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Neuropsychological Assessment of Refugee Survivors of War and Torture

A thesis submitted in partial fulfilment of the requirements for the degree of Doctor of Clinical Psychology at Massey University, Wellington, New Zealand

Bahrie Veliu
2013
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Abstract

This thesis presents the results of psychological and neuropsychological assessment of a group of refugees with PTSD and a group of refugees with co-morbid TBI and PTSD. The study was designed to evaluate the outcome related to co-morbid TBI+PTSD, compared to the outcome of PTSD alone. In addition, this study also evaluated the methodological barriers in neuropsychological assessment of refugees. Eighteen refugees diagnosed with PTSD and depression participated in the study. Seven of them reported head injuries that had led to loss of consciousness, and were assigned to the TBI+PTSD group with the remaining eleven in the PTSD only group.

Results indicated that neuropsychological assessment of refugees is challenging due to linguistic and cross-cultural barriers. Despite the adjustment of assessment according to suggestions from the literature, most refugees had difficulty doing the assessment, and for a small number assessment with the measures used in this study proved impossible. Non-parametric tests and boxplots were used to evaluate the differences between the TBI+PTSD group and the PTSD Only group in terms of psychological symptoms, self-reported functioning, and neuropsychological outcome. While no significant result was detected, possibly due to small sample size and high variability within the sample, the box plots revealed a number of tendencies that were consistent with the study’s hypotheses.
Acknowledgements

This thesis is the end of a long journey that has been challenging, stimulating and forever memorable. Foremost, I would like to express my gratitude to the people who participated in this research. Their willingness to participate despite their experiences was truly inspirational.

Words are short to describe my gratitude to my supervisor Janet Leathem for trusting me to do this project in the first place and for being an amazing supervisor throughout this research. She was encouraging, patient and created an environment that allowed me to grow and learn. I would also like to thank my second supervisor Nigel Long for his contribution to this research.

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I thank all my fellow labmates in the Cherubs lab for stimulating discussions and all the fun we had over these years. A special thanks to my friend, Fernanda Mottin, who has been a loyal companion throughout this time, and who has provided support and stimulating conversations that have helped many ideas emerge.

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Introduction and Overview

The idea for conducting research with refugees arose as a result of a request from Refugees as Survivors Trust to Massey University for neuropsychological assessment of a group of refugees with suspected traumatic brain injury (TBI) in addition to Post Traumatic Stress Disorder (PTSD), resulting from torture.

The agency “Refugees as Survivors” (RAS) is based in Wellington and Auckland and provides psycho-social services for refugees who have been victims of torture and trauma. Clinicians from this agency reported that a large number of their clients had sustained beatings to the head during torture and were experiencing neuro-cognitive symptoms consistent with TBI. It was decided that a research study could be developed that would have therapeutic benefits for refugees whilst also making a contribution to research knowledge by addressing questions about neuropsychological outcomes in this population. The research questions were developed following an extensive literature review and will be outlined later in this chapter.

Literature Review and Consultations

A literature review revealed that refugees are particularly vulnerable to neuropsychological and neurological difficulties. Most refugees have experienced some form of trauma, while around 60% have experienced torture (Quiroga & Jaranson, 2005). Reports from the refugee survivors of torture reveal that the torture often involved traumatic brain injuries (TBIs) ranging from direct blunt blows to the head, violent head shaking, asphyxia, malnutrition to serious penetrating head injuries (Moreno & Grodin, 2002; Rasmussen, 1990). In addition, PTSD was found in 69%-92% of victims of torture from six different countries (Moisander & Edston, 2003). PTSD is associated with brain abnormalities that lead
to problems in attention, memory, and learning (Brewin, Kleiner, Vasterling, & Field, 2007; McNally, 2006).

A number of researchers and practitioners have warned that given the high prevalence of PTSD in this population, the common symptoms of TBI including difficulties with memory, attention, distractibility and impulsivity may be easily labelled as PTSD, although in a subgroup of torture victims this may mainly be due to TBI alone (Moreno & Peel, 2004; Weinstein, Fucetola, & Mollica, 2001). Thus, in refugee populations, there is a high risk of failing to identify TBI due to overlapping symptoms. The identification of co-morbid TBI in PTSD is important as, depending on its severity, TBI can lead to long term disability in those that survive (Zec et al., 2001). In addition, numerous studies with US soldiers have indicated that TBI leads to more disability, no improvement over time and higher risk for psychiatric co-morbidity, particularly PTSD (Polusny et al., 2011; Vasterling, Verfaellie, & Sullivan, 2009b).

From the review of the literature on TBI and PTSD it became clear that a major problem in the neuropsychological assessment of refugees is identifying whether cognitive symptoms are due to TBI, PTSD, or both. Therefore a main topic of this research became evaluation of psychological, functional, and cognitive outcome of refugees with PTSD compared to those with co-morbid TBI and PTSD. Another salient issue identified in literature was that cultural factors are likely to complicate the neuropsychological assessment of refugees (Weinstein et al., 2001). A literature review of cross-cultural issues in neuropsychological assessment informed the study design and selection of measures, and guided the observations of the process of assessment.

**Initial Research Project**

The development of the design, hypotheses, and selection of measures was informed by this literature review, as well as consultation with cultural advisors and clinicians at RAS
who were all consulted about the unique cultural issues that needed to be addressed in the study design. They also provided cultural advice throughout the research.

Based on this, a project was developed to include three groups of refugees exposed to politically motivated torture. Group One were experiencing PTSD, Group Two PTSD and TBI; and Group Three neither TBI nor PTSD. The project was designed to address the following question and hypotheses:

What is the current level of neuropsychological functioning of three groups of refugees all exposed to torture and trauma? It was hypothesised that:

1. Refugees with neither PTSD nor TBI (Control Group) would score close to the average normative range.

2. Based on previous studies (Brewin et al., 2007) we hypothesised that refugees experiencing PTSD and no TBI (PTSD Group) would show a selective pattern of deficit, differing from the control group in verbal memory and attention. The effect size was expected to be small to moderate.

3. There would be variability within the group of refugees with TBI and PTSD (PTSD+TBI Group), according to the severity of TBI, (more severe injury associated with lower scores).

In addition, this study aimed to provide a new insight into the suitability of using neuropsychological measures and procedures with a diverse groups of refugees in New Zealand. To achieve this aim, observations and qualitative analysis of performance were conducted.

**Ethics Approval**

This project was granted ethics approval by the New Zealand Health and Disability Research Committee, Wellington (see Appendix A).
Application for Funding

Due to the cost of test translation and the cost of the interpreting, the regular research budget provided by the university was exceeded and additional funding was sought. A number of organizations were approached and although an application for First Grant Health Research Council, New Zealand (HRC) funding was unsuccessful, feedback and exchanges contributed to the improvement of the project (See Appendix I). A subsequently application to the Massey University Research Fund (MURF) was successful.

Data Collection

Data collection commenced in April 2009 and finished in the February 2010. During this time 20 participants were screened and 18 received comprehensive psychological and neuropsychological assessment. In December 2009, advertising commenced for the control group. Posters was translated into Arabic and Burmese as by that point of the project it became clear that the majority of potential participants would be of Burmese or Arabic language background (See Appendix K). The posters were placed in all the places that refugees frequently visit in Wellington including: Newtown Medical Centre, Newtown Library, Refugee Centres and English Language Centres. In addition, cultural advisors also informed their communities about the research inviting participation. In spite of this only one person volunteered (for the control group). There are a number of reasons that may have prevented the refugees from participating in the research. Firstly, as previous research indicates, refugees have low participation due to language barriers and unfamiliarity with research (Ellis, Kia-Keating, Yusuf, Lincoln, & Nur, 2007; Pernice, 1994). Secondly, due to limited funding, the study could not provide financial incentives and this may have been the main problem in recruiting participants particularly given the length of assessment.
Revised Methodology

As the research was progressing, it became increasingly apparent that each person was unique in terms of language, dialect, culture, education background, trauma and torture history, current stressors, personality, and coping style. In addition, a number of refugees were having difficulties doing neuropsychological assessment which appeared to be due to factors other than PTSD or TBI. Many participants needed significant help to perform the neuropsychological tasks that lacking inclusion of the context in which they obtain the scores would have led to invalid interpretations. Subsequently, it was decided that due to barriers and lack of a control group, it would be more appropriate to use a qualitative approach and report the data from three different aspects. These aspects are presented in the Results Sections I, II and III.

Results Section I reports qualitative results that addresses the question: What are the methodological and cross-cultural barriers in the neuropsychological assessment of refugees?

Results Section II reports the quantitative data for PTSD and PTSD+TBI group and addresses the question: Are there differences between PTSD and TBI+PTSD groups in demographic characteristics, psychological symptoms, self-reported functioning and cognitive test results?

Results Section III reports qualitative methods to address the question: What are the clinical issues in the neuropsychological assessment of refugees with PTSD and possible brain injury?

In order to provide background information in the neuropsychological sequelae related to TBI and PTSD and their co-occurrence, Chapter 1 will overview research studies that have used various samples. Chapter 2 will focus more specifically on literature on refugees where the rational for this study will be highlighted. Chapter 3 will evaluate theoretical and empirical research in cross-cultural neuropsychology in order to provide
background information on the cross-cultural assessment issues. The rational for the current study and methodology will be presented in Chapters 4 and 5 respectively. Chapter 6 will present the results of the current study. Discussion and recommendations for future studies will be presented in Chapter 7.
Chapter 1: Neuropsychological Sequelae

Posttraumatic stress disorder (PTSD) and traumatic brain injury (TBI) are highly prevalent among refugees and are the focus of the current thesis. The aim of this chapter is to review and synthesize neuropsychological studies for both of these disorders as well as studies examining their co-occurrence. This literature review presents studies with non-refugee populations with the aim of developing a clearer idea about the PTSD and TBI related outcomes prior to focusing more specifically on refugees in the chapter that will follow. The first part of this chapter will be an overview of post-traumatic stress disorder (PTSD). The review begins with a brief description of diagnostic criteria and the prevalence of PTSD, followed by a review of literature about the neuropsychological sequelae of PTSD. The influencing factors in the development of PTSD in reference to cognitive functioning will be briefly noted. The second part of this chapter provides a general overview of traumatic brain injuries. The overview will outline a brief definition of TBI, the causes of TBI, and the assessment of severity. Next, a detailed review of the literature on mild-TBI (MTBI) is provided (as this is the most frequent TBI sustained due to torture). This will be followed by a briefer review of the neuropsychological sequel of moderate to severe TBI. The last section will overview the literature on the co-occurrence of TBI and PTSD, which will be followed by an overall summary and conclusions.

Neuropsychological Sequelae of PTSD

Definition and Prevalence of PTSD

PTSD is a reaction that develops following an exposure to a traumatic event and is characterized by re-experiencing of original trauma(s) through flashbacks or nightmares, avoidance of stimuli associated with the trauma, and increased arousal, such as difficulty
falling or staying asleep, anger, and hypervigilance (DSM IV-TR, American Psychiatric Association, 2000). Rates of PTSD following a trauma experience average around 5-14% (Seligman & Reichenberg, 2011), although certain traumatic events such as torture are associated with rates of up to 67% (Jacobs & Iacopino, 2001). Important features of PTSD are also neuro-cognitive symptoms, such as attention and memory abnormalities (DSM IV-TR, American Psychiatric Association, 2000). Numerous studies have linked PTSD with neuropsychological disturbances and the following will overview this literature.

The Nature of Cognitive Impairment in PTSD

Literature about the cognitive functioning in PTSD has yielded inconsistent results (Brewin et al., 2007; Crowell, Kieffer, Siders, & Vanderploeg, 2002; Vasterling, Brailey, Constans, & Sutker, 1998). This has been attributed to the methodological shortcomings and inconsistencies identified by a number of reviews (Brewin et al., 2007; Danckwerts & Leathem, 2003; Horner & Hamner, 2002). Firstly, most studies have used small samples (e.g., n= 30 or smaller), which has prevented them from appropriately controlling for many confounding variables (e.g., co-morbidity, prior trauma, the level of exposure, and pre-morbid functioning). Secondly, the control samples have been used inconsistently (e.g., some studies used normal controls while others have included trauma exposed non PTSD subjects) and evidence from meta-analysis suggests that a larger effect size is observed in studies when PTSD subjects are compared to non-trauma exposed controls than trauma exposed subjects (Brewin et al., 2007). Thirdly, studies have inconsistently used cognitive measures, which has made it difficult to generalize and compare findings from various studies. Finally, the symptom validity measures have not been consistently used, thus failing to rule out secondary gain as a factor influencing PTSD association with cognitive deficit.
Despite the limitations and the conflicting results, a considerable body of research and meta-analyses have found evidence that PTSD may be associated with impairment in the following functions:

- **Overall intellectual function (IQ)** (Brandes et al., 2002; Gil, Calev, Greenberg, Kugelmass, & Lerer, 1990; Gilbertson et al., 2006; Golier et al., 2002; Roca & Freeman, 2001; Vasterling et al., 2002; Vasterling, Brailey, Constans, Borges, & Sutker, 1997), particularly verbal intellectual performance (Vasterling, 1997; Gil et al., 1990), although there is evidence that lower IQ may be a predating vulnerability factor (Kulka et al., 1990; Macklin et al., 1998; Vasterling, 2009).

- **Verbal learning and memory** (Bremner, Vermetten, Afzal, & Vythilingam, 2004; Elzinga & Bremner, 2002; Gil et al., 1990; Gilbertson, Gurvits, Lasko, Orr, & Pitman, 2001; Golier et al., 2002; Sutker, Allain, Johnson, & Butters, 1992; Uddo, Vasterling, Brailey, & Sutker, 1993; Yehuda, Keefe, Harvey, & Levengood, 1995).

- **Sustained attention, preservative responding, deficit in attention flexibility, and working memory** (Jenkins, Langlais, Delis, & Cohen, 2000; Koso & Hansen, 2006; Vasterling et al., 1998; Vasterling et al., 2002).

A meta-analysis which included 27 well controlled studies (Brewin et al., 2007) showed that PTSD populations show a decrement in memory functioning when compared to those without PTSD. Although the effect size was small to moderate, the finding was consistent across subjects with different trauma backgrounds (e.g., military, interpersonal, and state persecution). Verbal memory deficit was more associated with PTSD than visual memory deficit, indicating a selective rather than general pattern of memory deficit. Similar conclusions were also drawn by another meta-analysis by Johnsen and Asbjornsen (2008).
who also found that the largest effect size was in measures of verbal learning and memory (e.g., Wechsler Memory Scale and Rey Auditory Verbal Learning Test).

Studies that have evaluated the nature of memory problems have identified a specific deficit in the initial acquisition of information as the most frequent finding in PTSD (Vasterling et al., 1998; Vasterling et al., 2002). PTSD patients have impaired performance in tasks that require more processing efforts (e.g., RAVLT vs. CVLT), show proactive and retroactive interferences, and have disorganised learning (Uddo et al., 1993; Vasterling et al., 1998; Vasterling et al., 2002; Yehuda et al., 1995). Overall, these findings suggest that memory deficit in PTSD may be related to deficit in executive functioning which is involved in organizing learning and efficiently encoding the information (Isaac, Cushway, & Jones, 2006).

Further evidence of deficit in executive functioning in PTSD are neuro-imaging studies that have found abnormalities in several regions of the frontal system (e.g., orbitofrontal cortex, medial prefrontal cortex, dorsolateral prefrontal cortex and anterior cingulate cortex (Bremner et al., 1999; Rauch et al., 1999; Rauch, Shin, & Phelps, 2006; Shin, Rauch, & Pitman, 2006; Shin et al., 2001; Shin et al., 2005; Woodward et al., 2006). Furthermore, neuropsychological studies have also found deficit in other frontal lobe related functions including impairment in sustained, divided and focused attention; impaired cognitive flexibility and working memory; and perseverative responding (Jenkins et al., 2000; Koso & Hansen, 2006; Vasterling et al., 1998; Vasterling et al., 2002). A recent meta-analysis including 1080 subjects from 18 studies (Polak, Witteveen, Reitsma, & Olff, 2012) found that PTSD subjects had impaired performance compared to trauma exposed and normal controls in measures of executive functioning (e.g., Trail Making test B and Wisconsin Card Sorting Test-perseverative errors and categories completed) and Digit Span backwards.
(measuring working memory). Overall these results suggest that PTSD is related to deficit in verbal memory and executive functioning.

**Causes of Cognitive Deficit in PTSD**

Two hypotheses have been proposed regarding the etiology of the neuro-cognitive deficit in PTSD. One hypothesis proposes that PTSD causes cognitive deficit due to the negative effects of extreme stress on the brain. Evidence for this hypothesis comes from animal and human studies (e.g., Arnsten & Goldman-Rakic, 1998; Birnbaum, Gobeske, Auerbach, Taylor, & Arnsten, 1999; Ohl, Michaelis, Vollmann-Honsdorf, Kirschbaum, & Fuchs, 2000; Shansky & Morrison, 2009) which have demonstrated that extreme stress leads to damage in areas of the brain most vulnerable to the effects of stress (e.g., hippocampus, frontal cortex. A smaller hippocampus as well as functional and structural abnormalities have been noted in the prefrontal cortex of PTSD patients (Bremner et al., 1995; Bremner et al., 1997; Shin et al., 2004). Neuropsychological research has corroborated these findings by demonstrating PTSD related deficit in cognitive functions dependent on hippocampus and frontal cortex.

An opposing hypothesis proposes that neuropsychological functioning is a risk/resilience factor rather than an acquired sign of PTSD. Support for this hypothesis are studies that have found that lower intellectual functioning of veterans assessed prior to trauma exposure predicted subsequent development of PTSD (Brooks, 1976; Kulka et al., 1990; Marx et al., 2009; Vasterling, 2009). In addition, a study with a community sample exposed to natural disaster found that the development of the PTSD symptoms of re-experiencing and arousal was inversely associated with word recall, digit span, coding speed, and verbal intelligence, as assessed three years before the trauma exposure (Parslow & Jorm, 2007). However, the strongest evidence for this hypothesis comes from a monozygotic twin study
conducted by Gilbertson et al. (2001) who found that the twin who had PTSD had the same pattern of cognitive profile as their co-twin with no PTSD and no exposure to trauma. The exposed co-twins of PTSD subjects also performed more poorly than unexposed co-twins of veterans with no PTSD. Furthermore, several studies have found lower estimated pre-morbid cognitive functioning in people with PTSD (McNally & Shin, 1995; Vasterling et al., 2002; Vasterling, Brailey, Constans, & Sutker, 1998).

Thus, there is evidence that cognitive deficit may be a risk factor and a consequence of PTSD. However, the mechanisms by which this occurs are currently under study. A hypothesis put forward by Vasterling and Brewin (2005) proposed that neuropsychological functioning may mediate the experiencing of trauma. Thus, better cognitive functioning would enable people to better attain resources, return to work/study, create social support and be better enabled to form narratives to assimilate the traumatic memories. On the other hand, lower cognitive functioning increases the chances of developing PTSD via ineffective coping, and once PTSD develops it leads to further neuro-cognitive deficit which in turn maintain and exacerbate PTSD. However, this hypothesis is still to receive empirical support.

The Role of Co-morbidity in Neuropsychological Outcomes of PTSD

Anywhere between of 28% and 84% of people with PTSD also suffer depression (Keane & Kaloupek, 1997). Depression is associated with neuropsychological deficit in executive functioning (Grant, Thase, & Sweeney, 2001; Ottowitz, Dougherty, & Savage, 2002; Paelecke-Habermann, Pohl, & Leplow, 2005; Trichard et al., 1995; Veiel, 1997) and memory difficulties (Burt, Zembar, & Niederehe, 1995; Frasch et al., 2000; Ilsley, Moffoot, & O'Carroll, 1995; Marcos, 1994; O'Brien, Sahakian, & Checkley, 1993), which makes it difficult to ascertain whether the observed cognitive deficit is due to PTSD or co-morbid depression. Furthermore, despite much research attention devoted to PTSD related cognitive functioning, there is evidence that cognitive deficit is not unique to PTSD, but rather a part of
many other psychiatric disorders. For instance, a study (Gil et al., 1990) comparing people with PTSD with a sample of people with other psychiatric disorders (e.g., Major Depressive Disorder, Generalised Anxiety Disorder, Obsessive-Compulsive Disorder, Phobias) and normal subjects found that while the PTSD group performed lower than normal subjects it was no different from the sample with other psychiatric disorders.

Co-morbid Alcohol Abuse

Alcohol abuse is also frequently found in samples of PTSD, particularly in veteran samples who are more likely to abuse alcohol for long periods of time (Keane & Kaloupe, 1997). The effects of alcohol abuse on cognitive functioning have been well documented (Fama, Pfefferbaum, & Sullivan, 2004; Peterson, Rothfleisch, Zelazo, & Pihl, 1990; Pitel et al., 2007), however, there is evidence that the pattern of deficit in PTSD is different to that of alcohol. For example, two well-controlled studies demonstrated that while alcohol abuse was associated with visual memory deficit, PTSD was associated with deficit in attention, working memory and processing speed (Jenkins, Langlais, Delis, & Cohen, 1998; Samuelson et al., 2006).

Co-morbid Traumatic Brain Injury

The confounding effects of head injuries have received little attention despite the co-morbidity rates of up to 43% (Kennedy et al., 2007; Schneiderman, Braver, & Kang, 2008). Both disorders are associated with impaired memory, inability to concentrate, inappropriate modulation of anger and other emotions (Stein & McAllister, 2009) which makes it difficult to differentiate between the two. PTSD studies have not consistently controlled for the effects of TBI in the cognitive outcome of PTSD. A meta-analytic study (Brewin et al., 2007) found that studies that did not report exclusion of head injury subjects had smaller effects size than studies that excluded head injury subjects. This finding goes against the assumption that differences between PTSD and non PTSD subjects are exaggerated by possible presence of
Neuropsychological Sequelae

brain injury in PTSD subjects. The interpretation of this finding is limited by the fact that studies that have not excluded people with TBI, do not report specifically whether anybody in their samples suffered brain injury.

Summary and Conclusions

In summary, PTSD may adversely affect neuro-cognitive functioning particularly verbal learning and memory as well as executive functioning. Nevertheless, methodological difficulties have decreased the confidence in concluding that cognitive impairment is due to PTSD and not to other co-morbid conditions. While it is relatively clear that PTSD has a differential effect in cognitive functioning to that of alcohol, the same cannot be said about other psychiatric disorders and traumatic brain injury which frequently co-occurs in PTSD. Below, the effects of TBI, and in particular mild TBI (MTBI), are reviewed.

Traumatic Brain Injury

Definition

Traumatic brain injury (TBI) has been defined as an insult to the brain caused by an external force that may produce a diminished or altered state of consciousness which results in impaired cognitive abilities (Lezak, Howieson, & Loring, 2004). TBI is classified as open and closed. Open injuries occur as a result of an object fracturing the skull and penetrating the brain and these injuries are associated with localised damage and often lead to circumscribed neurological deficit (Lezak et al., 2004; Snyder, Nussbaum, & Robins, 2006). Closed TBI occurs more commonly and results from a blow to the head with a relatively blunt object or from the impact of the head with a stationary object, which results in cerebral contusion and/or diffuse axonal injuries (Levin & Grossman, 1982; Richardson, 2002). Cerebral contusion occurs when the brain impacts against the wall of the skull leading to damage to the orbital surfaces of frontal lobes, lateral and inferior surfaces of the temporal
lobes, temporal poles, and the cortex above and below the Sylvian fissures (Richardson, 2002). Diffuse axonal injuries occur as a result of a rotational acceleration movement between different parts of the brain which causes widespread damage to the nerve fibres in the white matter (Lezak et al., 2004; Richardson, 2002).

TBI may result from two processes: primary injury, which occurs due to the damage at the time of injury, and secondary injury, which results from complications such as raised intracranial pressure, intracranial haematoma, oedema, infection, and hypoxia (Richardson, 2002).

Classification of TBI Severity

A number of methods have been used in clinical settings and research to assess the severity of TBI. The Glasgow Coma Scale (GCS, Teasdale, Graham, & Jennett, 1974) is applied immediately after the injury and measures changes in consciousness. At a later stage of injury, the duration of altered consciousness is a marker of severity and is measured by Post-Traumatic Amnesia (PTA) or loss of consciousness (LOC) (Teasdale, 1995). Table 1 depicts the classification based on GCS and PTA.

Table 1

<table>
<thead>
<tr>
<th>Measure</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Glasgow Coma Scale</td>
<td>13-15</td>
<td>9-12</td>
<td>&lt;8</td>
</tr>
<tr>
<td>Post Traumatic Amnesia</td>
<td>5-60 min</td>
<td>1-24 hrs</td>
<td>1-7 days</td>
</tr>
</tbody>
</table>

Table adapted from Management of Concussion/mTBI Working Group (2009)

The reliability of the GCS can be compromised in cases when scores partially reflect the effects of factors other than injury (e.g., effects of drugs and alcohol present at the time of
injury, and effects of analgesics and sedatives) (Sherer, Struchen, Yablon, Wang, & Nick, 2008; Teasdale, 1995). In addition, the use of the scale soon after the injury does not take into account the development of secondary complications which may lead to the person being misclassified (Cohen & Gudeman, 1996; Sherer et al., 2008). While research suggests that PTA is more accurate than the GCS (Van der Naalt, Van Zomeren, Sluiter, & Minderhoud, 1999), its weakness lies in its failure to reliably discriminate people with moderate injuries from those with severe injuries (Fortuny, Briggs, Newcombe, Ratcliff, & Thomas, 1980).

Outcomes Following MTBI

MTBI is the most common of physical injuries to the head, accounting for 75% of all brain injuries (Langlois, Rutland-Brown, & Wald, 2006). The manifestation of MTBI consists of a cluster of symptoms named “concussion symptoms”, which include headache, dizziness, depression, anxiety, irritability, memory and attention problems that cannot be easily detected by neuropsychological measures or brain imaging (Dikmen & Levin, 1993). Meta-analytic studies have repeatedly demonstrated that while in the acute stages (within three months post-injury), there is evidence of a slight deficit in attention, processing speed and memory, these difficulties diminish by three months and sometimes even earlier (Binder, Rohling, & Larrabee, 1997; Frencham, Fox, & Maybery, 2005; Pertab, James, & Bigler, 2009; Rohling et al., 2011). However, a small portion of people with MTBI display persistent difficulties which have been named “post-concussion syndrome” (PCS) (Belanger, Curtiss, Demery, Lebowitz, & Vanderploeg, 2005) and will be evaluated in the following section.

Persistent Post-Concussion Symptoms Following MTBI

Around 10 to 20% of people who sustain MTBI experience post-concussion syndrome (PCS) months or years after the injury (Ponsford et al., 2012; Ryan & Warden, 2003). There is much controversy in the literature as to whether PCS is due to neuro-
pathological mechanisms related to the injury, pre and post injury psychological factors, or litigation (King, 2003). Linking PCS with MTBI has been challenging mainly due to negative neuropsychological and neurological findings (King, 2003), and the nonspecific nature of PCS symptoms which can characterise many other physical and psychological disorders (Meares et al., 2008; Ponsford et al., 2012), and are frequently reported by the general population (Zakzanis & Yeung, 2011).

Some have suggested that PCS is related to neurological dysfunction beneath the detection threshold of routine diagnostic procedures such as computed tomography (CT), magnetic resonance imaging (MRI), and electroencephalography (EEG) (Hayes & Dixon, 1994). Supporting this hypothesis is the evidence from animal and human post-mortem studies (Ponsford et al., 2000a) as well as studies using high resolution structural MRI which found that MTBI can cause damage to neuro-filaments (traumatic diffuse axonal injury) (McAllister, Sparling, Flashman, & Saykin, 2001; McCrea, 2007; Umile, Sandel, Alavi, Terry, & Plotkin, 2002). Further, reassessing meta-analysis of neuropsychological deficit following MTBI, Pertab et al. (2009) found significant heterogeneity between the outcome of neuropsychological measures, and identified a small group who displayed persistent difficulties but when their scores were grouped together in meta-analysis, lost their significance.

There is evidence that multiple concussions are a risk factor for prolonged cognitive deficit (Effgen, Gill, & III, 2012; Matser, Kessels, Lezak, & Troost, 2001; Ponsford et al., 2000b; Slemmer, Matser, De Zeeuw, & Weber, 2002), although other studies have failed to find such an association (Collie, McCrory, & Makdissi, 2006; Iverson, Brooks, Lovell, & Collins, 2006). There are suggestions that the interval between injuries and the severity of insult may moderate this relationship (Slemmer & Weber, 2005). Other risk factors reported are female gender (Farace & Alves, 2000), older age (Mosenthal et al., 2004), alcohol use
(Corrigan, 1995), prior neurological conditions (Ponsford et al., 2000b), and complicated MTBI (Borgaro, Prigatano, Kwasnica, & Rexer, 2003; Kashluba, Hanks, Casey, & Millis, 2008; Lange, Iverson, & Franzen, 2009).

Non-injury related factors identified as contributing to PCS include involvement in compensation issues/litigation (Belanger, Curtiss, Demery, Lebowitz, & Vanderploeg, 2005; Binder, 1997; Carroll et al., 2004; Lange, Iverson, Brooks, & Rennison, 2010; Lebowitz & Vanderploeg, 2005), co-morbid psychiatric disorders (Meares et al., 2008; Panayiotou, Jackson, & Crowe, 2010), pre-morbid personality abnormalities (e.g., somatisation, dependent, grandiose, borderline and obsessive-overachiever tendencies) (Greiffenstein & Baker, 2001; Kay, Newman, Cavallo, Ezrachi, & Resnick, 1992), and coping style (e.g., more positive appraisal of pre-morbid functioning than average people, lower expectation of recovery, attribution of non-specific symptoms to injury) (Gunstad & Suhr, 2001, 2002; Iverson, Lange, Brooks, & Lynn Ashton Rennison, 2009). These findings together have led to the “diathesis stress paradigm” which emphasises that while neurobiological mechanisms are responsible for the initiation of PCS, psychological factors are responsible for the persistence of PCS (Lishman, 1988).

In sum, the literature indicates that not all people fully recover following MTBI and the literature linking PCS with MTBI is equivocal. While much evidence reports possible non-organic origins of PCS, the current literature does not rule out the influence of a neurological basis of PCS.

**Outcomes of Moderate to Severe TBI**

Moderate and severe brain injury lead to more enduring cognitive deficit (Dikmen, Machamer, Temkin, & McLean, 1990; Mandleberg & Brooks, 1975; Millis et al., 2001; Ruttan, Martin, Liu, Colella, & Green, 2008; Zec et al., 2001), although a small number of people recover completely (Dikmen et al., 1990; Millis et al., 2001). As a whole, research
indicates that there is variability in the profile of cognitive impairment, the rate of recovery and the level of recovery (Mills et al., 2001). A number of factors contribute to this variability including increased injury severity (e.g., greater PTA, LOC) (Dikmen, Machamer, Powell, & Temkin, 2003; Rohling, Meyers, & Millis, 2003), presence of diffuse axonal injury (Felmingham, Baguley, & Green, 2004; Ramona O Hopkins, Tate, & Bigler, 2005), secondary complications (e.g., post-traumatic epilepsy) (Baguley et al., 2007; Mazzini et al., 2003), and individual factors (older age, prior neurological disorder, psychiatric co-morbidity, drug and alcohol use) (Dikmen et al., 2003; Millis et al., 2001).

The literature on moderate-severe TBI is associated with limitations such as: lack of agreement in definition of severity; inconsistent definition of cognitive domains and measures used; use of tests with poor validity and reliability; and use of tests with different normative data.

Despite variability and the limitations of the studies, a large literature indicates impairment in the following domains:

*Processing speed* as measured by Wechsler Adult Intelligence Scale (WAIS) has been found as the most sensitive measure to the effects of TBI (Axelrod, Fichtenberg, Liethen, Czarnota, & Stucky, 2001; Ferraro, 1996; Fisher, Ledbetter, Cohen, Marmor, & Tulsky, 2000; Madigan, DeLuca, Diamond, Tramontano, & Averill, 2000; Martin, Donders, & Thompson, 2000).

*Attentional dysfunction* has been found impaired particularly when measured by complex tasks (e.g., symbol search vs. digit span) (Mandleberg & Brooks, 1975; Shum, McFarland, & Bain, 1990). A meta-analysis (Mathias & Wheaton, 2007) revealed that people with moderate to severe TBI perform at least one standard deviation lower than controls in tasks that measures different aspects of attention (e.g., ability to orient attention, attention span, selective or focused attention, sustained attention, divided attention and supervisory
attention). A subsequent meat-analysis (Ruttan et al., 2008) indicated that deficits in attention are above and beyond the effects of impaired processing speed.

*Working memory (WM)* is involved in complex cognitive processes and involves both temporary storage and manipulation of information (Baddeley & Hitch, 1974). Functional MRI (fMRI) studies have reported that brain structures mediating working memory (e.g., dorsolateral prefrontal cortex) are frequently affected by TBI (Kasahara et al., 2011) and people with TBI have problems in the activation of WM (McAllister, Flashman, McDonald, & Saykin, 2006) and differential brain activation during performance of WM relative to uninjured people (Perlstein et al., 2004). Neuropsychological studies have found impairment on measures tapping into the WM central executive (Azouvi, Jokic, Van Der Linden, Marlier, & Bussel, 1996; Brooks, 1976; Curtiss, Vanderploeg, Spencer, & Salazar, 2001; McDowell, Whyte, & D'Esposito, 1997), with relatively spared slaves systems of WM (Azouvi et al., 1996; Perlstein et al., 2004; Vallat-Azouvi et al., 2007).

*Memory* is one of the most frequently affected cognitive domains after TBI (Vakil, 2005) and the most common complaint from patients with TBI (Arcia & Gualtieri, 1993). The information processing model of memory (Craik & Lockhart, 1972) has been widely used in TBI memory research. This model emphasises the processes involved in learning and memory and proposes three levels of information processing: encoding, consolidation, and retrieval. Encoding is a process which integrates sensory-perceptual, attention and cognitive mechanisms to acquire new information; consolidation is a process by which memory traces are maintained; and retrieval refers to the process of accessing and getting information out of the storage via recall or recognition (Craik & Lockhart, 1972).

Learning and memory have typically been assessed with tasks that present repeated trials of information such as the Rey Auditory Verbal Learning Test, California Verbal Learning Test, and Wechsler Memory Scale (Millis & Ricker, 1994). Numerous studies have
found that even beyond one year post-injury, TBI patients have significantly lower learning rate than controls in both verbal (Blachstein, Vakil, & Hoofien, 1993; Geffen, Butterworth, Forrester, & Geffen, 1994; Haut & Shutty, 1992; Novack, Kofoed, & Crossno, 1995; Zec et al., 2001) and visual (Brooks, 1976; Fisher et al., 2000; Hannay, Levin, & Grossman, 1979; Reid & Kelly, 1993; Shum, Harris, & O'Gorman, 2000).

Studies that have evaluated memory processes affected by TBI have yielded varying results. While some studies have found evidence of encoding problems due to disorganised, inefficient learning, and failure to use semantic clustering (Blachstein et al., 1993; Paniak, Shore, & Rourke, 1989), others have identified problems in consolidation as evidenced by fast forgetting rate, impaired recognition, and deficit in delayed memory in the absence of differences in initial acquisition (Kersel, Marsh, Havill, & Sleigh, 2001; Lezak, 1979; Lezak et al., 2004; Vanderploeg, Crowell, & Curtiss, 2001). Studies that have found improved performance in cued recall relative to free recall suggest the deficit is in retrieval (Baum, Vanderploeg, & Curtiss, 1996; Cooke & Kausler, 1995; Duchnick, Vanderploeg, & Curtiss, 2002; Nolin, 2006; Spencer, Vanderploeg, Curtiss, & Larrain, 1998).

It has been suggested that these results reflect the variability in the TBI population, with subgroups who have primarily encoding problems and others with consolidation and less frequently retrieval problems (Wright & Schmitter-Edgecombe, 2011; Wright, Schmitter-Edgecombe, & Woo, 2010). Given the widespread neural involvement in memory, the variability in the nature of memory problems following TBI is expected (Squire, 2004). There is some initial evidence that the site of pathology may predict memory problems (Crosson et al., 1999; Donders & Nienhuis, 2007). Further, studies have also demonstrated subgroups of people with TBI, each experiencing memory difficulties with theoretically driven memory processes (Millis & Ricker, 1994). Overall, the literature indicates variability in the pattern of
memory deficit in TBI which underscores the need for comprehensive assessment of memory processes.

*Executive functioning* refers to the ability to engage in independent, purposive, and goal-directed behaviours (Lezak et al., 2004). Impaired attention, poor response inhibition, distractibility, reduced self-generated behaviours, and difficulty benefiting from prior experience have all been associated with impaired executive functioning (Busch, McBride, Curtiss, & Vanderploeg, 2005). Impaired executive functioning in TBI results from injuries in frontal lobes and associated areas. Those with TBI have been found impaired in tasks of mental flexibility, ability to maintain a cognitive set, and divided attention (Brooks, Fos, Greve, & Hammond, 1999; Ferland, Ramsay, Engeland, & O'Hara, 1998). Deficits in reasoning, concept formation, learning from errors, and rule breaking errors have also been observed (Fisher et al., 2000; Hart, Whyte, Kim, & Vaccaro, 2005; Little, Templer, Persel, & Ashley, 1996; Mangeot, Armstrong, Colvin, Yeates, & Taylor, 2002).

*Visio-spatial* deficit is also a frequent sequelae of TBI which, despite recovery in a significant portion of TBI patients at one year post injury, can be an enduring deficit for some (Himanen et al., 2006; Mandleberg & Brooks, 1975).

Studies have reported that *motor functioning* is significantly slower than normal controls after moderate to severe TBI (Ariza et al., 2004; Dikmen et al., 1990; Haaland, Temkin, Randahl, & Dikmen, 1994; Schmitter-Edgecombe, Marks, Fahy, & Long, 1992; Swaine & Sullivan, 1996), although slow processing speed may contribute to impaired motor skills (Lezak et al., 2004). A comprehensive review concluded that motor weakness after TBI is of low incidence long recovery time, and has better outcome than cognitive and behaviour problems following TBI (Jang, 2009).

In summary, literature indicates that MTBI is associated with good outcomes for most people, although a significant proportion continues to experience difficulties beyond six
months and this review outlined some of the controversies about the origin of persistent symptoms following MTBI. This review indicated that moderate to severe TBI leads to longer term cognitive deficit that mainly affects processing speed, learning and memory, and executive functioning.

Co-Morbid TBI and PTSD

The Nature of Co-occurrence

The co-existence of MTBI and PTSD has been a subject of much debate (Bryant, Marosszeky, Crooks, Baguley, & Gurka, 2001). There have been suggestions that TBI is a protective factor in the development of PTSD due to amnesia that prevents the development of memories necessary for PTSD (Mayou, Bryant, & Duthie, 1993; Sbordone & Liter, 1995). In the case of moderate to severe TBI, there is evidence to support this hypothesis (Bryant et al., 2009; Koenigs et al., 2007). However, MTBI was found to be a risk factor for the development of PTSD in a study of 1167 survivors of traumatic injury (Bryant et al., 2009). The same study found that longer post traumatic amnesia was associated with less severe re-experiencing symptoms of PTSD, indicating that longer post-traumatic amnesia may protect against development of re-experiencing symptoms of PTSD, which provided support to the hypothesis that amnesia is a protective factor in the development of PTSD.

Despite the controversy, much research now supports the idea that PTSD can develop following MTBI (Bryant, 2008; Bryant et al., 2001; Elzinga & Bremner, 2002; Hoge et al., 2008) and studies have indicated that co-morbid MTBI and PTSD lead to worse outcomes than either disorder alone. For example, veterans with mild traumatic brain injury were more likely to have PTSD when compared to uninjured veterans and veterans with injuries to other parts of the body (Hoge et al., 2008; Lew et al., 2009; Terrio et al., 2009). Furthermore, Vietnamese ex-political detainees with traumatic head injury (THI) showed more severe
PTSD symptoms than PTSD diagnosed participants without THI and the same study demonstrated that THI was the best predictor of persistent depression amongst ex-detainees (Mollica et al., 2009). Based on the cognitive neuroscience framework, some authors have suggested that MTBI increases vulnerability to PTSD due to the disruption it causes to the cognitive resources (e.g., attention, memory, problem solving) that would otherwise be used to manage the aftermath of emotional trauma (Stein & McAllister, 2009; Vasterling, Verfaellie, & Sullivan, 2009a).

On the other hand, recent studies with individuals who have persistent symptoms following MTBI suggest that presence of PTSD leads to both increased severity of MTBI symptoms and the duration of recovery (Brenner, Vanderploeg, & Terrio, 2009). This "mutually exacerbating effect" (Stein & McAllister, 2009, p. 4) highlights the need for the identification of the presence of co-morbid MTBI and PTSD, particularly in those that are chronic users of mental health services.

Assessment Issues

The assessment of TBI and co-occurring PTSD is complicated due to overlapping symptoms. Both disorders are associated with impaired memory, inability to concentrate, and inappropriate modulation of anger and other emotions (Brenner et al., 2009). Therefore, TBI consistent symptoms cannot be used to diagnose or rule out TBI. For example, MTBI and PTSD were found to independently be associated with endorsement of three or more post-concussive symptoms in US soldiers (Schneiderman et al., 2008). Another study found that somatic symptoms (e.g., headache, dizziness) were more frequently endorsed by US soldiers with PTSD than those without (Hoge, Terhakopian, Castro, Messer, & Engel, 2007). Furthermore, in most cases PTSD is co-morbid with mild TBI which usually is not detected in neuro-imaging technology, therefore can only be diagnosed through structured clinical interview (Corrigan & Bogner, 2007). Identifying the markers of TBI (e.g., alteration of
Introduction

consciousness, post-traumatic amnesia) through historical self reports is challenging because alteration of consciousness and amnesia in MTBI is usually brief which makes it difficult to differentiate from the alteration of awareness and amnesia that people experience at the time of intense fear (Brenner et al., 2009, Bryant, 2008).

Neuropsychological Outcome of Co-Morbid TBI and PTSD

Whether co-morbid TBI and PTSD lead to cognitive deficit over above their individual effects is currently unclear (Gordon, Fitzpatrick, & Hilsabeck, 2011). Several studies have failed to find any difference between co-morbid TBI and PTSD and PTSD alone. For example, a study with a large veteran sample found no between group difference in measures of processing speed, inhibition, abstract concept formation, set shifting and maintenance, immediate memory, delayed recall, visual search, tracking, sustained attention, and working memory (Brenner et al., 2010). Lack of significant differences between groups (PTSD vs. PTSD+TBI) in measures of processing speed, executive functioning, and memory were replicated by another study of veterans (Gordon et al., 2011). Furthermore, a more recent study with veterans also found no between-group difference in general intellectual functioning, executive functioning, attention, processing speed, visuo-constructional abilities, verbal memory, and visual memory (Soble, Spanierman, & Fitzgerald Smith, 2013).

Two studies however have reported significant results. Brenner et al. (2010) found that compared to veterans with only PTSD, veterans with TBI+PSTD had lower scores in Stroop Word Reading. Campbell et al. (2009), in a study with three groups of participants: TBI+PTSD, TBI only, and PTSD only, found somewhat different results – with Stroop Color Reading and Color Word deficits associated more with PTSD, while TBI+PTSD was associated more with lower verbal processing speed than TBI or PTSD alone. However, when this study excluded 19% of the sample for insufficient effort, none of the results were significant.
Thus, no conclusive evidence can be drawn from this small number of studies with veteran samples where insufficient effort and high co-morbidity are frequently found (Horner & Hamner, 2002). Despite the limitations, it seems that there is more evidence that, at least for a veteran population, MTBI+PTSD does lead to worse cognitive outcome than PTSD alone. Because most of these studies are done in the post-acute stage of MTBI, it is likely that the results are due to the recovery of MTBI which according to much evidence for most people occurs within three months post injury (Binder et al., 1997; Frencham et al., 2005; Pertab et al., 2009; Rohling et al., 2011).

**Summary**

In sum, despite much research linking PTSD and TBI to cognitive deficit, there is currently no neuropsychological profile for either condition. Large variability in research methodology and variability in individual outcome following PTSD, TBI or both makes it difficult to draw firm conclusions, and use this information to aid differential diagnosis or to predict outcome. Particularly, the paucity in research studies of co-occurring TBI and PTSD which has yielded mixed results highlights the need for further research in this area. Furthermore, most research in PTSD and co-morbid TBI and PTSD has been conducted with veterans making it uncertain of whether those findings can be generalised to other populations.

These gaps in literature and lack of representation of refugee populations motivated the current research which aimed to explore the consequences of co-morbid TBI and PTSD in refugees who have not been represented in this literature. Refugees are often exposed to multiple traumas, where brain injury is usually one amongst many other traumas (Jacobs & Iacopino, 2001), which means that PTSD can precede and/or follow TBI. In such situations, the notion of TBI and PTSD having a “mutually exacerbating effect” may be more relevant.

In order to further develop the rational for the present study, the chapter that follows
Introduction

will overview the literature on TBI and PTSD in refugees.
Chapter 2: Neuropsychological Sequelae in Refugee Population

Previous reviews provided evidence that both PTSD and TBI are associated with cognitive impairment. The literature reviewed however has not included the refugee population. The aim of this chapter therefore is to first provide an overview of the risk factors for TBI and PTSD in this population and second to evaluate the neuropsychological research with this population. This review will uncover the gaps in this literature on which the rational for the current thesis is based.

The first part of this chapter will review the prevalence and risk factors of TBI in this population followed by a closer evaluation of the types of injuries that are likely to be experienced by refugees. This will be followed by an overview of existing evidence about the cognitive sequelae of TBI in refugees. The second part will overview the current research in the prevalence of PTSD in refugees, risk factors and neuropsychological findings with this population.

Traumatic Brain Injuries in Refugees

While there has been little attention paid to the neurological and neuropsychological consequences of war and torture in refugees, there is much evidence pointing to the presence of organic brain disorders in this population (Moreno & Grodin, 2002; Quiroga & Jaranson, 2005; Weinstein et al., 2001). Most refugees have experienced war trauma and around 60% have experienced torture (Quiroga & Jaranson, 2005). Torture is a risk factor for brain injury where blows and kicks to the head, electrocution, and asphyxiation are the main forms of torture, second only to beating to the body (Moreno & Grodin, 2002). A recent study of 488 treatment seeking tortured refugees in New York reported that 69% reported sustaining blows
and kicks to the head, and 55% reported loss of consciousness (LOC) during the injury (Keatley, Ashman, Im, & Rasmussen, 2013a). Similar rates of head injury were reported by Croatian prisoners of war (Begovac, 1993), torture victims from Gaza, Egypt, Mexico, Honduras and South Africa (McColl et al., 2010), and 73% of tortured victims from various countries (Rasmussen, 1990).

Generally, refugees with or without a history of torture report high levels of head injury. For example, Mollica, Henderson, and Tor (2002) found that amongst Cambodian refugees in Thailand, traumatic head injury (THI) was one of the most frequent sequelae of war and torture. Wars in Afghanistan and Iraq have increased the risk of head injuries due to roadside bombings, which has been the main weapon of war (Vasterling et al., 2009b) and 36% of Afghan refugees report injuries to the head and neck due to explosions (Nasir, Hyder, & Shahbaz, 2004).

Thus, the limited literature indicates high prevalence of head injuries (with many of these possibly resulting in brain injury) particularly in tortured refugees. The following sections will review the forms of injuries reported by refugees and the possible outcome related to these types of injuries. This will be followed by a review of the few studies that have evaluated consequences of head injuries in refugees.

**Forms of Head Injuries in Refugees**

Based on the research on the forms of torture and refugee experience, the injuries sustained by refugees are likely to be: a) blunt trauma due to beatings to the head and concussive waves of explosions, b) penetrating injuries due to gunshot wounds and stab wounds, c) brain injuries due to electrocution and chemical burns, d) hypoxia due to hanging, dry asphyxiation (face covered with plastic bag and/or forced to inhale chemicals), and wet asphyxiation (face submerged into water) (Hougen, 1988; Moreno & Grodin, 2002; Morentin, Idoyaga, Callado, & Meana, 1995; Rasmussen, 1990). In addition, refugees in
general and torture survivors in particular frequently report starvation which can also impact brain functioning (Mateen, 2010; Rasmussen, 1990).

**Blunt Trauma and Penetrating Injuries**

Blunt trauma (closed head injury) particularly caused by beatings are the most frequent forms of torture (Jacobs & Iacopino, 2001; Rasmussen, 1990). In closed injuries, the skull usually remains intact, however, depending on the severity of the impact, the injury can result in neuro-pathological effects due to the **primary injury** (bruising, brain rebounds and hits the skull which leads to contusion in prefrontal and temporal lobes and less frequently in the inferior part of the brain), and **secondary injury** (e.g., intracranial bleeding, edema, diffuse axonal injury, disruption of vasculature, metabolic changes, ischemia, post-traumatic seizures, hypoxia, and obstructive hydrocephalus) (Snyder et al., 2006).

Depending on the severity of trauma, closed head injury can be mild, moderate or severe (Management of Concussion/mTBI Working Group, 2009). As reviewed earlier, moderate and severe injuries are associated with long term cognitive deficit (Millis et al., 2001; Zec et al., 2001). On the other hand, MTBI is associated with a good outcome for the majority of people (Binder et al., 1997; Frencham et al., 2005; Pertab et al., 2009; Rohling et al., 2011), although a subgroup of MTBI patients experience long term difficulties, and some of the reasons for these symptoms were outlined earlier. Considering that refugees typically experience repeated head injuries and numerous other traumas, it is likely that even mild injuries can lead to more complications than are usually reported in a population with one trauma event (Mollica et al., 2009).

Penetrating injuries refer to trauma in which the skull is penetrated by a foreign body and are likely to produce more severe forms of TBI (Snyder et al., 2006). Penetrating trauma is less common in refugees and is usually caused by gunshot or stabbing (Moreno & Grodin, 2002). Gunshot wounds can lead to massive destruction leaving the survivor with multiple...
problems such as motor and sensory deficits as well as cognitive impairments (Arabi et al., 2001). Further, these injuries can be further complicated due to the secondary effects mentioned above (e.g., damage due to surgical procedure, ischemia, edema, infection, and posttraumatic epilepsy) (Arabi et al., 2001; Snyder et al., 2006).

**Asphyxiation**

Studies indicate that depending on the sample, 13-63% of tortured refugees have experienced asphyxiation during torture (Hougen, 1988; Morentin et al., 1995; Perera, 2007), with one study reporting that 2-8% of torture survivors experience epilepsy due to asphyxiation or electrocution (Rasmussen, 1990). Asphyxiation, regardless of the causes (e.g., hanging or exposure to chemicals), leads to the brain being deprived of oxygen and if this is for more than five minutes has the potential to cause permanent brain damage (Snyder et al., 2006).

Although there has been no study with asphyxiated refugees, numerous studies and case reports of people who have suffered hypoxia due to cardiac arrest, drowning or chemical poisoning have revealed long term cognitive deficits. The brain regions found most vulnerable to oxygen deprivation are the watershed areas, basal ganglia and hippocampi (Chalela, Wolf, Maldjian, & Kasner, 2001; Di Paola et al., 2008; Hopkins, Myers, Shohamy, Grossman, & Gluck, 2004), although general brain atrophy has been also reported (Hopkins, Gale, & Weaver, 2006). The most consistent neuropsychological finding is memory deficit (Caine & Watson, 2000), which rarely occurs in absence of other cognitive difficulties such as personality changes, visual-spatial deficit (Caine & Watson, 2000; Findley et al., 1986), and general cognitive deficit (Garcia-Molina et al., 2006; Wilson, 1996; Wilson, Harpur, Watson, & Morrow, 2003).
Electrical Injuries

Electrocution is a common form of torture. In a study of 410 Tibetan refugees in India who had experienced torture, 89% had experienced electrical shock (Mills et al., 2005). Anywhere from 8% to over 50% of torture survivors reported electrocution during torture in other studies with mixed samples of refugees (Moisander & Edston, 2003; Morentin et al., 1995; Perera, 2007).

Electrical injury (EI) results from the contact with an electrical source, and its severity depends on: the type and magnitude of current; the resistance of the body at the entry point; the current pathway; and the duration of current flow (Duff & McCaffrey, 2001). The consequences of EI can range from fatal to relatively mild burns and a damaged nervous system is particularly likely due to its low resistance pathways that attract the electrical current regardless of entry point (Duff & McCaffrey, 2001; Pliskin et al., 1994).

While there is no literature that has evaluated the cognitive effects of electrocution during torture, there is a body of literature about the cognitive outcome of EI as a result of accidental contact with manmade electrical source or due to lightning.

Studies have found that EIs are associated with a number of neuropsychological deficits including memory and learning, attention, processing speed, motor functioning, and decline in the overall intelligence (Barrash, Kealey, & Janus, 1996; Barth, Brelsford, Francis, & McArule, 1997; Hopewell, 1983; Janus & Barrash, 1996; Martin, Salvatore, & Johnstone, 2003; Pliskin et al., 2006; Pliskin et al., 1998).

Some have suggested that the neuropsychological sequelae after electrical shock resemble those of closed head injury (Barrash et al., 1996; Daniel, 1985; Duff & McCaffrey, 2001). Furthermore, several longitudinal studies have found evidence of progressive deterioration in the cognitive functioning of people with a history of EI (Daniel, 1985; Hooshmand, Radfar, & Beckner, 1989; Martin et al., 2003; Pliskin et al., 1998). In addition,
studies have found high levels of psychopathology in people with a history of EI, particularly depression, anxiety, and post-traumatic stress disorder, which appear to worsen over time (Kelley, Pliskin, Meyer, & Lee, 2006; Kelley, Tkachenko, Pliskin, Fink, & Lee, 1999; Kelly, Pliskin, Meyer, & Lee, 1994; Mancusi-Ungaro, Tarbox, & Wainwright, 1986; Ramati et al., 2009).

Overall, studies indicate long-term cognitive and emotional difficulties related to EI, although co-morbid psychiatric disorders and litigation may have affected the outcome (Ammar et al., 2006; Ramati et al., 2009). The studies reviewed have been conducted with victims of high voltage electrical injury which may result in different outcomes to electrocution which usually involves repeated electrical injuries which are delivered with devices such as stunt guns, cattle prods, generators, and wires plugged directly to a power outlet (Moreno & Grodin, 2002).

Malnourishment

The literature on the extent of malnourishment in refugees is sparse. However, refugees are at particular risk for prolonged malnourishment due to poverty, war, torture, and insufficient food supplied in refugee camps (Mateen, 2010). Recently, studies of newly arrived refugees in Australia found high rates of nutritional deficiency particularly iron, and vitamin D (Benson & Skull, 2007; Johnston, Smith, & Roydhouse, 2012; Tiong et al., 2006).

It is indicated that prolonged malnutrition leading to loss of body weight is associated with long-term changes in cognitive functioning. Following Danish survivors of World War II (WWII) concentration camps for more than 25 years, Thygesen, Hermann, and Willanger (1970) found that weight loss in excess of 35% of pre-confinement body weight was associated with changes in mental functioning and neurological impairment. Further, prisoners of the Korean war who suffered severe malnourishment performed more poorly than veterans with no history of malnourishment on tasks requiring attention, concentration,
and memory, abstraction and organizing functions (Sutker et al., 1992; Sutker, Galina, West, & Allain, 1990; Sutker, Vasterling, Brailey, & Allain Jr, 1995).

Other evidence of the link between malnourishment and cognitive deficit are the studies with people with anorexia which have repeatedly demonstrated that malnourishment leads to cognitive deficit which is more associated with weight loss than severity of illness (Gillberg, Råstam, Wentz, & Gillberg, 2007; Kingston, Szmukler, Andrewes, Tress, & Desmond, 1996; Lena, Fiocco, & Leyenaar, 2004; Roberts, Tchanturia, Stahl, Southgate, & Treasure, 2007; Szmukler et al., 1992; Tchanturia, Campbell, Morris, & Treasure, 2005).

Cognitive and Emotional Sequelae of Head Injury in Refugees

Numerous studies have reported high rates (up to 64 %) of abnormal neurological findings in refugees in general and torture survivors in particular (Bradley & Tawfiq, 2006; Mateen, 2010; Rasmussen, 1990; Thygesen et al., 1970). However, all of these studies have included headaches as a neurological symptom, although headaches is a non-specific symptom which is frequently found in the general population and people with other medical problems and it can also be a somatic symptom of psychological disorders (Goldfeld, Mollica, Pesavento, & Faraone, 1988).

There is also some limited evidence that head injury is associated with more psychiatric symptoms in a refugee population. For instance, Mollica et al.(2002) reported that Cambodian refugees with self-reported head injuries were more likely to be depressed and reported more severe PTSD symptoms. Keatley et al.(2013b) found a significant association between self-reported head injury and current sleep disturbances.

However, there is a lack of research on the neuro-cognitive sequelae of reported head injuries. In a sample of Vietnamese tortured refugees, Mollica et al. (2009) conducted the first and only neuro-imaging study. The authors compared three samples: survivors of torture with history of traumatic head injury, tortured survivors without head injury, and a
demographically matched control group of non-tortured survivors. Controlling for numerous confounds, THI was significantly related to cortical thinning in prefrontal-temporal regions which was consistent with the findings in other populations reporting blunt trauma to the head. Left prefrontal cortex thinning was significantly associated with more severe depression reported by the THI sample. This study provided some evidence that head injured refugees may be more likely to experience depression which may have an organic basis.

In sum, the research literature indicates that refugees are vulnerable to brain damage sustained through torture or war. Possible causes of organic brain damage in this population are traumatic brain injuries, electrical injuries, asphyxiation, and malnourishment and this chapter reviewed the outcome of these types of injuries in different populations. High rates of neurological symptoms have been reported in the refugee population, although the inclusion of non-specific symptoms in this category (e.g., headache) may have given an inaccurate picture. A study has demonstrate a link between reported head injury and brain atrophy in prefrontal areas of the brain in tortured refugees and other studies have found a link between reported head injury and more severe psychiatric difficulties. However, there is no study from the perspective of neuropsychology that has evaluated the cognitive functioning of refugees with reported head injury.

Neuropsychological Sequelae of PTSD in Refugees

The literature reviewed in Chapter 1, which covered PTSD related neuropsychological functioning, was conducted with various trauma samples, mostly US veterans. Because studies with refugees have used small and heterogeneous samples, meta-analyses have usually excluded these studies, which has left this population unrepresented. The extent to which findings in other populations can generalize to refugees is questionable. Refugees usually experience multiple and more severe traumas (e.g., torture), which is also confounded by ongoing stress related to settlement, forced separations from families, loss of
family members, lack of support systems, and poor access to treatment (Jacobs & Iacopino, 2001). There are suggestions that trauma induced brain abnormalities appear to be more likely in those individuals with chronic and severe PTSD (Crowell et al., 2002; R.J. McNally, 2006; Polak et al., 2012). The section that follows will evaluate the studies conducted with refugee populations.

An exhaustive search of databases (e.g., PsychInfo, Google Scholar, and Medline) resulted in only six studies. These studies are depicted in Table 2. Prior to reviewing the results of these studies, it is important that the methodological shortcomings of this literature are noted.

**Methodological Issues**

A chief methodological shortcoming of this literature is the use of small samples, with highly diverse populations. As depicted in Table 2, all these studies use N<30. Aside from one study, which uses a homogenous sample, all others have samples of participants from at least four different cultural and linguistic backgrounds. Although they use matched controls, the small sample size does not permit an adequate control of cultural and linguistic factors.

All the studies use a population with co-morbid depression, which impairs their ability to assess the direct link between PTSD and cognitive outcome.

None of the studies report whether the measures were translated and adopted to the cultural background of the participants, which makes the validity of the results uncertain. In addition, it is unclear whether they used interpreters and whether they made any adjustment to their assessment procedures.

All these studies assess one or two cognitive functions despite the fact that cognitive processes work in an integrative manner, where deficit in one cognitive process can impact upon the other. For instance, measuring memory without measuring the attention can lead to
difficulties in interpreting the outcome given that memory problems can be due attention difficulties.

**Outcome**

Keeping in mind all the methodological issues overviewed above, the following sections will outline some of the findings in these studies. Studies 1 and 3 (See Table 2) reported that while the PTSD sample performed similarly to controls in a task of attention span (digit span forward), they performed significantly lower in measures of working memory (digit backwards), and verbal learning (CVLT). Further, refugees with PTSD were more likely to exhibit difficulties in encoding and showed deficit in learning strategies (e.g., make more intrusion errors, show deficits in serial clustering, and show increased recency effect). Study 2 (with the same sample) reported that refugees with PTSD showed impairment in executive functioning such as larger number of errors in Wisconsin Card Sorting Test (WCST), and slower automatic processing as measured by the first two trials of Stroop Color-Word Test. These findings are consistent with findings with other populations with PTSD.

Two studies conducted with a sample of Arab and Kurd refugees (See Table 2, study 5 & 6) reported that, relative to the control group, the PTSD sample had impaired performance in measures of nonverbal reasoning (e.g., Raven’s Standard Progressive Matrices, Block Design, Figure Classification, Picture Arrangement), and deficit in measures of immediate visual memory. Another study (see Table 2, Study 4), conducted with a small but homogenous sample, also found that PTSD was related to lower performance in measures of non-verbal reasoning.
Table 2

Summary of Studies with Refugees with PTSD

<table>
<thead>
<tr>
<th>Study</th>
<th>PTSD Group</th>
<th>Control Group</th>
<th>Measures</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Johnsen &amp; Asbjørnsen (2009)</td>
<td>21 refugees from Yugoslavia, Middle East, Chile, Sri Lanka</td>
<td>21 demographically matched refugees. Trauma exposed without PTSD. California Verbal Learning Test (Semantic clustering, serial clustering, learning slope, consistency, intrusion, primacy, recency)</td>
</tr>
<tr>
<td>2</td>
<td>Kanagaratnam &amp; Asbjørnsen (2007)</td>
<td>Same as above</td>
<td>Same as above</td>
</tr>
<tr>
<td>3</td>
<td>Johnsen, Kanagaratnam, &amp; Asbjørnsen (2008)</td>
<td>Same as above</td>
<td>Same as above</td>
</tr>
<tr>
<td>4</td>
<td>Kivling-Bodén &amp; Sundbom (2003)</td>
<td>21 refugees from Yugoslavia with diagnosis of PTSD</td>
<td>12 refugees from Yugoslavia without PTSD</td>
</tr>
<tr>
<td>5 &amp; 6</td>
<td>Emdad, Sondergaard, &amp; Theorell (2005; 2003)</td>
<td>23 Kurd and Arab refugees with PTSD</td>
<td>17 ethnically matched refugees</td>
</tr>
</tbody>
</table>
Summary

Overall, the few studies with refugees have found PTSD related deficit in measures of intellectual functioning, verbal memory, visual memory, visuo-constructional skills, attention, and executive functioning. Lower cognitive functioning of refugees with PTSD replicates similar findings with veterans, however, differently from refugees, studies with veterans have found PTSD to be more related to verbal aspects of intellectual functioning and less to performance based tests (Bremner et al., 2004; Brewin et al., 2007; Vasterling et al., 1998).

Further, the observed deficit in visual short-term memory and visuo-constructional difficulties, are specific to the refugee group and not a common finding among the studies with military and interpersonal trauma. However, this could also be due to more frequent use of nonverbal tests with this population, possibly due to the current assumption that non-verbal tests are less susceptible to cross-cultural and language differences.

Whether the cognitive deficit in refugees is more severe in refugees than other PTSD populations is unclear because none of the studies have compared the results with other samples, possibly due to inequalities between these samples.

Refugees are a culturally and linguistically diverse population; therefore addressing neuropsychological sequelae in this population requires an understanding of the cross-cultural issues in the neuropsychological methods. For this reason the chapter that follows will overview the empirical and theoretical literature in cross-cultural neuropsychology in order to provide background knowledge about the methodological issues in neuropsychological assessment.
Chapter 3: Cross-cultural Neuropsychological Assessment

Neuropsychological assessment is an important tool in determining the level of cognitive and emotional functioning following brain injuries or other brain pathologies and it is also used as a diagnostic tool for a number of brain pathologies (Lezak, 2004). The level of cognitive functioning is measured by using statistical measures in a structured setting and comparison of individual test scores to the scores of normative samples. Presuming the equality of the individual with the normative sample in all the other variables, any deviation of individual scores from the norms is considered to be an indication of cognitive dysfunction. Despite its merits, the quantitative method is limited by a number of mediating and moderating variables that influence performance (Lezak, 2004).

Demographic variables, such as age and gender have been long acknowledged as factors influencing cognitive performance and, accordingly, separate norms are available for different ages (e.g., WAIS, WMS) and gender (e.g., Auditory Verbal Learning Test). Other factors which are major challenges for neuropsychological assessment are education and culture.

Neuropsychological measures have been predominantly developed in the West, with normative groups mainly educated, middle class, and white (Ardila & Moreno, 2001). The positive influence of education has been consistently documented on both verbal and nonverbal measures (Acevedo et al., 2000; Ardila, Rosselli, & Rosas, 1989; Klenberg, Korkman, & Lahti-Nuutila, 2001; Rosselli & Ardila, 2003; Rosselli, Ardila, & Rosas, 1990). Clearly, fewer years of education influences test performance, but more than that, the format and content of cognitive tests used in neuropsychological assessment also resemble the
format of school curriculums and assessment in western societies (Rosselli & Ardila, 2003). Further, the education systems usually reflect the cultural values of a society (Ardila & Moreno, 2001) and these values differ across different countries. Finally, the quality of education is also known to be an important variable interfering with cognitive performance (Kaufman, Cooper, & McGee, 1997; Manly, Jacobs, Touradji, Small, & Stern, 2002; Whitfield & Baker-Thomas, 1999). Accordingly, the use of measures normed with educated, middle class, and white people, with people of other cultures, and educational backgrounds is questionable (Ardila, 2005; Carstairs, Myors, Shores, & Fogarty, 2006; Manly, 2008).

Early studies in the area of cross-cultural neuropsychology have been driven from the racial differences perspective with a focus on cognitive test performance differences between the main stream majority in Northern America, where African Americans and Hispanics consistently obtain lower scores on cognitive measures despite matching in other variables such as education and socioeconomic status (see for review Rushton & Jensen, 2005). Similar results have been found in New Zealand with New Zealanders of European ancestry performing at higher levels than Maori New Zealanders (Ogden, Cooper, & Dudley, 2003; Ogden & McFarlane-Nathan, 1997).

Although this research has highlighted the problems of cultural influences on neuropsychological performance, the focus is on the western educated, English speaking minorities. This does not generalize to new immigrants who have additional language barriers and different educational and cultural backgrounds. This is particularly relevant given the research findings that the level of acculturation influences performance in neuropsychological measures (Arnold, Montgomery, Castañeda, & Longoria, 1994; Coffey, Marmol, Schock, & Adams, 2005; Kennepohl, Shore, Nabors, & Hanks, 2004; Razani, Burciaga, Madore, & Wong, 2007).
The limited research with populations other than Hispanics and African Americans is increasingly revealing how inappropriate neuropsychological measures are with people who are culturally and linguistically diverse (CALD). For instance, the original form of WAIS-R was piloted with a large group of Arabic speaking participants from Northern Sudan (Khaleefa & Ashria, 1995) who gave a high percentage of inadequate responses (e.g., 80% responded inadequately in Picture Arrangement and up to 60% in other subtests). They also had difficulty completing the tests within the prescribed time. When the test was adapted to include more familiar concepts and the time allowed increased, the cross-cultural differences were reduced. Similarly, Stanczak, Stanczak, and Awadalla (2001) found that the scores of normal Sudanese subjects were similar to those of brain injured Americans, thus highlighting the risk of misdiagnosis when this test is used as diagnostic tool with those who are CALD.

**Theories of Cross-cultural Neuropsychological Assessment**

**Education as an Underlying Factor in Cross-cultural Biases**

There have been suggestions that much of the observed variability in cross-cultural research is due to unequal education rather than cultural background per se (Ardila et al., 1989). Clearly, the years of education, the quality of education, and the country of education influence test scores (Acevedo et al., 2000; Ardila et al., 1989; Kaufman et al., 1997; Klenberg et al., 2001; Manly et al., 2002; Rosselli & Ardila, 2003; Rosselli et al., 1990; Whitfield & Baker-Thomas, 1999). However, studies have repeatedly found that discrepancies remain even when western educated minorities are compared to people with an English background (Heaton, Taylor, & Manly, 2003; Manly et al., 2002; Nabors, Evans, & Strickland, 2000). Addressing this specific question, Walker, Batchelor, Shores, and Jones (2010) found that while western educated and English proficient minorities performed better than non-western educated new immigrants, they both performed lower than English
background people, supporting the idea that it is not just education that underlies cross-cultural variations.

**Van Der Vijver’s Cross-cultural Biases**

Van de Vijver and Poortinga (2005) proposed four sources of bias in cross-cultural measurement: construct bias, method bias, instrument bias, and item bias. *Construct bias* refers to the situation when the construct measured is not identical across cultural groups (e.g., the test measures something other than an underlying ability or trait). The *method bias* refers to biases in sampling, instruments, and administration. The bias in sample occurs when the target sample differs from the normative group in different variables (e.g., education, test taking experience). The instrument bias refers to the test’s characteristics, while the administration bias refers to the process of test application which may be discriminative of one group and advantageous for another group (e.g., familiarity with test format, mode of responding, researcher-participant relationship). Finally the *item bias* in cross-cultural context can come from a number of sources primarily related to translation of the instrument.

**Greenfield’s Theory of Cross-cultural Biases**

Greenfield (1997) suggested that neuropsychological assessment is culturally biased because the “ability tests presuppose a cultural framework, and this framework is not universally shared” (Greenfield, 1997, p. 1). Greenfield proposed three fundamental cultural factors that differ across cultures leading to biases in cognitive testing: values and meanings, modes of knowing, and conventions of communication.

**Values and Meanings**

Greenfield (1997) suggests that in order for a measure to cross culture, there must be agreement on the values and meanings of a particular answer to a particular question. However, since values and meanings are culture specific, disagreement can often occur
(Greenfield, 1997). For instance, Cole, Gay, Glick, and Sharp (1971) found that people from Liberia categorized items of a object sorting task in functional pairing (e.g., put a knife and potato together) rather than expected linguistic categories (e.g., utensils, food).

Modes of Knowing

Reflecting the individualistic viewpoint inherent in the current cognitive assessment framework, one to one interviewing is seen as the only way to assess individual abilities. However, for collectivist societies, collaborative construction of knowledge is the norm (Greenfield, 1997). Therefore, requiring an individual response from a person with a collectivist background would be unfamiliar and could lead to distress and lack of cooperation (Ardila, 2005).

Related to this is the lack of familiarity people of some cultures have with the tests that require the respondent to provide reasons for their response (Greenfield, 1997). Although Greenfield concluded that it may be school dependent, the ability to separate the process of knowing from the object of knowing is not a universal ability. This means that some respondents may not understand common questions asked in cognitive tests such as: What do you think? How do you think this sequence should be continued? Testing Piagetian theory with children from Senegal, Greenfield (1997) noticed that when he tried to elicit a reason asking question such as “Why do you think the quantity of water is the same (or more or less)?” Or “why do you say it is the same?” children gave no answer. However when he asked “Why is the water the same?” children were able to provide answers similar to those given by Swiss children.

Conventions of Communications

Most cognitive tests presume that the relationship between the examiner and the participant is impersonal and no relationship is presumed between the examiner and the
participant. However, for many societies, this type of communication violates the conventional expectations, thus influencing the participant’s motivation and cooperation.

**Ardila’s Theory of Culturally Reinforced Skills**

Ardila (2005) postulated that culture determines what is relevant and what is not, at what age and in what way. Salmon, Jin, Zhang, Grant and Yu (1995) reported that Chinese elderly, both educated and uneducated, were resistant to drawing and writing because their culture reinforces other ways of responding. Furthermore, Roselli, Ardila, Bateman, and Guzman (2001) reported that Colombian children with limited exposure to western culture outperformed the American normative sample in the Seashore Rhythm Test (which measures music ability), thus, reinforcing the notion of culturally reinforced skills having a major impact on performance.

Further, for many neuropsychological measures, speed of response is an underlying component. Research suggests that time is perceived differently across cultures (Hughes & Trautmann, 1995, cited in Nell, 2000). While people in western societies are exposed to timed tests from an early age, thus reinforcing the value of “the faster the better”, this value is not relevant in other cultures (Nell, 2000). For instance, in a standardization study of WAIS-R in Sudan, Khaleefa and Ashria (1995) found that the most significant variable that explained intercultural differences in the performance of Sudanese and American samples was the time. Increasing the completion time of WAIS-R lead to the improvement of the validity of this test for use with Sudanese subjects. Another study comparing Russian and American subjects revealed that the American sample performed better only in timed tests (Agranovich & Puente, 2007).
Language as a Factor Underlying Cross-cultural Differences

The idea that nonverbal tasks are culture free remains popular (Rosselli & Ardila, 2003). However, research with varying cultural groups suggests that nonverbal tasks often produce larger cross-cultural differences than verbal tasks (Carstairs et al., 2006). Although nonverbal skills such as drawing a complex figure or drawing a map have been considered universal, research suggests that these are education dependent skills (Ardila, 2005) which do not exist in some cultures (Ardila & Moreno, 2001).

Test Translation

Based on the assumption that language is the factor underlying cross-cultural differences, it has been proposed that neuropsychological measures can transcend these differences with appropriate linguistic translation and administration preferably by a tester familiar with the language of the client. However, test translation cannot overcome the biases described in the literature (e.g., Van de Vijver and Poortinga, 2005; Greenfield, 1997; Ardila, 2005). Additional factors may also impact the validity such as: the target stimuli of a neuropsychological test may differ in frequency or salience across groups (Kempler, Teng, Dick, Taussig, & Davis, 1998).

Guidelines have been established to aid in the development and translation of tests into different languages (Loewenstein, Argüelles, Argüelles, & Linn-Fuentes, 1994; Van de Vijver & Hambleton, 1996). They stress the importance of in-depth knowledge of the culture and language to which the test is being translated or consultation with those who are competent in these domains.

Interpreter-Assisted Neuropsychological Assessment

Using neuropsychological assessment with new immigrants and refugees with diverse cultures and lack of English language is more complex and often involves use of interpreters
to overcome language barriers. However, the validity of neuropsychological assessment under such conditions has been questioned (Artiola i Fortuny & Mullaney, 1998). Artiola i Fortuny and Mullaney (1998) argued that interpreters have to be avoided because the accuracy of translation from the interpreter cannot be verified if the neuropsychologist is monolingual which can lead to misdiagnosis. Further complicating the issue is the literature regarding third party observer effects on neuropsychological test scores. Numerous studies have demonstrated that a third party observer leads to lower neuropsychological results (Axelrod et al., 2000; Constantinou, Ashendorf, & McCaffrey, 2005; Lynch, 2005), although a study suggested that the interpreters can lead to improvement of performance in verbal tasks, which indicates that the interpreter may have assisted the recall process (Casas et al., 2012). A meta-analysis indicated that the effects size of third party observers in memory tasks is moderate, and small in measures of motor, attention, and executive functioning (Gavett, Lynch, & McCaffrey, 2005).

Artiola i Fortuny and Mullaney (1998) have also argued that it is against the code of ethics (see Standard 2.01, APA code of ethics, 2002) to conduct interpreter mediated neuropsychological assessment and called for neuropsychologists to abandon this practice. However, the APA ethics code suggests that psychologists can “…provide services to individuals for whom other mental health services are not available and for which psychologists have not obtained the necessary training. Psychologists may provide such services in order to ensure that services are not denied.” (see Standard 2.01, (d) -APA code of ethics, 2002).

This is clearly an ethical dilemma that challenges neuropsychologists. Some have argued that when assessing CALD people for whom no culturally appropriate services exist, doing the best is better than not doing anything at all (Manly, 2008; Weinstein et al., 2001). Nell (2000) recommended that when using assessment instruments with a member of a group
for which validity or reliability is not established, the neuropsychologist should proceed with caution and be very careful to describe the limitations of the test results and interpretation.

Some recommendations for improving the validity of cross-cultural neuropsychological assessment (e.g., “doing the best”) have included: avoiding using normative data as comparison (Pedraza & Mungas, 2008), including “extended practice when assessing the non-test-wise-client” (Nell, 2000, p. 173); using a trained interpreter who can “write patient responses verbatim, discern subtle alternations in language, and communicate/translate back myriad of observations” (Perez-Arce & Puente, 1996, cited in Weinstein et al., 2001); provide sufficient preparation prior to the evaluation about testing processes (Shepherd & Leathem, 1999); and evaluate proficiency with English, reading ability in their native language, vocational background, degree of acculturation and variation within culture (e.g., urban vs. rural) (Manly, Byrd, Touradji, & Stern, 2004). Adding all these factors and analysing the performance profile, the interpretation should answer the question “Do the results make sense?” (Nell, 2000, cited in Weinstein et al., 2001).

Weinstein et al. (2001) recommend that these principles are used in the assessment of refugees for who alternative culturally appropriate services are not available.
Chapter 4: The Current Study

In the introduction it was stated that refugees experience high rates of PTSD and multiple injuries events that could lead to TBI. The review in Chapter 2 indicated that there is strong evidence that PTSD and TBI are associated with neuropsychological difficulties. Although neuropsychological outcomes related to co-occurring TBI and PTSD have not been studied sufficiently, much evidence suggests that TBI (mild TBI specifically) is a risk factor in the development and prolongation of PTSD symptoms. Chapter 2 reviewed the existing empirical evidence on the neuropsychological sequelae in the refugee population. This literature indicated that refugees are at risk of neuropsychological difficulties due to multiple psychological traumas and multiple injury events that can potentially lead to brain injuries. Despite being a high risk population, the neuropsychological sequelae in refugees are unknown. The few studies with small samples that have investigated the cognitive outcomes in PTSD provide limited evidence about the scope of neuropsychological difficulties in refugees. Further complicating the understanding of neuropsychological sequelae is the fact that refugees are a culturally and linguistically diverse population for whom neuropsychological measures are not designed. Further, as Chapter 3 revealed, cross-cultural neuropsychological research has not studied the refugee population. However, this literature highlighted the methodological difficulties in cross-cultural assessment and provided some recommendations that were incorporated in the current study.

Thus, a lack of literature is the rationale for the current study which aims to explore the neuropsychological issues in the refugee population with the aim of providing data that will help increase the research effort in this population and to unveil some of the issues specific to this population.
Due to the inability to locate a control group (see Method section for more information), the current study reports the data for two groups: TBI+PTSD and PTSD only. This is an exploratory study that aims to investigate the following questions:

1. What are the methodological and cultural barriers in neuropsychological research with refugees?

2. Is there any difference between the TBI+PTSD group and PTSD only group in demographic characteristics, trauma exposure, self-reported functioning, psychological and neuropsychological functioning?

It is hypothesised that TBI+PTSD group will report higher number of trauma events, more likely to have been tortured, experience higher levels of symptoms of anxiety and depression, have lower scores in neuropsychological tests, and report lower level of functioning.

3. Can neuropsychological assessment of refugees with co-morbid TBI and PTSD answer clinically relevant questions such as: diagnosis of TBI, determine relative contribution TBI and PTSD, and determine refugees’ current cognitive functioning in relation to their pre-morbid functioning?
Chapter 5: Method

Participants

Eighteen culturally diverse refugees attending the Refugees as Survivors (RAS) Trust in Wellington (New Zealand), an organization that provides psycho-social services for refugee survivors of trauma and torture, volunteered to take part in the study. The demographics of the group are shown in Table 3.

Advertisements (see Appendix K) for the control group were circulated through medical centres, English language schools for refugees, refugee organisations, and local libraries across Wellington. Only one person who did not meet the inclusion criteria showed interest in participating.

The Inclusion Criteria

Control Group

a) Refugee from the same countries as participants in experimental groups
b) Over 16 years of age
c) No current psychotic symptoms
d) Adequate visual acuity and hearing ability to complete the task requirements
e) Not undergone neuropsychological assessment within last five years
f) Speaks fluent English, Burmese, or Arabic

PTSD Group

a-f) As above but also:

  g) Meets criteria for PTSD

  h) No history of traumatic brain injury
TBI + PTSD Group

As above but also:

i) Experienced TBI (e.g., beatings to the head, near drowning, electrocution, gun wounds to the head during torture) with Glasgow Coma Scale Score of <14 and/or Post Traumatic Amnesia of 1 hour or more and/or LOC.

Table 3

Demographic Characteristics of the Sample

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Number of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>5</td>
</tr>
<tr>
<td>Male</td>
<td>13</td>
</tr>
<tr>
<td><strong>Age (range)</strong></td>
<td></td>
</tr>
<tr>
<td>25-30</td>
<td>3</td>
</tr>
<tr>
<td>30-35</td>
<td>2</td>
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<td>40-45</td>
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</tr>
<tr>
<td>55-60</td>
<td>3</td>
</tr>
<tr>
<td><strong>Country</strong></td>
<td></td>
</tr>
<tr>
<td>Burma</td>
<td>6</td>
</tr>
<tr>
<td>Iraq</td>
<td>2</td>
</tr>
<tr>
<td>Afghanistan</td>
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<tr>
<td>Sri Lanka</td>
<td>1</td>
</tr>
<tr>
<td>Eritrea</td>
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</tr>
<tr>
<td>Ethiopia</td>
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</tr>
<tr>
<td>Somalia</td>
<td>1</td>
</tr>
<tr>
<td>Iran</td>
<td>1</td>
</tr>
<tr>
<td>Palestine</td>
<td>2</td>
</tr>
<tr>
<td><strong>Education (years)</strong></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>2</td>
</tr>
<tr>
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<tr>
<td>5 to 8</td>
<td>10</td>
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<tr>
<td>&gt; 8</td>
<td>6</td>
</tr>
</tbody>
</table>
Presence of co morbid conditions (e.g., generalised anxiety disorder, depression and drug and alcohol abuse) was not an exclusion criterion because of the difficulty in finding a PTSD only sample. It was initially planned that if we had large samples the effects of these conditions would be controlled statistically.

As part of the study participants that completed the assessment received a full neuropsychological assessment and interview. Any valid results were discussed with the agency to assist with interventions.

**Characteristics of the Sample**

All eighteen participants had been diagnosed with PTSD and depression by their treating psychiatrists. Our assessment confirmed that all the participants were experiencing PTSD and depression. Eight participants who reported experiences of injury to the head accompanied with alteration/loss of consciousness were grouped in the TBI+PTSD group (N=8, 5 male, 3 female), the other participants were grouped in the PTSD group (N=10, 7 male, 3 female). Three participants in the PTSD group did not complete the assessment and were removed from the analysis. One participant was imprisoned during the course of the research and two others were unwilling to return for the second session. Three participants from the TBI+PTSD group were removed from the quantitative neuropsychological data, one of whom was removed from all the quantitative data analysis.

Thus, overall there were seven participants in the PTSD+TBI group, and seven participants in the PTSD only group that were compared in demographic characteristics, trauma exposure, and psychological symptoms. The comparison in neuropsychological data was done between five participants in TBI+PTSD group and seven participants in PTSD only group.

**Language**

The consent form, information sheets, psychological measures, verbal neuropsychological measures and instructions for all the neuropsychological measures were
officially translated into Burmese and Arabic (see Appendices). Standard translation procedures were used (i.e., translation from English to the participant’s native language and then blind translation back to original English, and comparison and consensus of translation by cultural advisors). The translated versions of measures which are in the public domain are attached in Appendices O-S.

Assisted by official interpreters, six participants were assessed in Burmese language, and five participants in Arabic language. The same interpreter was used for all the assessments with Burmese speaking participants. Three different interpreters were used for the Arabic speaking sample due to participants’ preference for different interpreters. Six participants (one each from Sri Lanka, Afghanistan, Ethiopia, Eritrea, Iran, and Burma) were assessed in English. All six were fluent speakers and had been speaking English for more than five years. The measures were subsequently translated into Somali language and a Somali interpreter assisted the assessment of a Somali speaking participant.

The official interpreters were employed via Wellington Interpreting Service. All the interpreters worked regularly for the RAS Centre, and had extensive work experience in psychological settings. The neuropsychological assessment with interpreters followed the guidelines of American Academy of Clinical Neuropsychology (Heilbronner, 2007). Prior to testing, the interpreters were familiarised with the standard instructions for each neuropsychological test and the response recording. The interpreters took notes of each response and the client’s responses for the AVLT test and Logical Memory were also audio recorded. After the testing, the interpreter and the researcher checked all recording forms, notes, and the audio recordings to ensure accuracy. The data recorded by the interpreter were put together with the data recorder by the researcher and were then entered immediately onto a data sheet to ensure that no information was lost.
Measures

Psychological Assessment

A semi structured clinical interview assessing current symptoms of anxiety, depression, brain injury, and substance abuse was conducted by the researcher. In addition, the Harvard Trauma Questionnaire (Mollica, 2001) was administered in order to measure the exposure to torture and trauma as well as symptoms of PTSD. The severity of depression and anxiety were measured using the Depression, Anxiety, Stress Scale (DASS) (Lovibond & Lovibond, 1995). Functional difficulties were assessed with the self report Patient Competency Rating Scale (Prigatano, Altman, & O'Brien, 1990) which asks clients to appraise their level of functioning in areas such as: interpersonal relationships, cognitive functioning, mood, and functional abilities.

Harvard Trauma Questionnaire (Mollica, 1998)

This test was designed to measure trauma, torture and PTSD symptoms in populations that have experienced high level of political violence and torture. Initially this measure was constructed with Indochinese population (Mollica, 1992), and later was translated and validated in 7 different languages (Cambodian, Vietnamese, Japanese, Laotian, Croatian, Bosnian, Arabic). The Harvard Trauma Questionnaire (HTQ) has been extensively used in international studies, particularly among refugees and conflict-affected populations (Hollifield, 2002).

The HTQ is composed of five parts: (a) trauma events, (b) personal description, (c) brain injury, (d) posttraumatic symptoms and (e) scoring of the instrument. The purpose of part 1 is to measure exposure to traumatic events. This section contains a list of 17 traumatic events to which respondents answer with: “Experienced”, “Witnessed”, “Heard about”, or “No”. A total score of 38 is possible. Section II contains two open-ended items. The first item asks the respondent to describe the most hurtful or terrifying event(s) that he or she has experienced, and
where this experience took place. The second item asks the respondent to describe the worst event that has happened in his or her current living situation. These are the only open-ended items on the HTQ and HTQ-R, allowing respondents to tell their story in their own words. The third section of the HTQ and HTQ-R contains questions regarding head injuries or head trauma such as beatings to the head, drowning, suffocation. The HTQ-R asks more specific questions about each of these events, such as whether a loss of consciousness occurred. Section IV of the HTQ contains a checklist of 16 symptoms equivalent of the DSM-III criteria of PTSD. In addition, 14 items culturally-specific for the groups assessed are added. For the purpose of the current study, only the first 16 items were administered due to unknown statistical properties of the culturally specific items.

Initial statistical properties of HTQ were tested in a convenience sample of 91 Southeast Asian patients attending a psychiatric outpatient clinic. The inter-rater reliability of the HTQ was $r = .93$ for Section I, .93 for Section II and .98. ($p < .0001$) for Section III. The HTQ had a sensitivity of 93% (i.e. 93% of patients with PTSD were correctly classified by the HTQ) and a specificity of 84% (i.e. 84% of patients without PTSD were correctly classified by the HTQ). For the purpose of the current study The Arabic Version of this measure was used, which was also translated into Burmese language.

Depression, Anxiety, Stress Scale (DASS) (Lovibonde & Lovibond, 1993)

This is a 14 item self-report scales designed to measure the level of depression, anxiety and stress. This self report scale lists core symptoms of depression, anxiety and stress to which respondents are asked to use 4-point severity/frequency scales to rate the extent to which they have experienced each state over the past week. Large sample studies using both normal and clinical population have shown that internal consistency of DASS ranges from .88 to .94.
Further, construct validity have also proven as supported by moderately high correlations of the DASS with indices of convergent validity (.65 to .75) and lower correlations and lower correlations of the DASS with indices of divergent validity (range -0.22 to 0.07) (Lovibonde & Lovibond, 1995). A cut off score of 5 for anxiety and 12 for depression is recommended. For the purpose of this study we used the validated Arabic version of this test. The test was translated in Burmese language for the purpose of this study. This test was chosen because it provided information for all three variables (e.g., anxiety, stress, depression). In addition this test was already translated and validated in Arabic language and had been used in other cross cultural studies.

The Patient Competency Rating Scale (PCRS)(Prigatano et al., 1990)

This test was initially developed to evaluate self-awareness following traumatic brain injury. The PCRS is a 30-item self-report instrument which asks respondents to rate difficulty in a variety of tasks and functions on a 5-point Likert scale. Self ratings are compared to those of an informant (a relative or therapist) who rates the subject on the identical items. Impaired self-awareness may be inferred from discrepancies between the two ratings, such that the subject overestimates his/her abilities compared to the other informant. Awareness of deficit may also be examined separately for the various domains including activities of daily living, behavioral and emotional function, cognitive abilities, and physical function.

While the validity of this measure has not been well tested, test-retest reliability of the PCRS has been reported as r = .97 for patients form and r = .92 for relatives form (Prigatano, Altman & O'Brien, 1990). In the current study, PCRS was translated into Arabic and Burmese languages. PCRS was selected because of its dual utility. Thus the patient’s self report provided information about their functioning in the all the domains (e.g., cognitive, emotional, social, and ADL’s), while the relative’s and the clinician’s reports were used as collateral information.
TBI Assessment

All the participants were screened for brain injury with the Harvard Trauma Questionnaire, Brain Injury Sections (Mollica, 2001). Participants who indicated trauma to the head were then interviewed. The interview included questioning about the event, the circumstances of injury, and the clinical symptoms following the trauma.

Following the protocol in Gronwall and Wrightson (1980), participants were asked to describe the event, starting from just before the injury occurred. They were then asked “And what happened then” until the account reached the point when they became conscious and were in hospital or other place. The duration of PTA was defined as the elapsed time between the accident and the return of memory. While recognizing that retrospective reports of amnesia may not be accurate, especially given the length of time since the injury, this criterion was the only means available to assess short periods of PTA. Because other factors can affect brain functioning, data were gathered by clinical interview about the lifetime history of brain injury and other events that can lead to brain dysfunction (e.g., malnourishment, electric shock, cerebral malaria).

Neuropsychological Measures

Neuropsychological measures were selected so that all cognitive domains were covered and on the basis that they were reported as less sensitive to cultural influences (Weinstein et al., 2001), brevity (while still maintaining the integrity of the assessment procedures), and had dual utility (e.g., were sensitive to PTSD induced neuropsychological impairment). The measures administered are depicted in Table 4 and described in the section that follows.
### Table 4

**Neuropsychological Measures**

<table>
<thead>
<tr>
<th>Domain Assessed</th>
<th>Measures</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall cognitive ability (IQ)</td>
<td>Self-report- Part I of history taking questionnaire (see Appendices L-N)</td>
</tr>
<tr>
<td>Verbal memory</td>
<td>Logical Memory I &amp; II, subscale of Wechsler Memory Scale - III (Wechsler, 1997b)</td>
</tr>
<tr>
<td></td>
<td>Rey Auditory Verbal Learning Test</td>
</tr>
<tr>
<td>Visual memory</td>
<td>Rey Osterrieth Complex Figure Test (Rey &amp; Osterrieth, 1993)</td>
</tr>
<tr>
<td>Working memory &amp; Information processing speed</td>
<td>Digit Span, and Symbol Search - WAIS III (Wechsler, 1997a)</td>
</tr>
<tr>
<td>Attention and concentration</td>
<td>Colour-Word Test - DKEFS (Delis, Kaplan, &amp; Kramer, 2001)</td>
</tr>
<tr>
<td>Visio spatial skills</td>
<td>Block Design test - WAIS III (Wechsler, 1997a)</td>
</tr>
<tr>
<td>Executive functioning</td>
<td>Colour-Word Test, 20 Questions - DKEFS (Delis et al., 2001)</td>
</tr>
<tr>
<td>Testing for response bias and incomplete effort</td>
<td>Test of Memory Malingering (TOMM) (Tombaugh &amp; Tombaugh, 1996)</td>
</tr>
<tr>
<td>Electronic finger tapping</td>
<td>Motor skills</td>
</tr>
</tbody>
</table>

**Rey Auditory Verbal Learning Test (Rey 1964)**

Rey Auditory Verbal Learning Test is one of the most widely used memory test which assess rote memorization, proactive and retroactive inhibition, retention, encoding versus retrieval, and subjective organization (Lezak, 2007). This measure comprises a 15-item list of words that is presented five times in the same order. Recall of the words in any order is counted after each trial. A delayed recall task is given after a short interval of time (20-30 minutes). There is also a recognition task. Internal reliability of total score is high (about 90%), while test-retest reliability has been found to be around .60 to .70 (Mitrushina & Satz, 1991). Content validity of this measure is appropriate as reported by a number of factor analytic studies.
Results of these studies indicate that the RAVLT scores load consistently with other verbal memory or verbal ability instruments. They do not load with nonverbal abilities such as motor or visuospatial skills. RAVLT is sensitive to neurological impairments (Powell et al, 1991), closed head injuries (Bigler et al, 1989, Shum et al, 2000), and psychiatric illnesses such as depression and schizophrenia (Moritz et al, 2001) and PTSD (Uddo et al, 1993). This measure was selected because of the richness of information it provided about learning and memory, because it had been validated in cross cultural samples (May et al, 1997), and because this measure has been found to be sensitive to cognitive deficit due to PTSD and TBI.

Rey Osterrieth Complex Figure Test (Rey & Osterrieth, 1993)

The Rey-Osterrieth Complex Figure (ROCF) test was designed by Rey (1941), and standardized by Osterrieth (1944) who developed 18 item, 36 point scoring system. The test is widely used in clinical and research settings to assess perceptual organization and visual memory. The test consists of four trials: the copy trial consists of copying a complex design into a sheet of paper, the two subsequent trials are the recollection of the design at immediate interval (5minutes) and delayed interval (25-30 min) and the last condition is the recognition trial. The scoring system divides the picture in 18 units which refer to specific area or detail of the figure. Since each correctly drawn and placed unit earns 2 points, the highest possible score is 36. ROCF has been widely used in clinical practice and with diverse normative samples. This test was chosen because of its dual utility (e.g., measures both visual memory and visuo-perceptual skills), and short administration time.

Logical Memory (WMS III)

Logical Memory is a subtest of Wechsler Memory Scale III that assess immediate and delayed recall of semantically organized stories. This test assesses the verbal memory by asking the examinee to recall two stories immediately following an oral presentation and again after a 30 min delay. In addition the recognition trial consists of questions which the examinee needs to
identify whether they are true or false. This test was translated in Arabic and Burmese language and response was tape recorded. The test was chosen because it contained stories that were simple and easily adjusted in another language. In addition, this subtest is the most valid measure of semantic memory with age and gender specific norms.

Wechsler Adult Intelligence Scale III

Three subtests of WAIS III used were: Digit Span, Symbol Search and Block Design. All the three subtests have appropriate statistical properties, as well as age and gender specific norms. The Digit Span subtest involves the oral presentation of randomly ordered digit. The number of digits increases by one until the participant consecutively fails two trials of the same digit span length. One condition of this test requires repetition of the numbers in the same order as read by the examiner (Digit Forward), and the other condition requires the recall of numbers in the reverse order (Digit Backwards). The test is designed to measure attention span and working memory. The Block Design subtest consists of blocks with different colourd sides (two red sides, two white sides, and two half red half white) to reproduce a specific deign from the stimulus pictures. The design may require the use of four or none blocks. The accuracy and completion time is recorded. This test is designed to measure visuo-constructional skills and is sensitive to demages to frontal and parietal lobe. The Symbol Search is designed to measure processing speed. This is a visual scanning task in which the examinee checks for target symbols in a series of search symbols. The aim is to search correctly for as many items as possible in 120 seconds.

Color-Word Interefernce Test

This test is based on the Stroop procedure (1935). The primary executive functioning measured by this test is the ability to inhibit an overlearned verbal response in order to generate a conflicting response. For example, the examinee needs to inhibit the reading of printed words in order to name the conflicting ink color in which the words are printed.
The test has two baseline conditions: naming of color patches and reading of words printed in black ink. The third trial is the inhibition condition in which the examinee must inhibit reading the word in order to name the color of the printed words. The fourth condition is inhibition/switching condition which requires switching back and forth between reading the ink colors and reading the words. Aside from measuring inhibition, this condition also measures cognitive flexibility. The response time used on each condition was recorded. This measure is widely used in studies with TBI and PTSD samples and has shown sensitivity to deficit related to these conditions.

20 Questions Test

This test is a subtest of DKEFS which is designed to tap into several executive abilities including: ability to perceive categories and subcategories, ability to formulate abstract questions in order to eliminate maximum number of the 30 items presented, and ability to use feedback to formulate efficient strategies. The test consists of a card with 30 common objects which can be divided in a number of categories and subcategories which differ in number of objects in each. The most effective strategy in this task is the ability of the examinee to ask Yes/No questions that eliminate the maximum number of objects regardless of whether the answer is yes or no. This test was selected because the objects of the test were common and universal (e.g., animals, fruit and vegetables) as well as being a less effortful test than other categorizing tests (e.g., Wisconsin Card Sorting Test).

Finger Tapping

Finger Tapping Test is a component of the Halstead-Reitan Battery (Reitan & Davison, 1974). Finger tapping equipment consisted of a counter with a lever mounted on a board. The examinee is instructed to rest the hand on board, and press the lever as quickly as possible until the examiner says stop. The opportunity for practice is given until the examinee has understood the task. Five 10 second trials are administered for each hand (dominant and non-dominant hand).
Raw scores are computed by averaging the number of taps across the five trials. The scores used for analyses were the average number of taps with the dominant hand, average number of taps with the non-dominant hand. This test is designed to assess motor speed.

Clinical inferences regarding laterality of lesions are often supported by an unexpected spread between the performances of the dominant vs. nondominant hands (Finlayson & Reitan, 1980; Haaland & Delaney, 1981). This test was selected because it is relatively short and easy to administer.
**Procedure**

Each participant was approached by their treating clinician at RAS and invited to participate. Those who volunteered to participate then met the researcher (BV) who went over the information sheet and consent form with them (through the interpreter for those that did not speak English). All participants were seen at the RAS centre.

For most participants, the first session included a semi-structured interview followed by administration of the psychological measures. The administration of neuropsychological measures was conducted a week later.

**Test Administration**

For the majority of the participants, the psychological measures were read aloud because participants were not familiar with filling out questionnaires and required additional explanations for most questionnaire items. Some participants could not understand the Likert Scale, and therefore it was demonstrated this by using the analogy of a glass with different amounts of water (e.g., starting from empty glass = the lowest value in the scale, until glass full = the highest value in the scale).

The neuropsychological testing was conducted over two to three sessions lasting one to two hours. Detailed information about the nature of testing was provided, emphasising the need to put in full effort, be fast on timed tasks, be focused, and do their best. The pre-prepared translated instructions were read to participants, after which they were asked to repeat their understanding of the instructions and invited to ask any questions.

Only the WAIS IV tasks (e.g., digit span, and symbol search, block design) provide the standard opportunity for practice prior to the start of the test. For measures that did not have standard practice trials, we used examples to help participants understand these tasks. For example, when given the instructions for the AVLT task, the examiner used the example of a shopping list to describe the demands of the test. When administering the Rey-Osterrieth
Complex Figure, participants were first asked if they had experience with drawing. If they reported no experience or little experience with drawing, a practice design was given to ensure that they understood the importance of accurate drawing. The practice item was adopted from Nell (2000, Fig. 9.2, p. 168). When the practice item was finished, the examiner talked through any discrepancy and asked the examinee to correct the mistakes. Once the practice was finished, they were asked to draw the Rey-Osterrieth Complex Figure.

Although extended practice is not recommended for the 20 Question Test, it was necessary to simplify the instructions. For example, after explaining the details of the task, the participants were told “Make a question that eliminates not only one item but many of them”.

The researcher wrote observations about the participant’s attitude towards testing, for example, motivation, interaction with the examiner (e.g., were they shy/familiar, did they try hard/give up easily), and their response style (e.g., did they approach tasks step by step or as a whole, was any one part of the task given more importance). To assess the influence of prior experience on performance, participants were specifically asked whether they had done similar tests in the past (e.g., at school).

Setting

All the participants were seen in RAS offices; this was important for two reasons. Firstly, all participants had trauma and torture history, therefore being in a place they felt safe was very important. Secondly, this ensured that their treating clinicians with who they had long-term therapeutic relationships were readily available in case they needed extra support.

Prior to data collection, I completed a clinical placement in RAS which allowed me to know and create trusting relationships with people that subsequently took part in the study, and also allowed me to develop working relationships with the psychologist, counsellors, and social workers at RAS whose roles were critical to this project. As part of preparation for this project, I also undertook a five day intensive training course titled: “Working with culturally
and linguistically diverse client-CALD” and working with interpreters. In addition, I took part in many community gatherings of refugees where I had a chance to learn about the cultural background of refugees.

Particular care was taken in making the assessment as relaxed and comfortable as possible. The participants were given tea and coffee and were frequently asked if they needed a break. I ensured that participants felt that their wellbeing was more important than the data for my research by always giving them choice, adjusting to their needs, and sensitively and empathically handling their trauma stories. In addition, disclosing to the participants that I had lived in a war-torn country and had experienced some of their difficulties in integrating in New Zealand was very helpful in quickly developing a trusting relationship with them.

**Ethics**

There were a number of ethical issues that arose in the study that needed to be addressed. As this research was being conducted with people with mental illness, ethics approval was sought and approved by the Central Region Health and Disability Ethics Committee. The Refugees as Survivors Centre (RAS) agreed that the research could be conducted in their centre. RAS also agreed that I could have access to the files of the people who consented to take part in the study. In addition, registered clinicians at the RAS centre were available to provide extra support for the clients participating in the research; they provided ongoing supervision for the researcher, and in some cases were present during the sessions when trauma exposure and PTSD were assessed.

A chief ethical concern was protecting participants from re-traumatisation. Since the assessment included interviews about trauma experience, it was crucial that the interviewer was prepared to ensure that people remained in an optimal level of arousal when talking about highly traumatic events and were able to regain emotional control before leaving the assessment session. The interviewer routinely assessed people’s personal resources to deal
with their emotions prior to talking about their trauma. Those that had their own resources (e.g., breathing, grounding techniques) were encouraged to use them when and if they needed. The clinicians at RAS ensured that people were familiar with these techniques prior to participation. At the end of the interview, some time was spent in decreasing the emotional distress by taking about positive topics. After the interview, the researcher and clinicians at RAS made phone calls to participants to help them deal with any emotional distress related to the interview. People that experienced distress had the opportunity to arrange extra sessions with their therapists.

Another concern was the vicarious traumatisation of the interpreters and the researcher. For this reason, the Wellington Interpreting Service provided a debriefing service for their interpreters involved in the research. Similarly, the researcher had frequent supervision provided by RAS, while a major part of supervision was provided by researcher’s primary supervisor who is a senior psychologist with an Annual Practicing Certificate (APC).

Another ethical concern was ensuring that cultural issues were treated sensitively given the differences in the cultural background between the researcher and the research participants. For this reason, it was important that the researcher was informed about the cultural and historical contexts of places where the participants were from. This was achieved through ongoing consultation with cultural advisors, reading of literature, and participation in cultural events of relevant cultural groups. Furthermore, the researcher used mindfulness skills and maintained a phenomenological stance to minimise the interference of her cultural and personal values in her interaction with research participants.

For most participants this was their first encounter with research and they were unfamiliar with the respective roles, research procedures, and the format of instruments used. In particular, neuropsychological testing was challenging for some of the participants. A considerable amount of time was spent prior to the assessment in explaining in detail the
nature of the research, the position of the researcher as a psychology student, their role as a participant, the interpreter’s role, the confidential nature of the research including the explanation about the confidentiality limits (e.g., if there was a concern about their safety or the safety of others), their choice to withdraw anytime and to decline to answer any particular question or to do any particular test, their opportunity to ask clarifying question, and their right to complain if they feel treated unfairly. Furthermore, due to their unfamiliarity with assessment methods and measures, they were given the opportunity for extended learning and practice.

Furthermore, to avoid the feeling of failure, participants were not exposed to harder tasks once he/she had failed in easier tasks. Also, the researcher closely monitored whether assessment was causing distress and dealt with these situations by allowing breaks or by abandoning the assessment when the participant became distressed.
Chapter 6: Results

This chapter commences with a description of the method of data analysis and describes the approach to both quantitative and qualitative data. The results then will be presented in three sections, each addressing specific study questions. The first section presents qualitative observations in each stage of the research to addresses the question of methodological and cultural barriers in neuropsychological research with refugees. The second section presents the descriptive and statistical analysis of data for the two groups, PTSD and TBI+PTSD, to investigate group differences in demographic characteristics, trauma exposure, psychological and neuropsychological functioning. The third section presents qualitative analysis of data for the TBI+PTSD group in order to explore the clinical issues in neuropsychological assessment of refugees with co-morbid TBI and PTSD.

Data Analysis Method

Approach to Qualitative Analysis

The observations collected about the barriers encountered, participants’ attitude towards testing, that is, motivation (were they shy/familiar, did they try hard/give up easily), interaction with the examiner, and their response style (e.g., did they approach tasks step by step or as a whole, was any one part of the task given more importance) were analyzed and described. In the results section I the observations were grouped according to each specific stage of data collection (e.g., recruitment and preparation for the assessment, administration of the assessment, and interpretation of the data). In the third results section observations along with test results were integrated to address specific questions. These data are reported in the Results Section I (Methodological barriers) and Results Section III (Exploring the clinical issues in neuropsychological assessment of refugees).
Approach to Quantitative Analysis

Descriptive analysis of the data for both groups was performed using SPSS. Due to the small sample size and high variability of the sample, a nonparametric test, Mann-Whitney U, was performed to evaluate the between group (PTSD only vs. TBI+PTSD) differences in the demographic characteristics, trauma exposure, psychological symptoms, and neuropsychological performance. Since we predicted that the TBI+PTSD group would differ from the PTSD group in terms of higher trauma exposure and psychological symptomatology and lower neuropsychological scores, one tailed significance scores are reported, with an uncorrected value $p = < .05$. In addition, Box-plots were used to evaluate differences in the median and the distribution of the sample for each variable.
Results I: Methodological and Cross-cultural Barriers

This section reports observations about the challenges in researching the refugee population encountered at each stage of the assessment process with a group of refugees from different cultural backgrounds. By focusing on the process variables (preparation, administration, scoring, and interpretation) rather than the scores, the elements of the neuropsychological assessment procedures that could account for much of the observed discrepancies in neuropsychological performance are highlighted. Furthermore, the current study also highlights additional challenges that arose, including: knowing little or no English; limited education and experience of western society; and having experienced long term discrimination, oppression, and trauma. This is illustrated with case study material where relevant. In addition, observations are made about specific neuropsychological measures and their ecological validity.

Preparation and Test Administration

Challenges Due to Use of Interpreters

A number of challenges were encountered in attempting to minimize the effect of the use of interpreters on validity. The first related to complexities regarding the availability and selection of interpreters for this particular group. Because most participants had experienced torture and trauma, it was important that the participants trusted the interpreter. However, at times, potential participants refused to take part in the study because the only available interpreter was a person who ethnically or racially belonged to the oppressing group in their country of origin.

The second more general challenge related to the reliance on interpreters for neuropsychological assessment. Interpreters had little experience of being involved in neuropsychological assessment and training had to be provided. Besides the training in testing procedure and scoring, training particularly emphasized the importance of the validity of the information in order to raise awareness about the importance of not altering the
response. Despite all the efforts for following the guidelines for using interpreters as developed by American Academy of Clinical Neuropsychology (Heilbronner, 2007), the presence of the third person often caused distraction. For instance, participants often tried to justify their poor performance to the interpreter indicating a level of discomfort the presence of the interpreter can cause. This was especially when they knew the interpreter (in spite of the cultural community in Wellington for both cultural groups being quite large). In addition, although only professional interpreters were used, there were noticeable variations in their interpreting skills and their understanding of the process of assessment which could have been reflected in the validity of data.

Interaction with the Researcher

Although communication between researcher and participant is ideally formal with professional boundaries to preserve the objectivity of the data, this proved difficult to maintain with this population. Well before testing could be undertaken, a long period of time was required to build the relationship to avoid re-traumatisation and to avoid violating social norms of communication. Participants had different ways of dealing with the trauma recollection, for example seven wanted to share their trauma stories at the outset and it seemed important for them to finish telling their stories before moving on to formal assessment. Other participants were reluctant to talk about their past and insisted that they do only the neuropsychological assessment. These individuals later were happy to talk about their trauma, which meant that they needed more time to establish a trusting relationship with the researcher at the outset. Some participants required a break between psychological assessment and cognitive assessment sessions.

Participants seemed to need to be less formal and connect with the researcher at a more personal level prior to feeling comfortable to do the assessment. For example, despite having a clear explanation about the nature of the assessment, one participant from Sri Lanka started each session by showing the researcher photos of different family events (e.g., his father’s funeral, and his brother’s wedding), while other participants invited the researcher to accompany them to cultural events of their community.
Communication During Structured Neuropsychological Testing

Neuropsychological testing involves the examiner following standard instructions and procedures as set out in test manuals. However, it often became necessary to repeat instructions in simpler language and to provide examples for some tasks that were not vulnerable to practice effects. Further, very early on it became apparent that the format of questioning was unfamiliar for this population, many having difficulty separating normal conversation from the testing. In spite of being asked to complete a task without interruption (and respectful repeated reminders not to do so) and appearing to have understood the instruction, participants would still start conversing in the middle of a (often timed) task. For instance, a participant from Iraq repeatedly interrupted his recall of the first story, WMS-IV, to talk about some other topic and four others started talking during the recall of Rey Auditory Verbal Learning Test. The procedure was adjusted using reminders – the examiner held a yellow paper to signal no talking.

Motivation and Other Factors

Motivation to complete the assessment was impacted by a number of factors. In spite of making the assessment as simple and short as possible, the assessment was experienced as lengthy and tiring particularly due to the extra time necessary for interpretation. Further, some found the tasks difficult and three participants, who initially agreed to participate, withdrew. Many participants had unexpected events occurring between sessions that led to them postponing the sessions for long periods of time. For example, several participants had traumatizing events happening with their families back in their country of origin as the assessment was progressing, one participant from Eritrea being re-traumatized when she received the news that her sister had been kidnapped by Eritrean militia.

For many participants, the motivation to complete the assessment was impacted by ongoing difficulties involved with the family reunification process. It was common for
participants to say that although they wanted to participate in the research, they could not concentrate on anything until they had reunited with their wife, children, or other family members.

None of participants had prior experience with cognitive testing. They all reported that spoken language was the primary means of responding in exam situations in their schools. Only two participants had any experience with drawing. None had experience with tasks such as Block Design, 20 questions, and timed tests.

Scoring and Interpreting

Age Appropriate Scoring

It was at times difficult to use age norms. For example, four participants did not know their real birthday and the date of birth was a random date that they gave themselves for the purpose of applying for refugee status:

S2: “I don’t know my real date of birth. My mother said I’m 25 years old but my passport shows that I’m 29 years old. I decided on the date of birth when I was applying to come as refugee. My father suggested at that time that I’m 29 years old, so I decided to go with that. I wasn’t registered in any document before”

Inferring the Pre-morbid Functioning

Estimation of pre-morbid functioning or previous cognitive functioning is based on demographic variables such as education, prior occupation, and socioeconomic status. However, as illustrated below, prior education, occupation, and socioeconomic status were often impacted by factors other than ability.

“I went to school in Afghanistan for 7 years, but I only learnt reading and writing in New Zealand. The school was very disorganized, one day I would go to school, the next day Taliban would come and close the school. Every day was uncertain, we couldn’t concentrate”.
“I only did 4 years school. I really liked learning but I was pushed to stop school because my parents couldn’t afford to let me go to school. I had to work the farm”

“I got no education in Somalia. Nobody in my tribe was allowed to go to school. I have learnt some writing in English school in New Zealand. I feel good I can write my name”.

“I couldn’t study or have a career like other people. I lived in refugee camp since I was a young boy until I came to New Zealand at the age of 29 years old”

Collateral Information

Information from family members who completed the Patient Competency Rating Scale - Relative form was available for only four participants. The other participants either had no family members in New Zealand, or family members were not able to attend or were unwilling to provide the information (often because they did not like to say anything negative). As can be seen from Table 5, reports from family members were generally more positive than the participant self-report and the reports from the counsellors.

Table 5

Overall Scores for PCRS Reports for Four Participants

<table>
<thead>
<tr>
<th>Participant</th>
<th>PCRS -Self Report</th>
<th>PCRS - Clinician’s Report</th>
<th>PCRS - Relative Report</th>
</tr>
</thead>
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<tr>
<td>S1</td>
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<td>3</td>
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<tr>
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<td>3.1</td>
<td>2.6</td>
<td>4.5</td>
</tr>
<tr>
<td>S3</td>
<td>2.8</td>
<td>3</td>
<td>3.2</td>
</tr>
<tr>
<td>S4</td>
<td>1.4</td>
<td>1</td>
<td>1.8</td>
</tr>
</tbody>
</table>

PCRS-Patient Competency Rating Scale
Reports on Specific Measures

Verbal Measures

*Wechsler Memory Scale IV – Logical Memory (Story 1 - Anna Thompson)*

The overall story was well remembered by most participants although for four participants the sentence stating that the woman went without food for two days triggered trauma as it reminded them of their own experience of going without food for days. That Anna Thomson worked as a cook in a school cafeteria was not remembered by most participants. Instead they recalled this part of the story as “Anna cooks”. Cultural advisors and the interpreter suggested that this could be due to few women working outside the family in these cultures.

*Logical Memory (Story 2 – David Cheng)*

This story was well accepted by most participants and generally recalled better than Story 1.

*Auditory Verbal Learning Test – AVLT*

This test was well accepted by most participants. Most had no difficulty understanding the instructions for the test and the words were easily understood and correctly remembered. There was a tendency for Burmese participants to perform better in this measure relative to other measures and to other participants. Consultations with the interpreters and participants revealed that listening and storytelling were a major part of Burmese culture.

“In my family we did not have TV or books to read, so it was part of every evening routine to sit with family members and share stories about the past and everyday life”.

*As a culture we value and respect people’s ability to listen*.”
“Schools in Burma usually rely in spoken language to test your ability. Usually teachers ask questions and the student answers. I never did a written test until English school in New Zealand”

Patient Competency Rating Scale

The Patient Competency Rating Scale (PCRS) (Prigatano et al., 1990) was initially developed to evaluate self-awareness following traumatic brain injury. The PCRS is a 30-item self-report instrument which asks respondents to rate difficulty in a variety of tasks and functions on a 5-point Likert scale. Self ratings are compared to those of an informant (a relative or therapist) who rates the subject on the identical items. Impaired self-awareness may be inferred from discrepancies between the two ratings, such that the subject overestimates his/her abilities compared to the other informant.

A number of issues arose in using this measure with this population. Firstly, the measure needed to be read aloud to most participants and extensive training was required to use the 5 point Likert scale. Secondly, functional difficulties were difficult to assess for men because the test is underpinned by a western point of view where men often share in the cleaning, cooking, and typically look after themselves in terms of activities of daily living. However, most men in this study reported that they did not do any house chores because that was the duty of their wife, daughters, or sisters. Similarly, asking women whether they could drive a car or handle their own finances led to confusion because these jobs were typically assigned to men in the cultures of these participants.

Nonverbal Measures

When using the nonverbal measures in this study, care was taken to provide optimal practice and notes were taken. Particularly for the timed tests, participants were prepared to work fast and they were allowed to finish the task even when the time elapsed. This allowed
Chapter 6

comparison with the norms, as well as whether or not they could complete with more time and avoided the sense of failure.

*WAIS IV- Block Design*

Observations were that four participants viewed this task as a child’s game and were offended by it, and for some it provoked high anxiety because they had not experienced this type of task before. The majority of participants asked for assistance and, in spite of this, only two participants achieved three dimensional designs within the given time.

*Color Word Test (DKEFS)*

The challenges associated with this test included a number of participants repeatedly stopping in the middle of the task despite repeated instructions to continue on until the end. Depending on the participant’s language, the translated words were shorter or longer than the English equivalent (two participants fluent in English completed the English version of the task and achieved average and above average scores but lower scores in their first language). As some participants could not read in English or their first language, (i.e., were illiterate) they were unable to read the words list.

*20 Questions*

Some participants (with less education) required more practice and repetition of instructions as noted above. In spite of this, the instructions for this test were understood by only two participants both of whom had higher education levels. To ensure that the lack of understanding was not due to translation error, the accuracy of the instructions was checked with translators. It was hypothesized that lack of understanding was either due to the cultural effects on the construct validity or due to complexity of instructions. The first hypothesis was supported by literature that has shown that categorization tasks tests abilities that are more characteristic of western educated people (Greenfield, 1997; Luria, 1932). To test the second hypothesis, the instructions were simplified. The altered instructions included the sentence:
“Make a question that eliminates not only one item but many of them”. The change of instructions led to many participants responding adequately.

In response to these instructions, 10 participants understood and were able to do the task although only a few used more than one strategy. In this case, while changing of standard instructions may have impacted the validity of the measure, this provides a good example of how a simple change of instructions can lead to better understanding of the task by an inexperienced examinee.

**Ecological Validity of Test Results**

Ecological validity refers to the extent to which test results relate to everyday functioning and is usually evaluated using statistical methods of comparison between test performance and real-world functioning indicators such as employment, self-report, and clinician ratings. Although evaluating the ecological validity of measures was beyond the scope of the current study, noticeable discrepancies between the obtained scores in particular tests and the participants’ capabilities in everyday life were observed. The following cases illustrate this:

**Case Study 1**

M, a 34 year old refugee from South-East Asia, had been in New Zealand for 20 months. He had completed four years of elementary school in his country of origin and had received some additional education in reading, writing, and religion. He had worked on the family farm until 10 years ago when he was captured and tortured by military over a two week period during which he sustained an injury in the right front side of his head that resulted in a loss of consciousness lasting 2-3 hours. During the neuropsychological assessment, M engaged well, was motivated and achieved average - above average scores on verbal memory measures, and low average scores in attention. Scores on tests of executive functioning, processing speed, and visuospatial and visuoconstructional ability were in the
impaired range. Specifically, he was unable to produce any block design and his copy trial of the Rey-Osterrieth Complex Figure was severely distorted. In addition, his performance on the finger tapping test was in the severe impaired range. These results were not due to lack of effort as he passed the TOMM test and clearly tried hard. However, his performance did not correspond with his functional capabilities as indicated by the following:

- His self-report of an average score of 4.5 (maximum 5) on the cognitive domain of Patient Competency Rating Scale, was collaborated by his clinician’s report.
- His occupation as a taxi driver relies on visuospatial and visuoconstructional domain and he reported no difficulty finding his way around or getting lost.
- After the injury, M escaped the prison and passed the border and escaped his country without any help.

There are several likely explanations for the discrepancy in results:

- M had three years of formal education which was undertaken during conditions of social instability and war.
- He comes from a small farming community, where there was little exposure to western ways of thinking, and he has minimal knowledge of English.
- M reported that he has never done a drawing or a test before and showed anxiety especially in tasks that he needed to manipulate with hands, and timed tasks (e.g. Rey-Osterrieth Complex Figure and Block Designs).
- M appeared very confident when doing verbal tasks, indicating good familiarity with this format of testing.

Case Study 2

L, a 29 year old man, arrived as a refugee in New Zealand in 2006. He had attended school in Afghanistan for seven years, had completed Level Three English in New Zealand since then and can communicate well in simple everyday conversational English. For the
least three years, L has worked as a tiler. L experiences PTSD and depression due to the many traumatic events he experienced in Afghanistan and during his escape journey. L obtained average and low average scores on most measures except for timed tests (e.g., Block Design Symbol Search, Finger Tapping, and Color-Word) which were in the impaired range. The most unexpected was his extremely low score on the Block Design Test. Time was not a factor influencing the result because he was asked to complete the designs after the time elapsed and was still unable to complete more than the two initial simple designs. Further, a good relationship between the examiner and the participant meant that he was not overly anxious and appeared to be putting in his full effort. However, this result did not correspond with his functional capabilities as indicated by the following:

- L reported no difficulty in his current occupation as a tiler, an occupation relying heavily on visuospatial and visuo-constructional ability.
- Further, his responses on cognitive items of Patient Competency Rating Scale indicated little or no difficulty.
- The most likely explanation for this result was that L had had no prior experience with the testing where manipulation of the materials with his hands was required.

**Results II: Differences between PTSD and TBI+PTSD Groups**

**Characteristics of the Sample**

Characteristics of the participants are depicted in Table 6. The PTSD+TBI group (N=7, 5 male, 2 female), did not differ significantly from the PTSD only group (N=7, 2 female, 5 male), in terms of age, education, and time in NZ. However, looking into the box plot data (see Figure 1) the following observations are noted. The PTSD sample was younger than the TBI+PTSD sample: all the participants in the PTSD sample were under the age of 39 years old, while 75% of TBI+PTSD group were older than 35 years, and 50% were older than
45 years. In terms of distribution, the TBI+PTSD group had a much wider distribution of scores than the PTSD only group. The PTSD only group had a higher education level ranging from 4 to 16 years of education compared to the TBI+PTSD group with a range of 0-10 years of education.

Table 6

Demographic and Clinical Characteristics of TBI+PTSD Group and PTSD Only Group

<table>
<thead>
<tr>
<th></th>
<th>TBI+PTSD (N=7)</th>
<th>PTSD (N=7)</th>
<th>Mann-Whitney U</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>Median</td>
<td>SD</td>
</tr>
<tr>
<td>Age</td>
<td>46</td>
<td>44</td>
<td>13</td>
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<td>5.3</td>
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<tr>
<td>Time in NZ</td>
<td>5</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Trauma Events</td>
<td>22</td>
<td>20</td>
<td>6</td>
</tr>
<tr>
<td>Depression</td>
<td>24</td>
<td>26</td>
<td>9</td>
</tr>
<tr>
<td>Anxiety</td>
<td>24</td>
<td>22</td>
<td>7</td>
</tr>
<tr>
<td>Stress</td>
<td>24</td>
<td>23</td>
<td>10</td>
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<tr>
<td>PTSD</td>
<td>3.2</td>
<td>3</td>
<td>4.8</td>
</tr>
</tbody>
</table>
Figure 1. Box plots comparing TBI+PTSD group and PTSD only group
Figure 2. Percentage of tortured participants in TBI+PTSD group and PTSD only group who reported experiencing beating to the head, electrocution, starvation, sleep deprivation and asphyxiation.

Trauma Exposure

There was no statistical difference between the groups in terms of trauma events experienced (see Table 6). Figure 2 shows that the TBI+PTSD group overall had a higher number of trauma events, where 50% of the sample experienced more than 20 trauma events, whereas 75% of PTSD only sample experienced less than 20 trauma events. Six out of seven participants in the TBI+PTSD group experienced torture, compared to four out of seven in the PTSD only group. Figure 2 displays the percentage of tortured participants in each group who experienced torture techniques that could have impacted on brain functioning. The figure indicates that all the tortured participants from both groups experienced beating to the head, starvation, and sleep deprivation. Two participants in the PTSD group experienced electrocution, compared to five participants in the TBI+PTSD group. Three tortured
participants in the TBI+PTSD group reported asphyxiation, while none of the PTSD only participants reported experiencing asphyxiation.

Psychological Symptoms

The mean, median, standard deviation, and differences test in measures of PTSD, Depression, Anxiety, and Stress are depicted in Table 6. There were no statistical differences between the groups in any of these measures of psychological functioning. The TBI+PTSD group reported higher PTSD symptoms as shown in Figure 1, and the statistical difference almost reached significance $z (-1.735), p=.097$.

Self-reported Functioning

As shown in Table 7 and Box-plot (Figure 1), the overall Patient Competency Rating Scale (PCRS) scores were slightly higher for the TBI+PTSD group (3.3 vs. 2.6), as were scores on all the individual domains of the PCRS. Only the PCRS-ADL scale reached statistical significance $z (-2.028), p<.05$.

Table 7

*Self-reported Functioning in Activities of Daily Living (ADL), Emotional, Interpersonal, Cognitive, and Overall PCRS, Patient Competency Rating Scale*

<table>
<thead>
<tr>
<th></th>
<th>TBI+PTSD (N=6)</th>
<th>PTSD (N=7)</th>
<th>Mann-Whitney U</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean Median SD</td>
<td>Mean Median SD</td>
<td>z p</td>
</tr>
<tr>
<td>PCRS ADL</td>
<td>4 4 1</td>
<td>3 3 1</td>
<td>-2.028 0.023*</td>
</tr>
<tr>
<td>PCRS Emotion</td>
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<td>2 3 1</td>
<td>-326 0.382</td>
</tr>
<tr>
<td>PCRS Cognition</td>
<td>3 3 1</td>
<td>2 2 0</td>
<td>-654 0.287</td>
</tr>
<tr>
<td>PCRS Interpersonal</td>
<td>3 3 1</td>
<td>3 3 0</td>
<td>-0.216 0.431</td>
</tr>
<tr>
<td>PCRS Overall</td>
<td>3 3 1</td>
<td>3 3 0</td>
<td>-0.789 0.231</td>
</tr>
</tbody>
</table>

* significant
Table 8

Mean, Median and SD and Differences in Scaled Scores of Cognitive Measures for PTSD Group and PTSD+TBI Group

<table>
<thead>
<tr>
<th></th>
<th>TBI+PTSD (N=5)</th>
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<th>Mann-Whitney U</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<td>Median</td>
<td>SD</td>
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<tr>
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<td>11</td>
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<td>3</td>
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<tr>
<td>LM-LC</td>
<td>10</td>
<td>10</td>
<td>2</td>
</tr>
<tr>
<td>AVLT-Trial 1</td>
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<td>5</td>
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<td>12</td>
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<tr>
<td>ROCF-DR</td>
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<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Digit Span</td>
<td>7</td>
<td>8</td>
<td>2</td>
</tr>
<tr>
<td>Symbol Search</td>
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<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Block Design</td>
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<td>4</td>
<td>3</td>
</tr>
<tr>
<td>20 Q-IA</td>
<td>7</td>
<td>7</td>
<td>2</td>
</tr>
<tr>
<td>20 Q-TQ</td>
<td>7</td>
<td>8</td>
<td>2</td>
</tr>
<tr>
<td>20 Q-TWAS</td>
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<td>9</td>
<td>2</td>
</tr>
<tr>
<td>Colour Reading</td>
<td>5</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Word Reading</td>
<td>4</td>
<td>4</td>
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<tr>
<td>Inhibition</td>
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<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Switching</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
</tbody>
</table>

LM-IR-, Logical Memory, Immediate Recall. LM-DR, Logical Memory Delayed Recall. LM-LC, Logical Memory Learning Curve. AVLT-IR, AVLT Immediate Recall. AVLT-DR, AVLT Delayed Recall. AVLT-LC, AVLT Learning Curve. ROCF-IR-Rey Osterrieth Complex Figure Immediate Recall. ROCF-DR, ROCF Delayed Recall. 20 Q-IA, 20 Questions Initial Abstraction. 20 Q-TQ, 20 Questions Total Questions. 20 Q-TWAS, 20 Questions Total Weighted Achievement Score

Neuropsychological Test Results

The mean, median, standard deviation, and differences test in measures of cognitive functioning are depicted in Table 8. The TBI+PTSD group had five participants, because two
Results

Results were excluded from the analysis due to invalid data. No statistical difference was found in any of the measures. The box plots (Figure 1) show that the PTSD only group tended to perform better in the three trials of the Rey-Osterrieth Complex Figure, and Block Design, whereas TBI+PTSD sample had higher scores in the Logical Memory-learning curve and the statistical difference almost reached significance $z (-1.69), p=.055$.

Results III: Clinical Issues in Neuropsychological Assessment of Refugees

The previous results sections reported the methodological and cross-cultural barriers involved in researching neuropsychological functioning of refugees. Despite the acknowledged limitations, we attempted to compare our two groups (PTSD and PTSD+TBI) on three variables: psychological functioning, current self reported functioning, and neuropsychological functioning. The results showed no consistent differences between the two groups. While our previous sections highlighted that doing rigorous research with this population is difficult due to cultural biases of the current neuropsychological methods and measures, heterogeneity of refugee samples, and difficulty in involving refugees in research, the question remains: Can neuropsychological assessment be useful with this population in the clinical setting and what needs to be considered when assessing the cognitive functioning of a refugee?

When assessing a refugee with PTSD and probable brain injury, three main questions may be asked in the clinical practice: Has this person sustained a brain injury?; What is the relative contribution of PTSD and TBI?; What could the client do before the injury(s) and what they can do now?

The following sections aim to explore these questions by providing case examples and observations that illustrate the challenges involved in answering these questions.
Diagnosis of TBI

To have sustained a brain injury, the person must have experienced a trauma to the head by an external object which results in structural brain damage or disruption of physiological brain functioning. Indictors of TBI are medical findings such as positive neuro-imaging loss/alteration of consciousness, and/or post-traumatic amnesia. While hospital records assist with the historical diagnosis of moderate-severe TBI, the “gold standard” for determining prior TBI is patient self-report, facilitated by structured or in-depth clinical interview (Corrigan & Bogner, 2007, p. 316).

TBI Screening

In the current study, the initial screening for TBI identified seven participants with probable brain injury. The characteristics of these seven participants, the characteristics of the injuries, and the self-reported symptoms post injury are depicted in Table 9. These participants were than interviewed in depth about the mechanism of injury, alteration/loss of consciousness due to the injury, and acute symptoms.

Determining the Mechanism of Injury

The description of the circumstances of injury and the mechanism of injury for each participant is shown in Table 10. As illustrated in these cases, aside for participant 2, all experienced multiple injuries and different mechanisms for each injury. Teasing out the circumstances of each traumatic event months and years after their occurrence was difficult due to memory fading and a lack of collaborative information. Furthermore, due to confusing circumstances, most participants had difficulty describing the weapon that was used. Although three participants reported bleeding as a result of the injury, it was not possible to determine whether they had an opened or closed injury, and whether the injury was a head wound and superficial, or whether it was a brain injury.
Determining Alteration/ Loss of Consciousness

Aside from participant 2, no collaborative information was available regarding the length of LOC or post-traumatic amnesia (PTA). To determine LOC/PTA, detailed questioning about the memories prior and after the injury was conducted. Tortured refugees were unable to give any information about time because they were usually blindfolded and isolated and had no way of measuring time. However, based on our best estimate, it seems likely that most sustained repeated and short periods of alteration/loss of consciousness.

Further complicating the issue is that they all sustained brain injuries in a highly traumatic context, where distinguishing whether the alteration of consciousness was due to physical trauma or psychological trauma was not possible at times. Accordingly, it was unclear whether a participant’s inability to recall the details of the injury was due to these factors, the brain injury itself, or a reluctance to re-visit the trauma. While in some cases, asking the person to compare the reaction between the traumas involving injuries to the head and other traumatic events not involving head injuries was helpful, this method was not helpful in a case of extended amnesia. For example, participant 6, who had been abducted and raped, remembered being thrown forcefully against a wall but nothing more until she found herself in a hospital a month later. Whether this “amnesia” was due to a brain injury or to psychological trauma or both was unclear.

Identifying Acute Symptoms

Post-concussion symptoms are a cluster of physical/somatic, cognitive, and emotional symptoms that begin or worsen immediately after the TBI event. These include dizziness, fatigue, disordered sleep, concentration problems, memory problems, slowed thinking, depression, anxiety, and irritability. While PCS in themselves do not mean that TBI has occurred, when these symptoms immediately follow an injury that has caused disruption of
consciousness, the likelihood of TBI is increased (L. A. Brenner, R. D. Vanderploeg, & H. Terrio, 2009).

Identifying the onset of PCS can only be done through retrospective self-reports. The reliability of these reports was questionable due to memory fading, multiple trauma events, confusion, and inability to pay attention to any symptom due to an ongoing fight for survival. Thus, participant 5 was unable to pay attention to any symptoms until he came to New Zealand. While some participants were able to name the symptoms following the injury, their symptoms were identical to their current symptoms (see Table 11), raising the question of whether they were remembering the actual post-injury symptoms or the general symptoms that they have been experiencing for a long period of time. The problem in attributing current PCS to historical brain injury is that PCS are not specific to TBI, and are frequently reported by people with psychological and other physical disorders (Hoge, Terhakopian, Castro, Messer, & Engel, 2007).
### Table 9

**The Characteristics of Participants and Head Injuries**

<table>
<thead>
<tr>
<th></th>
<th>P1</th>
<th>P2</th>
<th>P3</th>
<th>P4</th>
<th>P5</th>
<th>P6</th>
<th>P7</th>
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<td>32</td>
<td>40 to 46</td>
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<td>Sex</td>
<td>M</td>
<td>M</td>
<td>M</td>
<td>M</td>
<td>M</td>
<td>F</td>
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<td>Time since injury (years)</td>
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<td>14</td>
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<td>?</td>
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<td>&gt;2 hours</td>
<td>&lt;30, , &gt;1 day</td>
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<td>Unknown</td>
<td>&lt;30min</td>
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</tr>
<tr>
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<td>Y</td>
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<td>Y</td>
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<td>Y</td>
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<td>All body</td>
<td>Back/Neck</td>
<td>All body</td>
<td>All body</td>
<td></td>
</tr>
<tr>
<td>Frustrated/impatience</td>
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<td>N</td>
<td>Y</td>
<td>Y</td>
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<td></td>
<td></td>
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<td>Fear</td>
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<td>Y</td>
<td>Y</td>
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<td>Y</td>
<td>Y</td>
<td>Y</td>
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<tr>
<td>Personality change</td>
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<td>Y</td>
<td>N</td>
<td>Y</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Can't Identify**: Y

**Dissociations**: N
Table 10

*The Circumstances and the Mechanism of Head Injury*

<table>
<thead>
<tr>
<th></th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>K experienced beatings to the head and body, electrocution, malnourishment, and near drowning while he was repeatedly tortured in Iraq. While none of these events resulted in the loss of consciousness, he often experienced alteration of consciousness such as confusion and vision disturbances. K reported that the most significant injury was sustained as an asylum seeker on a boat in Australian waters. K remembered falling to the floor as a result of being pushed by the mass that were running from the tear gas and from authorities that were pushing and beating the crowd. As K tried to get up, a policeman hit him in the head with a &quot;metal baton&quot;. K lost consciousness and his first memory afterwards is of the next day. K experiences a number of symptoms following this injury (see Table 9).</td>
</tr>
<tr>
<td>P2</td>
<td>M was assaulted by his wife's brother due to family opposition to their inter-sectarian marriage. M was assaulted while he was working in his shop. Because M had no memory of the circumstances surrounding the assault, his wife provided the information. His wife assumed that the assaulted was carried out with a &quot;sword&quot; in the back of M's head. Although he experienced bleeding, it was not clear whether his skull was penetrated. (Now, six years from the injury, there are visible signs of the injury sloping down from right to left on the back of his head). He was taken to hospital where he stayed in a coma for a week. When he came out of the coma, he experienced a number of symptoms as listed in Table 9. The couple experienced another attack in 2006 where a bomb was thrown in their house causing burns to parts of M's body. He does not remember this event, and what is reported here is from his wife's account. Subsequently, the couple went to Malaysia where M had an MRI scan which showed a generalized mild cerebral atrophy.</td>
</tr>
<tr>
<td>P3</td>
<td>T sustained a head injury during torture. T remembered the interrogators slamming the right front side of his head to the wall resulting in LOC that would have lasted for 2-3 hours. This was an approximate guess based on information from a fellow prisoner. T remembered becoming conscious as he was taken to the cell, his right side of the head was bleeding. Given the circumstances of the injury, it is not possible to reliably determine the length of LOC and PTA. Furthermore, his experiences of LOC could have been confounded by his psychological reaction to severe beatings, and the lack of a clock to measure time. There was no evidence of retrograde amnesia (RA) as T remembers the moments preceding his injury (e.g., the start of the interrogation, the start of the severe beatings, and the moment his head was slammed to the wall). Acute symptoms are described in Table 9. T also experienced black outs two to three times due to electrocution and asphyxiation. In addition, T has experienced repeated and extended periods of starvation.</td>
</tr>
<tr>
<td>P4</td>
<td>W had been imprisoned for seven years during which time he was repeatedly tortured. During this time he sustained a number of injuries to the head and lost consciousness several times. The type of injuries included: repeated beatings to the head with hard objects (e.g., rifle, telephone), suffocation with a plastic bag and electric shock which was administered to his the hands. Beatings to the head led to loss of consciousness at least three times. The length of LOC was difficult to determine but at least in one occasion LOC was longer than 30 min. In addition, the suffocation led to losing consciousness for a short period of time (approx. five mins).</td>
</tr>
</tbody>
</table>
P5 A reported numerous occasions when he lost consciousness while being tortured. His loss of consciousness was due to beating to the head with a rifle and near drowning. He was unable to relay any information about the duration of LOC and PTA as he was confused and blindfolded during the entire time. A reported going for weeks without food and reported that he came out of prison looking all skin and bones. A couldn’t remember if he experienced any symptoms following his injuries as he had been focused on surviving and only noticed attention and memory difficulties after settling in NZ.

P6 F was kidnapped at the age of 14 when for approximately two months she was tortured and raped repeatedly. Her way of coping with this experience was to dissociate. She saw herself from a distance and didn’t feel any pain. However the last memory she has of this experience is being thrown forcefully in the floor. From that event she does not remember anything for a month, after which she woke up from what she called “coma” and found herself in hospital surrounded by nurses. She had blurred vision and was confused about being in hospital. The nurses told her that she had been in hospital for a month, mostly in a state of confusion with intermittent outbursts of anger and screaming. The symptoms that she noted are listed in Table 9.

P7 K reported two head injuries that involved loss of consciousness. The first injury occurred in Burma in December 2005, where a soldier struck her on the face with his elbow. This was a high impact hit that led to K falling on the back of her head on the floor and losing consciousness for a time period that she could not determine. Circumstantial evidence indicates that the loss of consciousness (LOC) could not have been longer than 10 minutes. K reported no pre traumatic amnesia; however she was confused two to three days post injury. As a result of this injury, K lost her teeth, the back of her head was swollen for a week, and she experienced confusion and noise in her ears. The second injury occurred in 2007 in Malaysia, where K was hit by a car while she was biking. The car hit her from behind and she fell unconscious with the front of her head on the footpath. People dragged her to a shop and she was conscious again within five minutes. She was taken to hospital where she spent three weeks. Subsequent to this injury, K experienced symptoms listed in Table 9.

Determining the Relative Impact of PTSD and TBI

Neuropsychologists are regularly asked to differentiate between the relative contribution of brain injury and psychiatric disorders in a person’s cognitive deficit (Uomoto & Fann, 2004). To answer this question, it is necessary that the pattern of cognitive deficit related to PTSD and TBI is understood. The literature review of PTSD and TBI concluded that:

PTSD mainly affects attention and verbal memory (Brewin et al., 2007), although this conclusion is mainly based on studies with US veterans, and western survivors of abuse and
car accidents. However, drawing any conclusion about PTSD related cognitive pattern in refugees based on only two studies with small populations and with highly heterogeneous samples is not possible. As is the case with our sample, PTSD samples reported in the literature usually experience co-occurring psychiatric disorders (e.g., depression) which make it difficult to separate out PTSD related outcomes.

The TBI outcome is variable, depending on the severity, mechanism of the injury, the site of injury, and individual psychological factors (Millis et al., 2001).

Given the diversity in the cognitive outcome related to PTSD and TBI, comparing individual outcomes with general outcomes reported in literature is inherently difficult even with non-refugee populations. However, the following section will report behaviour observations and test results of our sample to evaluate whether the question regarding the aetiology of cognitive deficit can be answered.

People Showing Clear Signs of TBI

In this study we identified two people (Participant 1 and 2) with symptoms that were more consistent with the outcomes of brain injury than PTSD. Although their quantitative data were invalid due to Participant’s 1 distractibility and Participant’s 2 apathy, the following observations and collaborative information indicated TBI consistent behaviour patterns that were easier to describe and related to possible underlying causes.

P I

K presented as a middle age Iraqi man who had completed a tertiary education and worked as a teacher and mechanic until he was imprisoned in 2000. After being released from the prison in 2001, he escaped Iraq and lived in numerous refugee camps until he arrived in New Zealand in 2003. While in Iraq, K looked after his family and was a respected member of his community. He was described by his wife as an independent, mildly tempered, and easy going man. However, K’s wife reported that when she reunited with K in NZ in 2004, he
was so different as to be almost unrecognizable. She found him very distractible, angry, impulsive, and forgetful. As a result their roles have reversed where she has full responsibility over the family affairs. K is currently on a disability allowance and he has only managed to learn a few words in English during the last six years. He has quit English classes after two attempts because he was unable to sit and concentrate. K's wife reported that K sleeps most of the day, forgets to look after his personal hygiene and when he is awake he wanders aimlessly. He is very impatient and can get very angry when frustrated. She gave examples of him hitting his head on the wall and having outbursts of screaming and crying. While K has experienced beatings to the head, electrocution, and asphyxiation during torture in Iraq, he reported that his symptoms started following the injury when he was caught in a boat that attempted to illegally enter Australia. During the assessment, K appeared easily distracted and frustrated, expressing very low tolerance for his mistakes. Despite understanding the nature of the assessment, he repeatedly stopped in the middle of the tasks (including the timed tasks) to talk about the topics that were coming to his mind. Some test stimuli triggered him to talk about his experiences. For example, Story 1 of the logical memory test (Anna Thomson), triggered him to talk about his experience when he didn't have food and his experience with police. K did not put in effort when he perceived a task as difficult and gave up easily, he also failed on easy tasks (e.g., digit span, AVLT) that should have been well within his grasp as a teacher and mechanic. Thus, while acknowledging the limitations of the current assessment, the observations and collateral information provided evidence that: a) K is highly distractible with a small attention span, and inability to focus attention; b) K experiences high levels of impulsivity, low frustration tolerance, and had little regard for assessment instructions; c) K showed impaired planning skills particularly in his approach to ROCF; and d) executive functioning related to inhibiting and switching were impaired in formal testing which was consistent with presentation where he was unable to
inhibit his thoughts and engage with the task. The site of injury, assessment results, and observations coupled with his self-report and his wife’s report that he has experienced personality changes since the injury are evidence that his cognitive functioning particularly related executive functioning is impaired.

\[ P \ 2 \]

M is a 45 year-old Iraqi man who had completed high school in a prestigious private school in Iraq. He described himself as a lazy student who did not participate in activities, was bullied and was perceived as weird. As an adult, he worked in his family owned shop selling chocolate ingredients. His wife remembered him as an active, competent, and cheerful person. M’s wife reported that subsequent to the injury he sustained during an attack (see Table 7), M’s personality has changed dramatically. She reported that:

- M’s personality is child-like (e.g., he cries like a child when he doesn’t get his way)
- He cannot plan ahead
- Makes the same mistakes and doesn’t learn from experience
- Is withdrawn and lacks any initiative
- Loses control of urine and bowels and is unconcerned about it
- Shows little emotion
- Lacks initiative - sits all day doing nothing
- Needs supervision inside and outside the house because he is inattentive and forgetful (e.g., he walks off paying little attention to traffic)
- When he washes himself he forgets parts of his body and can stay in the bathroom for long periods of time unless reminded what to do in a step by step manner.

During the assessment, M appeared anxious. His posture was slightly rigid and movement slowed. He made little eye contact and stayed with his head down. He was happy, however, sitting while his wife talked about him. His facial expression was one of
sadness/depression, sometimes appearing anxious. On a few occasions he expressed excitement in an exaggerated startled manner, when we talked about familiar topics, but overall, his affect was restricted, flat, and lacked spontaneity. Personal details and test performance were elicited only with continuous prompting. He was not overtly uncooperative, only rather inattentive. He displayed childlike behaviour (e.g., outside the context he would say “Do you like horses?” “I love horses” or he would say: “I’m very polite, do you think I am polite?”) M lacked the drive to participate in any task. Responses were difficult to elicit and when he answered his demeanour was suggestive of lack of effort. Although he obtained a low score on a test of effort, M’s scores were low because he failed to choose any item, rather than because he chose the incorrect one – accordingly the results were invalid. His willingness to participate was inconsistent and he expressed a lack of concern about correct performance. All neuropsychological test scores were at the extremely low range. Below are outlined behaviour observations of his performance:

**Learning and Memory Tests**

- The learning curve was flat. He failed to learn more than three words learnt in the first trial.
- Impoverished learning strategies (inefficient encoding strategies).
- Poor retrieval strategies (cuing did not help, recognition recall was as bad as free recall).
- Difficulty with temporal tagging of learnt information (mixing up the first and the second list of words). He mixed up the examiner’s name with the name of main character in the logical memory (Wechsler Memory Scale, logical memory).
- Intrusion and perseverations occurred within the task and across tasks. For instance, when he heard the word horse, he jumped excitedly saying “I love horses”. He than said the word horse repeatedly in each of six trials. Furthermore, while talking he would often be interrupted by other intrusive thoughts.
• M's performance was in the extremely low range in a measure of visual memory. His copy contained very few elements and he lost many elements of the design, making increasingly impoverished reproductions of the original figure as he went from immediate to delayed recall. This pattern of result is often found in patients with severe right hemispheric damage, particular right frontal. But again his effort level was questionable.

Attention and Concentration

• M's scores on attention tasks were invalid. However his general presentation, as noted above, during testing was suggestive of severe attention difficulties. He was unable to concentrate for long periods of time and highly distracted by any internal and external stimuli.

Executive Functioning

M was unable to complete executive functioning tests. The following paragraphs will report these observations clustered around the main executive functions as described by Lezak, Howieson, and Loring (2004).

Volition, Planning, Social Awareness

• M volunteered little and required continuous prompting. Lack of initiative was noted during test application. For instance, when presented with the Trail Making Test, he failed to start the test despite understanding the instructions. After the examiner made an initial move in his hand, he continued the task, finishing parts of Condition 1 with many mistakes which he failed to recognize.

• M was socially awkward and showed age inappropriate behaviours noted above.

• There were a number of indicators of deficit in M's planning ability. For example, the performance in Rey-Osterrieth Complex Figure was very fragmented and he had no awareness about the missing parts. Similarly, he impulsively arranged the block designs
but none of the designs represented the sample design. He was unaware of the obvious mismatch. The following extract also demonstrates M’s lack of planning ability:

Examiner: What activity would you like to do?
Client: Learn piano
Examiner: What should you do before beginning to learn piano?
Client: I would like to have a piano in a house with my wife.
Examiner: What else do you need to do?
Client: Nothing, just have the piano? Can you get a piano for me?

Self Regulation, Self Monitoring

- M displayed general response sluggishness. When he performed in a test requiring reading word or colours quickly, he started at a rapid rate but then slowed, appeared to forget the instructions, and then often just stopped all together.
- Perseverance is the ability to maintain a task despite distractions. Based on the observations of M’s performance, it is likely that this function is severely damaged.
- M displayed a consistent pattern where his performance would slow down; he would lose interest and give up. There were no discernible factors, for example distraction, causing this.
- M did not maintain arm extension or performance on the finger tapping task for the 10 seconds trial.
- Impersistence is particularly associated with the right hemispheric dysfunction and the rehabilitation prospect is poor for those that have marked impersistence,
Self Monitoring

- This executive function is manifested by person’s ability to self correct. M lacked this function, for example, he was sure that he did well when he did not. Furthermore, he made efforts to compensate in a very idiosyncratic manner. For example, when asked to tell the WMS - Story II for the second time, he started telling a story which had nothing to do with the second story.

- Finger Tapping assesses fine motor skills. Here as noted above, M had difficulty initiating movement and when he did with the help of examiner, he had difficulty inhibiting the movement of other fingers.

- Condition 1 of Trail Making Test was used to measure gross motor skills. He failed to initiate this task, quickly gave up and was unaware of the many mistakes he made.

Formulation

M is a right handed 45 year old man who was unable to complete most of the cognitive tests and received extremely low scores on all the tests. The pattern of scores is unlikely for even severe brain injury and may be partially attributed to his lack of effort. However, his presentation and part of his performance indicated real deficit in many areas most notably those related to frontal lobe functioning.

For instance, inability in inhibiting responses, lack of planning abilities, impaired ability to monitor behaviour, misuse of environmental cues, impulsivity, perseveration, lack of concern about correct performance, confabulation and child like behaviour are all manifestations of frontal lobe dysfunction and M displays all these symptoms. Furthermore, besides these personality changes, M displays disturbances in drive, mood, and affect, which are often found in patients with frontal lobe dysfunction.

However, attribution of these symptoms to disturbances in particular neuroanatomic loci are suggestive rather than conclusive. Lack of reliable information about both the lesion
and his premorbid psychological functioning as well as invalid test results make it impossible to draw any conclusions. This is further complicated by the fact that M has been diagnosed with PTSD and is depressed.

The question as to whether the suggested current functioning is due to brain injury, childlike dependency, depression, and/or PTSD can not be ascertained due to the limitations of this assessment. However, there are two possibilities:

First, M has sustained brain injury as supported by the report of loss of consciousness, the timeline of events and the later MRI results. However, there needs to be clarification regarding the circumstances of this injury. A question that arises is whether a hit/laceration from a sword to the back of the head can cause an injury resulting in such severe symptoms, particularly since the reported MRI results do not implicate the occipital region. Perhaps, however, there was contra-coup injury involving the frontal regions. However, because M has difficulty remembering the event, it is hard to determine what weapon was used thus leaving a possibility that another weapon (e.g., axe) with more impact may have been used.

Second, M reported that other people thought he was weird when he was young which may indicate some personality predisposition that may have been triggered by the trauma event in 2003. Thus, his previous trauma, and maladaptive coping may have led to M developing full dependency on his wife and his presentation and his lack of effort in performance is motivated by this dependency need.

**Individuals with More Subtle Cognitive Deficits**

When looking into the reported cognitive symptom of Participants 3,4,5,6 and 7 (see Table 11), it is observed that most did not show a distinctive pattern of cognitive symptoms. They all reported difficulty in attention, memory, slowed thinking, headaches, and increased anger which can be due to TBI or other causes (e.g., PTSD, depression). Only one participant reported personality changes which she described as dissociation. Three participants reported
that they got lost regularly. However, given that they came from small villages, living in a big new city could also contribute to their ability to navigate the place. Therefore, given that most refugees are likely to have sustained brain injury due to blunt trauma, asphyxiation, and electrocution, it is likely that most will not show unusual cognitive symptoms that can be easily attributed to organic brain injury.

Table 11

*Current Cognitive and Psychological Symptoms*

<table>
<thead>
<tr>
<th></th>
<th>P3</th>
<th>P4</th>
<th>P5</th>
<th>P6</th>
<th>P7</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cognitive symptoms</strong></td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>Headache</td>
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</tr>
<tr>
<td>Slowed thinking</td>
<td>Y</td>
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<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Poor concentration</td>
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<td>Y</td>
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<td>Y</td>
</tr>
<tr>
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<tr>
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<td>N</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Gets lost</td>
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<td>N</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Dizziness</td>
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<td>N</td>
<td>Y</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Personality change</td>
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<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>PTSD</td>
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<td>Y</td>
</tr>
<tr>
<td>Chronic pain</td>
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<td>Y</td>
<td>Y</td>
<td>Y</td>
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</tr>
</tbody>
</table>

In terms of neuropsychological profile (see Figures 3, 4, 5, & 6) of the four participants who were able to complete the assessment (Participant 5 was excluded from the analysis because he did not complete all the measures) the following observations were noted.

They all showed relative strengths in verbal memory measures versus non-verbal measures. Except for Participant 4, they all performed at extremely low range in measures of
visual memory. Because two participants performed in the extremely low range in the copy trial of this task, their scores in the immediate and delayed conditions of this task cannot be used as indicators of visual memory. One participant showed the usual pattern where the copy trial was better than immediate recall and immediate recall better than delayed recall. Another participant had the highest score in the copy trial but showed no difference between immediate and delayed recall.

Comparing across different conditions, the AVLT test (e.g., first recall, immediate recall, delayed recall, and learning curve) revealed an inconsistent pattern across participants: One participant showed relative weakness in the delayed recall, one participant showed relative weakness in the immediate recall, and two participants showed a relative weakness in the first recall. Further, two participants showed a pattern of relative weakness in the immediate recall versus delayed recall of the Logical Memory Test.

They all performed close to the average range in digit span (measure of simple attention span), and their performance in symbol search task (complex attention task) was consistently lower.

All our participants had difficulties with the colour-word test, all the participants achieved extremely low range results in trials 3 and 4 of this task (inhibition, switching).

Three participants achieved low average to average scores on the 20 Question test (measure of abstract thinking), and one participant achieved a borderline range result.

In a measure of visual-spatial skills, three participants achieved low average to average scores, and only one participant had difficulty performing this task and achieved a borderline range result. Aside from participant 4, they all achieved relatively lower scores in a measure of visuo-constructional skills (Copy Trial-ROCF).

Thus, the only consistent result across participants was that they all showed a relatively lowered performance in the complex attention task, and measures of executive
control, inhibition, and switching. In addition, they all achieved the highest scores in the measures of verbal memory, although they each showed a different pattern of performance. The results of the visual memory measure cannot be interpreted because most of them had difficulty doing the task, which means that if they were not able to copy the picture, they could not remember it.

While all the participants showed a relative weakness in attention and executive functioning, the severity of their impairment cannot be ascertained due to the effects of other factors such as culture and education, and inability to determine pre-morbid functioning. Similarly, while they all showed relative strength in measures of verbal memory, the extent to which this is attributed to the actual cognitive processes or their familiarity with the test format is questionable.
Determine Pre-morbid and Current Cognitive Abilities

Determining a Person’s Ability Prior to Injury

To answer this question, it is essential that pre-morbid functioning is determined, which is usually based on individual level of education, employment history, and performance in measures of pre-morbid functioning. Table 12 reports pre morbid and current functioning of the seven participants. Three of the participants had less than four years of education, and one participant had no schooling (i.e., illiterate). As illustrated in Table 12 and earlier in this chapter, the ability to attend school and have a job were related to social conditions, which impact confidence in interpreting previous work and education as reliable indicators of pre-morbid functioning. Noteworthy is Participant 2 who completed high school and worked as a shop assistant. However, he reported that he was not a good student and he achieved because his family was wealthy and supported him. Therefore, the extent to which he would be able to independently complete school or have a job was uncertain. In contrast, Participant 8 dropped out of school after four years of education due to financial difficulties, although she was a good student. She presented as an intelligent woman and was one of the few who successfully completed the complex task which is an indicator of intellectual ability (e.g., Block Design).

Thus, aside from for some cases (e.g., Participant 4), pre-morbid functioning is difficult to determine based on education and job history. However, given that intellectual functioning is to a large extent related to a person’s ability to problem solve and adjust to difficult situations, asking them how they dealt with complex situations before and after the injury may give some indication of their intellectual level across time.
Table 12

*Pre-injury and Current Self-reported Functioning*

<table>
<thead>
<tr>
<th></th>
<th>Pre-Injury</th>
<th>Current</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>K has a tertiary education and worked as a teacher and mechanic until he was imprisoned in 2000. After being released from the prison in 2001, he escaped Iraq and lived in numerous refugee camps until he arrived in New Zealand in 2003. While in Iraq, K looked after his family and was a respected member of his community. He was described by his wife as independent, mildly tempered, and an easy going man.</td>
<td>K is currently on a disability allowance. He has only managed to learn a few words in English during the last six years. He has quit English classes after two attempts because he was unable to sit and concentrate. K's wife reported that K sleeps most of the day, forgets to look after his personal hygiene, when he is awake he just wonders aimlessly, he is very impatient and can get very angry when frustrated. She gave examples of him hitting his head on the wall and having outbursts of screaming and crying. K’s wife reported that when she reunited with K in NZ in 2004, he was so different, almost unrecognizable. She found him very distractible, angry, impulsive, and forgetful. As a result the roles have reversed where she has full responsibility over the family affairs.</td>
</tr>
<tr>
<td>P2</td>
<td>M reported to have finished high school. He received a private school education because he apparently came from a wealthy family. He described himself as a lazy student who never participated in activities. According to his self report, as a child he was bullied by other children and people thought he was weird. However, as adult he worked in his own shop selling chocolate ingredients. His wife remembered him as an active, competent, and cheerful person.</td>
<td>M has been unemployed since the injury in 2003 and currently receives a disability benefit. M has not been able to learn English and he is fully dependent on his wife who looks after his personal hygiene, and all the other affairs. Due to his cognitive difficulties and anxiety M is unable to do any activity on his own or leave the house without his wife’s supervision.</td>
</tr>
<tr>
<td>P3</td>
<td>T had completed four years elementary school and had received some additional education in reading, writing, and religion in Monastery. He had worked on the family farm until ten years ago when he was captured and tortured by military. T escaped the prison and lived in a refugee camp in Malaysia. During this time he worked various manual jobs and supported his family back in Burma.</td>
<td>T currently lives alone in a council flat. He manages all his affairs independently, he attends English course regularly and works a few hours a week as a taxi driver. T spends most of his time trying to organize the escape of his family from Burma and with the help of his counsellor has prepared a family unification application.</td>
</tr>
<tr>
<td>P4</td>
<td>W had completed a university degree in engineering and worked as a pilot engineer prior to being imprisoned for seven years. After he was released from the prison, W escaped to Malaysia where he held a number of important jobs in managing refugee camps.</td>
<td>W lives with his wife and a two year old son. He is currently working as a painter part time and is attending a full time course at polytech and aims to have his business as a painter at the end of the course. W has attended a number of English courses and speaks English well. He manages all his family affairs, and provides financial support to his two children in Burma. W spends a considerable amount of time trying to organize the escape of his children from Burma.</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>P5</td>
<td>A had never attended school and was illiterate. He worked as a farmer, earning his money working in other people's farms.</td>
<td>A lives with his three daughters in a city council flat and receives government support. Since coming to NZ, he has learnt some English and was able to write his name. He reported that an English course has helped him with communication but he felt tired and was unable to concentrate for long in the class. Although he has not been able to find regular employment, A walks around the city all day looking for jobs. When he sees a building site, he asks people if they can give him a job and sometime this approach is successful. In terms of his daily activities, he reported that all the jobs at home are done by his daughters. A reported that his children also look after the finances because they can speak English.</td>
</tr>
<tr>
<td>P6</td>
<td>G completed four years of education. She liked learning but was forced to stop school due to social insecurity. G helped on the family farm and child rearing until she was kidnapped at the age of 14.</td>
<td>G lives as a single mother of a child. She has learnt English well and was able to complete the assessment in English. G manages to look after herself and her daughter with little support. She is not employed and receives financial support from government.</td>
</tr>
<tr>
<td>P7</td>
<td>K completed four years of education and although she reported being a good student, she had to stop school to help her family by doing paid jobs. She worked in other people's farms and also sold fruit and vegetables in markets.</td>
<td>K is a single mother of six children, two still living in Burma. K receives financial support from the government. She attends an English course regularly, but reports that the progress has been slow due to poor concentration. K does all the house work but is very dependent on her children for managing finances and other activities that require knowledge of English. K also reported that she needs support in finding places due to her inability to remember roads.</td>
</tr>
</tbody>
</table>
Determining a Person’s Current Abilities

In order to determine the current abilities of refugees, consideration of environmental demands are particularly important. Probably more than any other population, refugees experience dramatic changes to their environment. Therefore, their difficulty with adjustment may be due to increased environmental demands (e.g., learning a new language, adjusting with community support, changes in employments and the way of living. As demonstrated in Table 12 above, aside from one participant, all the others were unemployed and were receiving government support. While their symptoms clearly contribute to their unemployment, lack of English language knowledge and a New Zealand qualification were major barriers to their functioning. Furthermore, determination of a person’s current abilities requires that cognitive measures have appropriate ecological validity. As reported earlier in this chapter we found evidence that some measures had poor ecological validity.
Chapter 7: Discussion

The research literature has revealed that refugees are vulnerable to neuropsychological difficulties due to high rates of PTSD and TBIs (Jacobs & Iacopino, 2001; Moreno & Grodin, 2002). The lack of neuropsychological studies with this population motivated the current research. Being aware from the outset of the methodological and cross-cultural issues that characterise current neuropsychological methods, attempts were made to address these issues based on the recommendations from the literature. For instance, improving the validity of cross-cultural neuropsychological assessment by avoiding using normative data as a comparison (Pedraza & Mungas, 2008); including “extended practice when assessing the non-test-wise-client” (Nell, 2000, p. 173); using a trained interpreter who can “write patient responses verbatim, discern subtle alterations in language, and communicate/translate back myriad of observations” (Perez-Arce & Puente, 1996, cited in Weinstein et al., 2001); providing sufficient preparation prior to the evaluation about the testing process (Shepherd & Leatham, 1999); and evaluating proficiency with English, reading ability in native language, vocational background, degree of acculturation and variation within culture (e.g., urban vs. rural) (Manly et al., 1998).

These recommendations were incorporated in the current study that aimed to explore the effects of PTSD and TBI on the cognitive functioning of treatment seeking refugees. Furthermore, this research also had as a focus the evaluation of the methodological barriers in the neuropsychological research with refugees since cross-cultural neuropsychology has not represented this population.

Since the initial goal of quantifying and comparing the cognitive functioning of refugees with PTSD and with co-morbid TBI and PTSD was difficult to attain due to methodological barriers we encountered and the difficulties with engaging this population in
research, the main focus of this research became the exploration of the assessment issues in
europsychological research and clinical practice with refugees. The following sections
discuss these findings, outline the limitations of the current research and offer some
suggestions for further research and for neuropsychological practice with refugee population.

Methodological Barriers

The process of assessment of the participants in this study revealed a number of
methodological difficulties that could be encountered when neuropsychological assessment is
attempted with refugees. Key methodological difficulties were participants’ lack of
familiarity with the context of neuropsychological assessment, lack of prior experience with
testing particularly in performance based tests, lack of relevant demographic information,
lack of reliable markers of pre-morbid function, and poor ecological validity of
neuropsychological measures. Additional barriers that impacted on the engagement of
refugees in the research were the ongoing stressors that they were experiencing which will be
discussed in more detail later.

The observation of the process of assessment indicated that most refugees required
additional time to build rapport and the impersonal communication recommended in test
manuals was inappropriate. This finding is consistent with the Greenfield’s (1997) suggestion
that impersonal communication violates the conventional expectations of many cultures,
which can influence participants’ motivation and cooperation. This issue is particularly
relevant when working with a refugee population who have a history of torture, in which case
impersonal questioning can be a reminder of interrogation. Therefore, any study that targets
this population needs to consider the relationship between researcher and participants as an
important part of the design.

Most participants had recently arrived in New Zealand, with low levels of
acculturation and little exposure to any educational system let alone one based on western
models. In addition, they reported a lack of experience with the testing format, particularly nonverbal tasks. It was also clear that lack of experience and understanding of the nature of cognitive testing interfered with their ability to perform to the best of their ability. For many participants in our study more familiarity with testing (e.g., repeating instructions, more practice trials) would be required before a valid result could be obtained. However, for many measures this goes against the recommendation for maintaining standard procedure, and particularly in the context of quantitative research it can lead to invalid results.

Lack of prior experience with testing has been identified as an important factor that accounts for cross-cultural biases of neuropsychological assessment (Ardila, 2000) and many have recommended that neuropsychological procedures evolve to accommodate extra training for people with no prior experience. Indeed, Vygotsky (1986) proposed that the testing condition should be more dynamic, where feedback can be provided in order to determine an individual’s potential for learning given adequate experience. In addition, Greenfield (1997) proposed that a more dynamic assessment procedure would also assist in overcoming the disagreement in meaning and value between the examiner and examinee. Thus, giving the client the opportunity to communicate their interpretation of the task would help the examiner understand whether the client has the same understanding of the task. However, as yet there seems to be no significant progress towards accommodating these changes in neuropsychological assessment procedures.

The current study also found support for the concept of culturally reinforced skills proposed by Ardila (2000). Burmese people, for example, whose culture encourages listening and sharing stories, performed very well in verbal memory tasks, whereas drawing and building patterns with blocks was not well accepted by participants for whom this type of responding was unusual and even considered by some as children’s games. Similar results are found in literature with other populations (e.g., Salmon et al., 1995). What is noticeable in
our study and the study by Salmon et al. (1995) is the resistance of many cultural groups to performing nonverbal tasks.

When using nonverbal measures in this study, great care was taken to provide optimal practice and detailed recording of observations. In addition, participants were allowed to finish timed tasks even when the time elapsed in order to assess their performance without the time restraint which is known to affect cross-cultural application of these measures (e.g., Hughes & Trautmann, 1995). Despite these efforts, it was clear that nonverbal measures were more impacted by the lack of prior experience.

Another important observation in this study was the lack of ecological validity of some measures. While in this study it was not possible to test the ecological validity for the whole group, there were indicators of poor ecological validity particularly for visuospatial and visuo-constructional tasks and tasks of executive functioning. This is in line with general literature which has reported poor ecological validity of neuropsychological measures (Chaytor & Schmitter-Edgecombe, 2003), particularly measures of executive functioning (Odhuba, Broek, & Johns, 2005; Wood & Liossi, 2006). Clearly the use of measures that mimic demands of the person's everyday functioning (e.g., Rivermead Behavioral Memory Test) would have been more appropriate for the current research, although this would not have eliminated the problem of artificial settings (e.g., office vs. participant's environment). Ideally, fuller integration of testing, behavioural observation in the participant's own environment, coupled with the incorporation of research and technological discoveries, would have lead us to a richer understanding of the functioning of the individual in context, however, such an undertaking would have introduced additional costs and complexities that would need to be addressed in a much larger scale study.

Additional difficulties that impacted the engagement of the refugees in this research were related to the use of interpreters and to the trauma that they were experiencing.
Although we were prepared for many barriers in using interpreters as reported in the literature (e.g., third party observer effect, inaccuracy in interpreting), we encountered additional difficulties. For instance, being in a small city with a relatively small refugee population and limited number of professional interpreters meant that the interpreter and the participant often knew each other or the participant refused the interpreter due to their ethnic background. For this reason, a number of people who expressed interest could not participate due to not being able to find an appropriate match between interpreter and participant. This study indicates that even when using professional interpreters, selection of interpreters can be complicated. Also relevant to clinical practices that use interpreters for neuropsychological assessment, they need to take care in this selection to ensure engagement of refugees.

The majority of participants had unprocessed trauma that impacted their ability to participate fully in the assessment process. For a number of participants this was their first opportunity to discuss their past which led to some strong emotional reactions that needed to be dealt with before valid assessment could be pursued. Part of the reason for this was that the assistance that they were receiving was more focused on assisting them to cope with multiple current challenges and stressors. These stressors were often related to their ongoing fear for the fate of their loved ones back home and the ongoing problems with the family unification process. In addition, the lack of English language was often a major stressor, as many required assistance even for reading the mail. All these problems were regularly brought to the assessment session and needed to be treated sensitively before continuing. Therefore, a major learning point from this project was that working with refugees requires sensitivity, perseverance, and sufficient time and funding (not only for the time necessary for assessment, but the additional cost of translation and interpretation).
Refugees with PSTD Compared to Refugees with TBI+PTSD

Being aware that the methodological difficulties described above, as well as lack of a control group, impacted the validity of data collected in this research, a proper between-group comparison was not possible. However, we compared the two groups in terms of variables such as trauma and torture exposure history, psychological functioning, and self-reported functioning. In addition, a comparison in neuropsychological measures was conducted for some of the participants who were able to complete the assessment.

It was hypothesised that people with TBI in addition to PTSD would be more likely to be tortured, have more severe psychological symptoms (PTSD, depression, anxiety), would report poorer functioning, and would have lower scores in neuropsychological measures. Although no significant between groups differences were found, several tendencies were observed which may be relevant to note. Firstly, people who reported experiencing TBI were more likely to be tortured and experienced larger number of trauma events, which is consistent with our hypothesis and with the literature indicating that torture is a risk factor for TBI (Jacobs & Iacopino, 2001; Moreno & Grodin, 2002; Moreno & Peel, 2004). Furthermore, people with TBI and PTSD reported more severe symptoms of PTSD and anxiety, which again was consistent with our hypothesis and with the evidence that TBI has an exacerbating effect on PTSD symptoms (Hoge et al., 2008; Lew et al., 2008; Terrio et al., 2009). Contrary to our hypothesis, the TBI+PTSD group reported higher levels of functioning as measured by the Patient Competency Rating Scale, specifically their self reported functioning in activities of daily living was significantly higher than the PTSD group. Due to small number of participants and the groups not being matched, it is difficult to ascertain what a real reason for this result is. However, this would be consistent with literature suggesting that patients with TBI underestimate their difficulties (Prigatano, 1996; Prigatano et al., 1990).
In terms of neuropsychological data, two consistent tendencies were observed. The PTSD group tended to perform better in visual-constructional tasks and visual memory test whereas the TBI+PTSD group performed better in the logical memory-learning curve trial, a result that was close to significance. Whether this tendency reflects a possible difference in the pattern of cognitive outcome between these groups is not possible to ascertain due to a number of factors that we were not able to control. For instance, most participants in the TBI+PTSD group were Burmese, who as stated earlier had a strong verbal tradition, which could have been reflected in their higher scores in verbal tests. Further, the sample with PTSD was younger and had higher levels of education, and they had a number of experiences that may have led to cognitive deficit above and beyond PTSD and depression. For instance, all participants in the PTSD group had experienced prolonged periods of malnourishment, and four participants had experienced electrocution and asphyxiation although they reported no loss of consciousness due to these experiences. In addition, we were not able to reliably assess the pre-morbid functioning. Clearly larger matched samples that are more homogenous would be needed in order to clarify the additional impact of TBI in refugees with PTSD.

Clinical Issues in Neuropsychological Assessment of Refugees

This study indicated that conducting rigorous neuropsychological research with a refugee population, and particularly comparing group means, is very challenging and probably not valid. However, the question that arises from this research is whether neuropsychology can help this population in clinical settings. The identification of TBI in refugees with PTSD is important due to evidence suggesting that TBI exacerbates and prolongs PTSD and vice versa (Hoge et al., 2008; Lew et al., 2008; Terrio et al., 2009). Keeping in mind that neuropsychological assessment may be more useful on an individual basis than it is on a group basis, this thesis highlighted some difficulties in answering clinically relevant questions such as: Diagnosis of TBI in co-occurring PTSD,
determining relative contributions of TBI and PTSD, and determining a person’s current cognitive abilities in relation to their pre-morbid abilities.

**Diagnosing TBI and Differentiating from PTSD**

The results suggest that most refugees had sustained repeated mild injuries, and repeated exposure to electrocution and asphyxiation. These injuries typically are not detected by current neuro-imaging technology even when it is available; therefore clinical interview is the only method of assessment. As demonstrated in this research, the assessment of the presence of TBI based on self report was challenging due to a) difficulties involved in remembering the event(s) which have usually happened years prior to first clinical presentation, b) lack of collateral information, c) difficulties discerning between TBI and trauma related alternation of consciousness, d) exposure to multiple potentially injurious events, e) difficulty in remembering the onset of concussion symptoms and f) multiple current symptoms which characterise various diagnoses.

Furthermore, neuropsychological assessment was limited in answering the questions as to whether TBI has been acquired due to many factors including a) inability to assess pre-morbid functioning, b) inability to obtain correct demographic information, c) lack of collateral information, d) co-morbid depression, PTSD, history of malnourishment, which are all related cognitive impairment in their own right, e) impaired validity of neuropsychological measures due to language and cross-cultural effects, and f) difficulties assessing the influence of many historical and personality factors which influence the outcome following TBI. Similarly, differentiating between TBI related and PTSD related deficit in the face of all the other factors was not possible.

Clearly, based on the information provided in this thesis, the clinicians asked to diagnose TBI in refugees are faced with multiple diagnostic issues in addition to a lack of
crucial information and difficulties with measurements, which limit their ability to diagnose TBI, and differentiate between TBI and PTSD related cognitive deficit.

**Determining Refugees’ Current and Pre-morbid Cognitive Functioning**

As demonstrated in this research, assessment of pre-morbid abilities of refugees is difficult because they have lived for long periods in conditions of war and oppression which has impacted their ability to function to their full potential. As indicated in some of the case examples, the ability to obtain an education or have a job was more related to social circumstances and less to person’s personal abilities. Since it is not possible to determine what a person was able to do prior to injury, it is difficult to ascertain whether a change has occurred unless the person has experienced dramatic changes as illustrated by two case studies of people with pronounced executive deficit. Similarly, assessing current abilities needs to be done with care because there is a risk of underestimating a refugee’s abilities due to high environmental demands that they experience (e.g., learning a new language, adjusting to a new way of living).

Thus, for neuropsychological assessment to be useful, the focus should be not on determining the aetiology of the cognitive difficulties, but understanding the current difficulties regardless of their origin, although poor ecological validity of measures, may also limit this.

**Implications**

As reported in the literature, the current study demonstrates that refugees are prone to neuropsychological difficulties due to PTSD and depression, multiple events which may lead to brain damage such as malnourishment, asphyxiation, and electrocution experienced during torture (Jacobs & Iacopino, 2001; Weinstein et al., 2001). Refugees also have the challenge of settling in a new country, learning new languages, and finding jobs that require intact
cognitive abilities. Refugees who for any reason have impaired cognitive functioning require help in overcoming those challenges, and neuropsychology could potentially assist them.

However, as demonstrated in this study, current neuropsychological methods may be limited in diagnosing TBI, and reliably assessing refugees’ cognitive abilities. Particularly, neuropsychological methods are difficult to utilise in researching refugees due to the cross-culture and linguistic barriers, high cost of research, and difficulties in engaging this population in research. This finding has major ethical implications because it means that a vulnerable population is not being represented in the literature, and psychologists assessing cognitive functioning of refugees are faced with the ethical dilemma of not being able to validly provide the service or conducting culturally inappropriate assessment in the absence of empirical evidence with this population.

Clearly, more funding and resources are needed to research the cognitive sequelae and ways to overcome cross-cultural biases in neuropsychology in this population. Within the current neuropsychological paradigm, it is difficult to adjust assessment procedures to make them available to wider populations and at the same time retain the validity of the assessment.

Some solutions suggested are also challenging. For example, while developing separate norms for different cultural backgrounds is often advocated and applied (Manly, 2005), that does not overcome the problem of construct validity and method biases (F. J. R. Van de Vijver & Poortinga, 2005). Developing culturally relevant tests requires expertise within each specific culture which is usually not available, particularly in places where refugees come from. Therefore, whether neuropsychological methods will become useful for refugee population in a near future is uncertain.

**Contribution of the Current Study**

When this research commenced, there was little research that had explored neuropsychological functioning of refugees. The few studies that had evaluated the cognitive
outcome of PTSD of refugees, had not emphasised the methodological and cross-cultural barriers, leaving an impression that neuropsychological assessment could be undertaken with care with this population. In addition, most cross-cultural studies had been conducted with western educated minorities, which provided little insight into additional difficulties within the refugee population. Therefore, the main contribution of the thesis is the highlighting of methodological barriers in engaging traumatised refugees in this type of research and also in the limitations of neuropsychological methods and instruments when used to research this population. Furthermore, this study provides additional evidence that treatment seeking refugees are vulnerable not only to experiencing mental illness, but also are likely to have experienced TBI and a range of other experiences (e.g., malnourishment, electrocution, and asphyxiation) which impact brain functioning. Also, this thesis provides useful information for clinicians about the assessment issues involved in diagnosing TBI, differentiating between TBI and PTSD, and assessing current and pre-morbid functioning of refugees. Finally, this thesis contributes to raising the awareness in clinicians about a number of issues related to the process of assessment and to the selection and use of interpreters.

Limitations of the Current Research and Recommendations for Future Studies

A number of limitations characterise the current study. The main limitations are the use of small and diverse sample and lack of a control group. As discussed earlier, research with refugees is very costly due to translation, interpretation, and the effort required to engage this population in research. In the current research, although not foreseen at the outset, a lack of sufficient funding and the limited timeframe greatly impacted the ability to have a bigger sample and a control group. In addition, homogenous samples of refugees are difficult to be found particularly in countries with smaller refugee population due to high diversity within this population. Therefore, future studies would need to have larger and more
homogenous samples in order to clarify the additional impact that TBI has in refugees with PTSD. In addition, given that refugees are likely to have experienced a number of other potentially injurious events (malnourishment, electrocution, asphyxiation) and other psychiatric disorders, the effects of these variables need to be carefully controlled.

Other limitations noteworthy are the use of assessment measures which were not validated for this population. Following the usual practice in cross-cultural assessment, we used standard translation procedures; however validation of any measure was not possible to be done in this study. The validation of measures for refugees would be a difficult task for any research given the diversity in refugee samples. Furthermore, as revealed in this study, it is not only measures that need to be validated but neuropsychological assessment processes needs to also be adjusted to fit this population. Therefore, the ability of future research to understand neuropsychological sequelae in refugees is dependent on the development of cross-cultural neuropsychology. In the meantime, it would be useful for future studies to evaluate the cross-cultural validity of measures constructed with ecological validity in mind. In addition, large scale studies that integrate methods from different disciplines such as neuro-technology, occupational therapy, and behavioural science may be able to better research this issue.

**Conclusion**

Refugees are vulnerable to neuropsychological difficulties due to trauma and traumatic brain injuries. The cognitive difficulties are likely to affect their functioning, particularly given the high environmental demands that they face. Clearly, their cognitive symptoms need to be addressed in order to assist their social integration and also to inform psychological treatments that they receive for psychological symptoms. However, to date little research has addressed cognitive functioning of refugees with PTSD, and no research has been done with refugees with reported brain injuries and co-morbid PTSD. The current
research contributes to the literature by highlighting the presence of co-morbid TBI and PTSD in treatment seeking refugees. In addition, numerous methodological issues highlighted in this thesis may contribute in the designing of future studies that will be better equipped to address this important issue. At the same time, this study raises awareness in clinical practice of the multiple events that refugees experience which can lead to cognitive difficulties that can exacerbate psychological symptoms and lead to poor functioning. This thesis outlined a number of challenges in the assessment of TBI in the face of multiple co-morbidities in refugees and in the absence of crucial information to make diagnostic decisions. The difficulties in diagnosing however should not discourage clinicians from making their best attempts to identify multiple events and address the cognitive symptoms along with all the other physical, psychological, and social problems refugees face.
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References


Appendices

Appendix A: Ethics Approval

Central Regional Ethics Committee
Ministry of Health
Level 2, 1-3 The Terrace
PO Box 2013
Wellington
Phone: (04) 496 2405
Fax: (04) 496 2191
Email: central_ethicscommittees@moh.govt.nz

Health and Disability Ethics Committees
19 November 2009
Bahré Vellu
24 King Street
Mt Cook
Wellington

Dear Bahré

Neuropsychological functioning in a group of refugees with suspected traumatic brain injury (TBI) in addition to PTSD, resulting from torture, Bahré Vellu
CEN/08/09/046

The above study has been given ethical approval by the Central Regional Ethics Committee.

Approved Documents
- Consent Form: Neuropsychological Sequela of Torture, Version 1, 2008
- Information Sheet: Neuropsychological Sequela of Torture, Version 1, 2008
- Advertisement: Neuropsychological functioning in a group of refugees with suspected traumatic brain injury (TBI) in addition to PTSD, resulting from torture, Version 1, 2008
- Harvard Trauma Questionnaire in Arabic, Cambodian.

Accreditation
The Committee involved in the approval of this study is accredited by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, April 2009.

Progress Reports
The study is approved until 1 September 2010. The Committee will review the approved application annually and notify the Principal Investigator if it withdraws approval. It is the Principal Investigator’s responsibility to forward a progress report covering all sites prior to ethical review of the project in 19 November 2009. The report form is available on http://www.ethicscommittees.health.govt.nz. Please note that failure to provide a progress report may result in the withdrawal of ethical approval. A final report is also required at the conclusion of the study.

Amendments
It is also a condition of approval that the Committee is advised of any adverse events, if the study does not commence, or the study is altered in any way, including all documentation eg advertisements, letters to prospective participants.

Please quote the above ethics committee reference number in all correspondence.

The Principal Investigator is responsible for advising any other study sites of approvals and all other correspondence with the Ethics Committee.

It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

Yours sincerely

Sonia Scott
Central Regional Ethics Committee Administrator
Email: sonia_scott@moh.govt.nz
Appendix B: Information Sheet - English

Information Sheet
Neuropsychological sequelae of torture

Dear Mr./Ms,

You are invited to take part in a study that considers the effect of torture and trauma on psychological function. In our study we would like to examine whether what you have experienced has influenced your attention, learning and memory, and emotions. At the personal level, this information can help the “Refugees as Survivors” (RAS) staff to provide treatment and rehabilitation in the best way. At a more general level this research will allow us to better understand the neuropsychological consequences of torture and trauma. There has been very little previous research conducted in this area.

What does taking part involve and what you would be asked to do?

- Do a number of tests of memory, attention, and concentration and complete questionnaires about you emotions, thoughts and behaviours. All of the tests and questionnaires will be in your own language. You do not have to be able to write to take part. An interpreter will be available if you wish to speak in your own language.
- This assessment is expected to take around 3 hours, with breaks if you wish.
- The meeting will take place at the RAS centre.
- If you wish, you can bring with you a family member or support person.

How are people selected to participate in this study?

You have been invited to participate in this study because your treating clinician at RAS has indicated that you could be a suitable person to participate in this study. To take part you need to:

- Be aged 16 years and older
- Be consumers of RAS services.
- Be refugee and former victim of torture and/or trauma.
- Have sustained brain injury from torture OR/AND experience posttraumatic stress disorder.
- You do not experience any psychotic symptoms
- You have not had similar assessment in the last 5 years.

What are the benefits of participating in this study?

You will be helping us to learn more about the long term effects of trauma, which will in turn help those who are affected.

On a personal level, the results will provide your treating clinician at RAS with a better idea of your psychological strengths and weaknesses which assist in your treatment.

What negative effects could result for participating in this study?

How trauma experienced by refugees affects psychological functioning 1
Talking about past torture and trauma experience may be still distressing. A psychologist or a counsellor at RAS will be available to talk to you if needed and you don’t have to talk about things or do any tasks that are too distressing.

Will I receive any payment or reimbursement for participating in this study?
Reimbursement will be provided for the cost of travelling and parking.

Taking part in this study is voluntary:
It is your choice whether you take part or not in the study. If you do agree to take part, you can stop taking part at any stage without having to give a reason and this will not affect your continuing health care or rehabilitation at RAS.

What happens to the information collected in the study?
A brief report will be prepared and given to the RAS staff to discuss with you. If the assessment identifies depression or cognitive impairment were identified, counsellors would discuss this with you GP.

Otherwise, the things you say and the information we gather about you will be kept confidential and used for research purposes only. No material that identifies you will be used in any report on this project. The information you provide will be coded by number only and your results will be grouped with others, so there is no possibility that your results will be identifiable. A copy of the coded data will remain in the custody of Massey University. We will store your information in a secure location, and only those involved in this research programme will be able to see it. We will store your information for at least ten years after the end of the project, after which time our records will be securely destroyed.

Where can I get more information about the study?
For more information you can contact the following people:

Bahrie Velju  
Researcher
Email: bvelju@gmail.com
Phone: 801 5799 ext 62324

Professor Janet Leatham (PhD)
Supervisor
Email: J.M.Leatham@massey.ac.nz
Phone: 801 5799 ext 62035

If you have any queries or concerns about your rights as a participant in this research study you can contact an independent health and disability advocate. This is a free service provided under the Health and Disability Commissioner Act.

Telephone: (NZ wide): 0800 555 050
Free Fax (NZ wide): 0800 2787 7678 (0800 2 SUPPORT)
Email (NZ wide): advocacy@hdc.org.nz

This study has received ethical approval from Central Regional Ethics Committee.
Appendix C: Information Sheet - Arabic

ورقة المعلومات
الاعتلاء الدماغي الناجم عن التعذيب

لقد تم دعوتكم للمشاركة في دراسة تعاين تأثير التعذيب والصدمات على الوظيفة النفسية. في دراستنا تود أن نفهم إذا كان ما تعرضت إليه قد أثر على الذاكرة، التعلم، والذكاء، كما قد كننا على عناصر فردية، أما على الصيد الشخصي، فإن تلك المعلومات قد تساعد منظمة "اللاجئين الناجين" (RAS) على تقديم العلاج ودعم التأهيل. على سبيل المثال، والمعلومات ستساهم في إعداد البدائل أثناء التعرض للتعذيب والصدمات. هناك القليل من الابحاث السابقة في هذا المجال.

ما يتطلب من مشاركتكم وما هو مطلوب ملك؟
- القيام بعدم اختبارات ذاكرة، الانتباه، التركيز، وبحث القدرات الخاصة بك، الموافقة، والذكاء والعاطف.
- السؤال. يجب أن تكون جميع الاعتبارات والإستبانات والبيانات الخاصة بك ولخصا ليس مما أن تعرف الكتابة المشارك، في تلك المرة إذا كنت ترغب في أخذ تلك الخاصة.
- استبانات أخرى حوالى 3 ساعات، مع فواصل إذا رغبت.
- سوف يختار اجتماع في مركز (RAS).
- يمكنكم إحضار أفراد الأسرة معا أو أي شخص للدعم.

كيف يتم اختيار الأشخاص للمشاركة في هذه الدراسة؟
- قد تم دعوتكم للمشاركة في هذه الدراسة بناءً على توصية الطبيب المعالج في "اللاجئين الناجين" بإحكام الشخص للمشاركة في هذه الدراسة. المشارك في هذا الدراسة، المشارك في الحاجة التالي:
  - أن يكون عمره 16 سنة فأكثر.
  - أن تكون من مراعي خليجي.(RAS)
  - أن تكون من اللاجئين، وتحديدًا ساكنة من التعذيب وأو الصدمات.
  - أن يكون الشخص مترأض من جراء التعذيب أو كونك قد خضت تجربة الاستمرار والضغط النفسي.
  - الاستفسار.
  - لم تظهر عليك أي إعراض إدمان.
  - لم تشارك في أي تجربة في السنوات القصيرة الأخيرة.

ما هي وقائع المشاركة في هذه الدراسة؟
سواء تقو في جميعا في نفس فترة تعليم الاجلة لكل السكان، والتي تؤثر بدورة على مساحة هؤلاء.
وعلى المستوى الفعلي، فإن النتائج سوف تعود للطبيب المعالج في "اللاجئين الناجين" بفترة عامة يضمن ضعف النفسي والمساعدات في ملاحظة.

ما في الأثار السلبية التي قد تنتج عن مشاركتكم في هذه الدراسة؟

How trauma experienced by refugees affects psychological functioning (Arabic)
Appendices

Professors Jan-et Leathem
(PhD)
Supervisor
J.M. Leathem@massey.ac.nz
62035
021.801.5799

Bahrie Veliu
Researcher
bveliu@gmail.com
62324
021.801.5799

How trauma experienced by refugees affects psychological functioning (trauma)

Access the HDC’s Advocacy Team at 0800 555 050 (NZ wide) or advocacy@hdc.org.nz (NZ wide)

Page 139
Appendix D: Information Sheet - Burmese

How trauma experienced by refugees affects psychological functioning

140

Appendices
How trauma experienced by refugees affects psychological functioning v1-2008 Burmese
### Appendix E: Consent Form - English

#### Consent Form

**Neuropsychological sequelae of torture**

<table>
<thead>
<tr>
<th>Language</th>
<th>I wish to have an interpreter</th>
<th>Yes</th>
<th>No</th>
</tr>
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<tbody>
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<tr>
<td>Somali</td>
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</tbody>
</table>

I have read and understood the information sheet for volunteers taking part in this study. The nature and purpose of the study have been explained to me. I have had the opportunity to discuss this study and ask questions. I am satisfied with the answers I have been given. I have had the opportunity to use family support or a friend to help me ask questions and understand the study. I have had time to consider whether to take part.

I understand the following:

- Taking part in this study is voluntary (my choice). I may withdraw from the study at any time and this will in no way affect my continuing health care.
- I will be in control of what I do and what happens to me. I can ask questions or have a break when I need one.
- By participating I agree that the researchers of this study have access to my personal records at "Refugees as survivors" in order to gain information about my medical and demographic data.
- My participation in this study is confidential and material which could identify me will not be used in any reports on this study.
- I understand that my personal results of assessment will only be shared with me and my treating clinician at RAS.

I ________________________________ consent to take part in this study.

Signature: ________________________________ Date: ________________________________

I would like to receive a copy of the results YES / NO

Please send the results to email or postal address: ________________________________

(There may be a long delay between when you take part and when the results are known).

Please feel free to contact one of us:

Bahrie Veliu
Professor Janet Leatham PhD

Telephone 04 801 5799 ext 62324
Telephone 04 801 5799 ext 62035

This study has received ethical approval from the Central Regional Ethics Committee.
نموذج الموافقة
الإحالة الدماغي الناجح عن التعذيب

<table>
<thead>
<tr>
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<td>كوسوفو</td>
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<td></td>
</tr>
<tr>
<td>صومالي</td>
<td></td>
</tr>
</tbody>
</table>

قد قررت وفيت صفحات المعلومات الخاصة بالمشاركين في هذه الدراسة، وتم شرح طبيعة
وهدف الدراسة، ومثلت الفرصة لمنشأة هذه الدراسة موثوقية الاستماع، الذي أوصى
بذلك، وقد أقرت في الدراسة لاستخدام دعم الأسرة وصديق لمساعدتي في طرح الاقتراح،
وفهم الدراسة. كما كان لدي الوقت للنظر في المشاركة.

وأخلاقيات

• المشاركة في هذه الدراسة اختيارية (محسن أرادتي). وقد أصدرت من الدراسة في أي وقت اثناء و
• لا يؤثر هذا على حال من الأحوال، على استمرار الرعاية الصحية في
• سوف تكون مسيرة، على عقل، وعلى ما قد يحدث لي. ويمكنني طرح الاقتراح، أو هذا الاستماع
• عندما مستعداً لواحد.
• ان المشاركة هنا بانتظار بان يكون للباحثين في هذه الدراسة طريق إلى مسيرة الشخصية
• الموجودة في "الباحثين الناجين" (RAS) بحرية الحصول على معلومات خاصة بحالات الصحة
• والديموغرافيا.
• المشاركة في هذه الدراسة سرية كما أن المواد التي قد تحرر من الملكية للاستعمال، أو الاحترام
• أو الإعاقة، أو الاقتراح، أو التطبيق، أي الاتصال، سوف يتم الاحترام عليها فقط من قبل وسيلة المحترم لدى
• "الباحثين الناجين" (RAS).

أنا ___________ أوقع على المشاركة في هذه الدراسة.

التاريخ: ___________

لا يوجد على نسخة من الاقتراح: نعم / لا

ارجم الرسالة الناجحة إلى البريد الإلكتروني أو الخوان التالي:

(قد يكون هناك تأخير طويل بين وقت شاركك وما بين التعرف على الاقتراح).

لا تتردد رجاء في الاتصال، وبإذا ما ترغب في التفاوض:

Bahrie Veliu
 هاتف: 623524 04 801 5799

Professor Janet Leathem PhD
 هاتف: 623525 04 801 5799

لقد تلقنت هذه الدراسة الموافقة الأخلاقية من اللجنة المركزية للاخلاقيات الإقليمية.
## Appendix G: Consent Form - Burmese

### Consent Form (Burmese)

<table>
<thead>
<tr>
<th>Language</th>
<th>Consent Form Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>English</td>
<td>I wish to have an interpreter</td>
</tr>
<tr>
<td>Arabic</td>
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<td>Somali</td>
<td></td>
</tr>
</tbody>
</table>

**English**

I wish to have an interpreter

**Appendix G**

How trauma experienced by refugees effects psychological functioning - Consent Form

1. **Professor Janet Leathem PhD**
2. **Central Regional Ethics Committee**
Appendix H: Locality Assessment

**LOCALITY ASSESSMENT – by Locality Organisation**

Refer to pp10-12 of the Guidelines for Completion of the National Application Form for Ethical Approval of a Research Project

**Full Project Title:** Neuropsychological assessment of refugees - victims of torture who have experienced traumatic brain injury and posttraumatic stress disorder resulting from torture.

**Short Project Title:** Neuropsychological Sequelae of torture and posttraumatic stress disorder

Brief outline of study: A comprehensive neuropsychological assessment will be conducted with the refugees (consumer of RAS service) who have been exposed to torture and trauma. The data obtained will provide information regarding the neuropsychological sequelae resulting from traumatic brain injury inflicted by torture and neuropsychological outcome resulting from posttraumatic stress disorder.

Principal Investigator: Bahrie Veliu

Contact details: Massey University Psychology Clinic at 24 King St, Mount Cook

Local investigators: Ranka Margetic-Sosa
Clinical Manager
Wellington refugees as Survivors Trust

Contact details: level 5, 61-63 Taranaki St,
PO Box 6187 Wellington 61541
Phone: 04 381 3416
Fax: 04 384 7278
E-mail ranka.wnras@xtra.co.nz

Locality Organisation signoff
Ethics committees review whether investigators have ensured their studies would meet established ethical standards, if conducted at appropriate localities; each locality organisation is asked to use the locality assessment form to check that the investigator has also made the appropriate local study arrangements.

Ethics approval for study conduct at each site is conditional on favourable locality assessment at that locality.

Locality issues: (see guidelines for more information and examples)
2. Suitability of the local research environment

For example, have the resources (other than funding which is conditional on ethical approval) and/or facilities that the study requires locally been identified? Are they appropriate and available?

Answer: RAS has appropriate and available rooms for the research to be conducted.

3. What are the specific issues relating to the local community?

For example, are there any cultural or other issues specific to this locality, or to participants for whom study recruitment or participation is primarily at this locality? If so, how have they been addressed?

Answer: RAS has a preference that all research participants are seen at the RAS rooms as this is where they are most familiar and comfortable.

4. Information sheet/consent form contact details:

Contact details for Health & Disability Consumer Advocates:

Answer: Provided and displayed in RAS waiting areas and counselling rooms and RAS offices.

Contact details for any other important local services:

Answer: Provided and displayed in RAS waiting area. Some provided in different languages.

I understand that I may withdraw locality approval if any significant local concerns arise. I agree to advise the Principal Investigator and then the relevant ethics committee should this occur.

Signature: [Signature]

Date: 14 May 2008

Name: Ranka Margetic-Sosa

Position: Clinical Manager

Contact details:

Refugees as Survivors, level 5
61-63 Taranaki St, Wellington
Email ranka.wnras@xtra.co.nz
13 May 2008

Massey University
Psychology Department
24 King Street
Mount Cook Wellington

To Whom It May Concern

The Wellington Refugees as Survivors Trust is pleased to be involved as a ‘locality organisation’ for the proposed research project “Neuropsychological assessment of refugees—victims of torture who have experienced traumatic brain injury and posttraumatic stress disorder resulting from torture”

This will be an extremely important project as this type of research has not been carried out in New Zealand before. We look forward to working closely with the Massey University personnel.

Yours Sincerely

Jeff Thomas
General Manager
Appendix I: Health Research Council, NZ - Funding Application

HRC REF: 09/313

Referee's Index

Health Research Council of New Zealand
Emerging Researcher First Grant Application FG209

Do not include this page in the paper copies.

Research Title (50 characters maximum):
Neuropsychological sequels of torture

Applicant's name:

Title: 
Preferred Name: Bahrie
Surname: Veliu

Indicate type of computer used to complete this form: PC MAC

Double-click header, replace "09/xyz" with your application Ref#; replace "ni surname" with your surname. Double-click elsewhere on the form to return to main part of form.

The index below is hyperlinked to the various sections of this application. Click (or ctrl-click) on a section to navigate to it directly.

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MODULE 2: PROPOSAL .............................................5
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Section 2B - Description of Proposed Research....................................6

MODULE 3: REFERENCES .............................................12

MODULE 4: RELEVANCE OF RESEARCH TO SPECIFIC POPULATION GROUPS .............................................13
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MODULE 1: GENERAL INFORMATION

Research Title (80 characters maximum)
Neuropsychological sequel of torture

Host Institution
Massey University

Research Location
Wellington

Named Investigators (First investigator will be the contact)
Expand tables as necessary by pressing enter at the end of a row outside of the table.

<table>
<thead>
<tr>
<th>Title</th>
<th>First Name(s)</th>
<th>Surname</th>
<th>Ethnic Identity*</th>
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<td>1 Doctorate candidate</td>
<td>Bahrie</td>
<td>Veliu</td>
<td>Albanian</td>
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<tr>
<td>2 Professor</td>
<td>Janet</td>
<td>Leathem</td>
<td>NZ</td>
</tr>
<tr>
<td>3 Professor</td>
<td>Nigel</td>
<td>Long</td>
<td>NZ</td>
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Total Cost of Research $76,199 (Enter figure from the Module 5B budget)

Proposed Commencement Date July 2009 (dd/mm/yyyy)

Proposed Term of Research 24 months

Lay Summary of Research (150 words maximum)

Include research objectives, principal methodologies and potential health outcomes or impact.

Up to 35 thousand refugees are currently resettled in New Zealand and UN statistics indicate that up to 80% worldwide will have experienced torture. This study will investigate the neuropsychological outcomes related to torture induced brain injury and Post Traumatic Stress Disorder (PTSD) in refugees living in New Zealand.

Research suggests the prevalence of these conditions is high among torture victims and is often associated with psychiatric symptoms and impaired social functioning even 10 years post injury. Investigation firstly of the pattern of deficit induced by such brain injuries and secondly of the neuropsychological outcomes associated with PTSD will lead to improved diagnosis and treatment of conditions.

The research will inform neuropsychological rehabilitation programs in New Zealand, leading to improved social integration and improved quality of life for sufferers. Furthermore, it will provide neuropsychological assessment protocols and procedures for use with people of diverse cultural backgrounds.
HRC REF: 09/313

Applicant’s Details

<table>
<thead>
<tr>
<th>Applicant’s Full Name and Title</th>
<th>Bahrte Veliu</th>
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</tr>
<tr>
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</tr>
<tr>
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</tr>
<tr>
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<tr>
<td>Email</td>
<td><a href="mailto:bveliu@email.com">bveliu@email.com</a></td>
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<tr>
<td>FTE % on proposed research</td>
<td>100 %</td>
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Justification of role in the project:

This project is applicant’s doctorate thesis.

Present Position & Current employer

PhD candidate at Massey University

if the applicant intends to be absent for a period of longer than one month during the contract duration, please state the reason: N/A

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Honours, prizes, scholarships, etc

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<td>Undergraduate scholarship (3 years)</td>
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Relevant academic and research experience

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<td>2007</td>
<td>2008</td>
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<tr>
<td>Co-researcher “Child Labour in Kosovo”</td>
<td>2003</td>
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<tr>
<td>Co-researcher “Juvenile Offenders in Kosovo”</td>
<td>2003</td>
<td>2004</td>
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<tr>
<td>Co-researcher “Human Trafficking in South-Eastern Europe Founded by International Organization for Migration (IOM) and Population Service International (PSI), Kosovo”</td>
<td>2004</td>
<td>2004</td>
</tr>
</tbody>
</table>

Number of Publications (exclude abstracts, proceedings or letters published or presented)
Important Publications
Applicants should list no more than ten (10) peer-reviewed publications in reverse date order, starting from current year first. These should include the applicant's most important publications and where possible, publications relevant to the research proposed. It is helpful to include journal impact factors.

Delete these words and start typing here

List of Publications from previous five years
- List in reverse date order, starting from current year first,
- And highlight the ones most relevant to this proposal, by bolding the Applicant's name.
- You may include citations, impact factors, and/or journal rankings.

Delete these words and start typing here.

Other forms of research dissemination (1 page only)
The results of the research projects: "Child Labour in Kosovo" and "Juvenile offenders in Kosovo" were presented by myself and colleagues at a number of local conferences. The results of these studies were used by the Ministry of Social Welfare in Kosovo to inform policies and implement preventive and rehabilitation programs. In addition, the applicant has presented these projects at a regional conference organized by the Inter-University of Dubrovnik, Croatia. The outcome of the study "Human Trafficking in South-Eastern Europe" was used by the International Organization for Migration based in the region to inform strategies for prevention and treatment of victims of trafficking.

Signature
I certify that the information provided is current, accurate and correct.

Please note that by signing this you are agreeing to the stated FTE contribution.
MODULE 2: PROPOSAL

Section 2A – Summary of Research

Around one third of the world’s countries apply torture on a regular basis. Many survivors of torture escape their countries of origin and resettle in developed countries as refugees. Reports by the UN High Commissioner for Refugees (UNHCR) indicate that the number of refugees worldwide soared by 1.5 million to 11.4 million at the end of 2007. Of these, anywhere from 20% -100% depending upon the composition of the sample have experienced torture. New Zealand resettles refugees under various international agreements, key agreements comprising the 1951 United Nations Convention and the 1967 Protocol Relating to the Status of Refugees. It is suggested that the estimated number of refugees in New Zealand (NZ) is 25,000 and that approximately more than 2,000 new refugees enter NZ every year. However, looking at the increasing number of both quota refugees and asylum-seekers to NZ in recent years there may be as many as 35,000 refugees residing in NZ today. Reports from the survivors of torture reveal that the torture often involved traumatic brain injuries (TBIs) ranging from direct blunt blows to the head, violent head shaking, asphyxia, malnutrition to serious penetrating head injuries. For instance, up to 73% of torture victims report beatings to the head during torture, while the presence of neurological impairment has been reported by 64% of this population. This prevalence is very high and reveals the vulnerability of this population for poor psychiatric outcomes considering that untreated TBI is associated with significant risk for psychiatric problems even after 10 years. Despite being high risk population for neuropsychological difficulties, this population has not received significant attention from neuropsychologists. To date there has been no published study that has evaluated neuropsychological functioning of torture victims that have had beating to the head.

Victims of torture usually suffer a number of symptoms related to PTSD, depression and anxiety which overlap with the symptoms of TBI. Thus, common symptoms of TBI including memory, attention disfunctioning, distractibility and impulsivity may be easily labelled as PTSD, although in a subgroup of torture victims this may mainly be due to TBI alone. Therefore the current study will explore neuropsychological functioning in three groups of refugees exposed to torture, one without PTSD or TBI, one with PTSD only, and a third with TBI in addition to PTSD in order to explore differential diagnosis of both conditions. These groups will be matched as closely as possible for language, gender and education. Neuropsychological measures will be translated, and interpreters will be available as required for each assessment. Statistical and qualitative analysis of results obtained in this study will provide information about: the neuropsychological sequelae of torture induced traumatic brain injury, will evaluate the neuropsychological sequel of PTSD, when controlling for the additional impact that TBI has on neuropsychological functioning and will provide neuropsychological assessment protocols and improve on procedures for use with people of diverse cultural backgrounds.

The research will inform neuropsychological rehabilitation programs in New Zealand, initially at the ‘Refugees as Survivors’ Agency in Wellington and subsequently in Auckland and Christchurch, leading to improved social integration and improved quality of life for sufferers nationwide.
Section 2B – Description of Proposed Research

There is a 8 page limit for this section. A letter of support from your programme leader/Head of Department/research mentor should be attached at the end of this section (see Guidelines).

Applicant’s Background

I am a candidate in the DClinPsych programme at Massey University - Wellington. I have completed a Bachelor degree of Psychology at Pristina University (Kosovo) and Bachelor of Science with Honours in Psychology at Victoria University, Wellington. Last year I completed six Honours level clinical psychology papers at Massey University for which I gained a Postgraduate Certificate in psychology. As an undergraduate at Pristina University (Kosovo), I served as a co-researcher in three studies: “Child Labour in Kosovo”, “Juvenile Offenders in Kosovo” founded by the Ministry of Social Welfare and “Victims of Trafficking in Kosovo” founded by International Organization for Migration (IOM) and Population Service International (PSI), Kosovo. My honours project involved the design and implementation of a behavioural analysis programme. The results of the research (“Child Labour in Kosovo”, and “Juvenile Offenders in Kosovo”) were used by the Ministry of Social Welfare (Kosovo) to inform policy and improve the quality of their services. These results were also presented by myself and my colleagues at a regional conference held at the Inter-University of Croatia and at a number of locally organized conferences. In addition International Organization for Migration (IOM-Kosovo) has used the outcome of the research “Victims of trafficking in Kosovo” to provide reintegration and rehabilitation programs to the victims of sex trafficking.

Relevant work experience has included work in Aceh (Indonesia) with the International Organization for Migration in the reintegration programme for former political prisoners and former members of the “Free Aceh Movement-GAM” and I have also worked with children and families who were victims of war trauma/torture in Kosovo where I lived until 3 years ago. Having lived in Kosovo during the conflict has equipped me with a deep understanding of the traumatic experiences related to oppression and war, while being a human rights activist in post conflict Kosovo has provided me with a very good understanding of human rights issues especially related to victims, displaced people and refugees.

Since my arrival in New Zealand in 2005 with my New Zealand husband, I have sought opportunities to develop my research capabilities while also integrating into New Zealand society. The Honours year in Victoria University provided me with strong research skills and academic aspirations. However, it was at Massey University where I saw an opportunity to continue my research in a cross cultural setting while working with disadvantaged populations through this PhD study.

Rationale

Clinicians at the agency “Refugees as Survivors” (RAS) provide psycho-social services for refugees who have been victims of torture and trauma and have reported that a large number of their clients have had beatings to the head during torture and manifest neurocognitive symptoms consistent to TBI. In early 2008 this agency sought assistance from Massey University Psychology Clinic for neuropsychological assessment of a group of refugees with suspected traumatic brain injury (TBI) in addition to Post Traumatic Stress Disorder (PTSD), resulting from torture. Through discussions with RAS clinical staff, cultural advisors and management, a research study has been developed that would have therapeutic benefits to refugees whilst also making a contribution to research knowledge, in an area where very little is known.

Traumatic brain injury has long been suggested as a factor associated with psychiatric co-morbidity in survivors of mass violence and torture. However, the very salient nature of psychological trauma experienced by victims has lead to literature focusing on the evidence of PTSD, while little has been done in exploring neurocognitive sequelae of torture. Similar reports come from around the world. For example Strong (2003) reported that US soldiers
with TBI in addition to PTSD had more disability, showed no improvement over time and were at higher risk of psychiatric co morbidity. This highlights the importance of identifying the neurocognitive symptoms and addressing them in the treatment of torture victims. However, this task has proved difficult with a refugee population. This is because they usually speak different languages and come from different countries and cultural backgrounds, while all the neuropsychological assessment procedures and measures are English and have been developed and validated in the Western World. This study is the first initiative to evaluate torture from the perspective of neuropsychology and addresses two salient issues:

Firstly, by addressing methodological issues related to neuropsychological assessment of diverse populations and by evaluating the pattern of a neuropsychological profile related to different forms of torture induced TBI’s, this study will provide data that will be beneficial worldwide to health practitioners working with torture victims. More specifically, in New Zealand health practitioners that deal with refugees will be better informed about the assessment procedures of refugees who have suffered psychological trauma and better enabled to identify and subsequently address neurocognitive symptoms. In addition, they will also have available the valid psychological and neuropsychological measures used through my assessment process that will have been translated and validated in the languages of six nations. This will enable better integration of refugees into New Zealand society and improve the quality of life for sufferers.

Secondly, this study addresses the extent to which PTSD in itself can cause neurological deficit. Memory and attention complaints are always present in people experiencing PTSD. However, research evaluating the connection between PTSD and neuropsychological deficit has yielded inconsistent results. This has partially been attributed to methodology and the sample used by previous studies. For instance most of these studies have been conducted on Vietnam war veterans who many argue have either been exposed to toxins or have sustained brain injuries during combat, or have chronic conditions such as alcohol and drug abuse and dependency which in itself can cause neurological deficit. This current study addresses the methodological shortcomings that characterize previous research in the following ways: The current sample is comprised of a civilian population who have not been exposed to combat, gender representation includes female victims who have rarely been included in previous studies and finally, this study is able to evaluate the additional impact of TBI on PTSD by having a TBI+PTSD control group.

An understanding of the neuropsychological deficit associated to PTSD will inform and sensitize clinicians about problems that can occur in the treatment due to neuropsychological deficit. For instance, a PTSD patient with attention and memory problems is less likely to benefit from standard treatment unless the treatment considers the impact of the neuropsychological deficit and use strategies to overcome those difficulties. Further, expanding on the current knowledge of what function of the brain is impacted by PTSD, this study will contribute in advancing our understanding about the etiology and the mechanisms underlying the disorder.

Research Design and Methods
The current study aims to investigate the neuropsychological outcome related to torture induced TBI and PTSD in a refugee population living in New Zealand.

Aims
The main questions this study seeks to answer are as follows:
1. What is the current level of neuropsychological functioning?
   • In a group of refugees exposed to politically motivated torture without PTSD or TBI (Group 1)?
     - It is expected that Group 1 will obtain scores close to the average normative range,
HRC REF: 09/313

- In a group of refugees exposed to politically motivated torture with PTSD and no TBI (Group 2)?
  - Based on previous studies, it is expected that Group 2 will show a selective pattern of deficit, differing from the control group in verbal memory and attention. The effect size is expected to be small to moderate in size.

- In a group of refugees exposed to politically motivated torture with PTSD and TBI (Group 3)?
  - There will be variability within Group 3 scoring, based on severity of TBI, with those sustaining more severe injury obtaining lower scores, than with injuries of less severity.

Neuropsychological outcome will vary according to the technique/type of torture. Injuries will have been induced mainly from blows to the head, asphyxiation (both dry and wet), electrical shocks, and gun wounds. Accordingly a pattern similar to those found in people with similar injuries incurred in ways other than torture is expected.

2. What is the difference in neuropsychological functioning between Groups 1, 2 & 3?

It is expected that Group 3 will show impairment on more measures and to a greater degree than Group 2. Group 1 will have higher scores than both group 2 & 3.

It is expected that Group 3 will show a diffuse dysfunctioning or a localised dysfunctioning depending on the injury, while we expect that Group 2 will show impairment in the measures of attention and verbal memory measures (AVLT).

3. Finally, this study aims to provide a new insight into the suitability of using neuropsychological measures and procedures with a diverse group of refugees in New Zealand. This will be achieved by evaluating the differences between the control group and the normative data. We expect that participants in the control group will perform closely to normative data. Possible differences between these groups will indicate the influence of factors such as culture, education and language, which then will be thoroughly analysed.

In addition, observations and qualitative analysis of performance in the neuropsychological assessment will provide information that may explain the influence of culture in the process and explore potential adaptations. In addition, this study will also provide information about the problems with using interpreters in neuropsychological assessment and will inform ways to improve their use.

Participants

The study will use three groups: Group 1) A control group of refugees who do not experience PTSD and have not sustained TBI. Group 2) Refugees who have sustained torture and now experience PTSD; and Group 3) Refugees who have experienced psychological and physical torture resulting in both PTSD and TBI. It is planned to recruit 20 people for each group. Since this study is exploratory, this number is sufficient to provide initial indications as to the neuropsychological outcomes linked to these conditions. In addition, since the expected difference between the groups will be at least one standard deviation, 20 participants in each group provides sufficient power to detect the effect.

Participants in the "TBI+PTSD" group and the "PTSD only" will be identified by clinical staff at the RAS centre. Once these participants have consented to take part in the study they will be referred to the investigator for neuropsychological assessment. As part of the consent, the client will be agreeing to the researcher being permitted to access their files (kept at the RAS centre) prior to being seen. This will provide information on demographics, the nature and extent of torture and trauma, the nature of TBI and other medical and psychological problems.
and offset the need to ask for the information in session which could be re-traumatising and preserves confidentiality in the face of otherwise having to have an interpreter convey questions and responses.

The participants of the third group will be recruited through advertisements placed in locations where refugees are expected to visit (e.g., Cross Cultural Centre at Taranaki St.). Advertisements will be translated in all the languages involved in the study and will be displayed in large posters. Participants of this group will also be identified and referred by cultural advisors and staff members at RAS centre.

The inclusion criteria is as follows:

**Inclusion criteria:**

**Control Group:**

a) Refugee from the same countries as participants in experimental groups.

b) Over 16 years of age

c) No current psychotic symptoms

d) Adequate visual acuity and hearing ability to complete the task requirements

e) Not undergone neuropsychological assessment within last 5 years

f) No history of traumatic brain injury

h) Does not meet criteria for PTSD

**PTSD Group:**

i) Meets criteria for PTSD

**TBI +PTSD Group:**

a) Experienced TBI (e.g., beatings to the head, near drowning, electrocution, gun wounds to the head during torture) with Glasgow Coma Scale Score of <14 and/or Post Traumatic Amnesia of 1 hour or more and/or loss of consciousness (LOC).

b) Presence of co morbid conditions (e.g., generalised anxiety disorder, depression and drug and alcohol abuse) will not constitute an exclusion criteria for any group as the effects of these conditions will be controlled in data analysis.

**Procedure**

Prior to assessment, each participant will be individually approached by their treating clinician at RAS to arrange the time of assessment and agree on the number and the duration of each session. The researcher will see each participant individually. An interpreter will be present where required. For participants in the PTSD group and PTSD+TBI group, the assessment will take place at the premises of RAS centre while assessments for the participants in the control group will take place at the Psychology Clinic at Massey University.

At the beginning of assessment, a short semi-structured interview (lasting around 15 minutes) will be conducted in order to obtain relevant personal information not found in the files and information regarding head injuries. Participants will then be asked to complete the Patients Competency Rating Scale which asks clients to appraise their level of functioning in areas such as: interpersonal relationship, cognitive functioning, and functional abilities. In addition, the Harvard Trauma Questionnaire will be administered in order to measure the exposure to torture and trauma as well as symptoms of PTSD. Because of high co morbidity of PTSD with depression, anxiety, and drug abuse, participants will be screened for these conditions using Depression, Anxiety, Stress Scale (DASS) and the drug abuse part of history taking questionnaire.

Neuropsychological assessment will be identical for all three groups. The following neuropsychological measures will be administered in order to assess each functional domain:

- **Overall Intellectual ability (IQ):** Self-report, (Part I of history taking questionnaire, see Appendix 1).
- **Verbal Memory:** Logical Memory I & II, subscale of Wechsler Memory Test-III (WMS III) & Roy Auditory Verbal Learning Test.
Visual memory: Rey Complex Figure Test 18.
Working memory & Information Processing Speed: WAIS III subscales: Digit Span 19
Attention and concentration: Trail Making Test 1-4 20, Stroop Colour-Word Test (divided attention) 21, Connors Continuous performance test (sustained attention) 22
Executive functioning: Wisconsin Card Sorting Test 21, Stroop Colour-Word Test 20
Testing for response bias and incomplete effort: Test of Memory malingering 22
Motor Skills: Electronic finger tapping 23

The above tests have been selected based on a number of reasons:

Firstly, considering the diverse cultural background of our sample, tests that are reported to be less sensitive to cultural influences were primarily chosen.

Secondly, based on previous studies that have evaluated neuropsychological sequelae of PTSD, we have chosen the tests that have shown sensitivity to PTSD induced neuropsychological impairment.

Thirdly, tests were chosen in order to measure all functional domains.

Fourthly, another criteria for the test selection was the test's dual utility (e.g. the ability to measure more than one aspect of a domain) and ease of translation.

Finally, to save cost and time, shorter measures have been selected where possible while maintaining the integrity of the assessment procedures.

All the self-report measures and verbal neuropsychological tests will be officially translated into participant's native language using standard translation procedures. This procedure consists of:

1) Translation from English to participant's native language,
2) Blind translation back to original English,
3) Comparison and consensus of translation by a cultural advisor or a person familiar with psychological terminology who will be found with the help of the cultural advisors.

Neuropsychological testing will be done in collaboration with an official interpreter. The instructions for each neuropsychological test will be standard and pre-recorded on an audiotape. Also verbal measures (AVLT, Digit Span, scales of Wechsler Memory Test-III (WMS III): Logical memory I & II will be administered using a tape record. The responses will be audio recorded to ensure the accuracy of recording made by the interpreter.

Data analysis

Descriptive statistics examining scores on each measure for all groups (no PTSD or TBI group, PTSD group and PTSD+TBI group). T-test and ANOVA analysis will be used to evaluate the differences between: Control Group, PTSD+TBI group and PTSD only group in demographic, clinical and cognitive variables. Differences in neuropsychological results will be analysed by statistically controlling for age, language, education, estimated IQ, PTSD symptoms, symptoms of depression, general distress, and substance abuse. In terms of the statistical power, with a sample size of 20 per group in order to have a power of 80% to detect significant differences there must be at least 1 standard deviation difference between the means of the group. Based on prior research, it is expected that there will be at least 1.5 standard deviations difference in all measures between the TBI+PTSD group and normal group (depending on the severity of TBI, this difference will be bigger or smaller, however 1.5 is an average difference expected). Using the measures we have selected in a sample of just 20 we could be over 80% confident that even the small differences are detected. Similarly, a large difference is expected between the PTSD group and control in measures of verbal memory (AVLT 88% confidence), and, attention (Digit span backwards, 91%) and (Trail Making Test, 89%). We do not expect any difference between the PTSD group and the control group in other measures, and we do not expect any difference between the control group and normative data. The second part of data analysis includes the qualitative analysis of tests performance.

Relevance to Health

The current study is designed to investigate the neuropsychological outcomes related to torture induced brain injury and PTSD. Research suggests that the prevalence of these conditions is very high amongst torture victims. Mental injury is often associated with
psychiatric symptoms, neuropsychological deficits, and impaired social functioning. Detailed examination of which neuropsychological symptoms are due to PTSD and which are due to brain injury is important since some of the psychological symptoms reported by torture and trauma survivors may be secondary to organic central nervous system dysfunction rather than due to the psychological impact of trauma alone. Primarily by identifying the pattern of symptoms related to either PTSD or TBI, this research will provide a better understanding of differential diagnosis of these conditions and increase the chances that people with TBI do not go untreated. More specifically for people involved in this study, this data will inform the design and implementation of neuropsychological rehabilitation programs. Thus, RAS in Wellington will be the first agency to implement such a program that will later be expanded in the other RAS centres (Auckland, and Christchurch).

Secondly, it is often reported that people experiencing PTSD have difficulty with concentration, learning and memory. However, research to date has not explained the nature of these difficulties. The current study will reveal much more about the nature of these difficulties considering the comprehensive assessment that we are providing and the use of a civilian sample. Understanding whether there is a neuropsychological difficulty associated with PTSD and the nature of these difficulties holds potential to inform both clinical management of PTSD and theoretical conceptualization relevant to the disorder's etiology and maintenance.

Relevance to Maori Health Outcomes

How might your research contribute to the health needs of Maori? What is the health significance and context of this research to Maori? Discuss the incidence or prevalence in Maori, or indicate if not known to be significantly different from the general population.

Delete all the words below the heading and start typing here.

N/A

Dissemination of Results

A brief neuropsychological report for each participant (PTSD only group and PTSD+TBI group) will be given to the treating clinicians at Refugees as Survivors Centre. Upon completion of the study a summary of results will be given to all participants that request it. The results of the project will also be submitted to an international peer-reviewed journal for publication and will be presented at national or international conferences. The final report will be made available as an article in the online journal called "torture", which is the main source of international information on victims of torture. Further, an article will be made available through RAS website. Currently, the primary investigator and the clinical manager at Refugees as Survivors are discussing ways to include the outcomes of this research into a training program for health professionals "Working with culturally and linguistically different clients". This training is currently being piloted in Auckland, Palmerston North, Hamilton and Christchurch.

It is also expected that this research will be of interest to agencies such as Ministry of Health, and other agencies working with refugees and resettlement and the findings will be made available to them also.
MODULE 3: REFERENCES

There is no limit to the number of reference pages. Asterisks are to be placed besides applicant's publications.


MODULE 4: RELEVANCE OF RESEARCH TO SPECIFIC POPULATION GROUPS

1. Does your research involve one or more of the HRC's priority population groups? (✓)*

| Maori (if yes, Q2-7)         |                               |
| Pacific peoples (if yes, Q8-13) |                               |
| Children and youth (if yes, Q8-13) |                               |
| Older adults (if yes, Q6-13)   |                               |
| People with disability (if yes, Q8-13) | ✓                             |

* You can also complete these sections if your research does not directly involve priority populations, but you can provide information that would assist the reader to understand or appreciate the scope of your application.

Section 4A – Questions 2-7
Create subsections if required.

2. Describe the competency (e.g. cultural, relevant training, networks) of the research team to undertake the proposed research.

Delete these words and start typing here.

3. Identify the Maori groups consulted regarding this application and why and how they were selected.

| Iwi/hapu/Maori organisation as investigator |                               |
| Iwi group |                               |
| Maori health researchers |                               |
| Maori health group |                               |
| Other Maori group |                               |

4. Describe the process used with the above groups in the development of this application, their recommendations, and if they will have a role in the further development and/or implementation of this research project, or indicate if not applicable. Append any documentation resulting from that consultation.

Delete these words and start typing here.

5. If there are Maori participants in the project, how has tikanga been incorporated into the methodology? For example, what culturally appropriate methods will be used to recruit, how is data from Maori to be collected, stored and analysed?

Delete these words and start typing here.

6. Will this study lead to the development of Maori specific research methods? If so, please discuss.

Delete these words and start typing here.
### Section 5G – Other Support

Other Research Applications Awaiting Decision

Applicants must advise the HRC of the outcome of other research applications through their Research Office.

<table>
<thead>
<tr>
<th>Funding Agency</th>
<th>Title</th>
<th>Named Investigators</th>
<th>Start Date and Duration</th>
<th>Total Value</th>
<th>Date of Outcome</th>
<th>Areas of Overlap with this Application</th>
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</table>

Copy table and paste as necessary.

**Co-Funding:** What other agencies or end-users have been approached or committed to joint or partial funding of this research?

Delete these words and start typing here.

We are awaiting decision from The Victim Support in Wellington, and Neurological Foundation.
7. How, when and to what Māori groups, will the researchers actively disseminate research results?

Delete these words and start typing here.

Section 4B – Questions 8-13

Create a subsection within each question for each population group.

8. How might your research contribute to the health outcomes of the population to be studied? What is the health significance and context of the research to this population? (Discuss the incidence or prevalence in this population, or indicate if not known to be significantly different from the general population.)

Refugees are a particularly vulnerable population. Most refugees have experienced some form of trauma while around 80% have experienced torture. PTSD was found in around 69%-92% amongst victims of torture from six different countries. This prevalence is very high in comparison to that in general population which is estimated to be 7.8% (5% man and 10.4% woman). This is intuitive evidence given that the torture is a highly threatening and possibly associated with a more severe feeling of helplessness and lack of control. PTSD is associated with brain abnormalities that lead to problems in attention, memory, and learning. There are suggestions that trauma induced brain abnormalities appear to be more likely in those individuals with chronic or complicated PTSD. To date, no study has systematically evaluated the neuropsychological deficit resulting from PTSD related brain abnormality in refugee population and/or victims of torture. Understanding of these deficits would help in devising psychological treatments that address cognitive difficulties and also designing neuropsychological rehabilitation programs. Furthermore, as mentioned earlier, traumatic brain injury is highly prevalent amongst torture victims. Up to 70% report beaings to the head while up to 60% exhibit neurological symptoms. It is important that victims of trauma who also have brain injury are assessed and receive adequate treatment given that untreated TBI can lead to the experiences of trauma for longer time in addition to the decreased functional and interpersonal functioning.

Neuropsychological deficit can impact refugees more than any other population. That is because refugees have to resettle in a foreign country. This requires adjustment to new circumstances, new social environment and culture, new language, and different ways of living which are directly linked to individuals cognitive abilities. Thus, cognitive difficulties resulting from PTSD or TBI can lead to high levels of disability. This study will be able to shed some light on these difficulties and will also be able to develop methodologies for assessing this population and sensitize researchers to the problems that refugees face and the need for further research.

9. Describe the competency (e.g. cultural, relevant training, networks) of the research team to undertake the proposed research.

The primary investigator has worked in a number of cross cultural settings in Kosovo, New Zealand and Indonesia. In addition the primary investigator is currently attending a 5 day training for Mental Health Practitioners working with Culturally and Linguistically Diverse (CALD) Clients, organized by RASNZ (Refugees as Survivors) and WDHB (Wellernara District Health Board) in association Te Pou. In addition, the primary investigator participates regularly in the forums and seminars that are organized by Cross Cultural Centre in Wellington. Relevant to this project, the primary investigator has completed two postgraduate courses in neuropsychology (Neuropsychological Assessment and Neuropsychological Rehabilitation) and has completed a 6 week placement in Massey University Psychology Clinic, an agency specialised in neuropsychological assessment and rehabilitation. Furthermore, during the coming month, the primary investigator will undertake a 3 week placement at “Refugees as Survivors Centre” where she will gain further experience in working with refugees-victims of torture. As indicated earlier, the applicant is undertaking
clinical psychology training which enables her to conduct assessments and interventions under supervision.

Professor Janet Leatham is a leading expert in neuropsychology in New Zealand. She has an extensive research background in the neuropsychology of TBI. The second supervisor for this project is Professor Nigel Long whose area of expertise is Posttraumatic Stress Disorder.

10. Identify the stakeholder groups that were consulted regarding this application. Describe why and how they were selected.

Participants of this study are refugees from 7 different countries: Somalia, Sudan, Ethiopia, Afghanistan, Iraq, Cambodian and Burma. This project has been developed after consultations with staff members of RAS who have extensive experience working in cross-cultural settings with refugees of different backgrounds. In addition, consultation has taken place with Adam Awad who is Executive Chair of Change Makers Refugee Forum, a non-government organization comprised of representatives of 12 refugee communities who work together in supporting refugees in New Zealand and advocating for their human rights. Finally, ongoing consultations have taken place with community leaders, or community representatives for each cultural community involved in this study. Groups consulted include: Adam Awad- Executive Chair of Change Makers Refugee Forum and Representative of Somali community.

Samson Sahele: Representative of Ethiopian Community
Jean Claude - Sacheun – Cambodian Community Leader
Annie Coates – Representative of Burmese community
Sarjon Warde - Community Leader for Assyrian Community
Amad Rasheed - Leader of Al Rafedain Iraq which represents the Sunni and Shea communities
Robert Byer – Community Leader of Sudanese Community
Niaratullah Khalili - Community Leader for Afghan Community.
Tadesse Tujuba – Oromo Community leader

Attached is a letter of support from representatives of each cultural group involved in this project (See Appendix 2).

11. Describe the process used with the above groups in the development of this application, their recommendations, and if they will have a role in the further development and/or implementation of this research project, or indicate if not applicable. Append any documentation resulting from that consultation.

All the above mentioned individuals and organizations were contacted prior and during the development of this project. The recommendations provided by these groups have been incorporated into this project. In addition there is an agreement with these agencies for ongoing oversight of the cultural aspects of the research programme and availability for consultation on any specific issues that might arise with regards to best practice for working with the presenting issues of each participant.

12. Will the research generate data specific to one or more of these population groups? If so, please give details below. Describe any methodology of specific relevance to the study population.

The assessment measures will be validated and translated in 6 languages. The adequacy of neuropsychological test measures for use with diverse population will also be explored.

13. How, when and to what stakeholder groups, will the researchers disseminate research results?

At the completion of this study a summary of results will be sent to the Change makers forum where all the cultural advisors are represented. The organization RAS is directly involved in this study. They will receive individual reports for participants referred by this agency. Other
agencies concerned with refugees and the Ministry of Health may also be provided with a report.
MODULE 5: CONTRACT INFORMATION AND BUDGET

Use the Corresponding Excel Spreadsheet 'FG209Budget.xls' for Section 5A – 5D.

For the physical application:

Attach a printout of the spreadsheet Contract Information (Objectives and Milestones), Budget, MOU Budget (if applicable) and FTE Summary here and remove this page from the application.

Page orientation of the printed spreadsheet may be portrait (preferred) or landscape.

Ensure any page breaks are logically placed to facilitate review.

For the electronic copy of the application

Provide a separate electronic copy of the spreadsheet as a separate Excel file, when submitting the application Word file.
Section 5E – Justification of Expenses

Justification of Research Staff (as listed in budget)

Justify the role of all staff (named and un-named) for whom no Biographical Sketch is provided in Module 6. These may be research assistants, technicians, medical staff, interviewers, support staff or similar, whose names or position titles are listed in the budget under “Research Staff” and who have specific FTE involvements (see guidelines). Un-named post-doctoral fellows should also be justified here.

Delete all the words below the heading and start typing here.

Justification of Working Expenses (as listed in budget)

Research Assistants:

The research assistant will be a postgraduate student with an interest in the area of this study. The responsibilities for this person will be primarily on the scoring of the tests and data entry. Scoring and data entry for one assessment takes around 2.5 hours. It is expected that 3 assessments for a week will be conducted. Thus the research assistant will spend 7.5 hours weekly doing data entry.

Assessment of 20 participants and Report Writing:

As explained in the project proposal, one form of disseminating data is to provide a brief neuropsychological report for brain injured participants. These reports will be used by “Refugees as Survivors Centre” to guide treatment of these people. It is important that these reports are comprehensive and are in concordance with New Zealand health standards. Therefore, Massey University Psychology Clinic would be contracted to conduct these assessment and write reports. This agency is specialized in neuropsychological assessment and rehabilitation. In their usual practice, they charge 1500 dollars for assessment. They have provided a discounted rate of $1120 per participant. Thus, 20 participants x 1120 = 22400.

Interpreters

Professional interpreters will be accessed through interpreting service in the cross cultural centre at Taranaki Street, Wellington. This service has provided a rate of $ 85 per hour interpretation time. It is estimated that assessment for each participants will be 4 hours. Thus, 60 participants x 4 hours x $85 per hour is $ 20,400.

Test Translation

Translation from English to participant’s language will be conducted by the translation service in the Ministry of Internal Affairs. The below table provides

<table>
<thead>
<tr>
<th>Test</th>
<th>Language (example)</th>
<th>Price for Language</th>
<th>Price for 7 languages</th>
</tr>
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<td>AVL: List of words</td>
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<td>560</td>
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<td>Logical Memory- Wechsler Memory Test (2 stories)</td>
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<td>945</td>
</tr>
</tbody>
</table>

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CONFIDENTIAL
1. The 7 languages include: Arabic, Burmese, Cambodian, Farsi, Oromo, Amharic, and Somali.

2. Note that Harvard Trauma questionnaire has already been translated by previous researchers in a number of languages that are relevant to this project. These measures have been made available to us. Therefore this measure will be translated only in 5 languages.

Blind back translation of tests will be conducted by the translation service at the cross cultural centre. The above stated quotes apply for this as well.

**Test materials:**

The tests will be available through Massey University Test Library. It is only required to buy recording forms for WAIS-III* and D-FFES*. One record form costs 7 dollars. Thus, 60 participants x $ 7 is $ 420.

**Training and preparation of interpreters:**

This money will be used to pay interpreters to participate in the preparation and training session. In this one-hour training they will be familiarized with the assessment procedure. They will be informed about the nature of this assessment and their responsibilities during and after the assessment. The second hour will be spend in the recording of test instructions and

**Printing and photocopying**

<table>
<thead>
<tr>
<th>1800 single sided pages</th>
<th>$0.045 cent per page</th>
<th>81</th>
</tr>
</thead>
<tbody>
<tr>
<td>960 double sided</td>
<td>$0.075 cent per page</td>
<td>72</td>
</tr>
</tbody>
</table>

**Travel expenses**

Participants will be reimbursed for the travel expenses. Thus, $20 dollars for 60 participants =1200.

**Posters**

Four posters will be used for the recruitment of the control group. One poster costs $50. Thus 4 posters at 50 dollars is $ 200.
Section 5F – Listing of Previous / Current Contracts

List a maximum of 6 previous / current contracts for the Applicant as 1st Named Investigator from all agencies. Final HRC reports may be made available to the Science Assessing Committee on request.

<table>
<thead>
<tr>
<th>Funding Agency</th>
<th>Title of Research</th>
<th>Named Investigators</th>
<th>Start date and duration</th>
<th>Total Value</th>
<th>Nature of support (1 sentence)</th>
<th>If HRC contract, was Final Report filed? If not, why?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tr>
</tbody>
</table>
Section 5G – Other Support

Other Research Applications Awaiting Decision

Applicants must advise the HRC of the outcome of other research applications through their Research Office.

<table>
<thead>
<tr>
<th>Funding Agency</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Title</td>
<td></td>
</tr>
<tr>
<td>Named Investigators</td>
<td></td>
</tr>
<tr>
<td>Start Date and Duration</td>
<td></td>
</tr>
<tr>
<td>Total Value</td>
<td></td>
</tr>
<tr>
<td>Date of Outcome</td>
<td></td>
</tr>
<tr>
<td>Areas of Overlap with this Application</td>
<td></td>
</tr>
</tbody>
</table>

Copy table and paste as necessary.

Co-Funding: What other agencies or end-users have been approached or committed to joint or partial funding of this research?

Delete these words and start typing here.

We are awaiting decision from The Victim Support in Wellington, and Neurological Foundation.
Section 5H – Letters of Collaboration/Supporting Documents Index.

1. Locality Assessment from the Refugees as Survivors Centre
2. Letter of support from Refugees as Survivors Centre
3. Locality Assessment from Massey University Psychology Clinic
4. Letters from cultural advisors in the following order:
   - Mr. Sarjohr Varde - Assyrian Association
   - Ms. Annie Coats - Myanmar Group
   - Ms. Amaal Rasheed - Iraqi Community
   - Mr. Jean Claude Sacheun - Wellington Cambodian Community
   - Mr. Adam Awad - Wellington Somali Community
   - Mr. Tadesse Tujuba - Oromo (Ethiopia) community representative
   - Mr. Niamatullah Khalili - Afghan Community
   - Ms. Sado Oti - Wellington interpreters and representative of Somali women.
   - Mr. Samson Sahele - representative of Amharic (Ethiopia) cultural group and cultural advisor at RAS.
Section 5H – Letters of Collaboration/Supporting Documents Index.

1. Locality Assessment from the Refugees as Survivors Centre
2. Letter of support from Refugees as Survivors Centre
3. Locality Assessment from Massey University Psychology Clinic
4. Letters from cultural advisors in the following order:
   - Mr. Sarjohn Warde- Assyrian Association
   - Ms. Annie Coats- Myanmar Group
   - Ms. Amaal Rasheed- Iraqi Community
   - Mr. Jean Claude Sacheur – Wellington Cambodian Community
   - Mr. Adam Awad- Wellington Somali Community
   - Mr. Tadesse Tujuba – Oromo(Ethiopia) community representative
   - Mr. Niamatullah Khalili- Afghan Community
   - Ms. Sado Oti – Wellington interpreters and representative of Somali women.
   - Mr. Samson Sehale- representative of Amharic (Ethiopia) cultural group and cultural advisor at RAS.
HRC REF: 09/313
NI: Veliu

MODULE 6: BIOGRAPHICAL SKETCHES

Must be completed by all Named Investigators, excluding the applicant. The applicant’s details are given in Module 1B. It is recommended that post-doctoral fellows employed on the project provide a biographical sketch.

<table>
<thead>
<tr>
<th>Name</th>
<th>Janet Leathem</th>
</tr>
</thead>
<tbody>
<tr>
<td>Department</td>
<td>Psychology</td>
</tr>
<tr>
<td>University/Organisation</td>
<td>Massey University</td>
</tr>
<tr>
<td>PO Box/Street number &amp; name</td>
<td>PO Box 75624 King St</td>
</tr>
<tr>
<td>Suburb</td>
<td>Mt Cook</td>
</tr>
<tr>
<td>City and postal code</td>
<td>Wellington 6005</td>
</tr>
<tr>
<td>Telephone</td>
<td>(04) 8015799</td>
</tr>
<tr>
<td>Email</td>
<td><a href="mailto:J.M.Leathem@massey.ac.nz">J.M.Leathem@massey.ac.nz</a></td>
</tr>
<tr>
<td>Iwi &amp; hapu (if relevant)</td>
<td></td>
</tr>
<tr>
<td>Pacific ethnicity (if relevant)</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>Female</td>
</tr>
<tr>
<td>FTE (%) proposed research</td>
<td>10</td>
</tr>
</tbody>
</table>

Justification of role in the project:

This project will serve as partial fulfilment of doctorate in psychology at Massey University. I will act as supervisor or the academic as well as the clinical components of the work.

If a Named Investigator intends to be absent for a period of longer than one month during the contract duration, please state the reason and length of absence: N/A

Delete these words and start typing here.

<table>
<thead>
<tr>
<th>Degrees/Diplomas</th>
<th>University</th>
<th>Field</th>
<th>Year conferred</th>
</tr>
</thead>
<tbody>
<tr>
<td>PhD</td>
<td>Victoria University</td>
<td>Psychology</td>
<td>1981</td>
</tr>
<tr>
<td>M.A.</td>
<td>Victoria University</td>
<td>Psychology</td>
<td>1975</td>
</tr>
<tr>
<td>B.A. (Hons.)</td>
<td>Victoria University</td>
<td>Education &amp; Psychology</td>
<td>1973</td>
</tr>
<tr>
<td>B.A.</td>
<td>Massey University</td>
<td>Psychology</td>
<td>1972</td>
</tr>
</tbody>
</table>

Honours, prizes, scholarships, etc

Alma Baker Undergraduate Scholarship, Massey University, 1969-1970
James McIntosh Postgraduate Scholarship in Education, Victoria University, 1977
Women’s Study Award, Massey University, 1986

Relevant academic and research experience

<table>
<thead>
<tr>
<th>From year</th>
<th>To year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lecturer</td>
<td>1987</td>
</tr>
<tr>
<td>Senior Lecturer</td>
<td>1991</td>
</tr>
<tr>
<td>Professor</td>
<td>2000</td>
</tr>
<tr>
<td>Have supervised many Masters &amp; Doctoral students</td>
<td></td>
</tr>
</tbody>
</table>

Number of Publications (exclude abstracts, proceedings or letters published or presented)

CONFIDENTIAL
List of Publications from previous five years (2003 onwards)
List in reverse date order, starting from current year first, and highlight the ones most relevant to this application, by bolding the Author(s) name. You may include citations, impact factors, and/or journal rankings.


Other forms of research dissemination (1 page only)


HRC REF: 09/313


Signature

I certify that the information provided is current, accurate and correct, and that if this proposal is funded I will not receive funding from any and all sources which will exceed 100% FTE.

Please note that by signing this you are agreeing to the stated FTE contribution.
HRC REF: 09/313

MODULE 7: ADMINISTRATION

Do not copy any sections in MODULE 7. Send with original application only.

Section 7A – Ethical and Regulatory Agreement

<table>
<thead>
<tr>
<th>Named Investigator 1</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Bahria Veliu</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Research Title: Neuropsychological sequelae of torture

<table>
<thead>
<tr>
<th>Requires human ethical approval?</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Requires animal ethical approval?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

If this application does not require ethical approval, please briefly detail below:

Delete these words and start typing here.

If this application requires consent from other regulatory bodies such as ERMA, MAF, DOC, GTC, SCOTI or Biosafety, please detail below:

Delete these words and start typing here.

The following information will be used for administrative purposes.

<table>
<thead>
<tr>
<th>Is the proposed research a clinical trial, a community intervention study or innovative treatment?</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>If yes to the above, do you intend to have an independent Data Monitoring Committee?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>If yes to the above, will this be through the HRC’s Data and Safety Monitoring Board (DSMB)?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: Information on the structure and operating guidelines of the HRC’s DSMB are available from the HRC website. For further information please contact Leesa Rowlands, lrowlands@hrc.govt.nz

The applicant has read the ‘Guidelines on Ethics in Health Research’, available from the HRC website (http://www.hrc.govt.nz/assets/pdfs/ethgdlns.pdf) and agrees to abide by the principles outlined in it. The undersigned also agrees to provide written evidence before any research procedures commence, that in any study involving animal or human subjects, animal or human materials or personal information, a properly constituted accredited Ethics committee has examined and agreed to the ethics of the proposal outlined in this proposal. If minor changes in the research design or procedures have been required for ethical reasons, the HRC must be informed of them. The undersigned also undertakes to ensure that all regulatory consents are gained before research commences.

<table>
<thead>
<tr>
<th>Named Investigator 1</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Name:</td>
<td>Signed:</td>
<td>Date:</td>
</tr>
</tbody>
</table>

Head of Department/School/Faculty or Hospital

| Name: | Signed: | Date: |

FG209 Application form © 2008 Health Research Council of New Zealand. All rights reserved
Section 7B – Administrative Agreement

All HRC applications must include an undertaking to abide by the following administrative agreement:

1. It is understood and agreed that this application and any contract awarded as a result of this application is subject to the Health Research Council of New Zealand Rules (“Permissible Use of Research Funding and Operation of Contracts”). Funds will not be expended for any other purpose than described in this application.

2. The host institution agrees and undertakes to bear all risk and claims connected with any operation covered by this application and to indemnify and hold harmless the Council against any and all liability suits, actions, demands, costs or fees on account of death, injuries to persons or property, or any other losses resulting from or connected with any act or omission performed in the course of the research.

3. The host institution agrees and undertakes to support for the duration of any contract, the work described in this application by making available accommodation, basic facilities for research and the services necessary for its fulfilment.

4. The Head of Department agrees to accept this research within his/her department if a contract is made, agrees to provide workload relief for research staff working on this contract (Principles of Full Cost Funding), and is aware that s/he may be requested by the HRC to provide a confidential assessment of the research during the term of the contract.

5. The host institution official designated below agrees to ensure that the research will have been approved, where necessary, by the appropriate institutional biosafety committee and/or all other required regulatory agencies before research is commenced.

6. The applicant(s) agrees to allow specified personal information to be used for statutory and publicity purposes.

7. The host institution has in place policies and processes to ensure that consultation with Maori has occurred and the application is responsive to the needs and diversity of Maori.

We the undersigned have read the above administrative agreement and undertake to abide by the conditions of this agreement in respect of any contract made by the Health Research Council of New Zealand as a result of this application. We the undersigned confirm that the information provided in this application is to the best of our knowledge true, and that all sections are correct at the time of application submission.

NOTE: Only one fully signed copy of this page is required by the Council, this form must be returned to the Health Research Council of New Zealand with original copy of the contract application. Applications that do not have a fully completed administrative agreement will not be processed.

<table>
<thead>
<tr>
<th>Applicant</th>
<th>Signed</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name: Bahrie Veliu</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Head of Department/School/Faculty or Hospital</td>
<td>Signed</td>
<td>Date</td>
</tr>
<tr>
<td>Name:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Authorised official on behalf of host institution</td>
<td>Signed</td>
<td>Date</td>
</tr>
<tr>
<td>Name:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Position: Host name:</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Section 7C – Applicant Referee Nomination and Resubmission

**Resubmission**

If you are resubmitting an application and would like the previous review summary, applicant rebuttal and referee reports to be seen by the Science Assessing Committee reviewing the current application, complete the following section. If you do not want this application to be viewed as a resubmission, leave ALL these boxes blank.

- **I would like the Science Assessing Committee to see the assessment documentation from my previous application (please tick or leave blank)**
- **Previous application HRC reference number**
- **Previous First Named Investigator**
- **Previous research title**

#### Nominated impartial referees (Maximum of two)

<table>
<thead>
<tr>
<th>Referee Name</th>
<th>Professor Ian Evans</th>
</tr>
</thead>
<tbody>
<tr>
<td>Organisation and Address</td>
<td>Massey University, School of Psychology, Turitea, Palmerston North, Room P2.14</td>
</tr>
<tr>
<td>Telephone</td>
<td>+64 6 3569-099, Ext 2070</td>
</tr>
<tr>
<td>Email</td>
<td>+64 6 3569-099, Ext 2070</td>
</tr>
<tr>
<td>Area(s) of Expertise</td>
<td>Intellectual Disability, Mental Health, Psychotherapy, Autism, Children's Development</td>
</tr>
<tr>
<td>Relationship to applicant(s)</td>
<td>Lecturer</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Referee Name</th>
<th>Dr Moshe Landsman, PhD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Organisation and Address</td>
<td>Lecturer at Kaye Teachers College in Beer Sheva and visiting professor at the University of Prishtina, Kosovo</td>
</tr>
<tr>
<td>Telephone</td>
<td>972522620505</td>
</tr>
<tr>
<td>Email</td>
<td><a href="mailto:moshel@gmail.com">moshel@gmail.com</a></td>
</tr>
<tr>
<td>Area(s) of Expertise</td>
<td>Clinical Psychology</td>
</tr>
<tr>
<td>Relationship to applicant(s)</td>
<td>Supervisor and lecturer at the University of Prishtina, Kosovo</td>
</tr>
</tbody>
</table>

#### Referees unacceptable to applicant (Name of an individual or a research group)

<table>
<thead>
<tr>
<th>Name</th>
<th>Organisation</th>
<th>Reason (delete any that do not apply)</th>
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<tbody>
<tr>
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<td></td>
<td>Competition/Conflict of interest/Commercial sensitivity</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Name</th>
<th>Organisation</th>
<th>Reason (delete any that do not apply)</th>
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</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Competition/Conflict of interest/Commercial sensitivity</td>
</tr>
</tbody>
</table>
MODULE 8: CLASSIFICATION of RESEARCH

Do not copy any sections in MODULE 8. Send with original application only.

Section 8A – Australian and New Zealand Standard Research Classification (ANZSRC) and HRC Classification

Applicants are required to categorise their research in two ways. The HRC Discipline* and HRC Fields of Research** categories are listed in the Appendix 1 and 2 of the Guidelines. The ANZSRC codes for FOR*** and SEO**** classifications can be found on the HRC weblink (https://secure.hrc.govt.nz/classifications) – find the appropriate code(s) and insert in the table below.

<table>
<thead>
<tr>
<th>Research Descriptors</th>
<th>HRC Discipline*</th>
<th>ANZSRC Code</th>
<th>HRC Fields of Research**</th>
<th>ANZSRC Code</th>
<th>Weighting (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychology: Clinical</td>
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<tr>
<td>Neuropsychology</td>
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<td></td>
<td></td>
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<tr>
<td>Mental Health: illness</td>
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<tr>
<td>Injury</td>
<td></td>
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</tr>
<tr>
<td>MoRST Fields of Research (FOR)**</td>
<td>110999 Neuroscience</td>
<td>70%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>111714 Mental Health</td>
<td>20%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>111703 Care for Disabled</td>
<td>10%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MoRST Socioeconomic Objective (SEO)***</td>
<td>C920 199 Clinical Health</td>
<td>70%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>C959999 Cultural Understanding</td>
<td>30%</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Keywords

- Post-traumatic stress disorder
- Traumatic brain injury

HRC Discipline and Fields of Research classifications are for HRC purposes only.
ANZSRC information is for HRC and MoRST purposes.
* See Guidelines
** ANZSRC code
*** See Guidelines
**** ANZSRC code

Section 8B – Research Portfolios (RP) and Mapping Categories

Please refer to the HRC’s Research Portfolio strategies and tick (✓) the portfolio(s) to which your research proposal addresses an identified priority:

- Biological Systems and Technologies
- Communicable Diseases
- Determinants of Health
- Health and Independence of Population Groups
- Health & Disability Sector Management and Services
- Injury, Impairment, Rehabilitation and Disability ✓
- Mental Health and Neurological Disorders ✓
- Non-Communicable Diseases
- Rangahau Hauora Maori

This information will be used by the HRC Grant Approval Committee.
Please indicate with a tick (✓) the category that best describes the starting point of your research (tick one box only):

<table>
<thead>
<tr>
<th>Category</th>
<th>Ticked</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gene</td>
<td></td>
</tr>
<tr>
<td>Cell biology</td>
<td></td>
</tr>
<tr>
<td>Diagnostics</td>
<td>✓</td>
</tr>
<tr>
<td>Physiology</td>
<td></td>
</tr>
<tr>
<td>Pharmaceuticals/Treatments</td>
<td></td>
</tr>
<tr>
<td>Clinical studies</td>
<td></td>
</tr>
<tr>
<td>Clinical trials</td>
<td></td>
</tr>
<tr>
<td>Health economics</td>
<td></td>
</tr>
<tr>
<td>Clinical services</td>
<td></td>
</tr>
<tr>
<td>Knowledge Resources</td>
<td></td>
</tr>
<tr>
<td>Risk factors</td>
<td></td>
</tr>
<tr>
<td>Interventions</td>
<td></td>
</tr>
<tr>
<td>At-risk populations</td>
<td>✓</td>
</tr>
<tr>
<td>Community services</td>
<td>✓</td>
</tr>
</tbody>
</table>

This information is for HRC evaluation purposes only.
Appendix J: Cultural Advisors

19 May 2008
Massey University
Psychology Department
24 King Street
Mount Cook Wellington

To Whom It May Concern

Cultural Advice Confirmation

This letter is to inform that I have been contacted by Bahrie Veliu (doctorate student at Massey University) who has explained to me her research project "Neuropsychological assessment of refugees-victims of torture who have experienced traumatic brain injury and posttraumatic stress disorder". I would like to confirm that I consider this project appropriate and helpful for the participants involved. I also confirm that I support this project and I'm available to provide cultural advice throughout this project concerning the cultural group from Afghanistan.

Name: Niamatullah
Organization: Afghan community
Contact: Niamatullah14@yahoo.com
Signature: [Signature]
To Whom It May Concern

Cultural Advice Confirmation

This letter is to inform that I have been contacted by Bahrie Vellu (doctorate student at Massey University) who has explained to me her research project "Neuropsychological assessment of refugees-victims of torture who have experienced traumatic brain injury and posttraumatic stress disorder". I would like to confirm that I consider this project appropriate and helpful for the participants involved. I also confirm that I support this project and I'm available to provide cultural advice throughout this project concerning cultural groups from Somalia.

Name: Adam \\
Organization: Wellington Somali Council Inc. \\
Contact: 027 4125 758 \\
Signature:

[Signature]
19 May 2008

Massey University
Psychology Department
24 King Street
Mount Cook Wellington

To Whom It May Concern

Cultural Advice Confirmation

This letter is to inform that I have been contacted by Bahrie Velis (doctorate student at Massey University) who has explained to me her research project "Neuropsychological assessment of refugees-victims of torture who have experienced traumatic brain injury and posttraumatic stress disorder". I would like to confirm that I consider this project appropriate and helpful for the participants involved. I also confirm that I support this project and I'm available to provide cultural advice throughout this project concerning Somali women participants.

Name: 

Organization: 

Contact: 972 1463

Signature: 

Appendices
14 July, 2008
Massey University
Psychology Department
24 King Street
Mount Cook Wellington

To Whom It May Concern

Cultural Advice Confirmation

This letter is to inform that I have been contacted by Bahrie Veliu (doctorate student at Massey University) who has explained to me her research project “Neuropsychological assessment of refugees-victims of torture who have experienced traumatic brain injury and posttraumatic stress disorder”. I would like to confirm that I consider this project appropriate and helpful for the participants involved. I also confirm that I support this project and I’m available to provide cultural advice throughout this project concerning cultural groups from Burma.

Name: Annie Now Cooles
Organization: Myanmar Group
Contact: 04-979 2115
          027-460 7942
Signature: [Signature]
09 July, 2008

Massey University
Psychology Department
24 King Street
Mount Cook Wellington

To Whom It May Concern

Cultural Advice Confirmation

This letter is to inform that I have been contacted by Bahrie Veliu (doctorate student at Massey University) who has explained to me her research project “Neuropsychological assessment of refugees-victims of torture who have experienced traumatic brain injury and posttraumatic stress disorder”. I would like to confirm that I consider this project appropriate and helpful for the participants involved. I also confirm that I support this project and I’m available to provide cultural advice throughout this project concerning cultural groups from Iraq.

Name: Amaal Rasheed
Organization: Iraqi Community
Contact: 23222877
Signature: Amaal Rasheed
19 May 2008

Massey University
Psychology Department
24 King Street
Mount Cook Wellington

To Whom It May Concern

Cultural Advice Confirmation

This letter is to inform that I have been contacted by Bahrie Veliu (doctorate student at Massey University) who has explained to me her research project “Neuropsychological assessment of refugees-victims of torture who have experienced traumatic brain injury and posttraumatic stress disorder”. I would like to confirm that I consider this project appropriate and helpful for the participants involved. I also confirm that I support this project and I’m available to provide cultural advice throughout this project concerning Oromo cultural group from Ethiopia.

Name: TADESE Injua

Organization: Oromo Community Rep

Contact: 0224 73 35 2

Signature: [Signature]
Appendix K: Poster for Control Group

Research with Refugees

CAN YOU HELP?

Are you refugee/migrant older than 16 years and would like to help in a research we are doing with refugees who have been victims of torture and trauma?

We want to find out how trauma/torture affects concentration, memory and learning in refugees.

You will receive $20 for participation.

It you are interested in taking part in this research please phone: 04 091 5799 extension 82324

Or Please fill the form provided and place it in the mail box. The postage is free.

Knowledge of English is not necessary.

A professional interpreter will assist communication.

Once your expression of interest is accepted, we will call to make an appointment.

Thank you for considering this request!

Researcher: Bahrie Yelio
Supervisor: Professor Janet Leathem

0800 MASSEY
www.massey.ac.nz

Te Kupenga ki Puehuru

MASSEY UNIVERSITY
Appendix L: Background Information Questionnaire - English

Part I

Background Information:
(Takeout Information from the file, if not possible ask the participant to answer questions)

Name ___________________________ Today’s Date ___________________________

Sex _______ Date of Birth (Age) ___________ Place of birth ___________________________

What nationality do you mostly identify with ____________________________

Primary language ___________ Second language ____________________________

What language do you usually speak? ___________________________ Religion __________________________

How would you rate the level of English proficiency in scale 1-5 ? (E.g., 1- no English at all, 5- Fluent).

Language used in this assessment ___________________________ Hand used for writing __________________________

<table>
<thead>
<tr>
<th>Education history:</th>
<th>Years attended</th>
<th>Grade and degree achieved</th>
<th>Preferred subjects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Elementary</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Secondary</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>College/university</td>
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</tr>
</tbody>
</table>

Any special training ___________________________ Any training in New Zealand? __________________________

Did/Do you have problems with reading, writing, and or doing maths (describe) ____________________________

How would you describe your performance as a student? ____________________________

Which types of recreations you enjoy? ____________________________

Are you still able to do these activities? ____________________________

Current job or last job ___________________________ Job prior to injury __________________________

Previous work history ____________________________

Marital status _______ No of Children _______ Children living at home ____________________________

Mother’s education ___________________________ Mother’s occupation ____________________________

Father’s education ___________________________ Father’s occupation ____________________________

When did you arrive in New Zealand _______ Have you been granted asylum? Yes ______ No ______

Medical diagnosis, (if any) __________________________________________

Sleep pattern in general ___________________________ Last night’s sleep __________________________

Do you have a hearing problem Yes ______ No ______ Do you have a vision problem? Yes ______ No ______

Have you had a prior neuropsychological examination? Yes ______ No ______ If yes When ____________________________
## Part II

Please describe what happened.

<table>
<thead>
<tr>
<th>Type of Injury</th>
<th>Experienced</th>
<th>Loss of Consciousness</th>
<th>When</th>
<th>Over how long</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
<td>Hours</td>
<td>Minutes</td>
</tr>
<tr>
<td>Beatings to the head</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Suffocation or strangulation</td>
<td></td>
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</tr>
<tr>
<td>Near drowning</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Electric shock</td>
<td></td>
<td></td>
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<tr>
<td>Gun wound in the head</td>
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<tr>
<td>Other type of injury to the head</td>
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</tbody>
</table>

Time since injury ____________  Age when the injury occurred ________________

Symptoms that have resulted

__________________________________________________________

Any other significant sickness (e.g., hospitalizations for brain cancer, meningitis, stroke, heart attack; domestic violence, repeated shaking as a child, poisoning, seizure, major accidents).

Drinking alcohol: Rarely or never ______ 2 days/week ______ 3-5 days/week ______ daily ______

Usual number of drinks you have at one time ________ When was your last drink ________

If you don’t use alcohol at present, have you used alcohol but stopped ______ When ______

Medications & Use of Substances (e.g., prescribed medications, and recreational drugs). List current and past frequency and duration.

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________
Appendix M: Background Information Questionnaire - Arabic

الجزء الأول
معلومات عن خليفة الشخص
(يمكن استخراج المعلومات عن حالتك إذا لم تتناسب حالتك مع المشارك الإجابة على الاستمارة)

الاسم: 
تاريخ اليوم: 
السن: 
تاريخ الميلاد (الصرح): 
مكان الولادة: 
المدينة التي تعيش بها على الغالب: 
اللغة الأساسية: 
اللغة التي تتحدث بها غالباً: 
كيف تحترم مستوى الكلمة في اللغة الإنجليزية في القياس من 1 - 5 (1 = من غير الإنجليزية على الأطلاق، 5 = الإنجليزية بلغامة) 
اللغة المستخدمة في الكتابة: 
ال בלاتر التعليمية التي استخدمت في الكتابة:

العوامل ودرجة التحصيل المفيدة 

تاريخ التعليم 
التعليم الأساسي 
التعليم الثانوي 
كليات جامعة

هل لديك تاريخ في نيوزيلندا؟ 
هل كنت لديك/لديك مشكلات قراءة، كتابة، أو في الرياضيات (أعد تفاصيل)

كيف تصف حالتك كطالب؟ 
إي من أنواع الطعام يعجبك؟ 
هل تزيد حالياً على القبلة تلك الفعاليات؟ 
الوظيفة الحالية أو أخرى وظيفة: 
سبل العمل السابق:
العائلة الزوجية: عدد الأولدات الذين يعيشون في المنزل: 
الموظف الحالي للأم: 
الموظف الحالي للأب: 
هل تمكنت لجود؟ تم 
هل تمكنت لجود؟ لا 
إذا كان الجواب نعم، ما هو المشاكل الطبية (ان وجدها): 
نظام يوم الدراسة: 
هل لديك مشكلة سمع؟ نعم 
هل لديك مشكلة في البصر؟ نعم 
هل لديك مشكلة في السمع؟ نعم 
إذا كان الجواب نعم، ما هي ذلك: 
الرجاء وصف ما حدث:
الجزء الثاني
الرجاء وصف ما حدث

| نوع الإصابة | تعرضت لـ | تفادت الوسائل | متى | ما هي النبضة | ساعتين تاليتين
|-------------|----------|---------------|-----|-------------|-------------
| الضرب على الرأس | نعم | منع، الترفيع | 10
| القطع أو النق | نعم | منع، الترفيع | 5
| جرح ناجم عن اصطدام ناري في الرأس | نعم | منع، الترفيع | 3
| إصابات أخرى في الرأس | نعم | منع، الترفيع | 1

كم ماضى من الوقت على الإصابة

الاعراض الناجمة

أي اعراض محسوبة أخرى (مثل المكوث في المستشفى، مرض سرطان الدماغ، التهاب السحايا، الجلطة، النيما الصدرية، الحد الوردي، تكاثر هز الظلال، التسمم، الصرع، الحوادث الكبرى).

شرب الكحول: نادرًا أو أبداً  | يومًا في الاسبوع  | 3-5 أيام الاسبوع
عدد المشروبات المعتادة إن تشربها دفعة واحدة: إن كن أخبار لك: إذا كنت لا تشرب الكحول في الوقت الحاضر، هل كنت تشرب الكحول ثم توقفت: إن كن كان ذلك

المخاطر واستعمال المواد المخدرة (مثل الأدوية بوصفها طيبة، المخاطر التحفيزية، ادرج الاستخدامات الحالية والسلبية، ودة استئصالها:  

2
Appendix N: Background Information Questionnaire - Burmese

ယောက်ျား (၂)

ဒူးဒီယိုတိုင်းရိုးမှုများကိုရေးသားရန်

(စာအုပ်အတိုင်းရာတွင်သို့ရေးသောစာမျက်နှာများကို အညီညားစေရန်)

အမည် ________________________________

လေး (လူ) ______ ဗုဒ္ဓကျောင်း (အမည်) ______ ဗုဒ္ဓကျောင်း(အမည်) ______

အိမ် (လူအများကိုရေးသားရန်အတွက်) ______________

ပြည်သူ့ဝန်ကြီးမှု့အတွက် ______________

အမျိုးအစားများကိုရေးသားရန် ______________

အလှည်ဝါးကိုရေးသားရန် ______________

(၂၀၂၃၀၃၀၄ ကြည်းရှုကျွန်ုပ်ရဲ့အချက်ကို ဗုဒ္ဓကျောင်း(အမည်) ______________

အလှည်ဝါးကိုရေးသားရန် ______________

ယောက်ျား (စာအုပ်အတိုင်းရာ) ______________

<table>
<thead>
<tr>
<th>ကြည်းရှုကျွန်ုပ်ရဲ့အချက်</th>
<th>အလှည်ဝါးကိုရေးသားရန်</th>
<th>အလှည်ဝါးကိုရေးသားရန်</th>
</tr>
</thead>
<tbody>
<tr>
<td>ပြည်သူ့ဝန်ကြီးမှု့</td>
<td>စာအုပ်အတိုင်းရာ</td>
<td>စာအုပ်အတိုင်းရာ</td>
</tr>
<tr>
<td>အလှည်ဝါးကိုရေးသား</td>
<td>စာအုပ်အတိုင်းရာ</td>
<td>စာအုပ်အတိုင်းရာ</td>
</tr>
</tbody>
</table>

အမျိုးအစားများကိုရေးသားရန် ______________

အလှည်ဝါးကိုရေးသားရန် ______________

ယောက်ျား (စာအုပ်အတိုင်းရာ) ______________

<table>
<thead>
<tr>
<th>ကြည်းရှုကျွန်ုပ်ရဲ့အချက်</th>
<th>အလှည်ဝါးကိုရေးသားရန်</th>
<th>အလှည်ဝါးကိုရေးသားရန်</th>
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<tbody>
<tr>
<td>ပြည်သူ့ဝန်ကြီးမှု့</td>
<td>စာအုပ်အတိုင်းရာ</td>
<td>စာအုပ်အတိုင်းရာ</td>
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<tr>
<td>အလှည်ဝါးကိုရေးသား</td>
<td>စာအုပ်အတိုင်းရာ</td>
<td>စာအုပ်အတိုင်းရာ</td>
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<tr>
<td>ယောက်ျား (စာအုပ်အတိုင်း</td>
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<td>စာအုပ်အတိုင်းရာ</td>
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<th>ကြည်းရှုကျွန်ုပ်ရဲ့အချက်</th>
<th>အလှည်ဝါးကိုရေးသားရန်</th>
<th>အလှည်ဝါးကိုရေးသားရန်</th>
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</thead>
<tbody>
<tr>
<td>ပြည်သူ့ဝန်ကြီးမှု့</td>
<td>စာအုပ်အတိုင်းရာ</td>
<td>စာအုပ်အတိုင်းရာ</td>
</tr>
<tr>
<td>အလှည်ဝါးကိုရေးသား</td>
<td>စာအုပ်အတိုင်းရာ</td>
<td>စာအုပ်အတိုင်းရာ</td>
</tr>
<tr>
<td>ယောက်ျား (စာအုပ်အတိုင်း</td>
<td>စာအုပ်အတိုင်းရာ</td>
<td>စာအုပ်အတိုင်းရာ</td>
</tr>
<tr>
<td>မေးခွန်အမျိုးအစား</td>
<td>အဓိက</td>
<td>ပြင်ပလုပ်ငန်း</td>
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<tr>
<td>----------------------</td>
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</tr>
<tr>
<td>မေးခွန်အမျိုးအစား</td>
<td>အဓိက</td>
<td>ပြင်ပလုပ်ငန်း</td>
</tr>
</tbody>
</table>

ဖော်ပြပါသည် ၏ အဖွဲ့အစည်းအဝင်များအတွက် ဖြစ်သည်ကို အလွယ်တကူ ရှာဖွေနိုင်သည်။

စာပိုးတွေ့ရှိသည့်အချက်များကို အလွယ်တကူ ဖော်ပြပါသည်။
Appendix O: Patient Competency Rating Scale - English

Patient Competency Rating
(Patient’s Form)

Identifying Information

Patient’s Name: ____________________________________________________________

Date: __________________

Instructions

The following is a questionnaire that asks you to judge your ability to do a variety of very practical skills. Some of the questions may not apply directly to things you often do, but you are asked to complete each question as if it were something you “had to do.” On each question, you should judge how easy or difficult a particular activity is for you and mark the appropriate space.

Competency Rating

<table>
<thead>
<tr>
<th>Cntn do</th>
<th>Very difficult to do</th>
<th>Can do with some difficulty</th>
<th>Fairly easy to do</th>
<th>Can do with ease</th>
</tr>
</thead>
</table>

1. How much of a problem do I have in preparing my own meals?

2. How much of a problem do I have in dressing myself?

3. How much of a problem do I have in taking care of my personal hygiene?

4. How much of a problem do I have in washing the dishes?

5. How much of a problem do I have in doing the laundry?

6. How much of a problem do I have in taking care of my finances?

7. How much of a problem do I have in keeping appointments on time?
<table>
<thead>
<tr>
<th></th>
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<tbody>
<tr>
<td>8.</td>
<td>How much of a problem do I have in starting conversation in a group?</td>
<td></td>
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<tr>
<td>9.</td>
<td>How much of a problem do I have in staying involved in work activities even when bored or tired?</td>
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<td></td>
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<tr>
<td>10.</td>
<td>How much of a problem do I have in remembering what I had for dinner last night?</td>
<td></td>
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<tr>
<td>11.</td>
<td>How much of a problem do I have in remembering names of people I see often?</td>
<td></td>
<td></td>
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<tr>
<td>12.</td>
<td>How much of a problem do I have in remembering my daily schedule?</td>
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<tr>
<td>13.</td>
<td>How much of a problem do I have in remembering important things I must do?</td>
<td></td>
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<tr>
<td>14.</td>
<td>How much of a problem would I have driving a car if I had to?</td>
<td></td>
<td></td>
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<tr>
<td>15.</td>
<td>How much of a problem do I have in getting help when I'm confused?</td>
<td></td>
<td></td>
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<tr>
<td>16.</td>
<td>How much of a problem do I have in adjusting to unexpected changes?</td>
<td></td>
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<tr>
<td>17.</td>
<td>How much of a problem do I have in handling arguments with people I know well?</td>
<td></td>
<td></td>
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<tr>
<td>18.</td>
<td>How much of a problem do I have in accepting criticism from other people?</td>
<td></td>
<td></td>
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<tr>
<td>19.</td>
<td>How much of a problem do I have in controlling crying?</td>
<td></td>
<td></td>
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<tr>
<td>20.</td>
<td>How much of a problem do I have in acting appropriately when I'm around friends?</td>
<td></td>
<td></td>
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<tr>
<td>21.</td>
<td>How much of a problem do I have in showing affection to people?</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>22.</td>
<td>How much of a problem do I have in participating in group activities?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Can't do</td>
<td>Very difficult to do</td>
<td>Can do with some difficulty</td>
<td>Fairly easy to do</td>
<td>Can do with ease</td>
</tr>
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</tr>
<tr>
<td>23.</td>
<td>How much of a problem do I have in recognizing when something I say or do has upset someone else?</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>24.</td>
<td>How much of a problem do I have in scheduling daily activities?</td>
<td></td>
<td></td>
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<tr>
<td>25.</td>
<td>How much of a problem do I have in understanding new instructions?</td>
<td></td>
<td></td>
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<tr>
<td>26.</td>
<td>How much of a problem do I have in consistently meeting my daily responsibilities?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>27.</td>
<td>How much of a problem do I have in controlling my temper when something upsets me?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>28.</td>
<td>How much of a problem do I have in keeping from being depressed?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>29.</td>
<td>How much of a problem do I have in keeping my emotions from affecting my ability to go about the day's activities?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>30.</td>
<td>How much of a problem do I have in controlling my laughter?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix P: Patient Competency Rating Scale - Arabic

**ملاحظات شخصية**

<table>
<thead>
<tr>
<th>اسم المريض:</th>
<th>التاريخ:</th>
</tr>
</thead>
</table>

**التقييمات**

فيما يلي استطعن بطلب منك تحكم قد تكون لديك القيام بمجموعة من المهارات العملية المتعددة. بعض تلك الأمثلة قد لا تتطابق مباشرة على الأنشطة التي تقوم بها غالبًا، غير ذلك مطالب بكم كامل يسأل كما لو كان شيئاً "عليك القيام به". في كل سؤال، عليك الحكم على مدى سيولة أو صعوبة ذلك النشاط المعني هناك والتسجيل في الجدول المناسب.

**تقييم المهارات**

<table>
<thead>
<tr>
<th>لا يمكن القيام بالعمل</th>
<th>صعب جداً القيام</th>
<th>يمكن القيام بالعمل سهل نسبياً القيام</th>
<th>ممكن القيام بالعمل بسلاسة بالعمل</th>
<th>كم من مشاكل اعترالية في ما يلي؟</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

- 1. اعداد الوظائف الخاصة بي؟
- 2. تغيير ملمسي فيني؟
- 3. التفاهم بنطاقات الشخصية؟
- 4. هل الاستقلالي؟
- 5. سهولة الالتجاعدي؟
- 6. الإدراة الاداريات المكملة بالنسبة بي؟
- 7. الخضوع على المواضيع البدنية؟
- 8. هذه الملاحظة ضمن مجموعة؟
- 9. اقتصاد المشاركة فيأنشطة العمل حتى عندما نشعر بالقلق أو التنقب؟
- 10. تذكر ماهذا كان خفايا النباتية؟
- 11. تذكر إمساك الأشياء قادرة أشريها؟
- 12. تذكر الجدلية البدنية المحسنة؟
- 13. تذكر الإدمان الحديث الذي على القيام به؟
- 14. قدرة البسيطة لا الاضطرابات؟
- 15. الإجابة على مشاكل عندما تكون مشددة؟
- 16. كيف يمكن مع التغيرات غير الموقعة؟
- 17. التحكم بالجوانب مع الشخص الحساسين لدي؟
- 18. قبول الاعتقاد من الشخص المخربين؟
- 19. التحكم بالابتكار؟
- 20. التصرف بشكل سليم عندنا ما يكون حول الاستفادة؟
- 21. القيادة المتقدمة مع الأشخاص؟
- 22. المشاكل في الإجابة الجيدة؟
- 23. ملاحظة ما أنا ما قدر أو ما مكن لا يجوز شموما آخر؟
جداول الإنشطة اليومية
فهم التعليمات الجديدة
دورة الوفاء بمسؤليتها اليومية
المباشرة على مراقبة عندما يعطي شيء ما؟
التأثير على الإفصاح؟
مع مشاعر من التأثر على دردشي في القيام بالإنشطة اليومية؟
المباشرة على مهكم؟
Appendix Q: DASS - English

<table>
<thead>
<tr>
<th>DASS</th>
<th>Name:</th>
<th>Date:</th>
</tr>
</thead>
</table>

Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you over the past week. There are no right or wrong answers. Do not spend too much time on any statement.

The rating scale is as follows:

0 Did not apply to me at all
1 Applied to me to some degree, or some of the time
2 Applied to me to a considerable degree, or a good part of time
3 Applied to me very much, or most of the time

<table>
<thead>
<tr>
<th>Statement</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>I found myself getting upset by quite trivial things</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I was aware of dryness of my mouth</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>I couldn't seem to experience any positive feeling at all</td>
<td></td>
<td></td>
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<tr>
<td>I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)</td>
<td></td>
<td></td>
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<tr>
<td>I just couldn't seem to get going</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I tended to over-react to situations</td>
<td></td>
<td></td>
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<tr>
<td>I had a feeling of shakiness (eg, legs going to give way)</td>
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</tr>
<tr>
<td>I found it difficult to relax</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>I found myself in situations that made me so anxious was most relieved when they ended</td>
<td></td>
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<tr>
<td>I felt that I had nothing to look forward to</td>
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<tr>
<td>I found myself getting upset rather easily</td>
<td></td>
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</tr>
<tr>
<td>I felt that I was using a lot of nervous energy</td>
<td></td>
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</tr>
<tr>
<td>I felt sad and depressed</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I found myself getting impatient when I was delayed in any way (eg, lifts, traffic lights, being kept waiting)</td>
<td></td>
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</tr>
<tr>
<td>I had a feeling of faintness</td>
<td></td>
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</tr>
<tr>
<td>I felt that I had lost interest in just about everything</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I felt I wasn't worth much as a person</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I felt that I was rather touchy</td>
<td></td>
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<tr>
<td>I perspired noticeably (eg, hands sweaty) in the absence of high temperatures or physical exertion</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I felt scared without any good reason</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I felt that life wasn't worthwhile</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>22</td>
<td>I found it hard to wind down</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>23</td>
<td>I had difficulty in swallowing</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>24</td>
<td>I couldn't seem to get any enjoyment out of the things I did</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>25</td>
<td>I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>26</td>
<td>I felt down-hearted and blue</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>27</td>
<td>I found that I was very irritable</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>28</td>
<td>I felt I was close to panic</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>29</td>
<td>I found it hard to calm down after something upset me</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>30</td>
<td>I feared that I would be &quot;thrown&quot; by some trivial but unfamiliar task</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>31</td>
<td>I was unable to become enthusiastic about anything</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>32</td>
<td>I found it difficult to tolerate interruptions to what I was doing</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>33</td>
<td>I was in a state of nervous tension</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>34</td>
<td>I felt I was pretty worthless</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>35</td>
<td>I was intolerant of anything that kept me from getting on with what I was doing</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>36</td>
<td>I felt terrified</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>37</td>
<td>I could see nothing in the future to be hopeful about</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>38</td>
<td>I felt that life was meaningless</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>39</td>
<td>I found myself getting agitated</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>40</td>
<td>I was worried about situations in which I might panic and make a fool of myself</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>41</td>
<td>I experienced trembling (eg, in the hands)</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>42</td>
<td>I found it difficult to work up the initiative to do things</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Reminder of rating scale:
0 Did not apply to me at all
1 Applied to me to some degree, or some of the time
2 Applied to me to a considerable degree, or a good part of time
3 Applied to me very much, or most of the time
Appendix R: DASS - Arabic

Arabic DASS

<table>
<thead>
<tr>
<th>اسم:</th>
<th>التاريخ:</th>
</tr>
</thead>
</table>

لا قراءة كامل النصوص التالية تم ضع دورة حول الرقم 2014 أو 3 الذي يبين درجة انتقال هذا الشعر على في الأسود الماضي. لا يوجد إجابات صحيحة أو محددة. لا تقضي وقت طويل في أي منها.

استعمل الملاحظات التالية:

1. لا تتعلق علي أي تأثير
2. ينطبق علي بعض الشيء أو قليلًا من الأوقات
3. ينطبق علي جملة ومراعاة أو بعض الأوقات
4. ينطبق علي كثيرًا جدًا أو معظم الأوقات

| وحدت إيني مضطرب ومترمزج بسبب أمور تافتة جداً | 0 |
| شعرت ببعض في حلقي | 1 |
| لم ينظر إلي أن إمكانات الإحساس سماحًا بإلمام على الإطلاق | 2 |
| شعرت بصعوبة في النفس، المشاعر، اللحظة بدون القيام أو الجهود | 3 |
| حسدي منائي | 4 |
| لم ينظر إلي أن إمكانات أن أبدا في القيام بأعمال | 5 |
| كنت أتم إلى وجه قعم مفرطة للظروف والأشياء | 6 |
| شعرت بالارجاء (إذا رجلت لا تقوى على حمل مثل) | 7 |
| أحد صومي في الاسترخاء | 8 |
| وجدت نفسي في مواقع جميلة جدًا، و كنت مرتاحًا للغاية بروماها | 9 |
| شعرت بأن ليس لدي أي شيء أطلع إليه | 10 |
| وجدت نفسي أميل إلى الاضطراب والإزعاج بسهولة | 11 |
| شعرت بأنني استلحك الكثير في الطاقة العصبية (شعرت بأني استلحك الكثير من قدرتي على عمل التحرير العصبي) | 12 |
| شعرت بالحزن والإكتاب | 13 |
| وجدت أنني كلي السيء كلا أحيانا حتى (بأني الفوضى المضادة، إشارات البروز أو كنما طلب من الانتظار مثلا) | 14 |
| اتنابي شعر بالإغماء | 15 |
| شعرت بأني فقدت الاهتمام بكل شيء تقريبًا | 16 |
| شعرت بأنها قييم قليلا كشخص | 17 |
### Appendix S: DASS - Burmese

<table>
<thead>
<tr>
<th>DASS</th>
<th>အောက်တနောက်</th>
<th>ဖွဲ့စည်းချက်</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 သေချာစရာကိုယ်စားအစွဲအရည်အချင်း</td>
<td>0  2 3 4</td>
<td></td>
</tr>
<tr>
<td>1 သေချာစရာကိုယ်စားအစွဲအရည်အချင်း</td>
<td>0  2 3 4</td>
<td></td>
</tr>
<tr>
<td>2 သေချာစရာကိုယ်စားအစွဲအရည်အချင်း</td>
<td>0  2 3 4</td>
<td></td>
</tr>
<tr>
<td>3 သေချာစရာကိုယ်စားအစွဲအရည်အချင်း</td>
<td>0  2 3 4</td>
<td></td>
</tr>
<tr>
<td>4 သေချာစရာကိုယ်စားအစွဲအရည်အချင်း</td>
<td>0  2 3 4</td>
<td></td>
</tr>
<tr>
<td>5 သေချာစရာကိုယ်စားအစွဲအရည်အချင်း</td>
<td>0  2 3 4</td>
<td></td>
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<tr>
<td>6 သေချာစရာကိုယ်စားအစွဲအရည်အချင်း</td>
<td>0  2 3 4</td>
<td></td>
</tr>
<tr>
<td>7 သေချာစရာကိုယ်စားအစွဲအရည်အချင်း</td>
<td>0  2 3 4</td>
<td></td>
</tr>
<tr>
<td>8 သေချာစရာကိုယ်စားအစွဲအရည်အချင်း</td>
<td>0  2 3 4</td>
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<tr>
<td>9 သေချာစရာကိုယ်စားအစွဲအရည်အချင်း</td>
<td>0  2 3 4</td>
<td></td>
</tr>
<tr>
<td>10 သေချာစရာကိုယ်စားအစွဲအရည်အချင်း</td>
<td>0  2 3 4</td>
<td></td>
</tr>
<tr>
<td>11 သေချာစရာကိုယ်စားအစွဲအရည်အချင်း</td>
<td>0  2 3 4</td>
<td></td>
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<tr>
<td>12 သေချာစရာကိုယ်စားအစွဲအရည်အချင်း</td>
<td>0  2 3 4</td>
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</tr>
<tr>
<td>13 သေချာစရာကိုယ်စားအစွဲအရည်အချင်း</td>
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<tr>
<td>14 သေချာစရာကိုယ်စားအစွဲအရည်အချင်း</td>
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<tr>
<td>15 သေချာစရာကိုယ်စားအစွဲအရည်အချင်း</td>
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<td>16 သေချာစရာကိုယ်စားအစွဲအရည်အချင်း</td>
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<td>17 သေချာစရာကိုယ်စားအစွဲအရည်အချင်း</td>
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<td>18 သေချာစရာကိုယ်စားအစွဲအရည်အချင်း</td>
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<tr>
<td>19 သေချာစရာကိုယ်စားအစွဲအရည်အချင်း</td>
<td>0  2 3 4</td>
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<tr>
<td>20 သေချာစရာကိုယ်စားအစွဲအရည်အချင်း</td>
<td>0  2 3 4</td>
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<tr>
<td>---</td>
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</tr>
<tr>
<td>30</td>
<td>အိမ်ရိုပေးထားသောစာမျက်နှာလေးရှိရာတွင်</td>
<td>0</td>
</tr>
<tr>
<td>31</td>
<td>အိမ်ရိုပေးထားသောစာမျက်နှာလေးရှိရာတွင်</td>
<td>0</td>
</tr>
<tr>
<td>32</td>
<td>အိမ်ရိုပေးထားသောစာမျက်နှာလေးရှိရာတွင်</td>
<td>0</td>
</tr>
<tr>
<td>33</td>
<td>အိမ်ရိုပေးထားသောစာမျက်နှာလေးရှိရာတွင်</td>
<td>0</td>
</tr>
<tr>
<td>34</td>
<td>အိမ်ရိုပေးထားသောစာမျက်နှာလေးရှိရာတွင်</td>
<td>0</td>
</tr>
<tr>
<td>35</td>
<td>အိမ်ရိုပေးထားသောစာမျက်နှာလေးရှိရာတွင်</td>
<td>0</td>
</tr>
<tr>
<td>36</td>
<td>အိမ်ရိုပေးထားသောစာမျက်နှာလေးရှိရာတွင်</td>
<td>0</td>
</tr>
<tr>
<td>37</td>
<td>အိမ်ရိုပေးထားသောစာမျက်နှာလေးရှိရာတွင်</td>
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</tr>
<tr>
<td>38</td>
<td>အိမ်ရိုပေးထားသောစာမျက်နှာလေးရှိရာတွင်</td>
<td>0</td>
</tr>
<tr>
<td>39</td>
<td>အိမ်ရိုပေးထားသောစာမျက်နှာလေးရှိရာတွင်</td>
<td>0</td>
</tr>
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