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**BRAIN INJURY AND DISCRIMINATION:
THE EFFECTS OF VISIBILITY AND PERCEPTIONS OF
DANGEROUSNESS AND RESPONSIBILITY**

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ABSTRACT

The aim of the research outlined in the following pages was to examine the impact that the visible signs of brain injury and perceptions of dangerousness and responsibility have on participants' willingness to socialise with adolescent survivors of brain injury. The research has two articles, and Article Two has two studies.

In Article One, participants were shown a picture of either an adolescent male or female, with or without a head scar, with a brief vignette advising that the adolescent had sustained a brain injury. Participants reported that others would be more willing to socialise with the adolescents with a scar, than the adolescents with no scar, and female participants reported that others would be more willing to socialise with the female adolescent, than the male adolescent.

Article Two used a similar paradigm to Article One. Study one of Article Two replicated Article One and added an additional factor, knowledge about how to interact, as a factor influencing willingness to socialise. Results showed that participants with more knowledge about how to interact with survivors were more willing to socialise, than participants with less knowledge. Study two examined whether describing the adolescents as dangerous or responsible for contributing to, or causing their brain injury, would influence willingness to socialise. Results showed strong support for a danger model, where perceptions of dangerousness were mediated by fear. When the adolescents' were described as dangerous, fear increased and subsequent willingness to socialise decreased.

To a lesser extent, support was found for a responsibility model. Perceptions of being responsible (falling and sustaining a significant injury to the head after drinking too much alcohol) increased anger but anger in turn did not impact willingness to

socialise. Being described as not responsible (as a result of a brain tumour) increased pity, but again there was no relationship between pity and willingness to socialise.

This information is useful for rehabilitation professionals assisting adolescents' re-integration back into the community post injury. Informing survivors that people's attitudes may change once visible signs of injury heal may be relevant when managing expectations of how others may treat them. It may also be useful to discuss how others may perceive them when they have contributed to causing their current condition or are perceived as dangerous. Finally, knowledge about how to interact may be useful for policy makers when designing campaigns to reduce discrimination.

Candidate's Declaration

I, Lynette Foster, candidate for the degree of Doctor of Clinical Psychology at Massey University Wellington, do hereby certify that:

1. The papers and thesis contained herein comprise entirely my original work towards the degree,
2. This work has not been submitted to any other university or institution for a higher degree,
3. The thesis including papers is less than 65,000 words in length, excluding tables, references and appendices,
4. Ethics approval for the research was obtained from:
Study One - Massey University Ethics Committee: Southern B, Application 10/62.
Study Two - Massey University Ethics Committee: Southern B, Application 11/13.

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Lynette A Foster

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Contribution of author to project: The author was responsible for most aspects of this research, including the formulation of research questions and data collection in Wellington, data analysis and interpretation and write up of the papers and thesis.

CHAPTER 1

INTRODUCTION

The ideas for this research evolved from research that I had conducted at Masters level. The focus of that research had been to examine the effect that visible markers of brain injury had on the attributions made by the general public of an adolescent's undesirable behaviour. Results showed that when the brain injury was visible, people attributed the behaviours equally to brain injury and adolescence. In contrast, when the injury was not visible, people attributed the behaviours more to adolescence (Foster, 2010; McClure, Buchanan, McDowall, & Wade, 2008; McClure, Devlin, McDowall, & Wade, 2006). These results suggest that more consideration was given to the brain injury as the cause of the undesirable behaviour when visible signs of brain injury were present, than when they were not.

Thinking about the implications of McClure et al.'s (2008; 2006) findings and my Masters research and extensive reading in the areas of attribution theory, stigma and brain injury, raised questions about whether the visibility of a brain injury would influence discriminatory behaviours. Specifically, would the visibility of a brain injury influence people's willingness to socialise with adolescents who had sustained a brain injury. If people were more likely to excuse behaviour when a survivor of brain injury had a visible marker of injury (McClure, et al., 2008), then perhaps they would be more likely to socialise with or assist a survivor when a visible marker of injury was present. By comparison, survivors without a visible marker (and this applies to a large proportion of people with brain injury) may be more likely to experience discrimination. In support of this contention, Zahn (1973) found that young people with disabilities had better interpersonal relationships when their disability was visible than when it was not.

Willingness to socialise and visibility effects have not been specifically studied in terms of brain injury before, although the work of Linden and colleagues has gone some way towards this. Linden and colleagues found that there was more willingness to help and less prejudicial attitudes when adult survivors of brain injury had acquired their injury through organic or external means (e.g., brain haemorrhage) than when it was self-initiated or sustained by internal means (e.g., started a fight after drinking alcohol) (Redpath & Linden, 2004), and when the injury was not their fault (Linden, Hanna, & Redpath, 2007).

While these studies go some way towards the examination of stigma and brain injury, they do not examine the impact visible signs of brain injury have on attitudes. Furthermore, they do not identify how ‘blame’ or perceptions of responsibility lead to prejudicial attitudes and helping behaviour. Is there a direct relationship between the responsibility for a brain injury and attitudes, or is this relationship mediated or moderated by other factors? Examining mediating and moderating factors is essential when attempting to understand the processes of discrimination and the current research will address this, as well as the impact the visibility of a brain injury has on people’s willingness to socialise with survivors.

Related to this are findings from the disability literature associating the visible markers of disability with more prejudice and discrimination than when there are no visible markers of disability (Latner, Stunkard, & Wilson, 2005; Matthews & Harrington, 2000). However, typically, the literature examines physical disabilities and prejudice and discrimination. Considerable research examining prejudice, discrimination and stigma has also been conducted in the mental health field and it seemed appropriate to examine brain injury in a similar manner. There is considerable rationale for this. Some people believe that brain injury is associated with madness and

altered personality (Simpson, Mohr, & Redman, 2000) and others describe survivors of brain injury as mentally disabled (Linden & Boylan, 2010). Furthermore, complications resulting from a brain injury can include mania, post traumatic stress disorder (Kim et al., 2007) and depression (Tsaousides, Ashman, & Seter, 2008). Finally, aggression is associated with brain injury (Dooley, Anderson, Hemphill, & Ohan, 2008; Kim, et al.) and mental illness (Hiday, 1997), and both conditions are potentially hidden illnesses which may only become apparent to others during interactions.

Research examining mental illness and stigma has often employed Weiner's attribution model when attempting to identify the processes involved in stigmatisation of individuals with mental illness. Weiner's (1995) causal attribution theory proposes that individuals make cognitive appraisals regarding the controllability of a person's stigmatising condition and try to identify whether the person was responsible or not for causing their condition. A strong belief regarding responsibility elicits emotional responses such as anger or pity, which in turn influence behavioural responses (willingness to help or interact). For example, when the cause of a mental illness is self-inflicted (illegal drug use) reported beliefs about responsibility are higher, than when the cause is accidental or organic (as a result of an accident) (P. W. Corrigan, Markowitz, Watson, Rowan, & Kubiak, 2003). Higher beliefs about responsibility are associated with increased feelings of anger and less willingness to assist and lower beliefs about responsibility are associated with increased pity and more willingness to assist (Weiner, 1995).

Support for Weiner's attribution theory is found in the mental illness literature which shows that responsibility for causing an illness impacts emotions, and emotions subsequently influence behaviour and attitudes (P. W. Corrigan et al., 2002; Martin,

Pescosolido, & Tuch, 2000; Reizenzein, 1986; Weiner, Perry, & Magnusson, 1988).

The current research employs Weiner's model within a brain injury perspective.

There are a number of factors which potentially influence the willingness of the general public to interact or assist survivors of brain injury. A danger model has been developed to explain aspects of stigma in the mental illness literature (P. W. Corrigan, 2000; P. W. Corrigan, et al., 2003; P. W. Corrigan, et al., 2002). According to this model, when an individual with a mental illness is perceived as dangerous, fear increases and people are more likely to withhold assistance and avoid encounters, than when they are not perceived as dangerous (P. W. Corrigan, et al., 2003). The danger model may be relevant when examining brain injury and discrimination as research shows that students fear survivors of brain injury more than the general public does, describing survivors as violent, unpredictable and aggressive (Linden & Crothers, 2006). Qualitative research also found that the public reported that survivors of brain injury would have difficulties with aggression, frustration, and irritation and emotion regulation (Linden & Boylan, 2010). Based on these findings the current research examined perceptions of dangerousness as a factor influencing willingness to socialise with survivors of brain injury.

Other factors which may influence the willingness of the general public to interact with survivors of brain injury are: 1. people's level of familiarity with individuals with brain injury, and 2. knowledge about how to interact with them. Albrecht, Walker and Levy (1982) found that this uncertainty about how to interact influenced people's willingness to socialise with individuals with stigmatising conditions (conditions ranging from diabetes and cancer to mental illness and drug abuse). In preparing for the current research only one study was found that examined familiarity with individuals with brain injury and discrimination; where it was found

that people's familiarity (measured by asking a yes/no question) had no impact on prejudice and discriminatory attitudes (Linden, et al., 2007). However, the mental illness literature shows considerable support for a familiarity hypothesis. People with higher levels of contact or familiarity with individuals with mental illness report less stigma, relative to people with low levels of contact (P. W. Corrigan, Edwards, Green, Diwan, & Penn, 2001; P. W. Corrigan, Green, Lundin, Kubiak, & Penn, 2001; P. W. Corrigan, et al., 2003). Accordingly it seemed important to also consider the amount of familiarity (based on the amount of individual contact with survivors of brain injury) and knowledge about how to interact as factors influencing willingness to socialise with survivors of brain injury as part of the planned research.

Finally, there is a lack of research examining willingness to socialise with adolescents who have sustained brain injuries. Adolescence is a time of self doubt and some adolescents fear being judged about how they dress, behave or talk, and are preoccupied with differences between themselves and others (Miller & Sammons, 1999). The effects of navigating adolescence may be exacerbated when an adolescent sustains a brain injury. Accordingly, identifying factors which may impact this group is an important step towards developing strategies to assist with rehabilitation.

In summary, there is little research examining brain injury and discrimination and none found examining how and under what conditions adolescent survivors of brain injury experience discrimination. For example, do perceptions of dangerousness and responsibility influence stigmatising attitudes by impacting emotional responses (fear, anger and pity)? Furthermore, there is a lack of research exploring the effects that the visible signs of brain injury have on the willingness of other people to socialise with adolescent survivors of brain injury, and the effect the visibility of an injury has on perceptions of dangerousness and responsibility. Research examining these processes is

essential as it may assist in identifying factors that are important for successful community integration post brain injury. This, then, became the focus of the current research, which will be reported as two articles.

Article One examined whether visible markers of brain injury influenced people's predictions of the extent to which other people would be willing to socialise with adolescent survivors of brain injury. The effect of the gender of the observer (participants) and adolescent with brain injury were also examined. Familiarity with individuals with brain injury was examined as it was expected that participants' level of familiarity would influence their predictions of others' willingness to socialise. Article One asked participants their opinion about other people's willingness to socialise to minimise social desirability effects as the author collected data in public locations. Article One builds on previous research in two ways. It examined the impact the visibility of a brain injury had and the impact this has for adolescents, as opposed to adults.

Article Two has two studies. Study one replicated Article One and contributed to the literature by including a lack of knowledge about how to interact as a factor influencing discriminatory behaviour. Study two examined the effect visible markers of brain injury have on people's willingness to socialise with survivors of brain injury employing Weiner's full responsibility model and a danger model. Pity and anger were examined as mediators between the relationship of personal responsibility for a brain injury and willingness to socialise. Visible markers of brain injury were examined as moderators of this relationship. Fear was examined as a mediator in the relationship between perceptions of dangerousness and willingness to interact, as research shows that people fear individuals with brain injury (Linden & Boylan, 2010; Linden &

Crothers, 2006). Again, visible markers of brain injury were examined as moderators of this relationship.

Article Two built on and extended previous research in three ways. It examined mediating (pity and anger) and moderating (visible signs of injury) variables in the responsibility model. It examined a danger model in relation to brain injury for the first time, and included visibility effects as a moderator of this relationship. Finally, it examined a lack of knowledge about how to interact as a factor influencing willingness to socialise.

Chapter two provides definitions of brain injury and traumatic brain injury (TBI) and information about prevalence and causes. Chapter two also includes common misconceptions about brain injuries, secondary complications that may arise following a brain injury and community re-integration aspects of rehabilitation. Chapter three discusses visible and invisible disabilities and related research. Chapter four focuses on stigma and provides definitions for stereotyping, prejudice, discrimination and stigma and how these concepts are related in relationship to brain injury. Chapter five discusses other factors (perceptions about responsibility and dangerousness, familiarity and knowledge about how to interact) which may influence discriminatory responses. These chapters are followed by Article One and Article Two chapters and an overall discussion chapter.

CHAPTER 2

BRAIN INJURY

Definition and severity

Brain injuries are common and are caused by a variety of factors such as infections, brain tumours, drugs, alcohol, hypoxia (lack of oxygen to the brain) and solvents (Brain Injury New Zealand, 2011; Kelly, Brown, Todd, & Kremer, 2008). A traumatic brain injury (TBI) is caused by an external trauma to the brain by either an object penetrating the skull (open head injury) or a blunt force trauma to the head with no penetration (closed head injury) (Lucas & Addeo, 2006). Road traffic accidents, falls, sporting accidents, assaults and being hit by something are common causes of TBI (Lucas & Addeo; McKinlay et al., 2008). The cause of a TBI varies as does the subsequent severity of the injury.

There are a number of ways to ascertain the severity of a TBI including the time frame of posttraumatic amnesia (PTA: memory of events immediately following the trauma), Glasgow Coma Scale (GCS) and loss of consciousness (LOC) (Lucas & Addeo, 2006). When PTA is less than 1 hour the injury is rated as mild, 1 to 24 hours is rated as moderate and when PTA exceeds 24 hours the injury is rated as severe (Lucas & Addeo). The resulting classification system, mild, moderate or severe typically corresponds with the level of recovery, with longer PTA associated with poorer recovery (Lucas & Addeo).

The GCS measures best verbal response, eye-opening and motor responses (Teasdale & Jennett, 1974). Scores range from 3 to 15 points, with 13 points and above indicating mild TBI, 9 to 12 points indicating moderate TBI and 8 or less indicating severe injury. As well as indicating the severity of an injury, the GCS also indicates likely prognosis; the higher the score the better the prognosis.

A TBI is classified as mild when LOC is 30 minutes or less and moderate to severe TBI when LOC exceeds 30 minutes. The three measures of TBI severity discussed above overlap with regard to assessing deficits and the measure selected is based on the patient population, health professionals skill set and specific setting (i.e., whether it is in a doctor's office, hospital or at the scene of the accident) (J. D. Corrigan, Selassie, & Orman, 2010).

Prevalence and causes

Traumatic brain injury is quoted as one of the leading causes of disability and death for children, young adults and the elderly in the United States, where there are more than 5.3 million people living with a TBI related disability (Centers for Disease Control and Prevention, 2011). In New Zealand 90 people sustain a TBI every day, and 24,000 are diagnosed as having experienced concussion (classified as a mild TBI) every year (Brain Injury New Zealand, 2011). The implications of these statistics are rarely fully understood in terms of the financial cost to society and the subsequent cognitive, emotional, sensory and motor impairments which impact survivors' recovery and quality of life. Furthermore, unlike physical disabilities, which are mostly visible to others, TBI often has no outward sign of disability making it difficult for others to notice and accommodate subsequent deficits and difficulties experienced by survivors.

In the United States 506 per 100,000 people sustain a TBI each year and 269 per 100,000 in Finland (see review of epidemiology by J. D. Corrigan, et al. (2010)). The figure is considerably higher in New Zealand with 1750 per 100,000 people sustaining a TBI each year (McKinlay, et al., 2008). The reported statistics vary as a result of methodological differences. The type of data used for analysis, methods of calculating and the source of the data vary among researchers (J. D. Corrigan, et al.). Data may be obtained only from hospital admissions or include accident and emergency and doctors

visits. Research using self-report measures find higher incidences but may suffer from inaccuracies due to memory and reporting deficits (Body & Leathem, 1996). Research reporting lower incident rates of 100-300 per 100,000 per annum (Cassidy et al., 2004) and 269-506 per 100,000 (J. D. Corrigan, et al.) included only hospital admissions or visits whereas McKinlay et al.'s research included all medical assistance sought for TBI. McKinlay et al. found that 30% of all cases were admitted to hospital and the majority were seen by general practitioners or accident and emergency departments. As a result of the varying methodology practices it is difficult to accurately estimate actual prevalence; nonetheless, TBI is considered a significant health problem worldwide.

The New Zealand statistics reported above were from a Christchurch cohort study involving 1265 participants. This study found that 31.6% of the population suffered at least one TBI that required medical assistance by the time they were 25 years of age (McKinlay, et al., 2008). The highest rates of TBI were in the 15 to 20 age group and males had higher rates (38%) than females (24%) (McKinlay, et al.). These gender and age statistics with males, adolescents and young adults being more likely to suffer a TBI than females and older adults (excluding the elderly) are similar to overseas studies, e.g., Cassidy et al. (2004); J. D. Corrigan et al. (2010). The elderly are another at risk group, with several studies showing that after approximately 70 years of age the incidents rates of TBI increase with advancing age due to falls and motor vehicle accidents (Burns & Hauser, 2003).

Falls are reported as the most common source of injury up to 14 years of age in New Zealand and after 15 years of age rugby, assault, motor vehicle accidents and being hit with an object are reported as the most common causes of injury (McKinlay, et al., 2008). Other countries (United States, Australia and France) report similar statistics,

with road traffic accidents and falls accounting for the majority of TBI (Burns & Hauser, 2003; Cassidy, et al., 2004; J. D. Corrigan, et al., 2010).

In summary, TBI is one of the leading causes of disability and death worldwide with road traffic accidents and falls accounting for the majority of injuries. Adolescents and young adults are one of the most at risk groups with males twice as likely as females to sustain a TBI. Therefore, research is required to identify appropriate rehabilitation and education strategies to assist this high risk group, with an emphasis on males. Furthermore, the “invisible” nature of TBI needs to be considered when planning research to understand the impact visible and invisible injuries have on recovery. Finally, the high prevalence rates and the lack of outward signs of disability have resulted in TBI being described as the “invisible epidemic” (Centers for Disease Control and Prevention, 2011). Brain injuries are classified as a brain injury or a TBI dependent upon the cause of the injury; however, from this point forward, for ease of reading, all injuries will be referred to as a brain injury, except when discussing prevalence and cause statistics.

Misconceptions about brain injury

A brain injury can be a debilitating condition impacting all aspects of a survivor’s life. Survivors must focus not only on their recovery but also contend with misconceptions and beliefs held by the public and others about the recovery process and outcomes of brain injury. The public, family members of survivors of brain injury and health professionals hold a number of misconceptions about brain injury which may impact attention and care considerations. The public believe that brain injuries heal as quickly as physical injuries, and once survivors receive treatment and are discharged from hospital they are physically and mentally well (Swift & Wilson, 2001). Further, the public believe that the recovery from a brain injury is primarily influenced by the

amount of effort expended by a survivor and that complete recovery is possible in most instances (Gouvier, Prestholdt, & Warner, 1988; Hux, Schram, & Goeken, 2006).

There is a lack of awareness of the time frames involved in recovery and a lack of understanding that further injury is more likely due to survivors' vulnerability (as a result of cognitive or physical difficulties (Chamberlain, 2006)). Furthermore, the public and non-expert health professionals fail to appreciate that the ability to perform common tasks varies from day to day as a result of fatigue and sometimes undesirable behaviours resulting from a brain injury persist (Swift & Wilson, 2001). These misconceptions may impede survivors' recovery efforts. As a result of these common misconceptions about injury, which are held in Britain (Chapman & Hudson, 2010) and the United States (Hux, et al., 2006), inferences of 'malingering' are also implied by the public and health professionals (Chamberlain).

It is possible that misconceptions about brain injury endure and 'malingering' is implied as a result of the 'invisibility' of brain injuries. Even though people are aware of a person's brain injury, there may be no ongoing salient mark of injury to remind them of it (as with physical disabilities). Finally, common misconceptions, inferences of malingering and a lack of visible signs of brain injury may result in survivors receiving insufficient care and attention when seeking treatment and assistance with community re-integration. The current research examines community re-integration and how some common attitudes and beliefs held by the public may impact survivors' recovery efforts.

Secondary complications

A number of potential deficits and problems can develop post injury. They may develop as a result of brain damage sustained directly from the brain injury and/or develop as survivors learn to live with a brain injury and contemplate their life post injury and the effects the injury will have on their life. Survivors may experience

memory, attention and executive functioning problems (Draper & Ponsford, 2008) as well as behavioural and personality difficulties (Willer, Johnson, Rempel, & Linn, 1993). Furthermore, depression (Tsaousides, et al., 2008), post traumatic stress disorder and mania (Kim, et al., 2007) may develop as a result of the trauma experienced or difficulties adjusting to subsequent disabilities. Severe brain injury may result in the development of epilepsy which may occur months or years following the initial injury (Lowenstein, 2009). Survivors may experience social difficulties and have trouble obtaining employment post injury; they may be dependent on others and have difficulties with community re-integration (Brooks, Campsie, Symington, Beattie, & McKinlay, 1987; Kelly, et al., 2008; Sloan, Winkler, & Anson, 2007; Winkler, Unsworth, & Sloan, 2006). The following sections discuss these factors and others which may impact survivors' community re-integration efforts post injury.

Cognitive Outcomes

The subsequent type and level of cognitive impairment following a brain injury varies depending upon the severity of the injury, the location of injury and the time since injury (Dikmen, Machamer, Winn, & Temkin, 1995; Draper & Ponsford, 2008; Stratton & Gregory, 1994). Cognitive impairments may include difficulty with attention, cognitive flexibility, concentration, memory, orientation, language, executive functioning, motor functioning and self-awareness (Dikmen, et al., 1995; Millis et al., 2001). Impairments may improve over time, deteriorate further or not change at all, with memory, attention, executive functioning and processing speed being more likely to remain impaired five to ten years post injury (Draper & Ponsford; Millis, et al.).

Children and adolescents can experience similar cognitive impairments as discussed above post injury, although the severity of the injury does not always correlate with the severity of subsequent impairments (as can be the case for adults as

well) (Conklin, Salorio, & Slomine, 2008; Middleton, 2001; Wassenberg, Max, Lindgren, & Schatz, 2004). A number of factors such as premorbid functioning, age and the developmental level of the child influence subsequent problems experienced (Middleton). Suggestions that plasticity may facilitate normal development in children is not always supported as areas in the brain that are currently developing rapidly may be more vulnerable to damage, whereas areas that are already fully developed may incur a temporary loss and then recover (Middleton). For these reasons, it is essential professionals do not underestimate the effect mild injuries can have on children (Middleton). Finally, children and adolescents may appear highly intelligent but exhibit poor executive functioning skills, such as meta-representation, monitoring system difficulties, lack of insight, attention, organisation and orientation which influence their ability to plan and following through on goals (Middleton).

Emotional and behavioural outcomes

Common behavioural and emotional manifestations following brain injury for adults include verbal and physical aggression, inappropriate social behaviour (e.g., social awkwardness, non-compliance, behaving in embarrassing ways, excessive talking, bossiness, withdrawal, intrusive or prying, attention seeking and lighting fires), lack of initiative, perseveration and repetitive behaviour and inappropriate sexual behaviour (predominantly sexual talk) (Brooks, et al., 1987; Kelly, et al., 2008). Both Brookes et al. and Kelly et al.'s research involved survivors with moderate to severe brain injuries and Kelly found that the most common difficulties reported were verbal aggression, inappropriate social behaviour and lack of initiative.

Further, research with adult survivors of moderate to severe injuries supports the aggression findings (Baguley, Cooper, & Felmingham, 2006) and shows that survivors report more verbal aggression than uninjured individuals, and people with spinal cord

injuries (Dyer, Bell, McCann, & Rauch, 2006). An interesting finding in Dyer et al.'s research was that there was no difference in physical aggression between the three groups examined (brain injury, no injury and spinal cord injury). This in turn, suggests that survivors of brain injury are no more physically aggressive than the general public, a distinction that may not be recognised by the public.

For children and adolescents, it is often behavioural problems that trigger a referral for treatment (Middleton, 2001). Social disinhibition is commonly reported by others, which may be a result of reduced insight into the needs and feelings of others and inflexibility regarding play and activities (Middleton). Also adolescents and children (aged 7 to 15 years) may not be aware that their subsequent deficits impact their social functioning (Jacobs, 1993). This may arise as the children and adolescents have not been sufficiently informed about the relationship between their injury and subsequent behavioural difficulties (Middleton). Increased aggression, destructiveness, impulsivity and overactivity are common problems reported by parents post injury (McGuire & Rothenberg, 1986). Additional research supports the finding that children and adolescent survivors experience increased aggression post injury (as reported by parents) (Cole et al., 2008; Dooley, et al., 2008).

Psychosocial outcomes and community re-integration

Assisting survivors' return to the community following a brain injury is an essential component of rehabilitation and has been identified as a primary goal for survivors (Sander, Clark, & Pappadis, 2010). The emphasis is typically on 'full community integration' which involves education, vocational, recreational, social and community activities (Sander, et al.). The challenges involved in this goal are considerable, particularly considering the possible subsequent difficulties and deficits post injury. In support of this contention, research showed that the severity of an injury

and subsequent disability and challenging behaviour (loss of emotional control, disinhibition, impulsivity, frequent mood changes and irritability) predicted low community integration (Sloan, et al., 2007; Winkler, et al., 2006). Furthermore over time paid care facilitating active engagement reduces or ceases and gratuitous care increases, leaving the responsibility to family and friends (Sloan, et al.).

Obtaining employment post injury is one of the aspects of community integration that survivors have difficulty with. Kelly et al. (2008) found that 80% of adult survivors ($N = 190$) with moderate injuries were unemployed. High unemployment is reported in a number of studies, and chronic unemployment contributes to the development of low self esteem and depression (Morton & Wehman, 1995). A lack of employment reduces the chances of social and leisure activities often available when working. Another potential change for survivors is a reduction or cessation of leisure activities such as sports and membership of clubs due to physical, emotional or behavioural changes. Again, this reduces the chances for socialisation and peer support.

A lack of employment as well as behavioural, cognitive and emotional difficulties impact current relationships and impede the development of new relationships (Morton & Wehman, 1995). Existing friendships and networks may dissolve or reduce significantly increasing reliance on family members for social and emotional support. Physical difficulties (wheelchair use, difficulties in eating and personal care) may also reduce chances for socialisation and increase reliance on family members and prompt realisations about lost independence. The social isolation and dependence on family members impacts self esteem and increases the likelihood of depression (Morton & Wehman). A lack of socialisation also reduces the chances for re-learning and practicing social skills with peers (Morton & Wehman).

Socialising with peers is especially poignant for the group most at risk of sustaining a brain injury (15-24 years), as this is a time when they are separating from parents and family and joining others with similar outlooks and developing their own identity, which is intricately tied up with peer acceptance and support (Erikson, 1970; Miller & Sammons, 1999). As a result of subsequent behavioural, emotional and physical difficulties children and adolescents often lose friends and have difficulty developing new friendships (Middleton, 2001).

The potential number and range of subsequent changes and difficulties post injury understandably impact on survivors' attempts to re-integrate back into communities and friendships. Although anger management and training are often included in rehabilitation strategies, there is a lack of suitable courses or resources to assist with other prominent difficulties, such as inappropriate social behaviour, which impact on re-integration (Kelly, et al., 2008). To understand the effects aggression has on survivors' community re-integration efforts, the current research examines the impact perceptions of dangerousness have on people's willingness to interact with adolescent survivors of brain injury.

In conclusion, brain injuries occur frequently for young people aged 15-24 at a time in their life when they are separating from their parents and family and trying to fit in with peers. Being accepted by others is crucial as is appearance and how others perceive them. Understanding the public's attitudes towards this group provides useful information when assisting re-integrating back into society. For adolescents, as for all survivors of brain injury, the subsequent cognitive, emotional, behavioural and social outcomes post injury may result in undesirable or negative attitudes from others. This creates an unhelpful cycle where undesirable sequelae contribute to a lack of friendships and socialisation, impacting well being. Furthermore, understanding how visible signs

of injury (in this instance a scar) influence attitudes is particularly relevant for adolescents who may perceive a scar to be an added disadvantage, as it distinguishes them as different from others. The following chapter will discuss visible disabilities and the impact the visibility has on attitudes and outcomes.

CHAPTER 3

THE VISIBILITY OF A DISABILITY

Whether a disability is visible or not greatly influences the way a person is viewed or defined by others (Crocker, Major, & Steele, 1998). An absence of outward signs of disability implies an absence of disability and accordingly the individual is placed into categories based on gender, culture, life experiences, expectations and stereotypes (Miller & Sammons, 1999). Outward signs of disability, such as mobility, a missing limb, speech impediment or facial disfiguration prompt a disabled categorisation, which in turn influences expectations, i.e., people generally expect less from individuals categorised as disabled than they do for the able bodied (Stone, 2005).

A common misconception about survivors of brain injury is that you can tell that they have had a brain injury (Linden & Boylan, 2010). This may occur as we are taught that we can easily distinguish who belongs in which category (disabled or absence of disability) by visual or auditory cues (Stone, 2005). However, these perceptions are often unfounded as it is estimated that 40% of people with disabilities have no visible sign of disability (Asch, 1984). Whether these individuals experience discrimination once people become aware of their disability, and if so whether they experience discrimination in the same way or level as individuals with visible disabilities, is unclear. The current research addresses this distinction.

Several studies have reported the detrimental social outcomes experienced by people with disabilities. Examples include discrimination in obtaining and maintaining employment relative to able bodied persons. Ravaud, Madiot, and Ville (1992), for example, sent unsolicited job applications to over 2000 French companies describing a person with or without a disability, and with high or moderate qualifications. The highly qualified able bodied applicant was 1.78 times more likely to receive a favourable

response than the highly qualified disabled applicant, and the moderately qualified able bodied applicants were 3.2 times more likely to receive a favourable response than the moderately qualified disabled applicant.

Once people with disabilities obtain employment they report more overt and subtle discrimination as well as less procedural justice and lower levels of job satisfaction than able bodied employees (Snyder, Carmichael, Blackwell, Cleveland, & Thornton, 2010). Furthermore, non-physically disabled employees report more subtle and procedural discrimination and less perceived organisational support than employees with physical disabilities (Snyder, et al.). This last finding may highlight a distinction between visible and non visible disabilities, although it is difficult to infer this as Snyder et al. did not mention the specific disability of the non-physically disabled.

Discrimination is also reported by students in higher education environments. Students with physical disabilities report feeling marginalised, different and distanced from other students as a result of waiting outside emergency exits for entry and sitting at the front of the class (Holloway, 2001). Further research shows that students with mobility disabilities have less choice about which university or course they select, due to a lack of access and the necessity to remain close to medical facilities and family support (Hadjikakou, Polycarpou, & Hadjilia, 2010).

When a person has no visible signs of disability, discrimination is less likely to occur, unless the disability is revealed. Individuals with non visible disabilities may be reluctant to disclose their disability as disclosure may prompt unwanted sympathy, judgements about believability and impact existing relationships with others (Matthews (1994) as cited in Matthews & Harrington, 2000). Furthermore, disclosure may result in others being less inclined to accommodate the disability, as the person may look healthy and happy (McClure, 2011). Nondisclosure of a disability is also used for impression

management whereby individuals with non visible disabilities want to be seen “only” as a person (Matthews & Harrington, 2000). Concealing the disability also eliminates the possibility of being labelled disabled, thereby maintaining a “normal status” between the parties involved (Matthews & Harrington). As a result of possible consequences and the associated discrimination, individuals with non visible disabilities spend considerable time and effort concealing their disability from others (Matthews, (1994) as cited in Matthews & Harrington).

Therefore, from a discrimination perspective, in some instances having a non visible disability may be considered advantageous. However, there is a downside. The effort involved in concealing non visible disabilities may produce secondary effects such as increased anxiety due to the effort involved and worry about being discovered (Matthews & Harrington, 2000). Furthermore, people with non visible disabilities experience more emotional problems than people with visible disabilities (Ireys, Gross, Werthamer-Larsson, & Kolodner, 1994).

Brain injury is a disability which may or may not result in visible signs of neurological impairment. There may be noticeable thought, speech, motor or facial impairments or there may be no outward signs of impairment at all. In some instances survivors may initially have visible signs of brain injury in the form of bandages or scars but over time these disappear, leaving the survivor with no outward sign of brain injury, in spite of there often being significant non-visible injury, e.g., impairment of cognition and interpersonal function. Road traffic accidents and assaults are two common causes of TBI which may result in physical injuries (McKinlay, et al., 2008). Initially, the injury may be obvious to others (bandages, scars); however, these signs of injury may disappear or heal over time, leaving the survivor with no obvious outward

sign of disability. Brain tumours or haemorrhages are another type of brain injury that may produce similar effects.

To assist with effective rehabilitation it is essential to understand the public's likely response to survivors of brain injury both with and without outward visible signs of disability. This information is particularly relevant when assisting adolescents' rehabilitation following a brain injury as adolescence is a time of self doubt about appearance, looks and how they talk (Miller & Sammons, 1999), and this group (15-20 year olds) has one of the highest incident rates of TBI (McKinlay, et al., 2008). The current research explores these issues and examines whether the public's willingness to socialise varies dependent upon whether an adolescent survivor has a visible sign of injury or no visible sign of injury.

Research on visibility effects

McClure and colleagues examined visibility effects in relation to brain injury and attributions. They found that when a male adolescent survivor of brain injury had no visible signs of injury participants attributed his undesirable behaviours more to his adolescence than his brain injury (McClure, et al., 2008; McClure, et al., 2006). In contrast, when he had a visible sign of injury (head scar) participants attributed his undesirable behaviours equally to his adolescence and brain injury. This finding suggests that more consideration was given to the brain injury as the cause of the undesirable behaviours when a visible sign of injury was present. McClure and colleagues' research examined the impact of visible signs of injury on attributions, but there is a lack of research examining visible signs of brain injury and discrimination.

The current research considers this by examining the extent to which the visible sign of brain injury (in this instance a scar) impacts on the willingness of other people to socialise with an adolescent survivor of brain injury. The scar was chosen to represent a

visible sign of brain injury for a number of reasons. Road traffic accidents, falls and assaults are three common causes of TBI for adolescents (McKinlay, et al., 2008), often resulting in visible signs of injury to the head or face which may or may not disappear over time. Similarly, brain tumours may result in a scar as a result of surgical interventions which may later heal. A wheelchair was considered as an alternative outward sign of injury but not chosen as this was considered to be more representative of a physical injury as opposed to a brain injury. Facial asymmetry, speech and motor impairments were not chosen as they would have been difficult to photograph and they did not necessarily represent a visible sign that would disappear or heal over time.

Finally, portraying adolescents who had actually suffered a brain injury was not considered due to ethical concerns. Members of the public may have recognised the adolescent but were not aware of their injury, thereby potentially exposing the adolescent to stigma. If the adolescent had no visible sign of brain injury, then that would have to be imposed on their photo, which may be distressing for the adolescent. Conversely, we would have to digitally alter adolescents' photos that had facial scars which may cause distress as the photo without scars may remind the adolescent about their appearance prior to their injury.

In conclusion, people with visible and non visible disabilities face a number of issues and difficulties but these factors vary depending on the visibility of their disability. There is considerable literature examining physical disabilities, mental illness, brain injury and discrimination but no research was found simultaneously examining brain injury, visibility effects, adolescents and discrimination. The current research therefore examines the effect the visibility of a brain injury has on people's willingness to socialise with adolescents who have sustained a brain injury. The following chapter discusses stigma and related factors as the stigma concept provides a

conceptual understanding of the visibility distinction when related to managing disclosure and outcomes (discrimination).

CHAPTER 4

STIGMA

People with disabilities routinely experience discrimination relative to people without disability even when there is no outward suggestion that they deserve less opportunity (with regard to employment or renting a house), support or friendship (Miller, Parker, & Gillinson, 2004). Social psychology provides a conceptual framework when examining stigma and the related concepts of stereotyping, prejudice and discrimination (Crocker, et al., 1998; Hamilton & Sherman, 1994). These concepts and their inter-relatedness are discussed in the following sections.

Stereotypes, prejudice and discrimination

Stereotypes are collectively agreed upon ideas or beliefs that are held about social groups that can be quickly accessed (Hamilton & Sherman, 1994). Stereotyping occurs when labels link a person to particular characteristics of a social group (Goffman, 1963). Stereotypes are also described as cognitive schemas (Hamilton & Sherman) which influence encoding, storing and retrieval of group-based information (Biernat & Dovidio, 2000). Being aware of stereotypes is not necessarily negative; it is only when a stereotype is agreed to and an emotional response developed toward it that prejudice is implied (Biernat & Dovidio).

Prejudice, then, is a possible outcome of stereotyping and has been described as “an aversive or hostile attitude toward a person who belongs to a group, simply because he belongs to that group, and is therefore presumed to have the objectionable qualities ascribed to the group” (Allport, 1958, p. 7). Prejudice, therefore, has an evaluative component incorporating a cognitive (determining stereotype) and affective response (danger, fear) to beliefs (stereotypes). Discrimination flows on from prejudice and is the

behavioural response to prejudicial attitudes (e.g., not employing or renting a house to a person as a result of prejudiced attitudes) (Link & Phelan, 2001).

Stigma

Stigma is a more complex construct which may include all or some aspects of the processes discussed above at any one time. Based on the constructs discussed above, stigma occurs when labels (e.g., mentally ill) link an individual to stereotypical beliefs which prompt prejudiced attitudes, which are then acted upon (discrimination). However, there are more aspects related to the stigma construct than labeling, stereotyping, prejudice and discrimination. Additional aspects include different types and dimensions of stigma and factors influencing the development of stigma. The following paragraphs discuss some well known definitions of stigma and discuss different types of, and dimensions to, stigma.

Stigma was defined by Goffman several decades ago as “an attribute that links a person to an undesirable stereotype, leading other people to reduce the bearer from a whole and usual person to a tainted, discounted one” (Goffman, 1963, p. 11). Although this definition is still relevant today, it does not include the consequences of being stigmatised and the context and process of stigma. For instance, it is suggested that stigma occurs when a power imbalance exists, that is, when more powerful groups have the power to stigmatise other less powerful groups (Link & Phelan, 2001), and when someone possesses an attribute that is devalued in one social context (Crocker, et al., 1998). These additional factors suggest that stigma is a social construction which changes dependent upon culture and power balances (Dovidio, Major, & Crocker, 2000).

When considering these additional factors, stigma can be defined as a social construction; a distinguishing mark causes devaluation by others which occurs when a

power imbalance allows labeling, stereotyping, exclusion, status loss and discrimination (Dovidio, et al., 2000; Link & Phelan, 2001; Link & Phelan, 2006). This last definition conveys a fairly succinct description of stigma but it is important to bear in mind that not all components described are required at any one time for stigmatisation to occur and in the literature any of the components are interchangeable with the term stigma. Finally, the rationale behind the stigma concept is that when others are labeled, creating a “them and us” situation, and linked to stereotypes (which are typically undesirable attributes) a justification exists for discriminatory behaviour (Link & Phelan, 2006).

A number of different types and dimensions of stigma will be discussed below. Goffman (1963) differentiated between visible and invisible stigmatising conditions using the terms discredited and discreditable stigmas. A person with a visible stigma is stigmatised and discredited by others based on their visible sign of difference (ethnicity, disfiguration). A person with no visible sign of stigma is discreditable but not yet discredited. In these circumstances illness or disability can only be inferred based on other signals such as labels, behaviours or psychiatric symptoms. Individuals with invisible conditions face a dilemma when deciding whether or not to disclose their condition as there are advantages and disadvantages either way.

Goffman (1963) further classified stigma according to condition; tribal identities, blemishes of individual character and abominations of the body. Tribal stigmas are common stereotypes or group-based inferences about ethnicity, gender and age that are constantly activated as a result of repeated exposure and are therefore quickly accessed and retrieved (Biernat & Dovidio, 2000). Furthermore, tribal stigmas are consensually held and culturally transmitted within groups (Biernat & Dovidio). Individual character blemishes may involve similar processes as tribal stigma and include stigmatising conditions such as mental illness, where common stereotypical

beliefs include notions that people with mental illness are inferior and require coercive handling, also that they need to be cared for and are socially threatening (Angermeyer & Matschinger, 2004; Biernat & Dovidio; Holmes, Corrigan, Williams, Canar, & Kubiak, 1999).

Abominations of the body stigmas (disfigurement, some medical conditions, cerebral palsy) are generally less common and therefore not as readily activated and may invoke an emotional response first, as opposed to stereotypical knowledge, due to the visible nature of the condition (Biernat & Dovidio, 2000). Tribal and abominations of the body stigmas are typically visible stigmas whereas individual character stigmas can be visible or non visible.

Jones et al. (1984) identified six dimensions of stigma, these include; “concealability” (the visibility of the condition), “course of the mark” (will the condition become more salient or deteriorate over time), “disruptiveness” (level of impact on relationships), “aesthetics” (physical manifestation of stigma), “origin” (cause of condition) and “peril” (perceived danger to others). Concealability, aesthetics and disruptiveness are closely related to Goffman’s (1963) concepts of visibility, abominations and individual character blemishes, respectively. The cause of a stigmatising condition and perceived danger are concepts that have been well researched with regards to the impact they have on discriminatory and prejudiced attitudes.

Researchers argue that the most important aspects of stigma are the visibility and controllability or cause of a stigmatising condition (Crocker, et al., 1998). Visible stigmas activate schemas about stigmatising conditions which influence attitudes (Crocker, et al.) and perceived controllability has been shown to influence attitudes (Weiner, et al., 1988).

Finally, three types of stigma have been described in the literature; public stigma, self stigma and courtesy stigma. Public stigma refers to stereotypical, prejudiced and discriminatory practices directed by the general public towards the stigmatised (P. W. Corrigan & Wassel, 2008). Self stigma develops when stigmatised individuals internalise public stigma and apply the stereotype personally (P. W. Corrigan & Wassel). Goffman (1963) also coined the term “courtesy stigma”, where individuals who are associated with stigmatised individuals experience stigma. While these three types of stigma clearly identify groups impacted by stigma, the term ‘stigma’ in itself is a stigmatising term and several researchers suggest using discrimination instead. Using the term discrimination places the focus of research on the perpetrators of discrimination and changing factors associated with this, as opposed to focusing on changing factors associated with the recipients of stigma (Link & Phelan, 2001; Sayce, 1998). The brief descriptions discussed above show that stigma, stereotyping and prejudice are closely related constructs. To further understand their connectedness, related aspects of stigma, stereotyping and prejudice are discussed.

Relationship between stigma, stereotyping and prejudice

Stigma and stereotyping are related as stereotyping and stigma often co-occur but in some instances stigmatisation occurs without prior stereotyping (Biernat & Dovidio, 2000). For example, tribal and character blemish stigmas are more likely to invoke strong stereotypical beliefs and subsequent stigmas associated with these groups but abominations of the body (e.g., disfigurements) are more likely to produce affective reactions initially which impact stigma avoidance directly without necessarily invoking stereotypical knowledge (Biernat & Dovidio).

Stigma and prejudice are related as stigma (discrediting mark) most likely leads to prejudice (cognitive and affective response) but stigma is more encompassing and

includes additional factors such as character and identity attributions and individual and group reactions to the stigmatised (Dovidio, et al., 2000). Also, stigma is socially defined which infers that stigmatising “marks” vary over time and culture (Dovidio, et al.). Some researchers suggest that stigma and prejudice are similar constructs and that the difference in definitions results primarily from the populations studied (Stuber, Meyer, & Link, 2008). A review of 18 models of prejudice and stigma found support for this claim (Phelan, Link, & Dovidio, 2008). The review found that stigma researchers focus on individuals who are stigmatised as a result of “unusual” conditions (mental illness, facial disfigurement and HIV) as well as the stress resulting from the stigma or stress in maintaining vigilance (Stuber, et al.). Prejudice researchers focus on class, race, age and gender divisions, and structural forms of discrimination (Stuber, et al.). Finally, it is suggested that the term stigma can replace a number of the constructs discussed (labeling, stereotyping, prejudice and discrimination) and the processes can occur in varying degrees (Link & Phelan, 2001).

Stigma and brain injury

Some groups of people may be subjected to multiple forms of stigma. For instance, an adolescent with brain injury may be stigmatised due to their age (tribal), stigmatised as a result of their brain injury (blemish of character) and/or stigmatised as a result of facial disfigurement (abomination). Survivors’ of brain injury may internalise public stigma and develop self stigma, resulting in them believing stereotypical information about their injury or illness, impacting recovery. Furthermore, survivors’ of brain injury may experience stigma in different ways depending on whether they have visible markers of injury or not, and whether they choose to disclose or not disclose their injury.

When identifying who might experience different types of stigmatising conditions (tribal, character blemishes and abominations of the body), it is possible that when a scar or facial disfigurement is present an emotional response is the first reaction (abominations of the body), but when there is no physical sign of stigma, stereotypical or common beliefs are invoked (character blemish). The current research explores this distinction to ascertain whether the public's willingness to socialise with adolescent survivors of brain injury varies dependent upon whether their injury is visible (facial disfiguration; abomination stigma) or non visible (character blemish stigma).

In conclusion, the current research explores public stigma and focuses on the effect the visibility of a brain injury (character blemish and abomination stigmas) has on the willingness of others to socialise with adolescents who have sustained a brain injury. The cause of the brain injury is also examined as perceptions of responsibility may influence people's willingness to socialise with survivors and perceptions of dangerousness are examined as this may also influence others willingness to socialise. The following chapter discusses danger and responsibility models of stigma and other factors that may impact on people's willingness to socialise.

CHAPTER 5

DANGER AND RESPONSIBILITY MODELS

AND FAMILIARITY AND KNOWLEDGE ABOUT HOW TO

INTERACT

There are potentially a multitude of factors which may influence peoples' willingness to socialise with adolescent survivors of brain injury. Previous chapters discussed visibility, stereotyping, prejudice, stigma and the gender of the adolescent survivor as possible contributing factors. The current chapter will consider other factors purported to influence discrimination. The degree of injury or resulting disability, ethnicity, education, socio economic status, whether an individual has an authoritarian /coercion-segregation attitude and even the time of day may all influence discriminatory responses. However, the current research is focusing on people's level of familiarity or contact with individuals' with brain injury, causal attributions regarding the cause of a brain injury, perceptions of dangerousness and a lack of knowledge about how to interact with survivors of brain injury.

These factors were selected as they were shown to have influenced discriminatory behaviours in relation to mental illness and/or brain injury or were discussed as possible reasons why people would be reluctant to socialise with individuals with disabilities (lack of knowledge about how to interact). These concepts are discussed below.

Familiarity with individuals with brain injury

Familiarity with brain injury can be defined as the amount of knowledge someone has about brain injury and/or the amount of contact they have had with individuals with brain injury (Holmes, et al., 1999). Familiarity with individuals with mental illness has been examined using the level-of-contact report developed by

Holmes et al. The measure includes 12 items describing varying levels of personal contact such as: “I have watched a movie or television show in which a character depicted a person with mental illness”, “a friend of the family has a severe mental illness” and, “I have a severe mental illness” (Holmes, et al., p. 450). Respondents endorse statements they have experienced and the highest level of contact is used as the final indicator of degree of level of contact.

Using the level-of-contact report, the mental illness literature finds that people who have experienced more contact with individuals with mental illness are less likely to engage in stereotyping and discrimination (P. W. Corrigan, et al., 2003). Further research exploring the public’s perceptions of adults with mental illness found that greater familiarity with individuals with mental illness resulted in lower perceptions of dangerous (P. W. Corrigan, Green, et al., 2001). A similar pattern occurred with regard to endorsing prejudicial attitudes (authoritarian and benevolence) (P. W. Corrigan, Edwards, et al., 2001). However, there was an exception to these findings; adolescents who had more contact with individuals with mental illness were more likely to endorse dangerous perceptions and stigmatising attitudes (P. W. Corrigan et al., 2005). Furthermore adolescents who were more familiar with peers with mental illness were more likely to view them as more dangerous than adolescents with less familiarity.

Relative to the mental illness literature there is little research examining familiarity with individuals with brain injury and the impact the familiarity has on discriminatory behaviour. The only study found that specifically examined familiarity, brain injury and discrimination reported that participants’ contact with individuals with brain injury had no effect on prejudicial and discriminatory attitudes (Linden, et al., 2007). However Linden et al.’s research measured familiarity using a yes/no question with limited statistical power (P. W. Corrigan, Green, et al., 2001).

Related research examining brain injury, familiarity, visible signs of injury and attributions found that familiarity with brain injury did influence attributions. When shown a photo of an adolescent male with a head scar who was described as sustaining a brain injury, participants with more familiarity attributed his undesirable behaviours (angers quickly, lacks motivation and self confidence and sleeps a lot) more to his brain injury than his adolescence, than people with less familiarity, who attributed the behaviours more to his adolescence (Foster, 2010). Furthermore, when the adolescent was depicted with no scar there was no difference in attributions between the groups, suggesting that the scar acted as a moderator of the relationship between familiarity and attributions (Foster). The familiarity measure used in Foster's study differed from that used by Linden et al. (2007) (who used a categorical measure asking participants if they had had contact with people with brain injury – a yes or no response). Foster used a modified version of a nine-point level-of-contact scale developed by Holmes et al. (1999), which was then converted into high and low familiarity.

Lack of knowledge about how to interact

Another factor which may influence people's willingness to socialise with adolescent survivors of brain injury is a lack of knowledge about how to interact with survivors. This topic has received little attention in the mental illness and brain injury literature. One study, examining stigma and pharmacy students' beliefs about individuals with schizophrenia from six countries, found that perceptions that people with schizophrenia were "difficult to talk to" was one of three factors, along with unpredictability and perceptions of dangerous that predicted higher social distance (Bell et al., 2010). Crisp, Gelder, Rix, Meltzer, and Rowlands (2000) found similar results when examining mental disorders and the public's attitudes. Participants felt it was difficult to talk to people with any of the disorders described (drug and alcohol

addiction, eating disorder, panic attacks, severe depression, schizophrenia and dementia), and described people with alcohol and drug addiction and schizophrenia as dangerous and unpredictable.

Albrecht, Walker, and Levy (1982) found that being responsible for a stigmatising condition (conditions ranging from diabetes and cancer to mental illness and drug abuse) did not explain the willingness, or lack of willingness to socially interact. To understand why being responsible did not account for this, they asked participants why they thought other people did not want to socialise with individuals with stigmatising conditions. Ambiguity in the social interaction was cited; a lack of knowledge about how to interact or respond to people with stigmatising conditions and also apprehension about things they did not understand and new things. Also, threats to social and physical well being, physical offensiveness, moral weakness and feelings of guilt for being healthy were cited.

Albrecht et al. (1982) used open-ended questions in the third person to minimise social desirability effects and to negate the need to explain responses on a forced choice Likert scale or something similar. Questions included: "Some people do not like to be around a person who is physically disabled (or who has a social disability such as alcoholism or some other addiction). Why do you think they feel this way?" Their sample consisted of 150 managers enrolled in further education. The sample was all white college graduates, mostly married and urban dwellers. This limited sample may explain the differences found in the responsibility results which contradict P. W. Corrigan et al. (2003) and others research.

As identified by Albrecht et al. (1982) some people are unsure about how to respond or act in the presence of people with disabilities or mental illness and others believe that it is difficult to talk to them (Bell, et al., 2010). Perhaps they were raised in

a time when people with disabilities were in special classrooms, schools or were institutionalised (Miller & Sammons, 1999). Perhaps they are scared of saying the wrong thing or looking in the wrong place or using the wrong language (Miller, et al., 2004). Further, the brain's automatic response to differences, whether it is disability, appearance, illness or potential threat can prompt uncertainty, anxiety or avoidance behaviours (Miller & Sammons). Automatic reactions were essential early survival skills, however these, a lack of socialisation and being told "not to stare" by parents and others may all contribute to feelings of discomfort about differences and stop people engaging with people with disabilities.

We learn about how to respond to differences by watching others, and new encounters with individuals with differences facilitate new learning and a broadening of comfort zones. However, only recently have institutions become outmoded in some countries, resulting in people with disabilities and mental illnesses living in the community. New encounters that are unfamiliar prompt comparison with expected norms or ideals as we try to understand and accommodate differences (Miller & Sammons, 1999). Some people may have had little contact with individuals with disabilities and mental illness; therefore, it is not surprising that they may be anxious and uncertain about how to respond to differences. The current research will explore this concept by examining knowledge about how to interact as a factor influencing willingness to socialise.

Responsibility Model

Causal Attributions; effects of being responsible or not responsible for causing a brain injury

Attribution theory was identified as a suitable theoretical model to examine causal attributions and discriminatory attitudes towards survivors of brain injury. It was

chosen because it views people as active thinkers who evaluate events by looking for the cause of a situation and then use this causal information, which may be incomplete, in whatever manner they deem appropriate (Jones et al., 1972). Furthermore, attribution theories specifically examine the rules or processes people use when they evaluate the cause of events or behaviour (Jones, et al.). Therefore, attribution theory examines causal attributions (responsible or not responsible) and mediating factors which may influence that relationship. Mediating variables potentially explain how one variable leads to another variable (Baron & Kenny, 1986). For instance, it would be possible to determine whether there is a direct relationship between responsibility and willingness to socialise or whether the relationship is mediated by other factors such as anger and pity. Figure 1 shows an example of mediation.

Although there are a number of attribution theories, (e.g., Atkinson's theory of achievement motivation, Festinger's theory of cognitive dissonance and the Hull-Spence drive theory), Weiner's cognitive-emotional-behavioural attribution model was chosen as the theoretical basis for the current research for a number of reasons; it offers an explanation for the relationship between stigmatising attitudes and discriminatory behaviour, it provides a conceptual framework to examine multiple factors involved in discrimination and the approach can be applied in a broad range of social situations (Jones & Hastings, 2003; Weiner, 1995). Further, the model has already been used by a number of researchers when researching discrimination, prejudice and stigma, specifically when examining these concepts as they relate to mental illness and brain injury.

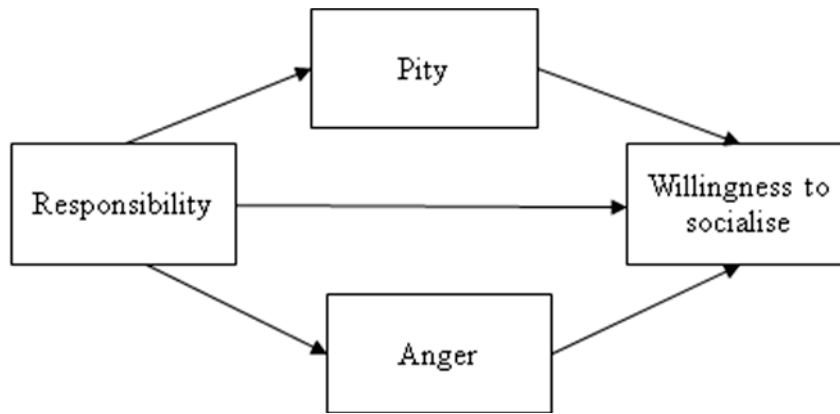


Figure 1: Weiner's attribution model showing a direct relationship between responsibility and willingness to socialise and the relationship mediated by anger and pity.

Weiner's Attribution Theory

Weiner (1995, 2006) proposed that people make cognitive appraisals about the controllability of a stigmatising condition and try to identify whether the person was responsible or not for causing their current condition. Responsibility judgments then influence affective responses (pity and anger) and subsequent attitudes and behaviours (willingness to socialise or help) (P. W. Corrigan, et al., 2003; Weiner, 1995, 2006). Weiner's attribution theory offers an explanation for how perceptions of responsibility lead to specific emotions and subsequent behaviour. Individuals appraise the controllability of a person's condition, when a condition is perceived as under a person's control (i.e., self-initiated causes such as drunk and got into a brawl) anger increases and pity decreases, aversively impacting attitudes and behaviour (less desire to assist). When a condition is perceived as not under a person's control (e.g., an organic cause such as a brain haemorrhage), anger decreases and pity increases, positively impacting attitudes and behaviour (more willingness to assist) (Weiner, et al., 1988).

Weiner's (2006) attribution theory also incorporates free will and assumes individuals have free will when choosing courses of actions. That is, when attributing

responsibility and behavior of others, individuals assume others assert their own free will just like they do. There is substantial support for Weiner's theory when applied to stigmatising conditions.

Weiner et al. (1988) manipulated the controllability of stigmatising conditions (AIDS, child abuse, obesity, Alzheimers disease, blindness, cancer, heart disease, paraplegia and Vietnam War Syndrome) and found that when participants (university students) were informed that the cause of a condition was controllable, blame and anger increased and pity and liking decreased. The desire to personally assist and give charitable donations also decreased when participants were informed that the onset of the condition was controllable. In contrast, when a condition was described as out of a person's control, pity increased and anger decreased. Further research found that describing the cause of a mental illness as biological or structural resulted in more willingness to interact, than when the illness was described as drug or alcohol related (Martin, et al., 2000).

Support for Weiner's attribution theory has also been found in the brain injury literature. One study manipulated the cause of an adult's brain injury (as a result of a brain haemorrhage or starting a fight after drinking alcohol) and found that participants were more willing to socially interact and help when the injury was acquired through organic means (brain haemorrhage) than self-initiated means (fight) (Redpath & Linden, 2004). Additional research found similar results; participants portrayed as having contributed to their injury received higher prejudicial evaluations than participants portrayed as blameless (Linden, et al., 2007).

While the research by Linden and colleagues goes some way towards the examination of discrimination and brain injury, it does not examine how causal attributions lead to discriminatory behaviour. That is, is there a direct relationship

between the responsibility for a brain injury and willingness to interact or is this relationship mediated or moderated by other factors, such as emotions, as suggested by Weiner. Work on these relationships has already been conducted in the area of mental illness.

P. W. Corrigan et al. (2003), for example, found that when participants were informed that the cause of a person's mental illness was not under their control, more pity and less anger was reported, than when they were not informed about the controllability of the illness. In contrast, when the illness was described as under their control, more anger and less pity was reported, than when participants were not advised about the controllability of an illness. Furthermore, participants' causal attributions about the controllability of a person's mental illness influenced their beliefs about responsibility, which influenced affective reactions and subsequent behavioural responses (help, avoidance and segregation) (P. W. Corrigan, et al., 2003). That is, judgements about responsibility mediated the relationship between the controllability of the mental illness and participants' behaviour. Also, affective reactions mediated the relationship between responsibility and subsequent behaviour.

Research examining adolescents' perceptions of peers with mental illness found that stigma diminished, helping behaviour increased and reports of fear and dangerous decreased, when a peer's mental illness was described as being caused by a brain tumor than when no information regarding the cause of the mental illness was given (P. W. Corrigan, et al., 2005). Furthermore, causal attributions did not differ between adolescents described as having a mental illness due to a brain tumor and adolescents described as having a mental illness when no information regarding the cause of the illness was given. Finally, when a peer was responsible for causing their mental illness

less pity and more anger were reported and subsequently less willingness to help (P. W. Corrigan, et al.).

Although there is considerable support for aspects of Weiner's attribution model in the mental illness literature there are some exceptions; P. W. Corrigan et al. (2002) found that the model was only partially supported. Using structural equation modeling (path model analysis), they found no associations between responsibility and both pity and anger and a negative association between anger and helping behaviour. However, P. W. Corrigan et al. found considerably more support for a danger model which will be discussed in the danger model section.

Based on Linden and colleagues' research (Linden, et al., 2007; Redpath & Linden, 2004), that being responsible impacts prejudicial and discriminatory behaviour, Weiner's full attribution model was used to examine whether the cause of an adolescent's brain injury influenced discriminatory behaviour, and whether this relationship was mediated by emotional responses (pity and anger).

Danger model

Another factor most likely to influence people's willingness to interact with adolescent survivors of brain injury is perception about dangerousness. The danger model (P. W. Corrigan, 2000; P. W. Corrigan, et al., 2003; P. W. Corrigan, et al., 2002) offers an explanation for how perceptions of dangerousness influence discriminatory responses. According to this model, information about perceptions of dangerousness impacts on emotional responses (e.g., fear) which in turn influence subsequent behaviour and attitudes (P. W. Corrigan, et al., 2002). That is, fear mediates the relationship between perceptions of dangerousness and willingness to assist. When a person is described as dangerous, fear increases and helping behaviour reduces. When they are not described as dangerous, fear reduces and helping behaviour increases.

Figure 2 depicts a danger model proposed by P. W. Corrigan (2000) showing fear mediating the relationship between perceptions of danger and willingness to assist. Considerable support for this model has been found in the mental illness literature.

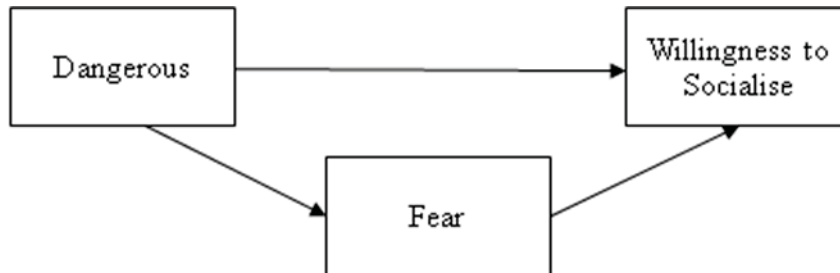


Figure 2: Danger model showing a direct relationship between perceptions of dangerousness and willingness to socialise, and fear mediating this relationship.

Using a series of ordinary least square regression equations P. W. Corrigan et al. (2003) found that describing an adult with schizophrenia as dangerous increased fear responses and reduced subsequent helping behaviours. They also found that being described as responsible for the onset of schizophrenia resulted in similar outcomes (less help and an increase in coercive treatment). P. W. Corrigan et al. (2002) also found support for a danger model using structural equation modeling (SEM). All standardised path coefficients were significant supporting a partial mediation model where fear mediated the relationship between perceptions of dangerousness and avoidant behaviours. Further research employing SEM found that when a peer with mental illness was described as dangerous, an adolescent's fear increased as did subsequent avoidant behaviour (P. W. Corrigan, et al., 2005).

Recent quantitative research comparing student and public perceptions about survivors of brain injury found that students feared survivors more, with students reporting higher levels of violence, unpredictability and aggression when compared

with the general public (Linden & Crothers, 2006). Additional qualitative research found that the public perceived survivors of brain injury as aggressive, frustrated, irritable and lacking in emotion regulation (Linden & Boylan, 2010).

No research was found that specifically examined a danger appraisal hypothesis in relation to brain injury. Accordingly, the current research sought to fill this gap using path analysis to examine fear as a mediator between the relationship of perceptions of dangerousness and willingness to socialise. Visible signs of brain injury were also examined as a moderator of the danger mediation model (i.e. moderated mediation). The following two chapters describe two research articles in the process of being submitted to journals. Article One examines the effect visible signs of injury and gender of the adolescent and participants have on willingness to socialise. Article Two has two studies. Study one replicates Article one and extends the literature by examining knowledge about how to interact as a factor influencing willingness to socialise. Study two examines the danger and responsibility models discussed above.

CHAPTER 6

ARTICLE ONE

Do visible scars influence people's predictions of other people's willingness to socialise with an adolescent with brain injury?

This paper is in the process of being submitted to The Journal of Head Trauma

Rehabilitation and the formatting is in the required style for submission.

Do visible scars influence people's predictions of other people's willingness to socialise
with an adolescent with brain injury?

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Keywords: brain injury, visible signs of brain injury, discrimination, adolescents

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Abstract

Primary objective: Identify whether visible scars associated with brain injury, gender of the adolescent with brain injury or participant, and familiarity with individuals with brain injury influence people's predictions of the extent to which other people would be willing to socialise with adolescent survivors of brain injury.

Research design: Participants ($N = 99$) were shown a photo of an adolescent with a visible sign of injury (head scar), or without, with a vignette advising them that the adolescent had sustained a brain injury. Between subjects 2 (Photo: scar or no scar) x 2 (Adolescent: male or female) x 2 (Participant: male or female) ANOVAs were used to analyse data.

Method and procedures: Participants completed questionnaires asking how willing they predicted other people would be to socialise with the adolescent portrayed and indicated how familiar they were with individuals with brain injury.

Main outcomes and results: As expected, participants reported that others would be more willing to socialise with the adolescents with a scar than the adolescents with no scar. Female participants reported that others would be more willing to socialise with the female adolescent than the male adolescent, and male participants reported that others would show no difference in willingness to socialise with the male or female adolescent. There were no reported participant gender differences in the scar condition, but females reported that others would be more willing to socialise in the no scar condition than males' predictions of others willing to socialise when the adolescent had no scar.

Conclusion: Visible signs of brain injury (in this case a head scar) influence people's predictions of others' willingness to socialise.

Keywords: brain injury, visible signs, adolescents, discrimination, familiarity

Introduction

It is estimated that 32% of New Zealanders (NZ) suffer at least one traumatic brain injury (TBI) that requires medical assistance by the time they are 25 years old [1]. The average incident rate of TBI in NZ, prior to the age of 25 years is 1750 per 100,000 per year [1]. In the United States of America (USA) lifetime prevalence is estimated at 506 per 100,000 [2]. Variations in reported prevalence rates are common due to methodological differences; data collection strategies vary, as do reporting guidelines and definitions of TBI [2]. Data may be collected from one source (hospital admissions) or additional sources such as accident and emergency departments and doctors' visits. McKinlay et al. collected data from all these sources which may explain why their rates are higher than the rates reported in the USA and other NZ statistics. In the USA data were collected from emergency department visits, deaths and acute hospital discharges [2].

Irrespective of the differences in the reported prevalence of TBI the effect on health services throughout the world is significant as is the number of survivors of brain injury requiring assistance and rehabilitation. Furthermore, brain injury is frequently associated with additional complications such as depression [3], aggression, post traumatic stress disorder [4] and behavioural and personality problems [5] which may complicate rehabilitation efforts. An important aspect of rehabilitation is successful community integration following a brain injury.

Successful community integration may be impeded by the misconceptions and associated attitudes that are held about people with brain injury. Some people believe that once survivors' physical injuries are healed, then their brain injury is healed [6] and others believe that recovery is dependent on the amount of effort expended by survivors [7]. A lack of awareness about the time frames involved in recovering from a brain

injury, coupled with a lack of visible signs of brain injury can prompt suggestions of ‘malingering’ from health professionals and the public [8]. The effect of having visible signs of brain injury or not having visible signs of brain injury and the public’s willingness to interact with survivors of brain injury has received little attention from researchers and is the focus of the current research.

Research shows that 15 to 20 year olds are at an increased risk of sustaining a TBI, relative to other age groups [1]. Adolescence is a time of self doubt, where concerns about the differences between themselves and others and worries about being judged about behaviour or dress are common [9]. Given adolescents increased risk of sustaining a TBI and the possible compounding effects of navigating adolescence, identifying factors which may impact successful community integration following a brain injury would be useful for this group.

Visible signs of disability

People with visible disabilities often experience more discrimination and prejudice than people with non visible disabilities [10, 11]. Brain injury research examining visible signs of injury (head scar or no head scar) and attributions for an adolescent’s undesirable behaviour, found contrasting results [12]. McClure et al. found that participants attributed an adolescent’s undesirable behaviour (angers quickly, lacks motivation and self confidence and sleeps a lot) more to his adolescence than his brain injury when there were no visible signs of brain injury. When there were visible signs of brain injury they attributed the behaviours equally to brain injury and adolescence, suggesting that more consideration was given to the brain injury as the cause of the adolescent’s undesirable behaviour when a head scar was present.

Understanding that people may react differently dependent upon whether a survivor of brain injury has a visible sign of brain injury or not is essential when

informing survivors about other people's likely attitudes and responses to them. As far as we are aware there has been no research examining the effects of visible signs of brain injury and discrimination. The current research extends the work of McClure et al. [12] and Foster [13] by examining the impact that the visible signs of brain injury have on the willingness of others to socialise with adolescents with brain injury.

Familiarity with brain injury

Another factor which may influence people's willingness to socialise with an adolescent with brain injury is the amount of contact a person has had with individuals with brain injury. The mental illness literature shows that more familiarity (measured by the level of contact) with people with mental illness was associated with less discrimination, relative to people with less familiarity [14, 15]. Higher familiarity with individuals with mental illness was also associated with less authoritarian and benevolent and prejudicial attitudes [16].

The literature examining familiarity with individuals with brain injury and discrimination is sparse. Linden et al. [17] found that people's level of familiarity had no effect on discriminatory and prejudiced attitudes. However, research examining brain injury, visual signs of injury and attributions did find differences between people with more and less familiarity [13]. When an adolescent was described as having a brain injury and his photo showed a scar, people with more familiarity attributed his undesirable behaviours more to his brain injury, than people with less familiarity [13]. Furthermore, people with less familiarity attributed his undesirable behaviours more to his adolescence than people with higher familiarity. When the adolescent had no scar there was no difference in attributions to adolescence and brain injury between people with more or less familiarity [13]. The current research will examine whether familiarity

with individuals with brain injury and having a scar or no scar impacts on peoples willingness to socialise with an adolescent with brain injury.

The Current Research

Although research has shown that visible signs of brain injury influence people's attributions for the undesirable behaviour of an adolescent male who had sustained a brain injury [12, 18], the authors found no research examining the effects of visible signs of brain injury and discrimination. Therefore, the current research continues to examine the impact visible signs of brain injury have on adolescents' lives by exploring whether the visibility of an injury influences other people's willingness to socialise. Visible signs of brain injury (scar or no scar) were manipulated as was the gender of the adolescent. Familiarity with individuals with brain injury and visible signs of brain injury were examined as it was expected that contact with individuals with brain injury would influence people's willingness to socialise with adolescents who had suffered a brain injury.

Aims

Past stigma research shows that people with visible disabilities are prejudiced against [10, 11]. In contrast, recent brain injury research shows that more consideration was given to the brain injury as the cause of an adolescent's undesirable behaviour when a visible sign of brain injury was present than when no visible sign of injury was present [12, 18]. Based on the brain injury literature it was predicted that people would be more willing to socialise with the adolescents with a scar than the adolescents with no visible sign of injury (hypothesis 1).

Gender effects of the participants and adolescents were also examined. Based on the brain injury literature, which found that the gender of an adult survivor of brain injury had no effect on participants' willingness to interact [19], it was predicted that the gender of the adolescent would not influence participants' willingness to socialise.

Furthermore, visible signs of injury were not expected to interact with the gender of the adolescent (hypothesis 2).

Although there is one study showing that females held less positive attitudes than males towards individuals with brain injury [20], there is a large body of research showing the opposite effect. This research shows that females hold more positive attitudes than males, although this research examined mental illness [21, 22]. The third hypothesis, then, is based on the mental illness literature as the brain injury results have not been replicated to date. It was predicted that female participants would be more willing to socialise than male participants, irrespective of whether the adolescent had a scar or not (hypothesis 3).

Finally, it was predicted that participants who had experienced more contact with individuals with brain injury would be more willing to socialise with the adolescents with a scar. However, no between group differences were expected when the adolescents had no visible signs of injury (hypothesis 4). This is predicted as previous brain injury research [13] found that people with more familiarity gave more consideration to a head injury as being the cause of an adolescent boy's undesirable behaviour when a scar was present than people with less familiarity. In contrast, there were no differences between people with more or less familiarity when there were no visible signs of injury.

Method

Participants

One hundred and seven people were approached and recruited in central Wellington, New Zealand. One case was removed due to the questionnaire being completed incorrectly. A manipulation check was performed after participants handed in the survey; participants were asked whether they had noticed the scar. Seven cases

were removed due to the participants failing to notice the scar, resulting in 99 cases. Data from 42 males and 57 females ranging in age from 16 to 87, with a mean age of 38, were used for analysis. Sixty six percent were NZ Europeans, 8% Maori, 3% Samoan, 2% Indian, 2% Chinese, 1% Cook Island Maori and 18% indicated other ethnicities. The NZ European statistics are consistent with NZ's 2006 Census report which indicates the New Zealand population to be made up of 67% NZ Europeans, 14% Maori, 9% Chinese and 7% for Cook Island Maori, Samoan, and Indian (Statistics New Zealand, 2011).

Materials and design

Vignette

A one-paragraph vignette with a photo of either an adolescent male or female was shown to participants. The photo showed the adolescent with either a head scar or no scar resulting in four conditions: no scar and female, no scar and male, scar and female and scar and male. The vignette was similar in the scar and no scar photo for each gender as described below:

Above is a photo of Karen/John. Karen/John lives with her/his parents and brother and goes to school in Wellington. She/he is good at biology/woodwork and wants to be a nurse/builder when she/he gets older. Karen/John has several friends and regularly gets together with them in the weekends. Karen/John has suffered from a head injury, which has injured her/his brain at the time of becoming an adolescent.

Willingness to interact

To measure participants' willingness to socialise with the adolescents portrayed, a questionnaire previously used to assess social distance from adults was utilised [23, 24]. The Willingness to Interact questionnaire had four questions which were rated using four-point Likert scales. The questionnaire was later adapted to rate children [25]. Changes made in the current research included changing child to adolescent and

inserting ‘do you think other people would be’ to reduce social desirability effects. The four questions were ‘how willing do you think other people would be to: (1) move next door to the family of this adolescent, (2) have their child make friends with this adolescent, (3) spend an evening socialising with that adolescent’s family and (4) have that adolescent in their adolescent’s classroom’? The reliability in the present study for the four-item scale was Cronbach $\alpha = 0.83$.

Familiarity scale

The familiarity scale has nine items and measures the level of intimate contact with individuals with brain injury. The scale was modified and adapted from familiarity scales previously used in mental illness and stigma research [26, 27]. The word mental illness was replaced with the word brain injury and three items were not included from the original scale created by Holmes et al. These items had been removed in subsequent studies as they were similar to other items [27]. Three clinical psychologists specialising in brain injury ranked the items based on intimacy of contact, and Kendall’s interrater reliability was 0.97.

The nine familiarity items were numbered from one to nine. The statements are rank order-based (whereby higher numbers indicate more contact with individuals with brain injury and lower numbers indicate less contact) and the highest number selected by participants was used as an indicator of their level of intimate contact with individuals with brain injury replicating previous practice [26]. Participants were asked to circle the number next to all statements that they had experienced in their life (see Appendix A). Statements included items such as ‘I have never observed a person with brain injury’ and ‘I live with a person with a brain injury’.

Additional details regarding age, gender, occupation and ethnicity were recorded and participants were asked whether they had children or cared for children.

Procedure

Ethics approval was granted by Massey University Ethics Committee: Southern B, Application 10/62. People who were sitting down were approached in outside locations in Wellington, New Zealand (i.e., outside shopping precincts and parks along the seafront) and asked if they had five minutes to view a photograph, read a short paragraph and complete a questionnaire about adolescents and brain injury. Completion of all surveys and debriefing occurred at the location participants were canvassed. They were advised that the research was voluntary, anonymous and part of a doctoral thesis at Massey University. Participants were further informed that they could withdraw at any time prior to handing in the completed questionnaire. Debriefing included advising participants that the adolescents in the photograph had not suffered from a brain injury and that the stories were fictional. Email addresses were recorded if people responded positively to receiving the results of the survey. At the end participants were offered a chocolate bar as a small token of appreciation.

Quasi-randomisation was accomplished by placing each condition in a separate folder in a satchel. The front folder was selected initially and when that survey was completed it was returned to the satchel and placed at the back of the group of folders. The front folder was then selected for the next participant. This procedure was repeated for all participants. This procedure was not entirely random as there were only four conditions and therefore it was possible to anticipate the next condition with potential bias occurring when selecting the next participant. A minimum of 20 participants were required for each condition as this sample size has previously been shown to be sufficient to achieve statistical significance [12, 18].

Results

The four willingness to socialise dependent variables (move next door, have their child make friends, socialise with the adolescents family and have that adolescent in their adolescents class) were combined and averaged to create a composite variable. This created an overall 'socialise' variable with a scale ranging from 1.0 (low social distance) to 4.0 (high social distance). This new composite variable was used for all analysis. Due to the small number of participants in some of the Familiarity conditions a dichotomous variable was created based on a median split to obtain adequate sample sizes for an ANOVA. Participants who rated their contact with individuals with brain injury as four or less comprised the low familiarity group and participants who rated their contact as five or more comprised the high familiarity group. This new composite variable was used for all analysis.

All data were analysed using SPSS and the ANOVA assumptions were met. Levene's test of equality of variance was non significant, $F(7, 91) = 0.83, p > .05$. To examine Photo and gender effects a 2 (Photo: scar or no scar) x 2 (Adolescent: male or female) x 2 (Participant: male or female) ANOVA was conducted. As expected, there was a main effect for Photo which approached significance, $F(1, 99) = 3.66, p = 0.059, \eta^2 = 0.04$; participants reported that other people would be more willing to socialise with the adolescent with a scar ($M = 3.35$), than the adolescent with no scar ($M = 3.15$) (hypothesis 1).

There was a significant main effect for the gender of the Adolescent, $F(1, 99) = 4.19, p < 0.05, \eta^2 = .04$, participants reported that other people would be more willing to socialise with the female adolescent ($M = 3.35$) than the male adolescent ($M = 3.14$). This was not expected, no difference in reported willingness to socialise with the male or female adolescents was predicted as previous research found no gender effects for

adult survivors of brain injury [19] (Hypothesis 2). However, there was an interaction between the gender of the Adolescent and Participant, $F(1, 99) = 4.55, p < 0.05, \eta^2 = 0.05$, (see Figure 1) which clarified the main effect. Additional analysis found that female participants reported that others would be more willing to socialise with the female adolescent ($M = 3.51$) than the male adolescent ($M = 3.08$), $t(55) = -3.22, p < 0.01$. In contrast, there was no difference in male participants' predictions of others' willingness to socialise with the female and male adolescents, $t(40) = 0.13, p > 0.05$.

There was no main effect for the gender of the Participant, $F(1, 99) = 0.85, p > 0.05, \eta^2 = 0.01$, which was also unexpected. We expected female participants to report that others would be more willing to socialise with the adolescents than male participants' predictions of others' willingness to socialise in both Photo conditions (hypothesis 3). However, there was an interaction between the Photo and the gender of the Participant, $F(1, 99) = 4.90, p < 0.05, \eta^2 = 0.05$ (see Figure 2) which clarified the main effect. Additional analysis found that female participants reported that others would be more willing to socialise in the no scar condition ($M = 3.33$) than males' predictions of others' willingness to socialise in the no scar condition ($M = 2.99$), $t(47) = -2.24, p < 0.05$. There was no difference in willingness to socialise between females' and males' predictions of others' willingness to socialise in the scar condition, $t(48) = 0.73, p > 0.05$ (see Figure 2).

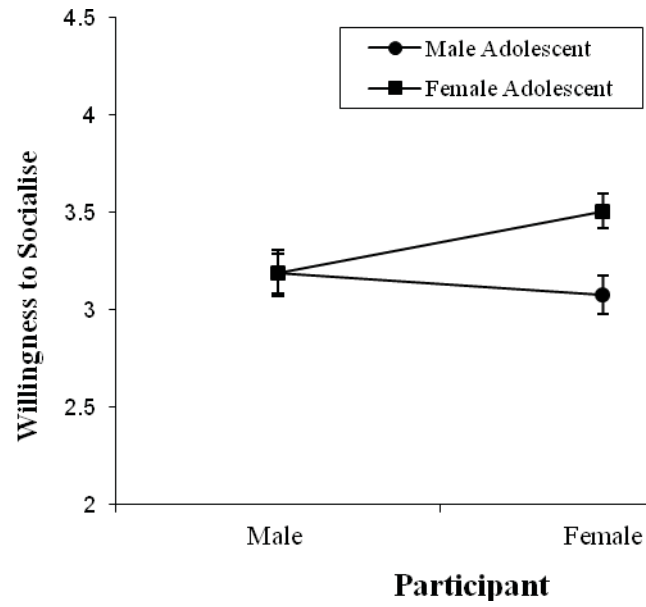


Figure 1: Two way interaction between Participant (male and female) and Adolescent (male and female). Standard error bars are also shown.

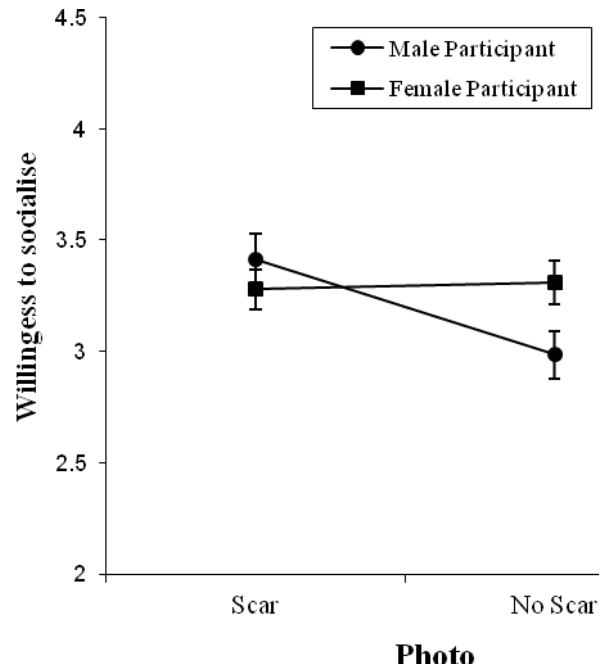


Figure 2: Two way interaction between Photo (scar and no scar) and Participant (male and female). Standard error bars are also shown.

To examine familiarity effects a 2 (Photo: scar or no scar) x 2 (Familiarity: high or low) ANOVA was conducted (hypothesis 4). There were no main effects for Photo, $F(1, 99) = 2.30, p > 0.05, \eta^2 = 0.02$, or Familiarity, $F(1, 99) = 0.001, p > 0.05, \eta^2 = 0.00$, and no interaction between Photo and Familiarity, $F(4, 99) = 1.47, p > 0.05, \eta^2 = 0.02$, therefore hypothesis four was not supported.

Discussion

The current study examined participants' perception of other people's willingness to socialise with adolescents who had sustained a brain injury. A visible sign of brain injury, the gender of the adolescent and participant, familiarity with individuals with brain injury were all examined as possible factors that would influence other people's willingness to socialise.

As expected, participants reported that others would be more willing to socialise with the adolescents with a scar than the adolescents with no visible sign of brain injury, although this finding was marginal ($p = 0.059$) (hypothesis 1). This finding extends previous research [12, 18] which found that a visible sign of brain injury (a scar) influenced attributions for an adolescent boy's undesirable behaviour. The current research shows that a visible sign of injury also influences people's perception of others' willingness to socialise with adolescents who have sustained a brain injury. This is an interesting finding as it differs from the disability literature which typically finds that people with visible disabilities experience more discrimination, than people with no visible signs of disability [10, 11].

A possible interpretation of the results is that adolescents may experience less discrimination, with regard to social interaction, when they have a visible sign of injury, than when they have no visible sign of injury. This suggests that participants made judgements about others' social interactions based on whether the adolescent had a

visible sign of injury or not. Another interpretation is that the scar may have acted as a visual confirmation of the information participants were given about the adolescent sustaining a brain injury. Finally, the scar may have increased empathic emotions which subsequently increased people's willingness to socialise.

It was further predicted that the gender of the adolescent and whether they had a visible sign of injury or not would have no effect on participants' reports of others' willingness to socialise; however, this hypothesis was not supported (hypothesis 2). Participants reported that others would be more willing to socialise with the female adolescent than the male adolescent. An interaction clarified this effect; female participants reported that others would be more willing to socialise with the female adolescent than the male adolescent and male participants reported that others would show no difference in their willingness to socialise with the female and male adolescents. This finding differs from previous research which found that the gender of an adult survivor of brain injury had no effect on the willingness of psychology students to interact and assist [19]. The differences between the survivors being examined (adolescents versus adults) and the participants (the public versus psychology students) may explain the differences found. Also, attempting to control for social desirability effects may have influenced responses. A possible reason for female participants reporting that others preferred to socialise more with the female adolescent could be that they feared the male adolescent, whereas the male participants did not, or male participants feared them less than the female participants.

We predicted that female participants would report that others would be more willing to socialise than male participants' reports of others' willingness to socialise, irrespective of whether the adolescent had a scar or no visible sign of injury (hypothesis 3). Partial support was found for this hypothesis; female participants reported that others

would be more willing to socialise in the no scar condition than male participants' predictions of others' willingness to socialise, but there was no difference in male and female participants reports of others' willingness to socialise when the adolescents had a scar. This finding provides partial support for the mental illness literature which shows that females hold more positive attitudes than males [21, 22] and differs somewhat with brain injury research which found that females held less positive attitudes than males [20]. Furthermore, this finding shows that female participants were not influenced by the scar but male participants were; males reported less willingness of others' to socialise when there were no visible sign of injury. Again, this finding may highlight a discrimination distinction, whereby the scar legitimatised the information given about sustaining a brain injury.

Finally, hypothesis four was not supported, it was predicted that when an adolescent had a scar, participants who had more familiarity with individuals with brain injury would report more willingness of others to socialise than participants who had less familiarity. However, support was found for the prediction that there would be no difference in willingness to socialise when the adolescents had no visible signs of injury. This finding suggests that people's level of familiarity with individuals with brain injury does not influence their perception of others' willingness to socialise with adolescents who have sustained a brain injury. Furthermore, the visibility of the injury does not differentially impact people with more or less familiarity. The results offer support for Linden et al.'s [17] research which found that people's level of familiarity with individuals with brain injury had no effect on discriminatory and prejudicial attitudes.

The following factors need to be kept in mind when interpreting the results. Hypothesis one and two interpretations need to be viewed in relation to the effect sizes

found ($\eta^2 = 0.04$). This effect size may be insufficient when considering clinical application. The familiarity results need to be viewed with caution due to the continuous variable being dichotomised. The current research measured one aspect of discrimination (people's perception of others' willingness to interact); therefore, generalisation is limited to this aspect of discrimination. Furthermore, the adolescents portrayed may have been viewed as middle class well mannered children, again limiting the generalisation to this group. Future research could use photos depicting a variety of lifestyles to examine these effects. This research examined a visible sign of brain injury and willingness to socialise but there may be multiple factors, such as emotions, perceptions of dangerousness and responsibility that may have influenced people's willingness to socialise as complex behaviour can be influenced by many factors. Future research could examine these factors. Finally, a scar is only one possible sign of brain injury; therefore, the results cannot be generalised to other signs of brain injury such as cognitive difficulties, wheelchairs or asymmetric facial features.

What implications do these findings have for understanding the impact visible signs of brain injury have on adolescents' reintegration into the community following an injury? Evidence-based information of this kind may be useful for clinicians who work with survivors to help them make sense of and respond appropriately to the perceptions and likely attitudes that the general population may have towards them. This includes discussing possible changes in others' attitudes when they initially have a visible sign of injury that later heals. Highlighting that there may be some disadvantages in having no visible signs of injury is poignant as adolescents are concerned about appearance and may assume that a lack of visible signs of injury is beneficial in all circumstances. Furthermore, discussing the relevant gender effects (depending on the gender of the adolescent) and how these interact with the visibility of a brain injury will

assist with the adolescent's expectations of socialising post injury. The information gained can also be used when designing campaigns to reduce discrimination aimed at this minority group.

In conclusion, the current research showed that the visibility of a brain injury influenced people's perceptions of others' willingness to socialise with adolescents who had sustained a brain injury. Specifically, participants predict that others would be more willing to socialise with an adolescent survivor of brain injury when they have a visible sign of brain injury than when they have no visible sign of brain injury. Female participants are not influenced by the visibility of a brain injury, but males are. Furthermore, females are more willing to socialise with a female adolescent survivor of brain injury than a male survivor, and males show no difference in their willingness to socialise. Notwithstanding the limitations discussed, the information found may be useful when assisting adolescents with reintegration into the community and when designing campaigns to educate the public.

Declaration of interest: The authors report no declarations of interest.

Appendix A

How familiar are you with people with brain injury? Please circle the number or numbers next to the statements which you have experienced in your life.

- 1 I have never observed a person with brain injury
- 2 I have watched a television show that included a person with brain injury
- 3 I have observed a person with brain injury
- 4 A close friend of the family has a brain injury
- 5 I have a relative who has a brain injury
- 6 I have worked or been in a class with a person with brain injury
- 7 My job includes services/treatment for people with brain injury
- 8 I live with a person with a brain injury
- 9 I have a brain injury

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CHAPTER 7

ARTICLE TWO

BRAIN INJURY AND DISCRIMINATION: TWO COMPETING MODELS – PERCEPTIONS OF RESPONSIBILITY AND DANGEROUSNESS

This paper is in the process of being submitted to The Journal of Head Trauma

Rehabilitation and the formatting is in the required style for submission.

Brain injury and discrimination:
Two competing models – perceptions of responsibility and dangerousness

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Abstract

Primary objectives: The first was to examine whether people's willingness to socialise with adolescent survivors of brain injury is influenced by gender, familiarity, knowledge about how to interact and the visibility of the brain injury. The second objective was to examine two models (perceptions of dangerousness and perceptions of personal responsibility for contributing to or causing a brain injury) for their effect on willingness to socialise and to understand how these perceptions lead to avoidant behaviour.

Research design: ANOVAs and structural equation modelling were used as path modelling tests of theoretical models, and are considered a robust measure of the size and direction of associations between groups of variables [1].

Method and procedures: Participants were canvassed via Facebook advertising and completed survey questionnaires after reading a brief vignette. Vignettes were varied to represent perceptions of dangerousness or being responsible and included a photo of an adolescent male or female, with or without a head scar.

Main outcomes and results: Participants were more willing to socialise with the adolescents with a scar than with no scar. Knowledge about how to interact with survivors impacted willingness to socialise, but familiarity did not. The full danger model was supported but only aspects of the responsibility model were.

Conclusion: The results provide useful information for rehabilitation health professionals working with survivors of brain injury. The implications of these findings are discussed with regards to assisting adolescents' re-entry into society post injury.

Keywords: brain injury, visible signs of brain injury, discrimination, adolescents, responsibility and dangerousness

Introduction

Brain injuries are common; approximately 5.3 million people in the United States live with a traumatic brain injury (TBI) related disability [2] and 32% of New Zealanders suffer a TBI that requires medical assistance by the time they are 25 years old [3]. The message that these statistics convey is that there is a high cost to society from a financial and structural point of view when considering treatment and rehabilitation factors. The impact of the initial injury and recovery from physical injuries is a small part of the picture from the survivor's perspective, as subsequent cognitive and behavioural difficulties can endure, impacting survivors' recovery efforts. Other people's attitude and behaviour also influence rehabilitation efforts as survivors re-enter society post injury and this aspect of rehabilitation is the first focus of the current research.

Sociological stigma models have previously been employed to examine factors which may impact survivors' re-entry efforts into society. One area of stigma research focuses on survivors' experiences (self stigma; internalisation of public stigma). The other area focuses on the public's attitudes towards survivors of brain injury (public stigma) [4]; which is the specific focus of the current research. Stereotyping, prejudice and discrimination are all aspects of public stigma. Stereotypes are specific beliefs and attitudes held about certain social groups that are quickly and easily accessed and consensually held [5]. Prejudice occurs when people evaluate groups based on stereotypes and develop aversive attitudes to them because they belong to a particular group [6], and discrimination is the behavioural response to prejudicial attitudes (avoiding interacting or not offering employment) [7]. Two models have been employed in the stigma and mental illness literature to explain aspects of public stigma; a

responsibility model (attributions about the cause of a condition) and a danger model (perceptions of dangerousness) [8, 9].

Responsibility model (causal attributions)

Weiner's [10] attribution theory has consistently been used when examining the impact that perceptions of responsibility have on people's willingness to help or interact with individuals with stigmatising conditions. The theory holds that people make cognitive appraisals about the cause of a condition, which then influence emotional processes (anger and pity) and subsequent avoidant behaviour or willingness to assist. Weiner suggests that people appraise the controllability of a person's stigmatising condition to determine whether they are responsible or not for causing it. Attributing responsibility for a condition increases anger and subsequently reduces the likelihood of helping behaviour. Attributing no responsibility for a condition increases pity and subsequently increases the likelihood of helping behaviour [9-11].

There is considerable support for Weiner's model in relation to a number of illnesses and disabilities. Research manipulating the controllability of AIDS, child abuse, obesity, Alzheimer's disease, blindness, cancer, heart disease, paraplegia and Vietnam War Syndrome found that when a condition was controllable or preventable, pity and liking decreased and anger increased [12]. In contrast, when a condition was described as out of a person's control, anger decreased and pity increased. Additional mental illness research found that when the cause of a condition was described as biological there was more willingness to interact, relative to when the cause was described as alcohol-related [13].

Brain injury research shows similar results; when the cause of a brain injury was described as organic (brain haemorrhage) there was more willingness to interact, than when the cause was described as self-initiated (fighting after drinking too much alcohol)

[14]. Furthermore, higher prejudicial evaluations are reported when a cause was described as self-initiated, than when the cause of the injury was described as organic [15]. The research described above supports aspects of Weiner's model; however, it does not examine how causal attributions lead to behavioural responses. Reizenzein's [16] research supports Weiner's full attribution model with regard to pity and anger mediating the relationship between responsibility or controllability, and subsequent behaviour and attitudes.

Using structural equation modelling (SEM, path model analysis), Reizenzein [16] examined students' perceptions about a hypothetical subway emergency and whether to loan class notes to a fellow student and found that emotions (pity and anger) mediated the relationship between controllability and helping behaviour in the directions suggested by Weiner. Mental illness research using regression analysis found similar results; when the cause of a person's schizophrenia was described as uncontrollable, pity increased and anger decreased, which then lead to an increase in helping behaviour and a decrease in coercion and segregation attitudes [9]. In contrast, when the onset of schizophrenia was described as controllable (e.g., caused by eight years of abusing illegal drugs) there was an increase in anger, a decrease in pity and a reduction in helping behaviour [9].

Although there is support for Weiner's full attribution model with regard to anger and pity mediating the relationship between responsibility and helping behaviour using regression analysis, one study using SEM found that all pathways were not significantly associated. Corrigan et al. [8] found only one significant association in the relationships – anger negatively predicted helping behaviour; all other relationships were non significant.

Judgements about responsibility seem to make sense when examining the relationship between stigma and discriminatory behaviour; however, emerging literature also shows that people perceive survivors of brain injury as dangerous, which is similar to perceptions about individuals with mental illness [17]. Furthermore, brain injury research shows that survivors of brain injury are viewed in a similar manner as individuals with mental illness. For example, Linden and Boylan [18] found that people with brain injury were described as mentally disabled. People also fear survivors of brain injury, describing them as aggressive, violent, and unpredictable, and lacking in emotional regulation [18, 19]. Also, subsequent outcomes following a brain injury can include conditions associated with mental illness such as depression [20], post traumatic stress disorder and mania [21]. The mental illness literature shows support for a danger appraisal hypothesis explaining aspects of stigma. Therefore, the current research will also examine this in relation to brain injury to identify factors which may impact on survivors' rehabilitation efforts when re-entering society post injury.

Danger model

Corrigan's danger model proposes that perceptions of dangerousness impact fear responses, which influence subsequent behaviours or attitudes [8, 22]. That is, fear mediates the relationship between perceptions of dangerousness and behaviour. Corrigan described the premise of the model as signals (labels, symptoms, skills deficit and appearance) influencing common stereotypical beliefs which then influence discriminatory behaviour. For example, a label of mental illness elicits stereotypical information (i.e., people with mental illness are dangerous) which then influences discriminatory behaviour (not renting a house or employing them). Similar to Weiner's [10] cognitive-emotion-behaviour (attribution) model Corrigan proposes that cognitions (stereotypical beliefs; people with mental illness are dangerous), elicit emotional

responses (in this instance, fear) which influences subsequent behaviour and attitude [22].

Using regression analysis, Corrigan et al. [9] found support for a danger model and Corrigan et al. [8] found support using SEM, where fear mediated the relationship between perceptions of dangerousness and avoidant behaviours. The current research replicated research on the danger model from a brain injury perspective using SEM, as research shows that people fear survivors of brain injury [19].

When selecting the responsibility and danger models we acknowledge that there are numerous possible or sufficient reasons when deciding on a course of action (pro-social or avoidance behaviour). For instance, similar ethnicity, time demands, personality, moral beliefs, insufficient skills or knowledge to engage, someone else will do it and no desire to be associated due to retaliation by others. Although these factors, and others, are definitely relevant they do not consider the cause or how someone came to be in their current condition and the impact of perceived dangerousness, which is one the focuses of the current research.

Populations

There are two groups identified in the literature as having an increased risk of sustaining a TBI; young people aged approximately 15-25 years of age and people over the age of 70 [2, 3, 23, 24]. Adolescence is associated with a time of self doubt about appearance and behaviour, concerns about how to act with regards to acceptance by peers, and a time of intense comparison between themselves and others [25]. Given these factors, it seemed appropriate to select this group when identifying factors which may impede successful community integration following a brain injury. Further, little is known about the public's attitude, with regard to their willingness to socialise, toward adolescent survivors of brain injury.

Visibility

The visibility of a disability greatly influences how others view, define, respond and interact towards individuals with disability [26]. An absence of outward signs of disability prompts a designation of non-disabled and individuals are categorised based on gender, ethnicity, stereotypes and expectations [25]. In contrast, an outward sign of disability prompts a designation of disabled and typically less is expected of these individuals than able bodied others [27].

The current research also examined the distinction between visible and non visible brain injuries and the impact the visibility has on others' willingness to socialise with them. The purpose of this is to identify whether survivors are differentially treated in society dependent upon the visibility of their brain injury. This information is useful when assisting survivors' reintegration efforts as initially survivors may have a visible sign of injury which may later heal; therefore, it is prudent to inform survivors of possible changes in others' attitudes. The current research used a scar to represent a visible sign of brain injury. This was chosen as it represents a visible sign of brain injury that may potentially heal over time, resulting in no visible sign of injury.

Other factors which may influence willingness to interact with survivors of brain injury

Familiarity with individuals with brain injury and knowledge about how to interact

The amount of personal contact others have had with survivors of brain injury and their knowledge about how to approach or interact with survivors may influence willingness to socialise. The mental illness literature measured familiarity based on the level of personal contact with individuals with mental illness [28]. Research consistently shows that people who have had more contact with individuals with mental illness report less stereotyping and discrimination [9], less prejudicial attitudes

(authoritarian and benevolence) [29] and lower perceptions of dangerousness [30] than people with less contact with individuals with mental illness. The one study found examining this issue from an adolescents' perspective showed contrasting results. Adolescents who reported more contact with individuals with mental illness were more likely to endorse stigmatising attitudes [31].

The brain injury literature examining this issue is sparse. One study found that familiarity had no impact on prejudicial and discriminatory attitudes [15]. However, this study measured familiarity using a yes/no categorical question [32] with limited statistical power [30]. An unpublished doctorate thesis, using a modified version of the mental illness level of contact report, also found that there was no difference in willingness to socialise with adolescent survivors of brain injury between participants with more and less contact with individuals with brain injury [33].

A possible reason for familiarity having little impact on attitudes and willingness to socialise in the brain injury literature is that another factor may interact with familiarity or another factor may hold greater influence when deciding upon courses of action. Knowledge about how to interact seems a likely factor. Research shows that the public and pharmacy students believe that it is difficult or hard to talk to people with mental illness (drug and alcohol addiction, eating disorder, panic attacks, severe depression, schizophrenia and dementia) [17, 34].

These studies found that perceptions of dangerousness, unpredictability and being difficult to talk to were three primary reasons identified when measuring avoidance behaviour. Albrecht, Walker, and Levy [35] asked participants why they would be apprehensive about socialising with individuals with stigmatising conditions ranging from diabetes and cancer to mental illness and drug abuse. They found that perceptions of dangerousness, a lack of knowledge about how to interact, and

uncertainty about things they did not understand were common reasons given. Based on these findings a short questionnaire examining a lack of knowledge about how to interact with survivors of brain injury was developed for the current research.

The current research

The current research is presented as two studies; Study one replicates and extends an experiment reported in an unpublished doctorate thesis [33]. ANOVAs were used to examine whether visible signs of brain injury (in this instance scar and no scar), familiarity with individuals with brain injury and the gender of the participant and adolescent survivor of brain injury, influenced people's perception of other people's willingness to socialise. The current study extends Foster's research by including knowledge about how to interact with survivors of brain injury.

Study two examines the two mediation models outlined above (responsibility and danger) using SEM in AMOS v17. Visible signs of brain injury (scar or no scar) are included as a moderator of the relationships described in the models. The scar manipulation was chosen as a scar represents a visible sign of brain injury which may disappear over time.

Aims

Study one - Based on Foster's [33] research it is predicted that: 1. Participants will be more willing to socialise with the adolescent with a head scar than the adolescent with no head scar. 2. Female participants will be more willing to socialise with the female adolescent and male participants will show no preference in their willingness to socialise with the male or female adolescents. 3. There would be no difference in willingness to socialise between participants with more contact with individuals with brain injury and participants with less contact. The familiarity hypotheses are based on Foster's and Linden et al.'s [15] research. 4. Knowledge about

how to interact with individuals with brain injury was examined as an exploratory factor related to familiarity; therefore, no specific hypothesis was provided.

Study two - There has been no research to date examining brain injury and willingness to socialise employing the full responsibility and danger mediation models described above. Based on the mental illness literature [8, 9] it is expected that support will be found for both mediation models. Fear is expected to mediate the relationship between perceptions of dangerousness and willingness to socialise, and pity and anger are expected to mediate the relationship between responsibility and willingness to socialise. There is no specific hypothesis for visible signs of brain injury (scar and no scar) moderating the relationships between responsibility and willingness to socialise and perceptions of dangerousness and willingness to socialise.

Study One

Method

Participants

Four hundred and seventy six participants were recruited via Facebook advertising. The two criteria for receiving the advertisements on Facebook included being over 20 years of age and being a New Zealand (NZ) resident. Seventy responses were deleted as the dependent variable questions had not been answered and an additional five were deleted due to an error in data collection (consecutive responses all had the same information including demographics, suggesting that the data had been duplicated in some way) leaving 401 participants. Of these, 72% were females, 77% NZ Europeans, 4% Maori, 0.5% Samoan, 0.8% Cook Island Maori, 0.3% Tongan, 0.5 % Chinese, 2% Indian and 16% other nationality. The NZ 2006 Census reports 67% NZ Europeans, 14% Maori, 9% Chinese and 7% for Cook Island Maori, Samoan, and Indian (Statistics New Zealand, 2011) suggesting an

underrepresentation of Maori and Chinese residents and an overrepresentation of NZ Europeans in the current study. Fifty one percent of participants were aged 20-29, 11% were aged 30-39, 9% were aged 40-49, 16% were aged 50-59 and 9% were aged 60 or over.

Materials and design

A photograph of an adolescent male or female, with either a head scar or no head scar was shown to participants. The male and female adolescents were the same in the scar and no scar photos. A brief vignette was presented beneath the photo which was identical for the adolescent male or female conditions with the exception of changing the gender and name details as shown below. Conditions for Study one are shown in Table 1.

Vignette

*Above is a photo of John/Karen. John/Karen lives with his/her parents and brother/sister and goes to school in Wellington. He/She likes reading and wants to be a teacher when he/she gets older. John/Karen has several friends and regularly gets together with them in the weekends. John/Karen has suffered from a brain injury, * which has injured his/her brain at the time of becoming an adolescent.*

Table 1. Study one conditions.

<i>Adolescent Gender</i>	<i>Photo</i>
Male	Scar
	No Scar
Female	Scar
	No Scar

Materials and design

In Study one ANOVAs were used to examine whether the visible signs of brain injury (in this instance scar and no scar), the gender of the participant and adolescent survivor of brain injury, familiarity with individuals with brain injury, and knowledge about how to interact with survivors influenced participants' willingness to socialise

with adolescent survivors of brain injury. The following measures were used in the analysis for Study one.

Willingness to Interact

To measure willingness to interact with the adolescents portrayed, participants completed the Willingness to Interact questionnaire previously used to assess willingness to socialise with adults with mental illness [13, 36]. The questionnaire was adapted to rate children by Martin, Pescosolido, Olafsdottir, and McLeod [37] and the current research changed child to adolescent.

The questionnaire has four questions: how willing would you be to; 1. move next door to the family of this adolescent, 2. have your child make friends with this adolescent, 3. spend an evening socialising with that adolescent's family and 4. have that adolescent in your adolescent's classroom. A seven-point Likert scale was used to rate answers with "1" indicating definitely unwilling and "7" indicating definitely willing. The reliability for the four-item scale in the current research was Cronbach's $\alpha = 0.92$.

Familiarity scale

The familiarity scale measures the level of intimate contact with individuals with brain injury and was adapted from a scale used when researching mental illness and stigma [28, 31]. The nine items are described in full in Appendix A. The scale was rated by three clinical psychologists specialising in brain injury to identify a hierarchical order of items and achieved an interrater reliability of 0.97. The items were numbered one to nine and participants circled any number that they had experienced with regard to contact with individuals with brain injury. The highest number circled (indicating more contact) was used as the indicator of the level of contact.

Knowledge about how to interact scale (knowledge scale)

The knowledge scale was created for the current research and had three questions asking participants whether they knew how to approach, talk to, or interact with individuals with brain injury. Participants were asked to circle a number from one to seven which best reflects their knowledge about how to interact. The knowledge scale is described in full in Appendix A. The reliability for the three-item scale was Cronbach's $\alpha = 0.97$.

There were six additional questions included in the survey which were used as manipulation checks or not utilised in the current research. There was one question each about responsibility, controllability and aggression, included as manipulation checks. The other questions concerned unpredictability and asked participants if they would describe the adolescent's current condition as a mental illness or a physical injury.

Participants were also asked their gender, age, ethnicity, occupation and whether or not they had children. The survey included additional questions concerning responsibility, controllability, and perceptions of danger, fear, anger and pity, which will be discussed in Study two.

Procedure

Ethics approval was sought and granted by Massey University Ethics Committee: Southern B, Application 11/13. Participants were taken to Massey University's online research section after clicking on a link from a Facebook advertisement. They were presented with an information sheet that advised them that the survey was anonymous and was part of a doctoral thesis at Massey University. They were further advised that they did not have to answer all questions, and to click the link at the bottom of the page to commence the survey.

The survey was managed using the Qualtrics system, which achieved randomisation of conditions by using ‘evenly presenting conditions’. This means that all conditions are randomly selected for the first run through and then a condition is not repeated until all other conditions have been repeated randomly. Upon completion of the survey participants were directed to a debriefing page which advised them that the adolescents portrayed had not suffered a brain injury and the stories told were fictional. They were advised that if they were interested in receiving the results of the survey they could email one of two authors listed.

Results

The four willingness to socialise dependent variables (move next door, have their child make friends, socialise with the adolescents family and have that adolescent in their adolescents class) were combined to create one overall ‘socialise’ variable with a scale ranging from 4 (low social distance) to 28 (high social distance) with a reliability of Cronbach’s $\alpha = 0.92$. SPSS was used to analysis data from the 401 participants identified above. The assumptions of ANOVAs were met; Levene’s test of equality of variance was non significant, $F(7, 376) = 2.00, p > .05$. Photo and adolescent and participant gender effects were examined using a 2 (Photo: scar or no scar) x 2 (Adolescent: male or female) x 2 (Participant: male or female) ANOVA. As predicted, there was a main effect for Photo, $F(1, 376) = 4.26, p = 0.04, \eta^2 = 0.01$. Participants were more willing to socialise with the adolescents with a scar ($M = 25.10, SE = .35$), than the adolescents with no scar ($M = 24.08, SE = .36$) (hypothesis 1). There were no other main effects or interactions. Therefore, hypothesis 2 was not supported, as predicted there was no difference in male participants willingness to socialise with the male or female adolescent; however, female participants showed the same preference,

when it was expected that they would be more willing to socialise with the female adolescent than the male adolescent, as found in previous research [33].

Although the Photo condition in the above analysis produced a significant result ($p = .04$) there is some need for caution when interpreting this due to participant inclusion criteria around the issue of outliers. Box plot, stem charts and histograms identified seven outliers in the dependent variable. The decision was made to retain the outliers as the low scores may have represented participants' true feelings about not wanting to socialise with survivors of brain injury as little social desirability effects occur when collecting anonymously. However, when the outliers were deleted from the sample, the 2 (Photo: scar or no scar) x 2 (Adolescent: male or female) x 2 (Participant: male or female) ANOVA main effect for Photo was non significant, $F(1, 369) = 1.92, p = 0.17, \eta^2 = 0.005$.

As the familiarity variable had too many levels for an ANOVA, the variable was dichotomised into a low and high familiarity variable. Items 1-3 were grouped together to create a low familiarity condition and items 4-9 were grouped to create a high familiarity condition as the high levels all entailed personal contact with survivors of brain injury. Photo and familiarity effects were examined using a 2 (Photo: scar or no scar) x 2 (Familiarity: high or low) ANOVA and the assumptions of ANOVAs were met; Levene's test of equality of variance was non significant, $F(3, 379) = 1.23, p > .05$. As predicted, there was no main effect for Familiarity, $F(1, 379) = 1.08, p = 0.81, \eta^2 = 0.00$, supporting hypothesis 3: that there was no difference in willingness to socialise between participants with more contact and participants with less contact. There was a main effect approaching significance for Photo, $F(1, 379) = 3.01, p = 0.08, \eta^2 = 0.008$.

The three knowledge questions also had too many levels for an ANOVA and were grouped into one global variable and this was dichotomised into a low and high

knowledge variable. Items one and two were grouped together to create a low knowledge condition and items 3-7 were grouped to create a high knowledge condition as the higher levels described being moderately sure or very sure about how to socialise with survivors of brain injury. A 2 (Photo: scar or no scar) x 2 (Familiarity: high or low) x 2 (Knowledge: high or low) ANOVA was performed. Levene's test of equality of variance was non significant, $F(1, 370) = .92, p > 0.05$. There was a significant main effect for Knowledge, $F(1, 370) = 8.54, p = 0.004, \eta^2 = 0.23$. Participants with high knowledge ($M = 25.02, SE = .30$) were more willing to socialise with the adolescents than participants with low knowledge ($M = 23.30, SE = .51$), suggesting that knowledge about how to interact with survivors of brain injury influenced willingness to socialise.

There was a marginally significant main effect for Scar, $F(1, 370) = 3.81, p = 0.052, \eta^2 = 0.01$, participants were more willing to socialise with the adolescents with a scar ($M = 24.74, SE = .38$), than the adolescents with no scar ($M = 23.59, SE = .45$). There were no other main effects or interactions.

Study Two

Method

Design

The vignette described in Study one was used in Study two with the following four variations. When the adolescents were described as responsible for contributing to their brain injury (self-initiated cause) the following was included in the vignette in the place indicated by an asterisk; *as a result of falling and sustaining a significant injury to his/her head after drinking too much alcohol*, and when the adolescents were described as not responsible (organic cause) the following was included in the vignette in the place indicated by an asterisk: *as a result of a brain tumour*. When the adolescents were described as dangerous the following sentence was included at the end of the vignette;

Since John's/Karen's injury he/she has been more angry and aggressive than he/she used to be and the other day he/she hit his/her brother/sister for very little reason.

When the adolescents were described as not dangerous the following sentence was included at the end of the vignette; *John/Karen is no more dangerous than the average teenager.* Thus, there were eight conditions for Study two as shown in Table 2. It is important to note that each condition included only the information about that factor; therefore, dangerousness information did not impact on responsibility information and responsibility information did not impact on dangerousness information.

Table 2. Study two conditions.

<i>Photo</i>	<i>Responsibility – no indication of dangerous</i>	<i>Dangerous – no indication of responsibility</i>
Scar	Responsible	Dangerous
	Not Responsible	Not dangerous
No Scar	Responsible	Dangerous
	Not Responsible	Not dangerous

Study two employed path analysis to examine two mediation models purporting to explain aspects of stigma. The danger model proposes that perceptions of dangerousness positively predict fear and fear negatively predicts willingness to interact or assist [22]. The responsibility attribution model proposes that attributing responsibility for a stigmatising condition positively predicts anger and anger negatively predicts the likelihood of interacting or assisting, and attributing no responsibility positively predicts pity and pity positively predicts the likelihood of interacting or assisting [10]. The photo variable (scar/no scar) was examined as a moderator in the danger and responsibility models to examine whether having a scar or not moderates the relationships described.

Danger model

Participants

The danger model analysis included only the data from the four dangerous conditions outlined in Table 2 (scar responsible/not responsible, no scar responsible/not responsible), resulting in 157 participants. Only data from these conditions were selected to ensure responses were un-confounded by issues regarding perceived responsibility. Of the 157 participants 70% were females, 75% NZ Europeans, 4% Maori, 1.3% Cook Island Maori, .7% Chinese, 1.3% Indian and 18% other nationality. The NZ 2006 Census reports 67% NZ Europeans, 14% Maori, 9% Chinese and 7% for Cook Island Maori, Samoan, and Indian (Statistics NZ, 2011) suggesting an underrepresentation of Maori and Chinese residents and an overrepresentation of NZ Europeans. Fifty eight percent of participants were aged 20-29, 10% were aged 30-39, 9% were aged 40-49, 15% were aged 50-59 and 9% were aged 60 or over.

Materials

The materials and design for the danger model included the materials described in Study one above as well as the fear measure described below.

Fear Scale

The fear scale was adapted from a scale developed by P. W. Corrigan et al. [9] and included four questions rated on a seven-point Likert scale. Questions included: from the information you have about John/Karen; 1. how dangerous would you feel he/she is, 2. how threatened would you feel by him/her, 3. how scared of him/her would you feel, and 4. how frightened of him/her would you feel? In the current research the reliability for the four-item scale was Cronbach's $\alpha = 0.91$ for males and $\alpha = 0.92$ for females.

Procedure

The procedure was identical to Study one; ethics was obtained from Massey University Ethics Committee: Southern B, Application 11/13, and participants were

canvassed and provided information and debriefed as outlined in Study one. AMOS v18 path analysis was used to examine mediation and moderation for the danger model.

Mediation and Moderation

Mediation examines the relationship of three or more variables (independent, mediating and dependent) and identifies whether the indirect relationship, which includes the mediating variable, explains any variance in the direct relationship from the independent to the dependent variable [38]. Moderation also examines the relationship of three or more variables and examines variables which potentially tell us under what conditions a relationship between an independent and dependent variable occur [39]. Although moderating variables can be continuous or categorical, typically they are categorical variables; for example, only under the condition of having a scar does the perception of dangerousness increase avoidant behaviour.

Structural equation modelling was selected to analyse both models as SEM employs path analysis to test theoretical models and is considered a robust measure of the size and direction of associations between groups of variables and allows measurement of multiple groups [1, 8]. Path modelling also shows direct effects from independent variables to dependent variables and indirect effects via mediating variables, thereby identifying mechanisms involved in complex relationships between variables.

Results

The fear variable had 9.6% data missing; therefore, an expectancy-maximisation (EM) analysis was conducted as missing values are problematic when using path analysis in AMOS [1]. EM estimates the means, variance and co-variance from completed data, where multiple regression equations are used to create predicting

variables, which generate estimated values for the missing data [1]. The new file created by EM was used for the following analysis.

Structural equation modelling requires that the variables of interest are significantly correlated for mediation to occur. Table 3 displays the correlations for all variables included in the danger model (using the data file prior to EM changes). A manipulation check using an additional question, “How aggressive do you think John/Karen is”, was moderately correlated with perceptions of dangerousness ($r = .54$) and fear ($r = .49$), suggesting that the dangerous conditions and fear scale measured perceptions of danger and fear, respectively, as intended.

Table 3. Pearson’s correlation matrix for the Danger Model

	Socialise	Dangerous	Fear
Socialise	1	-.44**	-.49**
Dangerous		1	.44**
Fear			1

$N = 157$

** correlation is significant at the $p < 0.01$ level (2-tailed)

The theoretical danger model outlined in Figure 1a was created in AMOS using unidirectional arrows to indicate path directions. To examine the hypothesis that fear would mediate the relationship between perceptions of dangerousness and willingness to socialise, where perceptions of dangerousness would positively predict fear and fear would negatively predict willingness to socialise, a bootstrapped analysis of the indirect effect was performed [1]. The size of the standardised indirect effect was (-.17) ($SE = .04$), with a significant 95% bias-corrected confidence interval (lower = -.26 and upper = -.10), $p = .001$, and the model explained 31% of the variance, providing support for the hypothesis that fear mediated the relationship between perceptions of dangerousness

and willingness to socialise. The model was a just identified model ($df = 0$); therefore, no model fit indices were obtained [1].

Standardised regression coefficients (betas) are reported in Figure 1a to facilitate interpretation and show that all pathways were significant, and in the hypothesised directions. Results show that perceptions of dangerousness positively predicted fear, and fear negatively predicted willingness to socialise. Perceptions of dangerousness also showed a direct effect, whereby perceptions of dangerousness negatively predicted willingness to socialise.

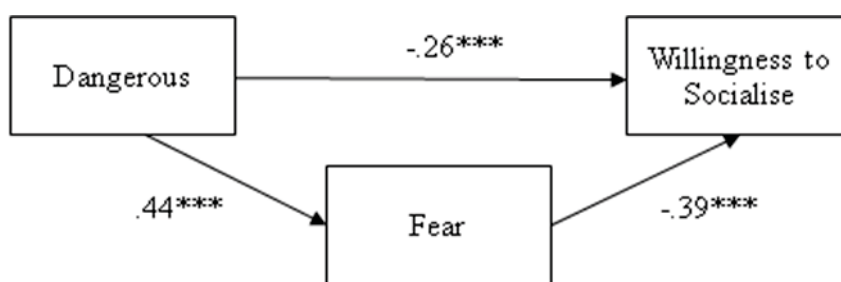


Figure 1a: Fear mediating the relationship between perceptions of dangerousness and willingness to socialise. $R^2 = .31$. $N = 157$. Standardised regression coefficients (Betas) indicate strength of relationships. *** $p < .001$.

Moderated mediation was performed to examine whether having a visible sign of brain injury (scar or no scar) would act as a moderator in the danger model. Manage groups in AMOS was used to split the data into the scar and no scar conditions. In the scar condition ($N = 80$), the size of the standardised indirect effect was $(-.24)$ ($SE = .06$), and there was a significant 95% bias-corrected confidence interval result (lower = $-.37$ and upper = $-.13$), $p = .001$, and the model explained 39% of the variance. Again, the model was a just identified model ($df = 0$); therefore, no model fit indices were obtained [1]. Betas are reported in Figure 1b to facilitate interpretation and show that all pathways were significant, and in the hypothesised direction. In the no scar condition ($N = 77$), the size of the standardised indirect effect was $(-.11)$ ($SE = .06$), with a significant

95% bias-corrected confidence interval (lower = -.24 and upper = -.02), $p = .014$, and the model explained 27% of the variance. Betas are reported in Figure 1b to facilitate interpretation and show that all pathways were significant, and in the hypothesised directions.

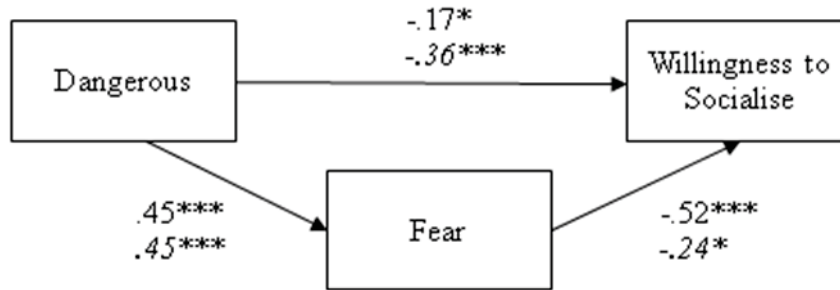


Figure 1b: Moderated mediation - fear mediating the relationship between perceptions of dangerousness and willingness to socialise and Photo (scar/no scar) moderating the mediated relationship. Regular font indicates Scar condition and italics indicate No Scar condition. Scar $R^2 = .39$, No Scar $R^2 = .27$. $N = 157$. Standardised regression coefficients (Betas) indicate strength of relationships. * $p < .05$, *** $p < .001$, ns = non significant.

When comparing the scar and no scar danger models; the scar results produced a larger effect size ($-.24$), than the no scar ($-.11$) and a larger beta for the mediated path from fear to socialise ($-.52$ v $-.24$), which is the path that tests moderated mediation (see Figure 1b). Together, these results imply that the presence of a scar, versus not having a scar, increases fear's ability to negatively predict willingness to socialise. A follow-up equality test (pairwise parameter comparison test of the critical ratio difference between the scar and no scar conditions fear to socialise pathway) was significant (z-score = 2.31, $p < .05$), suggesting that the danger mediation model is moderated by visible signs of brain injury. This implies that there is a difference between having a scar and not having a scar with regard to fear predicting people's willingness to socialise, where having a scar results in less willingness to socialise, relative to having no scar.

Responsibility model

Method and participants

The responsibility model analysis included only the data from the four responsibility conditions (scar responsible/scar not responsible, no scar responsible/no scar not responsible) outlined in Table 2, resulting in 160 participants. Only data from these conditions were selected to ensure responses were un-confounded by issues regarding perceived dangerousness. Of the 160 participants, 76% were females, 79% NZ Europeans, 2.7% Maori, 0.7% Samoan, 0.7% Cook Island Maori, 0.7% Tongan, 0.7% Chinese, 4% Indian and 11% selected other nationality. Based on the NZ 2006 Census reports outlined above this suggests an underrepresentation of Maori and Chinese residents and an overrepresentation of NZ Europeans. Participants indicated their age by placing a tick in one of five year groups; 58% were aged 20-29, 11% aged 30-39, 5% aged 40-49, 15% aged 50-59 and 11% aged 60 or over.

Materials and design

The materials and design for the responsibility model included the materials described in Study one above plus the anger and pity measures described below.

Anger Scale

The anger scale was taken from a scale used by Corrigan et al. [9] and included three questions rated on a seven-point Likert scale. Questions included: from the information you have about John/Karen; 1. would you feel aggravated by him/her, 2. how angry would you feel at him/her, and 3. how irritated would you feel by him/her? In the current research the reliability for the three-item scale was Cronbach's $\alpha = 0.87$ for males and $\alpha = 0.89$ for females.

Pity Scale

The pity scale was taken from a scale used by Corrigan et al. [9] and included three questions rated on a seven-point Likert scale. Questions included: from the information you have about John/Karen: 1. do you feel pity for him/her, 2. do you feel sympathy for him/her, and 3. how much concern would you have for him/her? In the current research the reliability for the three-item scale was Cronbach's $\alpha = 0.75$ for males and $\alpha = 0.73$ for females.

Results

The following data were missing: pity 7.5% and anger 10.6%. Table 4 displays the correlations for all variables included in the responsibility model (prior to EM changes). Again, an EM analysis was conducted as missing values are problematic when using path analysis in AMOS [1]. The new file created by EM was used for the following analysis. A manipulation check using the controllability and responsibility questions were moderately correlated with perceptions of responsibility ($r = .47$ and $r = .61$, respectively), suggesting that the responsibility condition measured perceptions of responsibility as intended.

Table 4. Pearson's correlation matrix for Responsibility Model

	Socialise	Responsible	Anger	Pity
Socialise	1	-.27**	-.11	.04
Responsible		1	.32**	.18*
Anger			1	.08
Pity				1

$N = 160$

* correlation is significant at the $p < 0.05$ level (2-tailed)

** correlation is significant at the $p < 0.01$ level (2-tailed)

To examine the hypothesis that pity and anger would mediate the relationship between perceptions of responsibility and willingness to socialise, where perceptions of

responsibility would positively predict anger and anger would negatively predict willingness to socialise, a bootstrapped analysis of the indirect effect was performed. The model shown in Figure 2a was created in AMOS and the unidirectional arrows indicate path directions.

The size of the standardised indirect effect was small (.004) ($SE = .03$), and the 95% bias-corrected confidence interval result was non significant (lower = $-.05$ and upper = $.06$), $p = .89$, which all suggests that mediation was not obtained. Although partial support was shown for the hypothesis, as responsibility negatively predicted anger and positively predicted pity. Also, the chi-square value, representing goodness of fit for the model was non significant, as required, $\chi^2(1) = .18$, $p = .67$, χ^2 to df ratio = $.18$, Critical $N = 160$, and the $NFI = .995$, $CFI = 1.0$, and $RMSEA = .000$ were all within acceptable levels suggesting a good fitting model [1]. The model explained 8% of the variance.

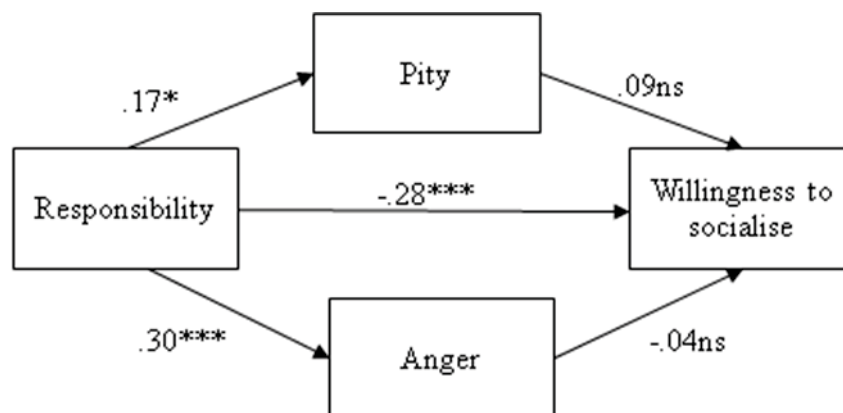


Figure 2a: Pity and anger mediating the relationship between responsibility and willingness to socialise. $R^2 = 08$. $N = 160$. Standardised regression coefficients (Betas) indicate strength of relationships. * $p < .05$, *** $p < .001$, ns = non significant.

In conclusion, the prediction that anger and pity would mediate the responsibility model was unsupported as the indirect effect was non significant but there was support for responsibility significantly predicting anger and pity as shown in Figure 2a. The betas in Figure 2a show that responsibility produced significant pathways to anger and pity and anger and pity produced non significant pathways to socialise and there was a direct relationship from responsibility to willingness to socialise.

Moderated mediation was performed to examine whether having a visible sign of brain injury (scar or no scar) would act as a moderator of the responsibility mediation model. The manage groups function in AMOS was used to split the data into the scar and no scar conditions. In the scar condition ($N = 78$), the size of the standardised indirect effect was $(-.04)$ ($SE = .05$), and there was a non significant 95% bias-corrected confidence interval result (lower = $-.15$ and upper = $.03$), $p = .25$, and the model explained 13% of the variance. Betas are reported in Figure 2b to facilitate interpretation and show that only the responsibility to anger pathway was significant. In the no scar condition ($N = 82$), the size of the standardised indirect effect was small $(.04)$ ($SE = .04$), and there was a non significant 95% bias-corrected confidence interval result (lower = $-.04$ and upper = $.14$), $p = .33$, and the model explained 8% of the variance.

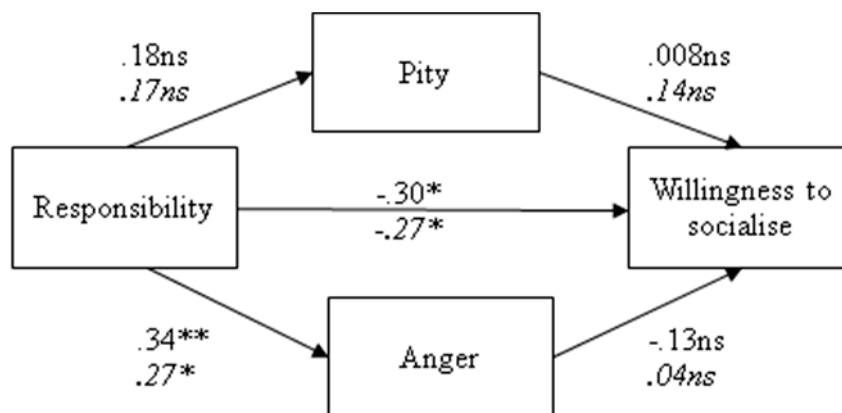


Figure 2b: Moderated mediation – pity and anger mediating the relationship between perceptions of responsibility and willingness to socialise and Photo (scar/no scar) moderating the mediated relationship. Regular fonts indicate Scar condition and italics indicate No Scar condition. Scar $R^2 = .13$, No Scar $R^2 = .08$. $N = 160$. Standardised regression coefficients (Betas) indicate strength of relationships. * $p < .05$, ** $p < .01$, ns = non significant.

When comparing the scar and no scar responsibility mediation model, all betas produced similar significances, suggesting that visible signs of injury do not moderate the responsibility model. The follow-up equality test for the anger to socialise pathway and the pity to socialise pathways were non significant (z -score = .94, $p > .05$ and z -score = 1.04, respectively), confirming this conclusion.

Discussion

The current research examined the impact visible signs of brain injury (in the form of a scar or no scar), gender, familiarity and knowledge about how to interact have on people's willingness to socialise with adolescent survivors of brain injury. In addition, two theoretical mediation models (danger and responsibility) purported to influence mental illness stigma were examined in an attempt to understand the mechanisms or processes involved in the discrimination.

Study One

Study one examined whether visible signs of brain injury and participants' level of familiarity with survivors of brain injury and their knowledge about how to interact with survivors influenced their willingness to socialise with survivors. Gender effects of the participants and adolescents were also examined. As predicted, participants were more willing to socialise with the adolescent with a scar, than the adolescent with no scar and participants' level of familiarity did not influence willingness to socialise, as found in previous research [15, 33]. Also as predicted, male participants reported no preference in their willingness to socialise with the male or female adolescent, but unexpectedly, female participants reported similar preferences, when it was expected that they would show a preference for socialising with the female adolescent, as found in previous research [33].

Why would people prefer to socialise with an adolescent with a scar, relative to an adolescent with no scar? This is an interesting finding as stigma research consistently shows that individuals with visible disabilities often experience prejudice and discrimination [40, 41]. Perhaps the scar acted as a visual confirmation of the information given about the adolescent sustaining a brain injury, or the visual reminder prompts a categorisation of disabled, thereby legitimising the role of disabled, prompting empathic reactions. Previous research supports the notion of a visible marker legitimising a disability. Zahn [42] found that young people, relative to older people, had better interpersonal relationships when their disabilities were visible, than when they were not visible. Finally, the visibility results imply that having a scar may assist when it comes to socialising, as it legitimises and confirms a disabled status which leads to a greater willingness to socialise.

The finding that a person's level of familiarity or contact with individuals with brain injury had no impact on willingness to socialise is perplexing, as considerable mental illness research shows that people who have experienced more contact with individuals with mental illness, report less discrimination and prejudice [9, 29, 30]. The current research employed a familiarity measure that had previously been employed in mental illness research; therefore, this could not account for the differences found. One mental illness article found that adolescents who reported more contact were more likely to endorse stigmatising attitudes [31], but this does not explain the findings in the current study as participants were adults.

Research examining brain injury and prejudiced and discriminatory attitudes found that participants' level of familiarity had no impact on attitudes [15], but as previously mentioned, in this study familiarity was measured by asking a yes/no categorical question [32] with limited statistical power [30]. In the current study, adults were asked their opinion about socialising with an adolescent survivor of brain injury and their family, and the level of familiarity or contact may not be relevant when considering responses to children, due to the adults' roles as care takers of children. Or the answer could simply be that familiarity has no impact on outcomes when examining brain injury, relative to mental illness.

To understand why people's level of contact with individuals with brain injury did not impact on willingness to socialise, as it does in the mental illness literature, another related factor was examined; knowledge about how to interact with individuals with brain injury. When knowledge was included in the familiarity analysis it produced a significant main effect, whereby participants with more knowledge were more willing to socialise with survivors, than participants with less knowledge. The results suggest that knowledge about how to interact is more relevant than the amount of familiarity or

contact people have had with survivors, when deciding about socialising with survivors. This suggests that campaigns aimed at reducing discrimination could include information about how to approach and talk to survivors of brain injury, as this may be a potential barrier to socialising.

A possible reason for levels of knowledge impacting outcomes and levels of familiarity showing no such impact is that the knowledge questions identified people who may attempt to socialise if they knew how to but familiarity only measured past contact experience. The past contact may not have been a conscious choice; circumstances may have dictated it (classmate or colleagues). If this is likely, then familiarity would not be an appropriate measure in the current research when identifying factors that may influence willingness to socialise.

Study Two

Danger model

Study two examined two theoretical mediation models purported to explain aspects of stigma. As predicted, in the danger model, fear mediated the relationship between perceptions of dangerousness and willingness to socialise, where dangerousness negatively predicted fear and fear negatively predicted willingness to socialise. This prediction was based on research showing that people fear survivors of brain injury [18, 19] and on previous mental illness research [8, 9]. The results show one mechanism by which information about perceptions of dangerousness influence willingness to socialise. When people perceive a survivor of brain injury to be dangerous (in this instance unprovoked aggression), fear increases, which then leads to a reduction in the willingness to socialise. However, there was only partial mediation as the direct effect from perceptions of dangerousness to willingness to socialise was also significant.

Visible signs of brain injury (scar or no scar) were included in the danger mediation model as a moderator to identify whether having a scar influenced the fear to willingness to socialise pathway. The strength of that pathway changed from $-.52$ in the scar condition to $-.24$ in the no scar condition, suggesting that having a scar increased fear's ability to negatively impact willingness to socialise. An equality test indicated that the difference between the scar and no scar fear to willingness to socialise pathway was significant, suggesting that the danger model is moderated by visible signs of brain injury. One could suggest that this result is intuitive as it is likely that having a scar invokes a larger fear response (due to the disturbing nature of scars) than not having a scar. However, the dangerous to fear pathway was identical in the scar and no scar conditions, it was the fear to socialise pathway that changed suggesting that having a scar increases fears ability to negatively predict willingness to socialise. This finding warrants further investigation to understand the processes involved.

Responsibility Model

There was partial support for the prediction. Perceptions of responsibility significantly predicted anger and pity in the hypothesised directions but there were no significant pathways to willingness to socialise from anger and pity. This result shows that perceptions of responsibility impact emotions (anger and pity), but emotions have no direct impact on willingness to socialise, providing partial support for Weiner's attribution model [10]. The responsibility findings differ somewhat to the mental illness research using SEM, which found only one significant pathway, from anger to helping behaviour [8]. The current results may have differed to Corrigan et al.'s. as their research asked participants to rate people with mental illness in general, as opposed to supplying a vignette about a specific person, as the current study did. The different populations studied may have contributed to the differences found (adults in Corrigan et

al.'s and adolescents in the current research). Also slightly different methodology may explain the differences found; the current study combined the individual anger and pity questions into one anger and pity variable and used these combined variables when creating the path analysis, whereas Corrigan et al. used confirmatory factor analysis within structural equation modelling, which analyses all questions separately (without combining to create one variable).

Visible signs of brain injury did not moderate the responsibility model when comparing the anger to willingness to socialise pathway and the pity to willingness to socialise pathway suggesting that, unlike the danger model, visible signs of injury do not impact the responsibility model.

When comparing the responsibility and danger models anger and fear typically produced higher associations with predictor and outcome variables than pity. It is possible that pity is a weaker variable as anger and fear may elicit the fight or flight response (in this instance flight) which is likely to produce a stronger response and pity is unlikely to elicit such responses. Again, when comparing both models the danger model produced higher betas than the responsibility model and produced significant pathways for all paths, suggesting that perceptions of dangerousness and fear impact willingness to socialise more than perceptions of responsibility. However, further research is required to test and compare both models to identify which factors (perceptions of dangerousness or responsibility) impacts more on outcomes and whether dangerousness and responsibility interact with each other.

The danger and responsibility model results are mostly consistent with the mental illness literature [8, 9], suggesting that similar stigma processes or mechanisms impact both individuals with mental illness and brain injury. Therefore, the mental illness literature examining discrimination and stigma, which is considerable, can be

used to inform the brain injury literature when discussing perceptions of dangerousness and responsibility. It is not surprising that these two fields would produce similar results given that survivors of brain injury have been described as mentally disabled [18].

Limitations

There are several limitations to consider when interpreting the results. The effect sizes in Study one are small ($\eta^2 = 0.01$) which may suggest little clinical application. Participant responses were based on what they thought they would do, not on actual behaviours; therefore, future research is needed to measure actual behaviours. The results are limited to adolescents and therefore can't be generalised to other populations and the adolescents portrayed may be considered white middle class people; therefore, generalisation is limited to this group. Using a medium such as Facebook to collect data raises issues of biased sampling. Also a scar is only one example of a visible sign of brain injury, other signs such as motor or physical difficulties may prompt different responses; therefore, the results cannot be generalised to these other signs of brain injury.

Future research could portray adolescents from different social economic status and racial groups. Furthermore, research asking adolescents opinions about socialising with adolescent survivors would be beneficial, particularly as adolescents are concerned with peer opinion and fitting in with peers.

The findings from the current studies provide valuable information for health professionals working with survivors of brain injury. Discussing with survivors possible implications of having a scar that later heals may assist when managing expectations of how others will treat them after visible signs of injury heal. Also discussing possible responses from others when they are perceived as responsible for their causing their injury or are perceived as dangerous is also useful when managing expectations of

others likely response to them. However, careful consideration to how this information is conveyed is necessary, keeping in mind the survivor's level of impairment and insight. Finally, the information obtained is useful when designing campaigns to address discrimination, particularly the knowledge about how to interact findings.

In conclusion, the current research shows that visible signs of brain injury (scar or no scar) may impact people's willingness to socialise, where having a scar may elicit a greater desire to socialise, relative to not having a scar. Furthermore, perceptions of dangerousness directly influence discriminatory behaviour as well as indirectly via emotional responses (fear). Perceptions of responsibility directly influence discriminatory behaviour and emotional responses (pity and anger) but emotions do not mediate the relationship. The information obtained provides useful knowledge for rehabilitation health professionals working with survivors of brain injury and people designing campaigns to reduce discrimination.

Appendix A

Familiarity Scale

How familiar are you with people with brain injury? Please circle the number or numbers next to the statements which you have experienced in your life.

- 1 I have never observed a person with brain injury
- 2 I have watched a television show that included a person with brain injury
- 3 I have observed a person with brain injury
- 4 A close friend of the family has a brain injury
- 5 I have a relative who has a brain injury
- 6 I have worked or been in a class with a person with brain injury
- 7 My job includes services/treatment for people with brain injury
- 8 I live with a person with a brain injury
- 9 I have a brain injury

Knowledge Scale

On a scale of 1 to 7 how would you rate your knowledge about how to approach a person with brain injury? (Circle one number below).

1	2	3	4	5	6	7
Not at all sure		Moderately sure			Very sure	

On a scale of 1 to 7 how would you rate your knowledge about how to talk with a person with brain injury? (Circle one number below).

1	2	3	4	5	6	7
Not at all sure		Moderately sure			Very sure	

On a scale of 1 to 7 how would you rate your knowledge about how to interact with a person with brain injury? (Circle one number below).

1	2	3	4	5	6	7
Not at all sure		Moderately sure			Very sure	

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CHAPTER 8

OVERALL DISCUSSION

Two research articles examined the impact that the visible signs of brain injury (scar or no scar) and perceptions of dangerousness and being responsible for contributing to, or causing a brain injury have on people's willingness to socialise with adolescent survivors of brain injury. A photo of either an adolescent male or female, with or without a head scar was shown to participants with a brief vignette describing the adolescents' current condition. Article One examined visibility effects, participant and adolescent gender effects and whether having previous contact with individuals with brain injury (familiarity) influenced willingness to socialise. Article Two had two studies. Study one replicated Article one and extended it by including knowledge about how to interact as a factor influencing willingness to socialise and Study two examined two theoretical models (danger model and responsibility model) purported to influence prejudice and discriminatory behaviour in the mental illness literature. The visibility of a brain injury was also examined to identify whether having visible signs of brain injury moderated the relationships described in the two models. This final chapter provides a summary of both research articles, followed by a discussion and implications section, then methodological limitations and future research and a conclusion.

Article One – Do visible scars influence people's predictions of other's willingness to socialise with an adolescent with brain injury?

Article One examined participants' perceptions of other people's willingness to socialise with adolescent survivors of brain injury. Participants were asked for their views about others willingness to socialise to reduce social desirability effects, as the researcher collected data directly by approaching people in outside malls and parks. Participants reported that other people would be more willingness to socialise with the

adolescents with a scar, than the adolescents with no scar (although the finding was marginal, $p = .059$). There were no participant gender differences when reporting others willingness to socialise in the scar condition but there were differences in the no scar condition. Female participants, more than male participants' reported that others would be more willing to socialise with the adolescents portrayed in the no scar condition. Combined, the above results suggest that having a scar differentially impacts on people's perceptions of others willingness to socialise, whereby more willingness to socialise is reported when a scar is present, than when a scar is not present and this distinction is stronger for females than males.

Female participants reported that others would be more willing to socialise with the female adolescent than the male adolescent and male participants reported that others would show no preference. Participants' level of familiarity with individuals with brain injury had no effect on reported willingness of others to socialise with the adolescents portrayed. That is, participants with high or low familiarity reported similar outcomes. Furthermore whether the adolescent had a scar or not, did not influence or interact with participants' level of familiarity and reported willingness of others to socialise with the adolescents. The current familiarity results support previous brain injury research (Foster, 2012; Linden, et al., 2007), which found that familiarity had little impact when measuring prejudice and discriminatory attitudes.

Article Two – Brain injury and discrimination: Two competing models – perceptions of responsibility and dangerousness

There were two studies in Article Two. Study one replicated and extended Article One by using a different population and examined a lack of knowledge about how to interact. As participants in Article Two were recruited directly from Facebook their responses were their own views on what they would do, rather than reporting on

their opinion about what others would do, as was the case for Article One. Again, participants were more willing to socialise with the adolescents with a scar, than the adolescents with no scars. Also participants with more knowledge about how to interact with survivors were more willing to socialise with adolescent survivors, than participants with less knowledge.

The primary objective of Study two was to examine two theoretical models shown to influence prejudice and discriminatory attitudes in the mental illness literature. The danger model proposes that perceptions of danger increase a fear response, which subsequently negatively impacts avoidance and helping behaviours (P. W. Corrigan, 2000). Structural equation modelling was used to test the hypothesis and, as predicted, perceptions of dangerousness positively predicted fear, and fear negatively predicted willingness to socialise. That is, fear mediated the relationship between dangerousness and willingness to socialise. A direct effect, where perceptions of dangerousness negatively predicted willingness to socialise was also found showing that dangerousness impacts willingness to socialise directly, as well as via fear.

To examine whether visible signs of injury moderated the mediated relationship in the danger model, analyses were performed on the scar and no scar conditions separately. The scar condition reported higher betas for the fear to willingness to socialise pathway (-.52) than the no scar condition (-.24) and produced a larger mediation effect (-.24) than the no scar condition (-.11). An equality test confirmed that the differences between the scar and no scar conditions were significant suggesting that having a scar increases fears ability to negatively predict willingness to socialise, relative to not having a scar. This is understandable given the intense emotional reactions a scar may evoke. The results show that being perceived as dangerous impacts emotions (e.g., fear) in a similar manner irrespective of whether there is a scar present

or not. Furthermore, when a scar is present, the ability of fear to negatively predict willingness to socialise is increased, suggesting that the emotional response is the factor impacting willingness to interact, not perceptions of dangerousness when comparing visible signs of injury and no visible sign of injury. This is further supported as the direct pathway from perceptions of dangerousness to willingness to socialise went from -.17 in the scar condition to -.36 in the no scar condition.

The responsibility model was based on Weiner's (1995) causal attribution model which states that people make cognitive appraisals about the cause of a stigmatising condition, which influence emotions and subsequent avoidant and helping attitudes. Specially, attributing responsibility for a current condition increases anger and anger subsequently reduces pro-social behaviour; in contrast, attributing no responsibility increases pity and pity subsequently increases pro-social behaviours (P. W. Corrigan, et al., 2003; Weiner, 1995, 2006).

As expected, being described as responsible, positively predicted anger but, unexpectedly, anger did not predict willingness to socialise. Also as expected, assigning no responsibility positively predicted pity, but pity did not predict willingness to socialise. There was also a direct effect from perceptions of responsibility to willingness to socialise. These results suggest that perceptions of responsibility impact emotions but emotions do not impact willingness to socialise, but perceptions of responsibility impact willingness to socialise directly. Additional moderation analysis found that visible signs of injury did not moderate the mediated relationships in the responsibility model.

Discussion and clinical implications

Although both articles in this research have been summarised in their respective chapters the following provides a broad overview of the combined results. The results from both articles suggest that having visible signs of brain injury (in the form of a scar)

may increase the likelihood of others socialising post injury, relative to having no visible sign of injury, suggesting that survivors are differentially treated dependent upon the visibility of an injury. This finding is notable as typically more prejudice and discrimination is reported when disabilities are visible (Latner, et al., 2005; Matthews & Harrington, 2000). Why would the current research find this opposing view?

The scar may have legitimised and confirmed a disability status leading to increased pro-social behaviour. In previous research Zahn (1973) found that young people with disabilities had better relationships than older people when their disability was visible, relative to when it was not visible and implied this was due to the visibility legitimising their current status as disabled. The current research explored people's opinions of adolescents, as opposed to adults, which may explain the results. Furthermore the current research measured willingness to socialise as opposed to hiring a disabled person or renting a house to them or asking opinions about forced institutionalisation, which are topics often measured when researching prejudice and discrimination. Socialising with an adolescent survivor of brain injury may be considered a more passive or benign activity than offering employment or accommodation, which is more long term and constant.

When considering Goffman's (1963) different conditions related to stigma (tribal identities, abominations of the body and individual character blemish stigmas) the findings imply that having a visible sign of brain injury in the form of the scar (which may potentially be categorised as an abomination stigma) results in more willingness to socialise, relative to having no scar (which may potentially be categorised as an individual character blemish stigma). This may suggest that different stigma conditions attract different levels of discrimination, although further research is required to examine this distinction.

The danger model results suggest that when people perceive survivors of brain injury to be dangerous (even when the perceived danger is relatively mild; e.g., hit his brother for very little reason), fear influences outcomes. The responsibility model results suggest that being described as responsible for causing or contributing to a brain injury directly influences willingness to socialise but this relationship is not mediated by emotions. These findings support previous brain injury literature about perceptions of people with brain injury being dangerous, and perceptions of responsibility influencing prejudice and discriminatory behaviour (Linden & Crothers, 2006; Linden, et al., 2007; Redpath & Linden, 2004) and are consistent with the mental illness stigma research (P. W. Corrigan, et al., 2003; P. W. Corrigan, et al., 2002).

As far as we are aware this is the first time a danger model has been applied to brain injury. Not only was support found for danger impacting discrimination directly but the mediation analysis shows the mechanisms involved in discrimination by providing information about how perceptions of dangerousness lead to outcomes. The model shows that fear mediates the relationship between perceptions of dangerousness and willingness to socialise. An explanation for fear mediating the danger model may be that fear evokes a fight or flight response (in this instance flight) thereby producing a larger reaction as people do not want to put themselves in potential danger.

A possible reason for the mediating variables pity and anger producing smaller effect sizes than fear and showing no relationship with willingness to socialise may be that they do not represent a threat to people's well being. Although if they did not represent a threat then it might be concluded that people would be more willing to socialise, which did not occur. The mental illness literature also finds negligible associations between variables in the responsibility model (P. W. Corrigan, et al., 2002) when measuring stigma, relative to the danger model, which like the current research,

shows strong support. This may suggest that Weiner's (1995) attribution model is a better fit when measuring pro-social behaviour under everyday conditions as opposed to when someone has a brain injury or mental illness.

One of the focuses of the current research was to examine factors which may influence others willingness to socialise with survivors' of brain injury post injury. Community integration is an important aspect of rehabilitation for survivors, parents and rehabilitation professionals, due to the effect socialising with others has on the psychological well-being of survivors and their families who support them (Geurtsen, van Heugten, Meijer, Martina, & Geurts, 2011; Sander, et al., 2010; Winstanley, Simpson, Tate, & Myles, 2006). Therefore understanding factors which may impede successful integration, especially for one of the most vulnerable groups (adolescents) is very useful for rehabilitation professionals.

The current research shows that the visibility of the brain injury, perceptions of dangerousness and responsibility, and the level of knowledge about how to interact impact other people's willingness to socialise with survivors. Incorporating information about these factors into rehabilitation may assist when managing survivor's expectations and re-entry into society post injury. Discussing the implications of having a scar may be useful given adolescents' concern about appearance. Discussing that others behaviour may change once the scar heals and is no longer visible may also assist. Explaining that having a scar may confirm a disability status may be useful, especially if the adolescent displays undesirable or aggressive behaviour as others may then attribute these behaviours more to the brain injury, rather than to the adolescent's personality, as found in previous research (McClure & Abbott, 2009).

Furthermore having a conversation with survivors about what they disclose to others may be useful, particularly if the adolescent contributed to causing their brain

injury. How this information is conveyed needs to be carefully considered, taking into account the survivors' level of impairment and insight. For example, post injury disinhibition may result in excessive disclosure of the injury (McClure, 2011), impacting others behaviour.

Finally, the finding that knowledge about how to interact influences willingness to socialise is useful for professionals when designing campaigns to reduce discrimination. This finding, when compared with the familiarity finding, suggests that campaigns educating the public about how to interact would be more useful than solely promoting contact with survivors of brain injury.

Limitations and future research

Generalisation is limited to the adolescents portrayed in the vignettes; therefore future research could portray adolescents from different socioeconomic groups to identify whether reactions are similar irrespective of socioeconomic status. Similarly portraying adolescents with varying perceived levels of attractiveness would be useful. Replicating the current research with adult survivors would be informative and asking other adolescents their opinions about adolescent survivors would provide useful information about peer behaviour.

Sampling from Facebook and approaching people in outside locations produces biased sampling as evidenced by the large number of female participants. Using Facebook eliminates people who do not have or use computers, thereby sampling only people with computer skills or people who are confident using computers and who have a computer. Approaching people in outside locations automatically excludes people who have no time or desire to go outdoors to eat lunch.

The dependent variable represented one aspect of discrimination (willingness to socialise) and the questions primarily asked about socialising with the adolescent's

family and having the adolescent make friends with their child and be in their child's classroom. Future research could ask participants directly about their willingness to socialise with and individuals with brain injury.

The current research used a scar as a visual sign of brain injury. Depicting survivors in a wheelchair, with motor, speech or cognitive difficulties may produce different results. A scar was chosen as it represents a visible sign of injury that may disappear over time. Cognitive impairments were not chosen as they were difficult to portray in a photo and a wheel chair was not selected as it may represent other disabilities. Finally, portraying an adolescent who had suffered a brain injury was not considered due to ethical considerations (may be recognised, would have to impose or remove a scar).

The current research did not provide additional information about possible subsequent cognitive difficulties such as impaired thought processes or undesirable behaviour, which may also influence decisions people make about willingness to socialise. The author also acknowledges that there are numerous possible or sufficient reasons for engaging, or not, in pro-social behaviour (i.e. similar ethnicity, time demands, personality or moral beliefs, insufficient skills, someone else will do it, private person). Although these factors, and others, most likely contribute, they do not consider the cause or how someone came to be in their current state, which is the focus of the current research. Finally, measuring actual behaviours may produce different results than those obtained here, as the current research asked people what they would do or what they thought others would do. The scar results in the ANOVAs in both article one and two need to be viewed with caution as the effect sizes were small which may not translate into clinical application.

A control group was not included in the current research as previous research found that when asking people to participate in research about “adolescents and brain injury” and having headings on the questionnaires that said “adolescents and brain injury” was sufficient to differentiate between control groups and experimental groups (Foster, 2010).

Future research could compare the danger and responsibility models to identify which produces the strongest effects in a combined SEM model and explore interactions between the dangerousness and responsibility variables. Replicating the current paradigm with adults and measuring additional factors such as willingness to employ or rent a house and coercive and benevolent attitudes (institutionalisation) would provide a broader measure of stigma.

Conclusion

The current research shows that the visible signs of brain injury (scar or no scar) impact others willingness to socialise with adolescent survivors of brain injury. Perceptions of dangerousness impact willingness to socialise directly and indirectly through emotion (fear) and responsibility directly influences willingness to socialise. Knowledge about how to interact with survivors was found to influence willingness to socialising with adolescent survivors, but people’s level of familiarity with brain injury did not. This information is useful for health professionals working with adolescent survivors of brain injury and when designing campaigns to combat discrimination.

Appendix A – Photos

**THESE PHOTOS CANNOT BE COPIED OR USED WITHOUT
WRITTEN PERMISSION FROM THE AUTHOR**

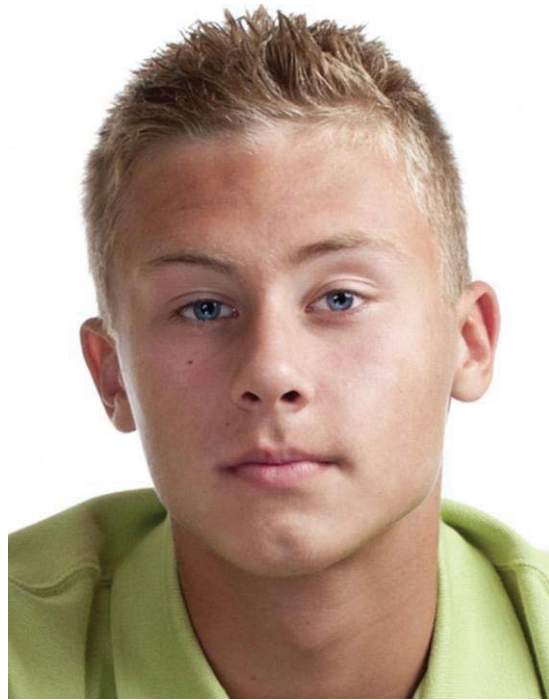


Figure 1: Male no scar photo used in Article One and Two



Figure 2: Male scar photo used in Article One



Figure 3: Male scar photo used in Article Two



Figure 4: Female no scar photo used in Article One and Two



Figure 5: Female scar photo used in Article One



Figure 6: Female scar photo used in Article Two

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