



The impact of traumatic brain injury on the mental health outcomes of individuals and their family carers

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Abstract

Traumatic brain injury (TBI) is one of the leading causes of death and life-long disability. The impact of TBI on the person and family carers is significant and long-term, such that persons with TBI require continuing support and care in various aspects of their lives many years after the injury. Family carers also require ongoing support. Mental ill health is one aspect that greatly impacts on the lives of these people. People with TBI may experience a range of psychiatric symptoms, such as depression, anxiety disorders, mood disorders or panic disorder. They are also at risk of suicidality and offending behaviours. Family carers of people with TBI also experienced a range of psychological distress. TBI also impacts negatively on the quality of life of the individuals and their family carers. There is a definite role for mental health services and practitioners to provide support to people with TBI and their family carers. This review paper argues for an appropriate level of mental health support for people with TBI and their family carers because the concerns are not only health-related but are a social concern for the community and government.

Keywords

traumatic brain injury, mental illness, suicide, disability, quality of life, rehabilitation, carers

Introduction

Traumatic brain injury (TBI) is one of the leading causes of death and life-long disability, and a major health problem worldwide that is costly in terms of health care expenditure and productivity losses for the community (Max, MacKenzie & Rice, 1991; Teasell, Bayona, Marshall et al., 2007; Xu, Liu, Xiao & Li, 2007). There are two types of traumatic brain injury — open head injury or closed head injury. Traumatic brain injury may be the result of motor vehicle accidents, falls or other injuries to the brain (Australian Institute of Health and

Welfare, 2003). In Australia, more males (69%) were likely to acquire TBI than females, and TBI-related hospitalisation rates for males peaked between the ages of 15 and 24 years (Australian Institute of Health and Welfare, 2007). Rates of TBI-related hospitalisation also rise steeply beyond the age of 75 years for both males and females (Australian Institute of Health and Welfare, 2007).

It is known that the majority of persons with TBI continue to experience significant long-term problems that require ongoing support (Australian Institute of Health and Welfare,

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2007; Colantonio, Ratcliff, Chases et al., 2004; Corrigan, Whiteneck & Mellick, 2004; Hoofien, Gilboal, Vakil & Donovan, 2001; McCabe, Lippert, Weiser et al., 2007; Nabors, Seacatt & Rosenthal, 2002; Onsworth, Turpin, Carlson & Brennan, 2004; Tate, Broe, Hodgkinson & Cameron, 2007; Tate, Cameron, Winstanley et al., 2004; Tate, Stretles, Hodgkinson & Veerabangsa, 2003; Tomberg, Toomela, Ennock & Tikk, 2003). Mental health concerns are some of the long-term consequences of TBI that require continuing clinical management and support (Draper, Ponsford & Schonberger, 2007; Rogers & Read, 2007; Simpson & Tate, 2007; Stalnacke, 2007; Torsney, 2004). This review paper will explore the impact of TBI on mental health and quality of life of individuals and their family carers, and highlight that people with TBI are often a 'hidden disability' group (Australian Institute of Health and Welfare, 2007) that may fall between the gaps for appropriate and continuing mental health support.

Psychiatric consequences for adults

People with TBI might experience a range of psychiatric symptoms such as (a) depression (Alderfer, Arciniegas & Silver, 2005; Deb, Lyons, Koutzoukis et al., 1999; Douglas & Spellacy, 2000; Draper et al., 2007; Fann, Burrington, Leonetti et al., 2004; Glenn, O'Neill-Pirozzi, Goldstein et al., 2001; Jorge, Robinson, Moser et al., 2004; Jorge, Starkstein & Sergio, 2005; Koskinen, 1998; Kreutzer, Seel & Gourley, 2001; Leon-Carrion, Serdio-Arias, Cabezas et al., 2001; Van Reekum, Bolago, Finlayson et al., 1996; Stalnacke, 2007), (b) anxiety disorders (Deb et al., 1999; Draper et al., 2007; Fann et al., 2004; Van Reekum et al., 1996), (c) mood disorders (Bowen, Neumann, Connors et al., 1998; Jorge et al., 2005), (d) personality disorders (Van Reekum et al., 1996), (e) schizophrenia (Nielsen, Mortensen, O'Callaghan et al., 2002), and (e) panic disorder (Deb et al., 1999). These individuals are also at a higher risk of suicide than the non-brain injured population (Kishi, Robinson & Kosier, 2001; Leon-Carrion et al., 2001; Oquendo, Friedman, Grunebaum et al., 2004; Simpson, 2004; Simpson & Tate, 2002). It appears that depression and anxiety disorders may be common in people with TBI (Alderfer et al., 2005; Jorge et al., 2005). According to Jorge et al. (2005), 40% of persons with TBI experienced

major depression. The authors also noted that anxiety disorders, substance abuse, dysregulation of emotional expression and aggression were frequently associated with major depression.

Leon-Carrion et al. (2001) conducted a series of neuropsychological assessments in a study of 39 persons with traumatic brain injury 18 months after being discharged from hospital. They found that 48.6% met the diagnostic criteria of clinical depression, of whom 65% had suicidal ideation or tendencies. Douglas and Spellacy (2000) also reported that 57% of adults with TBI of about 3.5 to 10 years post-injury and 60% of their carers showed significant symptoms of depression. Fann et al. (2004) reviewed the prevalence of psychiatric illness following TBI in an adult population one year prior to injury and three years post-injury. They found that 49% of patients with moderate to severe TBI demonstrated evidence of psychiatric illness one year after their injury, compared to 34% of those with mild injury and 18% of those non-traumatic brain injury comparison groups. The study indicated that those with a prior history of psychiatric illness had a higher incidence of psychiatric disorders following injury. They also found that the risk of psychiatric illness was more likely in the first six to twelve months following injury.

Psychosocial functioning and its relationship with mental health were investigated by Stalnacke (2007). Psychosocial functioning (as measured by community integration, life satisfaction and social support) and symptoms (as measured by post-concussion, post-traumatic stress and depression) in 163 persons with mild traumatic brain injury 3 years after the injury, revealed that many of these individuals experienced low levels of life satisfaction (46%), vocation (42%), leisure (43%) and psychological health (60%). Depression was the most frequent secondary condition after injury and was significantly associated with life satisfaction measures ($p < .0001$); that is, the level of life satisfaction decreases with increasing scores of depression (Stalnacke, 2007).

In another larger sample study, Kreutzer et al. (2001) conducted a comprehensive assessment of 722 persons ($M = 2.5$ years post-injury). They found 42% met the criteria for a DSM-IV diagnosis of major depressive disorder. Similar

findings have also been reported in comparative studies. Deb et al. (1999) identified that 13.9% of 164 persons one year post-injury had depression compared to 2.1% of the general population. Panic disorder was reported in 9% compared to 0.8% of the general population. Jorge et al. (2004) found that 51.6% of their patients developed a mood disorder within one year following injury as compared to 22% of a control group. They also found that anxiety disorders and aggressive behaviour were frequent; and that those who developed major depression had a significantly higher history of mood and anxiety disorders. The association between psychosocial outcomes and severity of TBI was investigated by Draper et al. (2007) with 53 individuals 10 years following TBI that ranged from mild to very severe. They found that persons with TBI who had more severe anxiety and depression would have poorer psychosocial functioning. Lack of money appeared to be a significant predictor of psychological wellbeing of the person with TBI (Douglas & Spellacy, 2000). Individuals with TBI (57%) expressed the lack of social network in terms of friendship or relationship with others ('loss of friends' or 'I feel lonely') that may contribute to poor mental health outcome (Douglas & Spellacy, 2000).

Suicidality of adults with TBI

A growing area of concern is the issue of suicidality in persons with TBI. Research indicates that suicide ideation is common in persons with TBI (Kishi et al., 2001; Mainio, Kylionen, Viilo et al., 2007; Oquendo et al., 2004; Simpson, 2004; Simpson & Tate, 2002, 2007). While it is not within the scope of this paper to explore this issue in depth, these studies highlight the urgency to address the issue of suicidality. In a study of 172 persons with TBI, Simpson (2004) found clinically significant levels of hopelessness (35%), suicide ideation (22%) and suicide attempts (19%). Simpson also found that there is a lifetime prevalence of 1.86 suicide attempts, with the median time of 2.5 years after the injury. The findings reiterate similar concerns of other researchers in this area.

In a systematic review of the literature, Simpson and Tate (2007) found that persons with TBI were at 3 to 4 times greater risk of death by suicide than the general population and had high levels of reported suicide attempts (18%) and

clinically significant suicide ideation (21-22%). In a sample of 255 persons with mild traumatic brain injury, Oquendo et al. (2004) found that suicide attempts may be predicted by aggression. Mainio et al. (2007) reported that the presence of psychiatric and alcohol issues, severity of the injury, male gender and age are important factors to consider as potential predictors of suicidal behaviour in persons with traumatic brain injury. Therefore, there is ample evidence to suggest a link between TBI and suicidality. More importantly, the research indicates the need for early detection and intervention for the person, and family support to minimise the risk of suicide in persons with TBI (Kishi et al., 2001; Oquendo et al., 2004; Simpson, 2004; Simpson & Tate, 2002, 2007). Given the risk of suicidality, there is a definite role for mental health practitioners to identify and treat people with TBI.

Serious behavioural issues and TBI

There are several studies that have established a link between crime and/or violent behaviour and brain injury (Brower & Price, 2001; Chan, Hudson & Parmenter, 2004; Colantonio, Stamenova, Abramowitz et al., 2007; Diamond, Harzke, Magaletta et al., 2007; Leon-Carrion & Ramos, 2003). Other studies have highlighted the sexually inappropriate and sexual offending behaviours of persons with TBI (Bezeau, Bogod & Mateer, 2004; Simpson, Blaszczyński & Hodgkinson, 1999; Simpson, Tate, Ferry et al., 2001). Many of the offending behaviours are serious, such as assault, robbery and homicide (Chan et al., 2004; Colantonio et al., 2007). Leon-Carrion and Ramos (2003) strongly advocated for early detection and treatment of head injury before it impacts more severely later in the life of these individuals. Another concern is the use of alcohol and drugs following TBI (Ponsford, Whelan-Goodinson & Bahar-Fuchs, 2007). Ponsford et al. (2007) found that alcohol and drug use appear to be common, particularly among young males years after the injury. Hence, it may be argued that the impact of TBI is not simply a medical and health issue; more importantly, there is a case to argue that the impact is also a social issue for the community and government. This is especially so given that people with TBI are at risk of behaviours that may lead to incarceration (Chan et al., 2004; Colantonio et al., 2007).

Quality of life issues

It appears obvious that poor mental health consequences may adversely impact on the quality of life of persons with TBI (Doigh, Fleming & Tooth, 2001; Man, Lee, Tong et al., 2004), with many having difficulty accessing employment and re-integrating into the community years after the injury (Man et al., 2004; Tate et al., 2003, 2004). Man et al. (2004) suggested that low social role functioning and community integration might also be predictors of lower quality of life. Steadman-Pare, Colantonio, Ratcliff et al. (2001) explored the factors associated with quality of life 8 to 24 years after TBI in 274 persons, using a series of questionnaire instruments. They found that psychosocial factors such as mental health and wellbeing and social support were strongly related to better quality of life. For example, persons who experienced depression reported lower quality of life ratings, and those who were in relationships reported significantly higher quality of life than those who were single (Steadman-Pare et al., 2001). Other factors that had a strong correlation with higher ratings of quality of life were the ability to get along with people, the ability to afford things, and the ability to engage in work and leisure (Steadman-Pare et al., 2001).

Parents of children with TBI also reported a poor quality of life in their children marked by cognitive, emotional and behavioural difficulties (Limond, Dorris & McMillan, 2009). In their review of 47 children with mild or moderate-severe TBI a few years after the injury, Limond et al. (2009) found that quality of life was significantly lower in 13 times as many children with TBI than from the normative population in the United Kingdom. Quality of life following TBI may be mitigated by the coping and social support of the person; that is, better support and coping strategies can lead to improved quality of life (Tomberg et al., 2007).

Impact of TBI on the mental health of children and adolescents

The consequences of TBI for children and adolescents are similar to those experienced by adults. Children and adolescents who survive TBI are at significant risk for ongoing health, psychosocial, behavioural, functional and academic problems (Barker-Collo, 2007;

Hawley, 2004; Hessen, Nestvold & Anderson, 2007; Viguier, Dellatolos, Gasquet et al., 2001; Ylvisaker, Adelson, Braga et al., 2005). The impact may also be experienced several years after the injury (Hessen et al., 2007). Hessen et al. (2007) investigated long-term neuropsychological outcome after mild traumatic brain injury in paediatric ($N = 47$) and adult ($N = 74$) population groups 23 years after the injury. A positive outcome of this study was that overall participants with mild TBI had neurological test scores within the normal range and had average levels of education. A lower percentage of them were on disability benefit compared to a demographically matched Norwegian population. However, they found significant relationships between severity of head injury and current neurological function in the paediatric group; particularly, post-traumatic amnesia (PTA) sustained for more than 30 minutes or a combination of PTA for more than 30 minutes and pathological EEG within 24 hours could significantly predict poor neurological outcome after 23 years. Poorer neuropsychological outcome was found for children with complicated mild head injuries than for adults with similar head injuries. The study calls into question a currently common conception that young children with TBI have a better prognosis than adults (Hessen et al., 2007).

An important part of any child or adolescent's life is education. Persistent cognitive impairments can adversely affect several domains of academic performance. Some of the problems reported most frequently are difficulties in attention and memory, speed of processing information and expression, sensory-motor functioning, reasoning and problem-solving skills (Barker-Collo, 2007). In a study of 74 children with TBI in comparison with 13 children with orthopaedic injury, Barker-Collo (2007) found that severity of injury correlated with increase in mental health concerns (such as anxiety and depression), social and thought problems, and in particular, attention problems. She also found that increased age related to increased parental reports of attention problems, while increased hospital stay related to increased withdrawal and thought problems.

Similar to adults with TBI, another significant consequence is behaviour problems following TBI (Fletcher, Ewing-Cobbs, Miner et al., 1990;

Hawley, 2004). Fletcher et al. (1990) found that severely injured children had more school problems and participated in fewer social activities. Hawley (2004) examined the relationship between behavioural problems and school performance following TBI in 67 school-aged children matched with 14 uninjured children. She found that two-thirds of children with TBI showed significant behavioural problems, significantly more than the control group. These children also had a lower mean IQ than those without behavioural problems and 76% of children with behavioural problems also had difficulty with school work. One of the problems with the study by Fletcher et al. (1990) is the lack of description of the behaviours that might explain the difficulties these children experienced at school. Furthermore, the sample size of both studies was small and therefore one has to be cautious in interpreting the results. Nevertheless, it is important to highlight that the impact of TBI on children and adolescents is significant. In a review of major developments of the past 20 years in the management of children with TBI, Ylvisaker et al. (2005) reported that well-conceived interventions can improve family resilience and problem-solving ability, thereby improving the child's outcome, particularly behavioural outcomes. They argued that there is strong rationale for intensive and ongoing services and supports for families.

Impact of TBI on the mental health of family carers

Family carers of people with TBI experience significant stress, depression, anxiety and emotional distress (Anderson, Parmenter & Mok, 2002; Gervasio & Kreutzer, 1997; Gillen, Tennen, Affleck & Steinpreis, 1998; Harris, Godfrey, Partridge & Knight, 2001; Liss & Willer, 1990; Perlesz, Kinsella & Crowe, 2000; Willer, Allen, Liss & Zicht, 1991; Winstanley, Simpson, Tate & Myles, 2006; Wood & Yurdakul, 1997). In an extensive review of the effects of TBI on marital relationships, Liss and Willer (1990) reported that the effects of TBI were an additional strain on the spouse and on marital relationships. Spouses reported feelings of anxiety, isolation and a sense of loss (Liss & Willer, 1990). In a structured small-group study of 20 men and 11 women with TBI, and their spouses, Willer et al. (1991) noted significant problems in their relationships, and some of the

shared concerns of both men and women with TBI were loss of autonomy (such as gainful employment), loneliness and depression.

In a larger study, Wood and Yurdakul (1997) examined the relationship status of 131 persons with TBI and reported that 49% of the sample had divorced or separated from their partners during a 5 to 8 year period following TBI. The study did not suggest a relationship between severity of TBI and marital relationship breakdown; instead, the neurobehavioural consequences may be a factor. Anderson et al. (2002) investigated further the impact of neurobehavioural problems of TBI on the family functioning and psychological wellbeing of 47 female and 17 male spouse/caregivers, using a cross-sectional design. They found that neurobehavioural problems adversely affected family functioning and caused psychological distress in spouses/caregivers. The high levels of family dysfunction is concerning partly because the psychological distress experienced may negatively impact on the rehabilitation of the person with TBI (Anderson et al. 2002).

Perlesz et al. (2000) assessed psychosocial outcomes following TBI in 79 family members, including relatives more peripheral to the person with the injury, about 19.3 months after injury. They found primary carers, mainly wives and mothers, were at greater risk of poor psychosocial outcome, compared to other carers. Anxiety and depression are common among family carers of people with TBI (Douglas & Spellacy, 2000; Gervasio & Kreutzer, 1997; Gillen et al., 1998). Gillen et al. (1998) found 47% of carers met the criteria for depression initially and 43% met the criteria 6 months later. They also found that 17% of those who were not depressed initially subsequently met the criteria for depression. Gillen et al. (1998) also reported that a predictor of depression was a previous depressive episode prior to the injury being sustained. They found that lifetime depression of carers related to the individuals with TBI who had histories of alcohol and substance abuse, risk-taking behaviours and anti-social behaviour.

Using a larger sample size of 116 family carers, Gervasio and Kreutzer (1997) investigated the level and type of psychological distress in family carers of adults with TBI. The majority of the caregivers were females ($N = 89$) and included spouses/partners (59.5%) and parent/relative/

sibling (40.5%). The authors found that 44% of the caregivers had clinically elevated scores on the questionnaire, indicating psychological concerns in caregivers, in particular obsessive-compulsive behaviour, anxiety, hostility and psychoticism. Gervasio and Kreutzer (1997) also noted that spouses reported significantly more distress than other relatives (e.g., parents) on almost all subscales of the questionnaire. As indicated in the studies above, the prevalence of mental illness such as depression and anxiety impacts on carers. This affects family cohesion and carers' ability to care for the person with brain injury (Douglas & Spellacy, 2000; Gillen et al., 1998). These studies also suggest that social support and family coping strategies may mediate the effects of brain injury (Douglas & Spellacy, 2000; Gillen et al., 1998). Family carers play a pivotal role in the rehabilitation process and therefore it is important to understand how they adjust to the adverse effects of TBI.

Family carers reported excessive demands on their time, having too little leisure time, and too many responsibilities, as the social problems they encountered (Douglas & Spellacy, 2000). For carers, the daily demands of living with a person with TBI are overwhelming. According to Douglas and Spellacy (2000), 45% of carers' depression scores were predicted by their scores on social support, linking lack of money and excessive responsibilities in caring for the person with brain injury. The comments by carers in the study reflected that the needs for respite care and day activity services would mitigate the excessive responsibilities experienced by carers (Douglas & Spellacy, 2000). The deleterious impact of TBI is not only felt by immediate family carers such as spouses and parents; other relatives of the person with TBI may also experience poor mental health outcomes. Winstanley et al. (2006) found that widespread psychological distress was evident among 134 close relatives, where 50% of relatives met the criteria for caseness on the GHQ28 associated with heightened levels of anxiety and somatic complaints. They found that poor levels of participation in occupational activities and independent living skills were additional factors contributing to distress in relatives. Family members who perceived their needs as being adequately met were less likely to be distressed,

and more likely to report more positive levels of family functioning. These findings by Winstanley et al. (2006) suggest that increasing resources such as respite and case management may have positive effects for relatives.

The studies reviewed highlight the adverse impact on spouses and family carers of individuals with TBI. The support and assistance that need to be provided to family carers are important, as they form part of the rehabilitation process of the person with TBI. The research reviewed also highlights to clinicians, policy makers and service providers that the 'client' in the rehabilitation process is not just the person with TBI; the 'client' should include the family carers who support the person with TBI on an ongoing basis. The shift in focus is important for appropriate planning, formulation of policy and allocation of adequate resources to ensure better re-integration into the community. Failure to do so will only be costly for the society and government, as when families break down, the 'burden' of caring will become the responsibility of government agencies.

Support services

It is not uncommon for persons with TBI to require a range of support services several years post-injury (Chan, 2008; Hodgkinson, Veerabangsa, Drane & McCluskey, 2000; Limond et al., 2009; Rotondi, Sinkule, Balzer et al., 2007). Carers of persons with TBI reported similar support needs (Chan, 2007; Rotondi et al., 2007). The support needs may range from financial services, legal matters, transport, vocational services, respite, case management, information about support needs or medical and health care needs; through to assistance to respond to the needs of the person with TBI (Chan, 2007; 2008; Hodgkinson et al., 2000; Rotondi et al., 2007). Rehabilitation of persons with TBI predominantly focuses on the physical and cognitive impact of the injury; however, there is increasing evidence to shift the emphasis of rehabilitation to include assessment and treatment of mental health concerns following injury (Rogers & Read, 2007). More importantly, there are therapeutic gains to be made as part of the rehabilitation program and when the person with TBI is discharged into the community for continuing care (Rogers & Read, 2007; Simpson & Tate, 2007).

Given the increasing evidence of mental health concerns in TBI, it is reasonable that the brain injury rehabilitation team should consist of professionals trained in psychiatric rehabilitation (Torsney, 2004) and to monitor the mental health of persons with TBI (Fann et al., 2004). As presented in this paper, the evidence for the inclusion of such expertise in a rehabilitation team is compelling. That is, it has been shown that people with TBI are at risk of mental health problems and the impact also affects the mental health of family carers. Similarly it is reasonable that mental health professionals are trained to identify the co-morbidity of TBI in persons with mental health concerns and their family carers. Mental health professionals may overlook the significance and impact of a neurological incident in the history of the person as it is not uncommon for these individuals or their families not to report the incident of brain injury (Torsney, 2004). Hence, screening for TBI should be considered (Diamond et al., 2007; Hux, Schneider & Bennett, 2009; Simpson & Tate, 2007).

Screening for TBI has several advantages that can assist in timely and effective early interventions (Hux et al., 2009). Settings such as homeless shelters, mental health and correctional facilities, refuges, and developmental disability agencies could be considered (Hux et al., 2009). Simpson and Tate (2007) posit an argument that general practitioners (GPs) play a critical role in the continuum of care for people with TBI, in particular the prevention of suicide. They outlined several strategies for how GPs can support persons with TBI; these include detection and assessment, identifying suicide ideation, treating the mental health concerns, and increasing levels of social support. In the Australian context, it is usual for the GP to be the first point of contact for primary health care. Hence, it is logical and most appropriate, as Simpson and Tate (2007) have argued, for GPs to be aware of the mental health needs of people with TBI, particularly regarding the risk of suicidality.

While there can be further argument for specialist services and education for mental health practitioners, it is more important to have a systemic response to address the gap in services. A systemic model in Australia is the

Department of Human Services, Victoria (2001) strategic plan. The strategic plan aims to address the specific needs of people with TBI and mental illness and acknowledges the complex and diverse needs of this population. Following on from this strategic plan, the department developed a state-wide protocol that outlined the principles for specialist mental health services for people with TBI and how to access specialist services for this population group (Department of Human Services, Victoria, 2004). Having a state-wide response may assist in ensuring that appropriate services are being provided to people with TBI by the relevant service providers, both government and non-government.

Conclusion

There is ample evidence that people with TBI and their family carers experience continuing mental health issues that impact on their quality of life and wellbeing. The consequences of TBI explored in this paper included psychiatric, behavioural concerns, offending behaviours, and a poor quality of life outcome for the person and family carers. There is an urgent need to advocate for a consistent and systematic approach to mental health support within rehabilitation and generic services in the community. A state-wide response to people with TBI and mental health issues is critical in leading a systemic response as the impact is also a social issue of concern to the general community and government.

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