably false	False
A head injury can cause brain damage even if the person is not knocked out	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A little brain damage doesn't matter much, since people only use a part of their brains anyway	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It is obvious that someone has brain damage because they look different from people who don't have brain damage	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Whiplash injuries to the neck can cause brain damage even if there is no direct blow to the head	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Section D: Brain injury sequelae

D1.

	True	Probably true	Unsure	Probably false	False
It is common for people with brain injuries to be easily angered	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If you don't lose consciousness you haven't had a brain injury	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



	True	Probably true	Unsure	Probably false	False
When people have a serious traumatic brain injury they will usually also have a fractured skull	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It is possible that a person's personality will change after brain injury	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Problems with speech, coordination, and walking can be caused by brain damage	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Problems with irritability and difficulties controlling anger are common people who have had a brain injury	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Most people with brain damage are not fully aware of its effect on their behaviour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Brain injury patients usually show a good understanding of their problems because they experience them every day	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Brain injuries may cause one to feel depressed, sad, and hopeless	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Drinking alcohol may affect a person differently after brain injury	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It is common for people to experience changes in behaviour after a brain injury	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Section E: Unconsciousness

E1.

	True	Probably true	Unsure	Probably false	False
When people are knocked unconscious, most wake up quickly with no lasting effects	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
People in a coma are usually not aware of what is happening around them	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



	True	Probably true	Unsure	Probably false	False
Even after several weeks in a coma, when people wakeup, most recognise and speak to others right away	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Section F: Amnesia					
F1.					
	True	Probably true	Unsure	Probably false	False
People usually have more trouble remembering things that happen after an injury than remembering things from before	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sometimes a second blow to the head can help a person remember things that were forgotten	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A person with a brain injury may have trouble remembering	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
People with brain injury can forget who they are and not recognise others, but be normal in every other way	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Section G: Recovery					
G1.					
	True	Probably true	Unsure	Probably false	False
Recovery from brain injury usually is complete in about 5 months	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Complete recovery from a severe brain injury is not possible, no matter how badly the person wants to recover	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Once a person is able to walk again, his or her brain is almost fully recovered	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Slow recovery may continue even 1 year after the injury	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



	True	Probably true	Unsure	Probably false	False
People who have had one brain injury are more likely to have a second one	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It is necessary for a person to go through a lot of physical pain in order to recover from a brain injury	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Once persons with a brain injury realize where they are, they will always be aware of this	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A person who has recovered from a head injury is less able to withstand a second blow to the head	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A person who has a brain injury will be "just like new" in several months	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Asking persons who have a brain injury about their progress is the most accurate, informative way to find out how they have progressed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It is good advice to remain completely inactive during recovery from brain injury	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Once a person recovering from a brain injury feels "back to normal," the recovery process is complete	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How quickly a person recovers depends mainly on how hard he or she works at recovering	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Section H: Rehabilitation

H1.

	True	Probably true	Unsure	Probably false	False
"Cognitive" refers to thinking processes such as memory, attention, and learning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



	True	Probably true	Unsure	Probably false	False
"Cognitive" refers to the ability to move your body	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The primary goal of brain injury rehabilitation is to increase physical abilities such as walking	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Section I: Knowledge of Traumatic Brain Injury

II.

	True	Probably true	Unsure	Probably false	False
I have a good knowledge of the symptoms of concussion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have a good understanding of the symptoms of traumatic brain injury	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If I saw someone who'd had a blow to the head, I'd be able to tell if they had a brain injury (e.g. concussion)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If I saw someone who'd had a blow to the head, I would know whether it was appropriate for them to receive medical attention	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I would be able to describe what happens to the brain when it is damaged	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Thank you for completing this survey!

Appendix C

Jamovi output for ancillary analysis.

Results

Repeated Measures ANOVA

Within Subjects Effects

	Sum of Squares	df	Mean Square	F	p	η^2_p
CMTBI_Subcales	1.40e+6	7	200580	597	<.001	0.491
Residual	1.46e+6	4340	336			

Note. Type 3 Sums of Squares

[3]

Between Subjects Effects

	Sum of Squares	df	Mean Square	F	p	η^2_p
Residual	517443	620	835			

Note. Type 3 Sums of Squares

Post Hoc Tests

Post Hoc Comparisons - CMTBI_Subcales

Comparison		Mean Difference	SE	df	t	Ptukey
Prevent	- Concuss	8.768	0.961	620	9.119	<.001
	- Brain Dam	-10.950	0.807	620	-13.574	<.001
	- Sequel	5.016	0.843	620	5.951	<.001
	- Unconsc	33.534	1.454	620	23.062	<.001
	- Amnes	42.995	0.934	620	46.040	<.001
	- Recove	8.586	0.861	620	9.976	<.001
Concuss	- Rehab	2.026	1.111	620	1.824	0.604
	- Brain Dam	-19.718	0.781	620	-25.240	<.001
	- Sequel	-3.752	0.830	620	-4.521	<.001
	- Unconsc	24.766	1.401	620	17.672	<.001
	- Amnes	34.227	0.970	620	35.302	<.001
	- Recove	-0.182	0.882	620	-0.206	1.000
Brain Dam	- Rehab	-6.742	1.064	620	-6.335	<.001
	- Sequel	15.966	0.692	620	23.063	<.001
	- Unconsc	44.484	1.318	620	33.747	<.001
	- Amnes	53.945	0.848	620	63.647	<.001
	- Recove	19.536	0.738	620	26.476	<.001
	- Rehab	12.976	0.991	620	13.091	<.001
Sequel	- Unconsc	28.519	1.280	620	22.272	<.001
	- Amnes	37.979	0.794	620	47.842	<.001
	- Recove	3.571	0.768	620	4.650	<.001
	- Rehab	-2.990	1.036	620	-2.885	0.077
Unconsc	- Amnes	9.461	1.328	620	7.124	<.001
	- Recove	-24.948	1.328	620	-18.783	<.001
	- Rehab	-31.509	1.473	620	-21.386	<.001
Amnes	- Recove	-34.409	0.914	620	-37.657	<.001
	- Rehab	-40.969	1.082	620	-37.873	<.001
Recove	- Rehab	-6.561	0.917	620	-7.153	<.001