

## **Mild Traumatic Brain Injury (mTBI) Also Affects Families, Not Just the Patient**

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### ***ABSTRACT***

*The effects of mild traumatic brain injury on an individual have been discussed in the literature, with specific emphasis on somatic, cognitive and psychological consequences after the injury. Further focus has also been placed on diagnosis, assessment and, to some extent, treatment modalities used within the field of mTBI.*

*There is currently limited research that have focused on the impact mTBI have on the family and reintegration after injury and this paper aims to pull together evidence from the field of mTBI, TBI, PTSD and military deployments, to identify what impact mTBI may have on family reintegration and how the family can be best supported to enable recovery and adjustment after mTBI.*

## **1.0 IMPACT OF MILD TBI ON THE FAMILY**

### **1.1 Overview**

Since 2000, approximately 260 000 US service personnel have sustained a TBI, the majority of these classified as mild (DVBIC). Although the majority of individuals recover fully after a mTBI, there is a small percentage of individuals who continues to experience cognitive, somatic and emotional changes. The exact reason for this is still not clear and researchers have attempted to identify factors that could contribute to this delayed recovery.

Moderate and severe TBI have been studied by a large number of researchers and the role the family plays in terms of recovery continues to be a topic of research. The effects of traumatic brain injury on family relationships have been explored by numerous researchers (Tyerman & Booth, 2001; Laroi, 2003; Landau & Hissett, 2008). Following a TBI, family members' responsibilities can include helping individuals manage activities of daily living, appointments and finances as well as offering emotional support and help with socialisation, thus playing a crucial role in reintegration following injury.

There is, however very little evidence exploring the impact of mTBI on family reintegration currently. To date, most of the mTBI research has focused on the individual, not on the significant impact physical, emotional, cognitive and behavioural changes can have on family relationships after an mTBI.

### **1.2 Military, Mental Health and Family Reintegration**

Behavioural changes and relationship challenges have been a long standing concern following soldier returning from deployment.

The risk of developing psychological difficulties following military deployment has been discussed within the literature and according to the Mental Health Advisory Team (MHAT) (2008); it is more likely that individuals will develop mental health difficulties as a result of stress on the family (this is related to difficulty with reintegration after deployment and difficulty with re-establishing roles/responsibilities). There is also a heightened risk of divorce and domestic violence in returning veterans (Marshall, Panuzio & Taft, 2005).

It is also estimated that up to 19% of combat veterans returning from Iraq and Afghanistan go on to develop post-traumatic stress disorder (which can be either isolated or with a mTBI) and numerous studies have demonstrated the relationship between PTSD and problematic family functioning (Hopwood & Watt, 2003, Orcutt et al., 2003) highlighting the multiple factors that can interfere with reintegration into home life after deployment and sustaining a life changing, sometimes 'invisible' injury.

As there is a significant overlap between somatic, cognitive and psychological symptomatology after an mTBI, it is important to understand the impact psychological changes after an mTBI can have on the family life, despite the lack of empirical evidence to support this notion.

Service members with mild TBI can have a range of cognitive, physical, and psychological symptoms and in most cases, these symptoms resolve promptly. However, a small subset can experience persistent symptoms post 3 months that can create unique treatment challenges; emotional, somatic and social interaction changes can all affect the family dynamic (Hyatt, 2013). The injured service member may express stress in the form of anger, depression, and anxiety and sometimes it can be perceived by family members as a personality change. Without prompt recognition and intervention, mTBI can have a major impact in terms of reintegration into the family.

Evidence from the TBI literature, in specific a study conducted by Wood and Yurdakul (1997), highlighted a change in marital status following head injuries of varying degrees/severity, specifically that almost 50% of individuals were divorced or separated after the head injury (follow-up was conducted on average 8 years post injury), identifying a significant break-down in family relationships following TBI.

When evaluating whether family members receive input or support to prepare themselves for the caring role they have to play, it appears that despite the rehabilitation teams' best efforts to educate and prepare families, many report feeling overwhelmed and poorly equipped to provide for the individual's complex long-term needs (Gillen et al., 1998 & Hall et al., 1994). Research indicates a family's ability to cope in the face of stressors, influences the quality of support they can provide to the injured individual (Oddy & Herbert, 2003).

### **1.3 mTBI and Family Integration**

Bay, Blow & Yan (2012) found that individuals with an mTBI who have low levels of belonging and a poor valued fit and involvement with others were more likely to have subjective difficulties with emotional control, social interaction and also lacked confidence, highlighting the relationship between social support and recovery after TBI. The study also found that the focus of treatment should also involve regaining a sense of belonging as this is likely to improve psychosocial outcomes. This is further supported by Bell et al (2008) who found that focusing on symptom management alone, will hinder psychosocial and in turn, overall recovery.

Laudau & Hissett (2008) conducted a qualitative study where they examined the loss of self and identify ambiguity and the impact of this on the family following an mTBI. Individuals following an mTBI described changes with their self-image, reduced confidence and generally a loss of their sense of self, highlighting the complexity of this injury. It is also likely that if one member of a family's roles and identify are in question, that this will have a significant impact on the family system. Laundau and Hissett go on to further discuss that after

an mTBI, the individual's boundaries within the family have to be renegotiated, especially due to the emotional changes this person is experiencing. Changes in socialisation, mood & temperament, call impact on how the individual interacts with the family and with a change in these, family dynamics are likely to change. "Returning to normal" is not always realistic and the focus has to be shifted towards developing/creating the person they want to become therefore the family has to work together to move towards finding a "their new joint reality" which will reduce ambiguity and false hope.

Hyatt (2013) identified, which supports the findings of Landau and Hissett (2008), that finding the "new normal" appears to be one of the main focuses of family reintegration and three themes were identified: 1) facing up to the service member's unexpected homecoming, 2) managing unexpected changes in the family routine and 3) experiencing mismatched expectations and adjusting to new expectations for the family. He also found that longer marriages (>10 years) appears to adjust faster to changes following injury. He also found that there were other specific challenges with returning from deployment with a mTBI such as changes/disruption to normal family routine (delayed (and unexpected) changes), understanding how to fit injury related changes into the family dynamics and managing and resolving mismatched expectations.

Lefebvre and Levert (2012) attempted to capture the experience of individuals and their families after sustaining an mTBI. Themes that were identified through the focus groups, specifically related to intervention and recovery were the firstly, the need for expert, early follow-up. They also reported that there was a need for clear, accurate information and that a lack of information has disastrous consequences for the individuals who develop chronic difficulties in the medium and long term, and for those around them. They agreed that their mTBI symptoms did not resolve with time as so many health professionals profess, and the findings showed that all their difficulties were made worse by lack of understanding of why they have not improved.

Faced with difficulties that they did not fully comprehend, combined with the inability to resume their pre-injury functional level can lead to a reduction in self-esteem. Most family members spoke felt the need to support the person however, did not feel they had to tools to do this. On-going problems can lead to a requirement to change family dynamic, with others taking on more roles than pre-injury.

There appears to be consensus from participants that a lack of support for the family in the acute care is a problem as most of the attention is focused on the individual whom sustained a TBI rather than be inclusive of the family. This ties in well with Gillen et al (1998) & Hall et al (1994) who found that despite some input in the acute setting, families still feel ill-equipped to deal with the brain injured individual on return from hospital; it is clear that little has changed in the way family education and support are conducted and the impact it makes on family reintegration.

### **1.4 Current Military Information/Treatment Programmes**

Within the US military, the Defence and Veterans Brain injury Centre (DVBIC) have developed a Family Caregivers Guide to help support the transition from 'family member' to 'caregiver' after the service member sustained a traumatic brain injury. Although this guide mostly focuses on a more significant TBI, some of the information can be generalised to the mild TBI population.

This guide/booklet aims to encapsulate some of the key themes identified through research such as including the caregiver/family member in the rehabilitation pathway, providing them with clear, accurate information, both in visual/written format as well as contact details of clinicians that are a part of the holistic treatment approach. It is also acknowledged in the booklet that a key component of changing roles and relationships following a TBI, is to ensure that the care giver looks after their own health and wellbeing and practical approaches, tips and ideas

are provided, also contact details of where support can be obtained (Traumatic Brain injury: A guide for caregivers of service members and Veterans, DVBIC).

Within in the UK, the charity, Headway has written a booklet on “Caring for someone with a brain injury” again, with the focus on more significant TBIs. The Defence Medical Rehabilitation Centre Headley Court, as part of their mTBI service, designed a one page leaflet for relatives, explaining what an mTBI is and what they can expect. Family members are also encouraged to attend sessions with the injured service person to help support reintegration and educate the family member on how they can support them.

## **2.0 SUMMARY OF INTERVENTION TO SUPPORT FAMILY INTEGRATION**

There is clearly a requirement to ensure family education and support are offered to best enable the service person to reintegrate following a mTBI. This intervention should aim to include the recommendations below, this has been extrapolated from the literature review:

- **The need for expert, early follow-up;** early assessment and intervention of mTBI and other difficulties following accident/injury is crucial to recovery and rehabilitation.
- **The need for clear, accurate information; This does not mean leaflets only,** but face-to-face sessions with family members are essential to help prepare them for their role in the recovery process.
- **Remediation of mTBI difficulties** is essential, but the clinician needs to ensure that a **holistic** approach is used. This has to include the family members in the treatment process alongside the biopsychosocial aspects of care.
- **Collaboration and integrated care and to include family dimension in the service:** following an mTBI, individuals report what would be most beneficial to their recovery but also work towards improving and protecting family relationships, are collaboration between all health care professionals and using both physical as well as psychological treatment approaches (holistic). Considering the biopsychosocial aspects of care is essential. Persisting deficits may subsequently require the whole family dynamic to be reorganized, with family members taking on more responsibilities than before.
- **Identify reconstruction:** Supporting individuals to recalibrate how they view their injury, themselves and others are vital to the recovery process; what can initially be perceived as a significant loss can become something more positive (gains after the mTBI) – personal growth experience. A key concept to facilitate this is for the individual and family to face reality and accept changes (growing “together”). Input to address “mismatched” expectations and promote acceptance of “new” normal is essential and mTBI intervention should not only focus on the service member, but also involved the spouse/family members.

## **3.0 CONCLUSION**

Mild traumatic brain injury remains a complex condition to treat as the symptoms are multi-faceted. The longer-term consequences and changes as a result of an mTBI can have a detrimental impact on not only the service person, but also on family relationships. This can be due to the perception of the spouse of “personality changes” within the individual such as increased anger, frustration, anxiety and loss of motivation and self-esteem. This is likely linked to the impact the cognitive and physical sequelae have on the person’s sense of self and their own adjustment process. These symptoms interfere with a couple’s communication and relationship and thus challenge marital satisfaction.

Using a holistic approach early after injury, involving the family within the recovery process and supporting healthy family dynamics will ultimately support improvements following an mTBI. Finding ways to support the individual and family to manage emotional distress and accept enduring changes after the mTBI may be key to post-injury family reintegration.

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