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ABSTRACT

Traumatic brain injuries (TBI) can result in a variety of physical, cognitive, behavioural, and social changes for the survivor, which in turn impact on the lives of family members, relationships within families and family systems as whole. Traditionally, services have focused on the rehabilitation of the individual, but more recently there has been increased attention given to the provision of support and intervention for other family members. The present study describes family-focused therapy with five families, including the problems families encountered, how these were addressed in therapy, therapy outcomes and challenges therapists experienced. Therapy drew on a variety of models including behavioural therapy, family systems therapy and narrative therapy. Nine themes relating to issues experienced by families were identified, including: difficulties experienced were unexpected; increased anger, irritation and outbursts; challenges within marital relationships; family discord; changes to parenting and parent/child relationships; lack of motivation; lack of understanding from others; grief and loss; and negative experiences with helping professions. A varied approach to therapeutic intervention was required in order to accommodate the diversity of these issues. Analysis of standardized questionnaires revealed improvement on measures following therapy, with some deterioration at follow-up. Family members were generally satisfied with the service based on feedback questionnaires. Benefits of therapy described by families included having the space to talk and listen, survivors gaining increased insight, increased understanding from others, gaining increased acceptance, and the benefits of having professional input. The therapists identified a number of clinical and service-level challenges, but concluded that family-focused therapy can be a useful addition to the rehabilitation process following TBI.
Completing this thesis would not have been possible without the involvement, help and support of many people whom I wish to acknowledge. First, I would like to express my heartfelt thanks to the families who participated in this study, and who allowed us to walk with them for a time, in the hope that their experiences might help others. To the academic and administrative staff at the University of Auckland, all of whom have had a hand at guiding me through my professional training that has culminated in this thesis and clinical portfolio. I wish to express particular thanks to my second research supervisor, Associate Professor Suzanne Barker-Collo for her guidance and support, and to Professor Fred Seymour, who has been the most dedicated and supportive primary research supervisor a student could hope for. I also wish to acknowledge the hours of time Fred gave to this study as therapist, all of which were out of normal working hours and this certainly meant that he went above and beyond the call of duty. I thank the professionals who assisted in recruitment for this study, in particular Stephen Jenkins at the Brain Injury Association who was generous with his time and resources, and was a huge help in identifying potential participants.

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Finally, to my family. Mum, Dad, Michael, Tom and Gill, you have each provided me support in ways that are too numerous to name here (and that is a wonderful problem to have)! In particular, thank you to my parents Akampiya and John for instilling in me the values that drew me to this career and for providing me with the opportunities and support that made realizing this goal possible.
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CHAPTER ONE

INTRODUCTION

In a matter of seconds, a Traumatic Brain Injury (TBI) can cause changes that may have a profound impact on the lives of survivors and those close to them. Brain injuries of all severities can lead to a variety of physical, cognitive, emotional, behavioural, and social changes (Tyerman & King, 2008), and these can be extremely difficult for the survivor. However, the effects of TBI often reach well beyond the individual and can significantly impact on the lives of family members, relationships within families and family systems as a whole.

Prior to embarking on my professional training in Clinical Psychology, I worked in two voluntary roles that provided me with insights into the experiences of TBI survivors and their families. The first of these was with Headway, a brain injury support and advocacy charity in the United Kingdom. The second voluntary role I undertook was as a psychologist’s assistant at a residential rehabilitation service in Auckland, New Zealand. During these experiences I became witness to the dramatic effect brain injuries can have on survivors and their families. It became apparent to me how important it was for families to feel supported, and it concerned me that specific intervention for strained family systems was often not available. Thus, when the opportunity arose as part of my professional training to conduct research in the field of family intervention after TBI, I welcomed this opportunity to contribute to an area that had been of interest and concern for some time.

Early TBI research typically focused only on survivor experiences following the injury, and the impact on families was less considered. However, in recent decades there has been increasing focus on the experiences of the affected family. One of the early papers on these impacts was the 1988 article *Brain Damage is a Family Affair*, written by the leading clinical neuropsychologist, Muriel Lezak. Based on her research and extensive clinical experience with families following a brain injury (hereafter referred to as “TBI Families”), she described a variety of common difficulties and sadly concluded that while a few families become strengthened by the challenges they face, “… most hobble along, crippled and in pain, their problems unrecognized and unending” (Lezak, 1988, p. 123).

Although this quote paints a rather dismal picture for families living in the wake of brain injury, as the field of neurorehabilitation has developed professionals have become increasingly aware of the potential impacts for TBI Families, and better appreciate the need
for interventions at the family level. Indeed, many clinicians and researchers have turned their attention to exploring how best to support such families. However, the current body of literature is limited, and there is a need for more research in this important area.

The study reported in this thesis aims to contribute to this area of research. It is exploratory in nature, and designed to investigate a small-scale service that was established to provide family-focused therapy to TBI survivors and their families in Auckland, New Zealand.

This chapter begins by describing the nature of TBI, and briefly outlines the incidence of TBI in New Zealand. The chapter then provides an overview of the ways in which TBI impacts on the survivor, including a specific section on mild TBI (as more than half of the survivors in the present study had injuries classified as ‘mild’). This is followed by an outline of the literature on family impacts. This subsection on family impacts includes research on family reactions to TBI, family functioning following TBI, and the various effects on individual family members and relationships within the family. An outline of the existing literature on intervening with families or family members following TBI is then presented, and is divided into those articles that are purely theoretical in nature and those that present empirically evaluated interventions. Finally, the chapter provides an overview of the current rehabilitation and support services available in Auckland and presents a rationale for the present study, and the study aims.

The Nature of Traumatic Brain Injury

Traumatic Brain Injury occurs when an external physical force causes injury to the brain. TBI can be either ‘penetrating’ or ‘closed’. Penetrating injuries occur when the skull and protective layers surrounding the brain (meninges) are penetrated by a missile, or other external object and the brain is exposed. Closed injuries occur when physical forces cause injury to the brain, but the skull remains intact (Lezak, Howieson, & Loring, 2004).

Closed injuries typically result from blunt impact such as sudden changes in velocity characteristic of road traffic accidents, assaults, falls, or sporting accidents (Tyerman & King, 2008). Penetrating injuries may arise if the skull is fractured and bone fragments are pushed through the meninges and into the brain, or from events such as gunshots or bomb blasts (Tyerman & King, 2008).

Damage to the brain typically occurs in two stages; the ‘primary’ injury and the ‘secondary’ injury (Hannay, Howieson, Loring, Fischer, & Lezak, 2004). Primary injuries occur at the time of trauma, while the secondary injuries occur as a result of the physiological
processes caused by the primary injuries (Hannay et al., 2004). Primary injuries are typically of two kinds. The first is ‘diffuse axonal injury’, which occurs when the brain is subjected to violent movement and the delicate neuronal axons stretch and compress, causing them to tear or shear (Tyerman & King, 2008). The second kind of primary injury is ‘haemorrhagic contusion’, or bruising. This can occur at the site of impact (‘coup’ injury) or directly opposite (‘contecoup’ injury), as the force of the impact causes the brain to bounce back against the inside of the skull. Haemorrhagic contusions are most common on the underside of the frontal lobes and the temporal poles, where the internal skull surface is sharpest and space for the brain to move is most confined (Tyerman & King, 2008). Secondary injuries can be incurred in a number of ways and may occur over the days to weeks after the primary injury. These include haemorrhage (bleeding), haematoma (accumulation of blood following haemorrhage), hydrocephalus (accumulation of cerebrospinal fluid in the ventricles of the brain), cerebral edema (brain swelling), infection from wounds, hypoxia (insufficient oxygen), and hypotension, or loss of blood flow (Tyerman & King, 2008).

Traumatic Brain Injuries are categorised by severity, into ‘mild’, ‘moderate’ or ‘severe’ injuries. Severity of injury can be assessed in a number of ways. These include measurement of: (a) the lowest point of consciousness; (b) the length of unconsciousness; (c) the presence of neurological signs (observed either in person or using neuro-imaging); and/or (d) the length of post-traumatic amnesia (PTA), this being the length of time between injury and when conscious and continuous memory returns (Tyerman & King, 2008).

The most commonly used method for categorisation of injury severity involves obtaining a score for the lowest point of consciousness, as measured by the Glasgow Coma Scale (GCS; Teasdale & Jennett, 1974). In order to obtain a GCS score, an individual is assessed for eye movements, verbal responses, and motor responses. Scores range from 15 (full consciousness), to 3 (deep coma). Glasgow Coma Scale scores can be measured on multiple occasions over time in order to assess changes in the survivor’s condition. Traumatic Brain Injuries are considered ‘severe’ if the lowest GCS score is 8 or below, ‘moderate’ if the lowest GCS score falls between 9 and 12, and ‘mild’ if the lowest GCS score is between 13 and 15 (Tyerman & King, 2008).

As distinct from TBI, Acquired Brain Injury (ABI) is a term for a broader range of brain injuries, which include but are not limited to those incurred by trauma. Examples of injuries classified as ABI include injury as a result of stroke, hypoxia, damage from toxins or disease, and aneurisms (Lezak et al., 2004). This distinction is important as research in the area of brain injury sometimes includes subjects with ABI, and is thus not limited to
individuals with traumatic injuries. When the inclusion of ABI survivors has been noted in the literature reviewed in this thesis, this will be highlighted.

**Incidence of TBI in New Zealand**

Traumatic Brain Injury is a major public health concern both internationally and in New Zealand. A recent population-based study in New Zealand found an incidence rate of 749 mild-TBIs per 100,000 population, per annum, and 41 moderate to severe-TBIs per 100,000 population, per annum (Feigin et al., 2013). This study, which was based in a large geographical area that was representative of New Zealand’s total population, used multiple and overlapping sources to identify TBI cases (e.g., hospitals, sports clubs, coroners, etc). The authors highlight that these rates are higher than those reported in previous studies conducted in high-income countries (e.g., Burns & Hauser, 2003), especially in regards to cases of mild TBI. The use of multiple overlapping sources of information meant that instances of TBI that may have not been picked up in studies relying solely on hospital records (e.g., individuals with concussion who don’t present to hospital, and non-hospitalized fatalities) were recorded (Feigin et al., 2013).

Advancements in medical techniques for the management of brain trauma are increasing the survival rate of TBI victims who, who a few decades ago, would have died as a result of their injuries (Hsiang & Marshall, 1998). This means that we are experiencing an increasing number of individuals who are living with the complex neurological, behavioural and social sequelae of TBI (Lezak et al., 2004). Of course, this means that more families are also living with these sequelae and it is in regard to these consequences of TBI that the focus of this chapter will now turn.

**Impact of TBI on the Survivor**

The brain is an exceedingly complex organ, responsible for the countless functions of human experience. Amongst other things it defines who we are, the way that we perceive ourselves, the way we perceive and operate within our world, and the ways in which we relate to others. It is therefore not surprising that injury to the brain can have an enormous impact on the life of the survivor. As a result of the injury itself, and/or secondary psychosocial processes, survivors may experience a variety of physical, cognitive, emotional, psychiatric, personality, identity, behavioural and social changes (Coetzee, 2008; Fann et al., 2004; Tyerman & King, 2008). These changes interfere with daily living and can lead to
significant disability in many cases. Several areas of impact on the survivor are identified in the following subsections.

**Physical and Somatic Effects**

Traumatic Brain Injury survivors may experience a variety of physical effects following their injury. These may include reductions in strength, balance and coordination, and severe cases may result in paralysis. Fatigue, sleep disturbance and changes in sexual responses are common (Oddy & Herbert, 2008). Sensory disturbances may include dizziness, double vision, visual field deficits, light sensitivity, noise sensitivity, tinnitus, and deficits in hearing, taste or smell (McAllister, 2011; Tyerman & King, 2008).

**Cognitive Effects**

The most common cognitive changes following TBI include difficulties with attention and concentration, new learning and memory, slowed speed of information processing, and changes in executive functioning. Executive functions are higher order functions that encompass reasoning, problem solving, planning, self-awareness and self-monitoring (McAllister, 2011; Tyerman & King, 2008). Traumatic Brain Injury survivors may also exhibit subtle difficulties in language skills such as comprehension, verbal fluency, and word finding. Less frequently, greater impairment of language skills (e.g., dysphasia, acquired dyslexia) may result, as may other more specific impairments such as visuo-perceptual problems, or spatial and constructional difficulties (Tyerman & King, 2008).

**Emotional and Psychiatric Effects**

Traumatic Brain Injuries may lead to a change in the way emotion is experienced and expressed (Tyerman & King, 2008). These changes vary from subtle mood changes to more serious psychiatric problems (Vaishnavi, Rao, & Fann, 2009).

Common emotional changes include apathy, irritability, labile mood, flattened mood, loss of confidence and reduced self-esteem (Ciurli, Formisano, Bivona, Cantagallo, & Angelelli, 2011; Tyerman & King, 2008). Irritability appears to be particularly problematic, possibly due to the impact it has on others. Irritability can be conceptualised as both an emotional reaction, such as anger or annoyance, and an excessive behavioural response, such as verbal aggression (Yang, Hua, Lin, Tsai, & Huang, 2012). Studies have found that between 15% to 37% of TBI survivors of all severities self-report irritability in the first year post-injury (Ciurli et al., 2011; Deb, Lyons, & Koutzoukis, 1999; Kim, Manes, Kosier,
Baruah, & Robinson, 1999), and that both survivor and family-member reports of survivor irritability are significantly higher than compared to pre-injury irritability, and controls (Yang et al., 2012).

Psychiatric disorders are more prevalent amongst TBI survivors than in the general population, and injuries of all severities are associated with elevated risk of mental health problems (Fann et al., 2004; Morton & Wehman, 1995). One study found that at an average of eight-years post-injury, 80% of TBI survivors (including mild, moderate and severe injuries) met the criteria for Axis I psychopathology, and 44% of the total group met criteria for two or more Axis I diagnoses from the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV; American Psychiatric Association, 1994; Hibbard, Uysal, Kepler, Bogdany, & Silver, 1998). The most common psychiatric problems in TBI survivors have been found to be depression and anxiety (Hibbard et al., 1998; Morton & Wehman, 1995).

**Behavioural Effects**

A variety of behavioural changes may occur after TBI. Common changes include impulsivity, disinhibition, lack of motivation, lack of initiation, social inappropriateness and displays of anger and aggression (Alderman, 2004; Tyerman & King, 2008). Displays of anger and aggression seem to be particularly problematic, especially for the people close to the survivor. Outbursts may be partially due to neurological damage which interferes with self-regulation and impulse control. However, psychosocial factors may also contribute (Alderman, 2004). In the family environment, feelings of inadequacy, competition for attention, frustration about unrealistic expectations and feeling undermined by family members may result in increased outbursts or aggression (Larøi, 2003). These behaviours are a significant contributor to family stress (Alderman, 2004), are damaging for family relationships, and marriages marked by increased anger after ABI have been associated with higher rates of divorce (Kreutzer, Marwitz, & Kepler, 1992).

**Social Effects**

While social changes following TBI can be relatively minor for some, for others the injury will have a huge impact on the way they experience social relationships. The physical, emotional, cognitive and communication changes that can occur following TBI impacts upon what survivors are able to think, feel, do and communicate, and these changes may affect their ability to maintain roles and relationships (Bowen, Yeates, & Palmer, 2010). As well as
detrimental changes to family relationships, the number and quality of friendships frequently diminish, and problems associated with social adjustment and loneliness are common (Morton & Wehman, 1995). For many, the injury will result in significant restrictions to their independence, return to work and participation in leisure activities (Tyerman & King, 2008).

**Self-Awareness/Insight Deficits**

Another area that can be affected following TBI is the survivor’s degree of self-awareness, or insight (O’Callaghan, McAllister, & Wilson, 2012). Impairment in self-awareness or insight in this context, often referred to as ‘anosognosia’, includes the degree to which the TBI survivor understands that he or she has experienced changes as a result of the TBI (be they physical, cognitive, emotional, behavioural or social), and also understands the potential impact of those changes upon others (Johnson & McCown, 1997; Prigatano, 1992).

Examples of how survivors may lack awareness regarding impacts of their TBI can be found in studies that identify differences between difficulties reported by survivors, compared with those reported by non-injured family members. In their study of irritability post-TBI, Yang and colleagues (2012) found that 15% of TBI survivors of all severities (mild, moderate and severe) reported that they experienced increased irritability post-TBI, while 29% of their family members reported increased irritability in the survivor. Similarly, a discrepancy in survivor and family member reports of family functioning was identified by Gan and Schuller (2002). These authors found that non-injured family members reported unhealthier family functioning when compared to population norms, while the survivors reported no such differences in family functioning. This tendency for survivors to under-report problems compared to the reports of family members has also been noted by other authors (e.g., Brooks, Campsie, Symington, Beattie & McKinlay, 1987; Prigatano, 1996).

**Changes to Identity**

The impairments described thus far can have a profound impact on the identity of the TBI Survivor. Following TBI, survivors may experience discrepancies in their sense of self, or in other words, their sense of what they should be able to do compared to what they are currently able to do (Gracey, Evans, & Malley, 2009). Functional changes, role changes, and effects on relationships may all impact on survivors’ identities. Making sense of ‘who one is’ post-injury is a significant issue and an important task for many survivors (Bowen et al., 2010). As Coetzer (2008) asks, “looking beyond objective symptoms and signs associated
with brain injury, can it be that one of the potentially most enduring changes after brain injury relates to the subjective experience of who someone is and is seen to be?” (p. 767).

**Mild TBI**

The characteristics of mild TBI deserve particular description, as more than half of the survivors in the present study had injuries that were classified as mild, and there are some particular challenges faced by survivors of mild TBI. As has already been explained, a TBI is classified as mild if the lowest GCS score is between 13 and 15 (Tyerman & King, 2008). Mild TBI, which is also commonly referred to as ‘concussion’, results when acceleration-deceleration forces applied to the moving brain cause shearing and distortion of the neuronal and vascular components of the brain, which in turn lead to a cascade of neurochemical, metabolic and ionic changes (McAllister, 2011). There appears to be a cumulative effect to concussions, whereby a history of concussion can lead to increasingly severe effects of future concussions (Iverson, Gaetz, Lovell, & Collins, 2004) and a slower rate of recovery (de Beaumont, Lassonde, Leclerc, & Theoret, 2007). In addition, it has been found that some individuals with mild TBIs that include a focal lesion or depressed skull fractures may experience a similar degree of impairment to those individuals with moderate TBI (Williams, Levin, & Einsberg, 1990).

Typical post-concussive symptoms include cognitive complaints (impairments in attention, memory and information processing), physical/somatic complaints (headaches, sleep disturbance, fatigue, dizziness, tinnitus, sensitivity to noise and light), and affective complaints (irritability, depression or anxiety). This constellation of symptoms is often referred to as ‘postconcussion syndrome’ (McAllister, 2011). These difficulties typically resolve within the first three months after injury. However, for a small percentage of people they will remain well beyond this typical period of recovery and full recovery may never occur (McAllister, 2011). The topic of recovery after mild TBI is controversial, as in some cases survivors present with subjective complaints that appear disproportionate to the severity of injury. It is thought that a number of factors can affect the severity of subjective distress and disability in mild TBI survivors with persistent post-concussive symptoms, including premorbid functioning and personality, psychosocial stress, psychiatric problems and involvement in compensation claims (McAllister, 2011).

In light of the nature of post-concussive difficulties and the potential longevity of these, it is not surprising that families can be impacted by mild TBI. In an early study examining family member experiences of mild TBI survivors, the symptoms that family
members reported as most problematic were depression, personality change, increased anger and irritability (Livingston, Brooks, & Bond, 1985). A particular challenge for survivors of mild TBI is the common attitude that concussion is a relatively benign injury and quick, spontaneous recovery is the norm. This may be a particular problem in countries such as New Zealand, where concussion from contact sports occurs frequently and members of the public do not necessarily understand the detrimental effects of the injury (McKinlay, Bishop, & McLellan, 2011).

Impact of TBI on the Family

It is clear that sustaining a TBI can impact survivors in many different ways, but what are the challenges that their family members experience as a result of such a life-changing event? The distress caused to families can manifest in many ways, including high levels of stress and subjective burden, psychopathology and compromised family functioning (Kreutzer, Gervasio, & Camplair, 1994b; Livingston & Brooks, 1988; Marsh, Kersel, Havill, & Sleigh, 1998) and in many cases the family members may experience more distress than the person with the injury (Brooks, 1991).

The following section will provide a summary of the literature on family experiences after brain injury, starting with family reactions to TBI. Five subsections will follow, that describe the impact on family functioning, caregiver distress, marital impacts, impacts on children and on the parent/child relationship, and financial impacts. This body of research focuses on the more detrimental and challenging aspects of family experiences after TBI, and it is important to note that not all families will experience such difficulties.

Family Reaction to TBI

Given that TBI occurs as a result of some form of trauma, the time around the injury occurrence can be very distressing for families. First they learn that there has been an event such as an accident or assault that their loved one has been involved in, and then they learn that a brain injury has occurred as a consequence. Family reactions to TBI are likely to differ, depending on the severity of the injury. In cases where the injury is mild, the reaction may be minor as there may be little impact on the family system. However, in some instances, especially where post-concussive symptoms persist, family members’ initial concerns following the injury can be followed by alienation of the survivor, as a result of their “apparent normalcy in the presence of his/her anxiety, depression, loss of self-esteem, and increasing dysfunction over time” (Cavallo & Kay, 2011, p.549).
In families where the TBI is more severe, Lezak (1986) uses a six-part model to conceptualize the emotional reactions and family process in coming to terms with changes in the survivor. She highlights that the pattern is not necessarily linear, and families may progress through the stages at different rates, bypass some stages, or experience them in a different order. She explains that the stages often overlap, and may shift back and forth prompted by changes in the survivor, or for other family members, such as reductions in burden or fatigue (Lezak, 1986).

The first stage of Lezak’s (1986) model occurs in the initial three months following the survivor’s return home following the injury. Family members perceive the survivor as being a little difficult, but typically attribute this to fatigue, lack of strength, or resulting from the indulgences of hospital staff. The second stage occurs up to nine months after the survivor returns home. The family’s optimism and energy begins to diminish, and the survivor may be perceived as uncooperative, unmotivated and self-centered. This perceived lack of motivation may be seen as hindering a full recovery, and family members often experience feelings of anxiety and bewilderment. In the third stage the situation for families worsens. This typically occurs in the second half of the first year at home. As the survivor’s strength and vigour returns, he or she may attempt to return to premorbid activities that are no longer safe to do, while avoiding seemingly more obvious tasks, such as helping with household chores. This can highlight the survivor’s difficulties with judgment, and prompt family members to perceive the survivor as irresponsible, self-centered and lazy. This may result in feelings of disappointment and displeasure amongst family members. In this stage, close family members may also experience feelings of self-blame, guilt and frustration. It is also during this stage that the survivor’s difficult behaviours and maladaptive reactions may become habitual responses. Family members begin to realise that these changes in the survivor may be enduring, and become aware of how the permanence of these difficulties will affect their own lives. This stage can continue indefinitely.

The fourth stage described by Lezak occurs around nine months since coming home and can also continue indefinitely. In this stage, family members gain an understanding of the full extent and chronicity of the survivor’s deficits, and this realisation can lead to feelings of depression and despair. However, this awareness allows the primary caretaker to more realistically consider the welfare of the survivor and the future and wellbeing of the family and its members. The awareness achieved in this stage is important in order to prepare the family for realistic and much-needed mourning, and it is in this stage that many families are first likely to ask for psychological help. The fifth stage is characterised by active mourning
by family members, whereby hope is relinquished that the survivor’s premorbid functioning and personality will return. The process of mourning for a living person can be a delicate and socially unacceptable task, and as such, the process may be obstructed by a range of factors including guilt, social pressures, and fond memories of the survivor. This stage begins 15 months or later after returning home, and is time-limited. Finally, for family members who come this far, approximately 18 to 24 months after the survivor’s return home, the sixth stage begins. Here, Lezak describes a period whereby family members can reorganize their lives, to allow for more emotional satisfaction and personal growth amongst members. Caregivers may begin to detach emotionally, freeing them from anger and guilt and allowing them to rebuild their lives with meaning. In this stage relationships between family members and the survivor may be reinterpreted, and separation or divorce may occur (Lezak, 1986).

Another framework for conceptualizing the family process of adaption following brain injury has been proposed by Perlesz, Furlong and McLaughlan (1992). These authors describe four key, non-sequential tasks that families must negotiate in their process of adaption post-ABI. The first task described is that of ‘grieving’, which these authors acknowledge can be complicated given it is done in the presence of the survivor, and can be difficult when one does not fully understand that exact nature of what has been lost (e.g., survivor’s cognitive abilities, quality of relationships, etc.). The second task is that of ‘restructuring’, which the authors say is dependent on role changes in the family. This restructure can be sudden, bought about in the ‘crisis’ period where family life is often governed by medical and rehabilitation appointments. As this period passes, family members must resume an active lifestyle. Perlesz and colleagues suggest that this requires family members to acknowledge losses, and accept the often-permanent nature of the family restructure. The third task described is the task of ‘developing a new identity’. All family members may experiences changes to their identities as a result of the TBI and must come to terms with these changes in themselves, and in other family members, including the survivor. The authors state that this requires “coming to terms with losses and giving up the yearnings for a complete yet unattainable recovery” (p. 148). The fourth task which family members negotiate is ‘growing through adversity’, whereby individuals can recognize their strengths and courage, and appreciate the knowledge and experience they have gained in coping with adversity.
Family Functioning Following TBI

Research examining the impact that TBI has on family functioning confirms that in many cases the TBI has a detrimental effect on such functioning. For families characterised by stable, healthy functioning prior to the injury, the long-term nature of brain injury may prevent them from returning to such stability (Rosenthal & Young, 1988). In families with poor premorbid family functioning, difficulties may be exacerbated by the injury. Pre-injury psychiatric, psychosocial and family problems, which compromise healthy family functioning, have been shown to be prevalent among persons with brain injury (Kreutzer, Gervasio & Camplair, 1994). Pre-existing family difficulties, combined with the stress and burden of caring for an injured relative, may contribute to unhealthy family functioning (Kreutzer et al., 1994b).

Research examining family functioning frequently uses the Family Assessment Device (FAD; Epstein, Baldwin, & Bishop, 1983) to measure such functioning. This self-report measure assesses the six dimensions of family functioning proposed in the McMaster Model of Family Functioning (Epstein, Bishop, & Levin, 1978). These are Problem Solving, Communication, Roles, Affective Responsiveness, Affective Involvement, and Behaviour Control. A seventh scale, General Functioning, measures overall health-pathology.

Kreutzer, Gervasio, and Camplair (1994b) used caregiver scores on the FAD to assess family functioning in 62 families following mild to severe TBI, a mean of 16 months post-injury. They found that 56% of families displayed unhealthy overall functioning as measured by the General Functioning subscale. These families were also characterized by unhealthy functioning on five subscales of the FAD. This is similar to levels of problematic functioning in clinical normative samples (Kabacoff, Miller, Bishop, Epstein, & Keitner, 1990), and considerably worse than non-clinical normative samples (Kreutzer et al., 1994b).

In the study reported by these authors, family communication problems were most prevalent. Scores that reflected problematic communication characterized almost three quarters of the TBI Families. Items on the Communication subscale address the extent to which feelings and thoughts are openly and clearly expressed between family members (Kreutzer et al., 1994b). The authors suggest that low scores may reflect the survivor’s impaired communication and linguistic abilities (often evident as reduced capacity for self-awareness, and reduced ability for socially appropriate conversation), as well as the family members’ reluctance to express negative feelings to the survivor (Kreutzer et al., 1994b).

Almost 60% of caregivers achieved scores that reflected problematic functioning on the Affective Involvement subscale. This subscale assesses ‘enmeshment’ (or over-
involvement) and disengagement of family members, and most of the items relate to
disinterest and self-centeredness among family members. Kretuzer and colleagues suggest
that low scores for this subscale may reflect the survivor’s self-centeredness and lack of
empathy, which is common in brain injury survivors. It may also reflect caregiver feelings
that other family members are not attentive to his or her needs and interests (Kreutzer et al.,
1994b).

Slightly less than half of caregivers gave scores that reflected problematic functioning
on the Behaviour Control subscale. This subscale relates to the pattern families adopt for
dealing with behaviour in physically dangerous situations, situations which involve
psychobiological needs and drives, and situations which involve socialising behaviour
between both family and non-family members (Ryan, Epstein, Keitner, Miller, & Bishop,
2005). Kreutzer and colleagues (1994b) did not discuss the Behaviour Control results in their
publication, although given the prevalence of behaviour difficulties in TBI survivors
(Tyerman & King, 2008), it is not surprising that such a large proportion of caregivers
reported difficulties in this area.

About half of the families in this study were characterized by problematic functioning
with Affective Responsiveness, being the extent to which family members share feelings of
tenderness and love (Kreutzer et al., 1994b). The authors suggest that this may be reflective
of the impaired ability of the survivor to experience or communicate positive and tender
feelings. Alternatively, it may be that the caregiver is not experiencing such feelings towards
the survivor, possibly because of the alteration in the survivor’s character (Kreutzer et al.,
1994b), or due to the change in roles from that of a marital partner to that of a caregiver.

Approximately half of caregivers achieved scores that indicated problematic
functioning on the Roles subscale, which assesses the degree to which responsibilities are
distributed equitably and tasks are carried out independently (Kreutzer et al., 1994b). This
dimension is of particular relevance in TBI, because of the reorganization of roles that is
often required within families as a result of the injury. Many of the caregivers in this study
clearly felt that responsibilities and decision-making were not undertaken equitably (Kreutzer
et al., 1994b).

Finally, just under 30% of caregivers gave scores on the Problem Solving subscale
that reflected unhealthy functioning (Kreutzer et al., 1994b). This subscale achieved scores
most similar to the non-clinical normative sample in Kabacoff et al.’s. (1990) study. Kretuzer
and colleagues commented that frequently caregivers experienced enhanced feelings of
competence arising from the increased practical, on-the-spot decision-making that is often necessary in the role of caregiver.

Other researchers have also found similar levels of unhealthy functioning in families, as indicated by caregiver’s scores on the FAD (Anderson, Parmenter, & Mok, 2002; Winstanley, Simpson, Tate, & Myles, 2006).

Unlike studies that have relied solely on the caregiver’s perspective in assessing family functioning, a Canadian team of researchers investigated family system outcomes following ABI and included perspectives from multiple family members, including parents, spouses, offspring and siblings (Gan & Schuller, 2002). In this study, the Family Assessment Measure-III (FAM-III; Skinner, Steinhauer & Santa-Barbara, 1995) was administered to 43 ABI survivors of all severities, along with 92 family members. The authors found that family members reported worse family functioning compared to population norms. There were no significant differences between family relationship status and FAM-III scores, providing evidence that it is not only caregivers who experience distress around their family’s functioning, but all family members may be affected (Gan & Schuller, 2002). As highlighted earlier in the sub-section regarding deficits in self-awareness, in this study scores achieved by the survivors on the FAM-III did not indicate distressed family functioning compared to population norms. This confirms that survivors may have reduced awareness of the impact of the sequelae of their injury, on their family (Gan & Schuller, 2002).

Evidence suggests that the degree of psychological distress in relatives and unhealthy family functioning is not associated with the severity of injury (Gan & Schuller, 2002; Livingston et al., 1985; Ponsford, Oliver, Ponsford, & Nelms, 2003), or time since injury (Gan & Schuller, 2002). Rather, emotional distress in relatives and poor family functioning has been found to be influenced by the degree of changes in the survivor’s behaviour control (Kreutzer, Gervasio, & Camplair, 1994a; Marsh et al., 1998; Oddy, Humphrey, & Uttley, 1978; Ponsford et al., 2003), cognitive functioning and emotional state (Ponsford et al., 2003; Schönberger, Ponsford, Olver, & Ponsford, 2010; Testa, Malec, Moessner, & Brown, 2006).

Longitudinal research over five years has indicated there is a reciprocal relationship between family functioning and family members’ emotional distress (Schönberger et al., 2010). It appears that over time, family functioning may mediate the impact of behavioural changes in the survivor on family members’ levels of anxiety and depression (Anderson et al., 2002; Schönberger et al., 2010). Not only is healthy family functioning desirable for the happiness and wellbeing of all family members, but problematic family functioning has also
been found to have an adverse effect on the functional outcome of the survivor (Sander et al., 2002).

**Caregiver Burden and Psychological Distress**

Of all family members, typically the person who assumes the role of primary caregiver bears the most burden, while the stress experienced by other family members will differ depending on their level of independence from the TBI survivor, and from the primary caregiver (Lezak, 1988). Primary caregivers, who are most often spouses or parents of the survivor, can bear enormous strain in their new and unexpected role of caregiving.

In this context, the term “caregiver burden” encompasses the range of emotional, social and physical effects experienced by the caregiver (Livingston & Brooks, 1988). Early writers on caregiver burden following TBI differentiated between ‘subjective burden’, being the caregiver’s perceived amount of strain, and ‘objective burden’, being the measurable effect of burden on the caregiver, which is typically related to the severity of injury and the degree of survivor’s limitations (Livingston & Brooks, 1988). The amount of subjective burden experienced by caregivers appears to increase with higher number of survivor limitations, particular those related to emotional and behavioural disturbance (McKinlay, Brooks, Bond, Martinage, & Marshall, 1981).

Adverse caregiver impacts that have been reported in the literature include depression, anxiety, psychosomatic disorders, increased stress, poor social adjustment and social isolation, financial problems, vocational and role changes, and increased prescription and non-prescription drug use (Brooks, 1991; Florian & Katz, 1991; Kreutzer et al., 1994a; Lezak, 1988; Livingston & Brooks, 1988; Livingston et al., 1985). Amongst these adverse impacts, increased levels of anxiety and depression appear to be one of the most commonly reported consequences. In studies of emotional distress in caregivers of TBI survivors, around one third of caregivers have been found to experience clinically significant levels of anxiety (Kreutzer et al., 1994a; Marsh et al., 1998) and one quarter reported clinically significant levels of depression (Kreutzer et al., 1994a). Unfortunately, levels of distress and burden do not appear to dissipate over time, with longitudinal studies showing consistent or increasing levels of burden up to seven years post-injury (Brooks et al., 1987; McKinlay et al., 1981).

Researchers have examined whether particular caregiver characteristics may influence the amount of burden and psychological distress experienced by caregivers. Two commonly
examined characteristics are the relationship of the caregiver to the TBI survivor, and the
gender of the caregiver.

Some researchers report that female spouses tend to be more vulnerable to
psychological distress than male spouses. Linn, Allen and Willer (1994) found that wives had
higher self-report scores for depression and anxiety symptoms than husbands, even after
scores were corrected for population-wide gender differences. The authors suggest some
possible explanations for this finding, including female spouses having more objective
burden placed on them compared to male spouses, and the possibility that male and female
spouses experience similar amounts of psychological distress but females acknowledge their
distress more freely (Linn et al., 1994).

There is disagreement in the literature regarding whether the caregiver’s relationship
to the survivor influences the degree of burden and psychological distress experienced by the
caregiver. A number of authors have found no differences in the levels of stress and burden
experienced by parents caring for injured children, and adults caring for injured spouses
(Allen, Linn, Gutierrez, & Willer, 1994; Brooks et al., 1987; Livingston et al., 1985; Oddy et
al., 1978). However, findings from a number of other studies indicate that spouses experience
more burden and psychological distress than care-giving parents (Gervasio & Kreutzer, 1997;
Kreutzer et al., 1994b).

Marital Impacts

The impact on a marriage after TBI can be significant. In circumstances where the
injury is more severe, spouses often take on the care-giving role, which is associated with a
range of adverse impacts as discussed previously. In addition, the non-injured spouse may
experience a loss of their main reciprocal relationship, whereby the roles change “from
confidante, lover, and shared decision maker, to caretaker, independent/ dependent non-
equals” (Perlez, Furlong & McLachlan, 1992, p.149). This change in roles may be
experienced with discomfort for both partners (Kreutzer et al., 1994b).

Thus, marital difficulties are prevalent amongst couples after TBI. Marital
dissatisfaction (Blais & Boisvert, 2005; Gosling & Oddy, 1999; Wood, 2005), dyadic
maladjustment (Peters, Stambrook, Moore, & Esses, 1990), and disturbance to sexual
intimacy (Gosling & Oddy, 1999; Oddy, 2001) have been reported in couples after brain
injury. Studies examining the frequency with which relationships break down after TBI have
reported varied separation rates. Studies focusing on relationships after severe injuries have
reported a separation rate of between 40% and 55% up to seven years post-injury (Oddy,
Although these rates may have been considered high when these studies were conducted, more recent research suggests that separation rates may not be higher than in the normal population.

Wood and Yurdakul (1997) found that amongst a group of 131 survivors of mild to severe TBI who were in stable relationships at the time of injury, during a five to eight year period post-injury, 49% of relationships had ended by divorce or separation, which was consistent with the national average rate of divorce in the United Kingdom.

Tyerman and Booth (2001) outline common issues that arise in marital therapy following TBI. Such issues include survivor aggression and unpredictability, communication difficulties between partners, challenges adapting to role changes (such as increased responsibility and decision-making in the non-injured partner, and dependency for the survivor), strained relationships between the survivor and their children, social isolation and restricted leisure time, deterioration in sexual relationship and reduced emotional intimacy, and competing perceptions of the TBI and its effects.

**Impacts on Children, and on the Parent/Child Relationship**

The experience of having a parent with a TBI can be enormously upsetting and disruptive for children. Children must learn to adapt to a parent who may have changed in character, and to adjust to the family re-organization and role changes that are common after TBI. In their study of the outcomes of a multi-family group treatment programme for families after TBI, Charles, Butera-Prinzi and Perlesz (2007) noted that “many children struggled to make sense of complex and contradictory feelings such as anger, sadness and resentment coexisting with loving and compassionate feelings toward their parent with ABI” (p.70).

Indeed, the quality of the parent/child relationship is often disrupted following TBI. In a study with 24 families where a child was living with a parent with brain injury, 42% of families reported a reduction in the quality of relationship between parents and child (Pessar, Coad, Linn, & Willer, 1993). Both child and parents may feel this loss keenly. In the aforementioned study, which assessed a multi-family group treatment programme, parents spoke of the loss of connection with their children, and fears about the deterioration of their parent/child relationships. Parents spoke about the challenges of redefining their relationships with their children in the wake of the TBI, and searching for ways to contribute as a parent despite their difficulties (Charles et al., 2007).
The disruptions experienced by children in families where a parent has sustained a TBI may lead to behavioural problems. One study found that in families with a parent with TBI, 90% reported at least some problematic behavioural change in children since the parent’s injury (Pessar et al., 1993).

**Financial Impact**

Many families experience adverse financial impacts as a result of the TBI. Financial difficulties may result from lost income, due either to the survivor not working or the caregiver having to reduce or cease working in order to care for the survivor. Also, if medical treatment and/or rehabilitation is not covered by insurance, accumulating medical bills and necessary housing adjustments may also lead to financial difficulties. In an American study, researchers surveyed 32 families of children who had survived a TBI and found that 30% of these families reported a reduction in financial wellbeing or loss of job (Montgomery, Oliver, Reisner, & Fallat, 2002). A similar, or even more extreme financial impact could be expected in those families where an adult sustains a TBI.

**Summary of Impacts**

In summary, research over the previous three decades has shown that there are considerable adverse consequences for individuals and families where a brain injury has occurred. Individuals with injuries of all severities may experience a variety of adverse physical, cognitive, emotional, social, and identity changes as well as deficits in regard to their awareness and insight. Families and their individual family members may also face tremendous difficulties, including psychological problems, stress and burden, problematic family functioning, disruption to relationships and financial hardship. Indeed, as Bowen, Yeates and Palmer (2010) argue, “it is equally useful to think of ‘brain-injured relationships, families and systems’ as it is to think of ‘brain-injured individuals’” (p.9). It is the plight of these ‘brain-injured families’ that has inspired the clinicians and researchers involved in the studies outlined below, and in the research study reported in this thesis, to consider how best to help survivors and their loved ones cope in the aftermath of brain injury.

**Interventions with Families Following TBI**

Research into family-focused interventions with TBI survivors and their families has been slowly gathering momentum in the last three decades. Historically, rehabilitative services have paid little attention to the relatives of survivors, and interventions have been
primarily focused on the survivor (Stejskal, 2009). In the late 1980’s Rosenthal and Young (1988) noted an increasing focus on involving families in the rehabilitation process and there is now a growing body of literature in the area of family-focused interventions after TBI.

Family-based interventions are not only important to help family members with their own challenges, but in many instances the adjustment of the survivor is impacted by the adjustment of the family. Thus, as Bowen, Yeates and Palmer (2010) observe, “taking a broad approach that includes working with the family is often a very helpful and intuitive way to help the individual” (p 9).

Within the literature, some describe interventions or provide case-studies of family interventions no empirical measurement. Other studies do provide empirical measurement but only a few of these interventions have involved the whole family. The majority of studies involve either the survivor and primary caregiver, or the primary caregiver alone.

The next two subsections of this chapter will first summarise theoretical papers and non-empirically evaluated interventions, followed by a summary of empirically evaluated interventions.

**Summary of Theoretical Papers and Non-Empirically Evaluated Interventions**

In their early paper on the theory and practice of family intervention after TBI, Rosenthal and Young (1988) outline a variety of possible interventions when working with families after TBI. They propose that these interventions should be used according to individual family needs and the stage of rehabilitation. Their paper is most relevant to cases of severe injuries where a hospital stay is required, although it nonetheless provides a good overview of various interventions that could be helpful to a more diverse population of TBI survivors. Six types of intervention were identified.

The first type of intervention described by these authors is family education. This type of intervention provides information on the nature and impact of the injury, and orients and trains family members in the treatment of the TBI survivor. The importance of family members receiving information at all stages of rehabilitation is also emphasised by Cavallo and Kay (2011). These authors note that education is the most crucial intervention in the early stages following TBI, and that families should be informed of the physical aspects of brain trauma, the treatments being used and the reasons for these, what to expect over the coming weeks, how to make sense of behavioural and cognitive changes in the survivor and how to respond to these changes. Providing information on treatment options is also recommended. However, these authors note that it is not possible to provide families with long-term
prognoses in the early stages following TBI, and that the provision of information should be
timed to be sensitive to how much information the family is able to process. For example,
families need to sustain hope in the early stages of recovery, and pessimistic projections
should be avoided at this stage (Cavallo & Kay, 2011). Psychoeducation is also
recommended as a necessary intervention in the case of mild TBI. Survivors and family
members should be informed of the pathophysiology, common sequelae, time and course of
recovery, and the possibility of longer-term limitations should be explained (McAllister,
2011).

The second type of family intervention described by Rosenthal and Young (1988) is
family counselling and family therapy. Counselling can assist families to express and work
though difficult emotions such as feelings of loss, helplessness, sadness, guilt and anger. It
can also be helpful to guide families through the stages of rehabilitation and provide support
on how to manage the TBI survivor and their sequelae within the family system. In the case
of mild TBI, Rosenthal and Young highlight that if difficulties are still present three months
post-injury, it may be helpful to attend family counselling to “help cope with their fears as to
the permanence of the disability and to help find effective ways to compensate for the
neurobehavioral and physical deficits before the mild head injury results in severe emotional
distress and chronic disability” (p.49).

Family therapy is differentiated from counselling in that it attempts to produce
behavioural change in the marital or family unit (Rosenthal & Young, 1988). These authors
describe family therapy as being useful in cases where a family dysfunction was evident prior
to the TBI, or when the family reaction to the TBI leads to communication and interactional
patterns within the family system that are maladaptive. Rosenthal and Young define the
purpose of family therapy as being “to resolve the dysfunctional communication and
interaction patterns in a way that develops or re-establishes a clear hierarchy that provides for
executive control and fosters the development of each family member” (p. 47). They go on to
highlight some common approaches to family therapy that may be used with TBI Families.
These include: “emphasising the mutuality of responsibility for the family problems and
shifting the burden of causality from the identified patient to the dysfunctional areas of the
family system; focusing on and strengthening the positive aspects of the family system;
exploring dysfunctional interaction patterns by re-enacting family conflicts and assisting
family members to substitute conflict-resolution strategies that are acceptable within their
system; and prescribing ‘homework assignments’ to practice outside the sessions to foster
generalization of behaviour change” (p. 47). Rosenthal and Young note that while family
therapy can be helpful throughout the rehabilitation process, families may also find it helpful to continue well beyond the time that the TBI survivor completes formal rehabilitation.

The third type of intervention outlined by Rosenthal and Young (1988) is marital and sexual counselling. Given the relationship difficulties after TBI as described above, marital and sexual counselling may be helpful to some couples. Rosenthal and Young suggest that counsellors attempt to explore these issues during the acute stage. Although some couples may not be ready to confront these issues this early in the recovery process, it enables couples to view the counsellor as available and open to discussing these issues in the future. The authors point out that often couples are more receptive to working on relationship and sexual issues once the survivor has been home for a period and individuals have realised that more permanent personality and behaviour changes may have occurred.

The fourth type of intervention outlined by Rosenthal and Young (1988) is family support groups, noting that in some instances other families who have been through similar experiences may be better placed to provide emotional support and information to families than are rehabilitation professionals. The authors suggest that family support groups can assist families in coping with the social isolation and public embarrassment caused by deficits in the TBI survivor. Furthermore, the nature of families coming together can alleviate the sense of aloneness and foster a sense of belonging and understanding. Family support groups can also be helpful in normalizing experiences of adjusting to the TBI.

The fifth type of intervention described is family networking (Rosenthal & Young, 1988). This involves immediate and extended family members gathering with friends, acquaintances, and communities for a series of group problem-solving meetings, with a view to helping the group to “identify and anticipate problems, generate solutions, and provide the human resources to implement solutions” (p. 48). Another form of family networking is linking families in the acute stage following TBI with other families further along in the recovery process, in order to provide support and information.

Finally, the sixth type of intervention described by Rosenthal and Young (1988) is family advocacy. This can be an important form of support for families who will inevitably face significant demands, especially in cases where the family is required to interact with a number of agencies and rehabilitation professionals. Families often lack the information, understanding and/or emotional capacity to make the necessary decisions. In these instances, rehabilitation professionals must advocate for the needs of survivors and their families.

Whatever approach is taken, these authors highlight the need for professionals to be cognizant of and apply the principles of family systems theory when working with TBI
Families. Specifically, they say that “all the individuals within a system are psychologically and behaviourally connected to each other; that these connections develop over the life cycle of the family and can be lawfully described; a significant change in the behaviour of one member produces change for all members of the system; [and] each family system is unique” (Rosenthal & Young, 1988, p. 43).

Other authors have also more recently recommended a family systems perspective when working with TBI survivors and their families. For example, Maitz and Sachs (1995) discuss this approach, particularly highlighting the issues of power (the ability of people to control resources such as information, services, or money) and authority (the right to exercise power) within the family. Using a brief case-study approach to supplement their discussion, these authors point to ways in which power and autonomy are expressed in the family’s adjustment to brain injury, and treatment implications for families. They suggest that family structure is threatened following TBI, and that this leads to a disruption in the power-balance between family members, creating ‘disequilibrium’ within the family system. They argue that “from a family systems perspective, the primary treatment goal after a TBI is to re-establish a workable family structure…[which] should include a distribution of power and authority that meets the needs of the family and the individual family members” (p. 3).

Larøi (2003) also advocates a family-systems approach when working with families after brain injury, and highlights the collaborative nature of the relationships between families and rehabilitation professionals. As other authors have done (e.g., Cavallo & Kay, 2011; Rosenthal & Young, 1988), Larøi discusses the importance of family education and support as a basic component of family work after brain injury. He echoes the reasons outlined by Rosenthal and Young, and adds that education is important in order to avoid family members misinterpreting the survivor’s problematic behaviours (e.g., personalizing problem behaviour, or misinterpreting problem behaviour as laziness). Larøi goes on to say that family therapy is important for facilitating change in the family unit that can alleviate some of the difficulties experienced by families after TBI. The focus of his discussion of family therapy is on the usefulness of Structural Family Therapy (see Minuchin, 1974) with families following TBI. Citing Miller (1993), Larøi highlights that one of the key tasks in family therapy is to assist the TBI survivor to transition into their new role within the family, and to support other family members to adjust to the new family roles. He goes on to provide five case examples illustrating role changes in the family. He also advocates considering Narrative Therapy (see White and Epston, 1990). When faced with pessimistic views and interpretations on behalf of family members, he recommends drawing attention to alternative
perspectives or stories than those put forward by the family (Andersen, 1987; Larøi, 2003). In his concluding remarks Larøi emphasises that therapeutic approaches used with TBI Families should be theoretically flexible, and because of the idiosyncratic nature of presentations in both individuals and families, a therapist should have “a wide and varied therapeutic arsenal at his disposal” (p. 184) since an individualised approach will most likely be necessary.

The idea that therapists need to have a flexible theoretical approach when working with families after TBI is also endorsed by Perlesz, Furlong and McLachlan (1992). These authors argue that an eclectic and flexible approach to clinical work, drawing upon a variety of therapeutic approaches, is helpful as the needs of families change over time.

In their book which describes taking a relational approach to rehabilitation after brain injury, Bowen, Yeates and Palmer (2010) also discuss the use of interventions that draw on a variety of approaches, including “systemic family therapy, narrative therapy, emotion-focused therapy, the holistic approach to rehabilitation, models of identity reconstruction such as the ‘Y-shaped model’, behavioural experiments in a social context, [and] therapy that draws on ideas of transference and countertransference” (p. 3). These authors provide a series of case-descriptions that offer examples of relational thinking and intervention in the context of rehabilitation after brain injury.

**Summary of Empirically Evaluated Interventions**

There are a growing number of studies that describe empirically evaluated interventions and provide outcome data. As noted earlier, the majority of these involve either the caregiver alone, or the caregiver and TBI survivor. Few studies include other family members.

There is great variation in the types of interventions described. Most interventions fit into the categories described by Rosenthal and Young (1988): education, family therapy and counselling, marital and sexual counselling, family support groups, family networking, and family advocacy. The most common interventions appear to be based on psychoeducation. Far less common are studies that involve family therapy. The following section provides an overview of studies of interventions that have included empirical evaluation of their effects, starting with those studies that most closely resemble family therapy. These studies will be discussed more fully because of their direct relevance to the present research. This will be followed by briefer outlines of studies that provided families with other methods of intervention, such as education and advocacy.
Individual family therapy (Perlesz & O'Loughlan, 1998). The intervention described in this small pilot study was individual family therapy provided to 15 families where a family member had sustained a severe TBI. The therapy was provided at an ABI specialist family therapy service in Victoria, Australia. Families attended for varying lengths of time and number of sessions, depending on their needs. The average number of sessions was 8.4 (with a range of one to 22 sessions) and the average time in therapy was 9.5 months (with a range of 1 to 18 months). No further information on the therapy is provided, and the authors use the terms ‘therapy’ and ‘counselling’ interchangeably (Perlesz & O'Loughlan, 1998).

There were a variety of family structures in this study, including: spousal relationships where one spouse had sustained a TBI; parents of children with TBI; an adolescent with TBI and his mother, aunt and sister; a man with TBI and his wife and two adult children; and a young man with TBI, his mother and brother. The average age of the injured person was 31.2 years with a range, of 12 to 55 years. All injuries were classified as severe. The average time since injury was not reported.

Families were monitored over a two-year period, with standardized measures administered pre-intervention, 12-months following the commencement of therapy, and 24-months following the commencement of therapy. The following outcome measures were assessed: symptoms of depression, anxiety, somatic complaints and social dysfunction in survivors and non-injured family members, using the General Health Questionnaire-28 (GHQ-28; Goldenberg, 1981); mood states for survivors and non-injured family members (tension-anxiety, depression-dejection, anger-hostility, vigour-activity, fatigue-inertia, and confusion-bewilderment), using the Profile of Mood States (POMS; McNair & Droppleman, 1981); level of perceived or subjective burden in non-injured family members’, using the Subjective Burden Scale (SBS; McKinlay et al., 1981); the psychological and social adjustment to the injury by the survivor and non-injured family members, using the Social Adjustment Scale – Self Report (SAS-SR; Weissman & Bothwell, 1976); and the characteristics of the social environment in each family, using the Family Environment Scale (FES; Moos & Moos, 1981).

Perlesz and McLaughlan reported that in general, psychosocial outcomes for participants improved over their time in therapy. Individuals with TBI and their primary caregivers experienced a significant and sustained decrease in psychological distress, and carers reported a reduction in burden and strain. Levels of family conflict also reduced and family cohesion and adjustment improved from pre-therapy to 24-month follow-up. While
reported levels of anger reduced significantly during the first 12-months of counselling, at 24-month follow-up they had returned to their original level. Marital adjustment deteriorated between 12-months and 24-months, with couples reporting at 24-months a similar level of adjustment to that reported prior to counselling. Thus, while the intervention was successful in improving some areas for participants, it was not successful in helping couples to achieve improved relationships in the longer-term (Perlesz & O'Loughlan, 1998). The authors highlight that the families reporting an increase in anger in the second half of the study were also families where it was the spouse (as distinct from a child) who had sustained the TBI. It was also these same families that reported a deterioration in the marital relationship.

Despite not being successful in helping couples achieve improved relationships in the longer term, the study findings provide promising results for the efficacy of family therapy after TBI in reducing psychological distress, burden, strain, and family conflict. The authors highlighted the need for more research on increasing spousal support following TBI, with particular attention paid to the heightened anger that frequently occurs following TBI (Perlesz & O'Loughlan, 1998).

**Family Support Programme (Smith & Godfrey, 1995).** A New Zealand-based research group described and evaluated a cognitive-behavioural-based family support programme for 14 TBI survivors and their families. The programme was a home-based intervention, with input provided as needed to survivors and their families. The programme included rehabilitation for cognitive impairment, cognitive-behavioural therapy-based input for anxiety, depression, grief, negative self-concept, irritability, awareness deficits and catastrophic reactions. There was also training to improve social competency, behavioural adaption and family functioning. A large component of the programme was education for family members (Smith & Godfrey, 1995).

Fourteen TBI survivors of all injury severities and their families were in the treatment group, and outcome data were compared to that of 20 TBI survivors and their families who had previously received hospital-based care. Families in the treatment group received four, one-hour education sessions, followed by regular visits over the following two-year period. The average hours of contact per family in the treatment group was 27.6 hours.

Both groups were assessed six-months and two-years post-injury. Psychometric measures used to measure outcomes were the Symptom Distress Scale (Partridge, 1991) to measure distress related to TBI symptoms, Symptom Recognition Scale (Partridge, 1991) to
measure survivor awareness of deficits, the Zung Self-Rating Depression Scale (Zung, 1965) to assess depression, and the Rosenberg Self-Esteem Inventory (Rosenberg, 1965).

The results indicated that the family support programme was beneficial in some areas. In terms of outcomes for family members, at two-years post-injury, those in the treatment group had lower levels of distress about TBI-related symptoms, lower levels of depression and higher self-esteem, than family members in the control group. Results for TBI survivors were less promising. Those in the treatment group had more insight into the effects of their injury at six-months, although TBI survivors in the control group had equal levels of insight by the two-year period. TBI survivors in the treatment group had higher levels of depression at six-months compared to survivors in the control group. There was no significant difference in terms of self-esteem. The authors conclude that the programme decreased the amount of time it took survivors to gain insight, but point out that increased insight may be associated with increased emotional distress.

Brain injury family intervention (BIFI) (Kreutzer, Kolakowsky-Hayner, Demm, & Meade, 2002). In response to a perceived lack of structured family interventions, a team of researchers in the USA developed such a treatment approach called the ‘Brain Injury Family Intervention’ (BIFI; Kreutzer, Kolakowsky-Hayner, Demm & Meade, 2002). The BIFI was designed for working with moderate-to-severe ABI survivors and their families, although some outcome studies include families where a mild injury had occurred. Guided by Family Systems Theory and Cognitive Behavioural Therapy, the curriculum has 16 topics and provides education, psychological support and skill building for families. The BIFI also includes a set of evaluation tools.

The first stage of the BIFI is assessment, which utilises information from record reviews, standardised assessment tools, interviews and observations. Treatment can be given through a range of modalities (family therapy, marital therapy, individual therapy, group therapy and bibliotherapy). The 16 topics in the curriculum cover a comprehensive range of issues associated with ABI, and are structured into four groups, which include: (a) recognising and coping with changes; (b) understanding and promoting long-term recovery; (c) effectively managing stress and other problems, and (d) working effectively with rehabilitation professionals.

The topics related to recognising and coping with changes include understanding the typical consequences of brain injury, recognising ambivalent feelings and developing strategies for positive coping, recognising that brain injury happens to the entire family, and
recognising the detrimental effects of guilt and the need to care for one’s self. The topics that relate to understanding and promoting long-term recovery include appreciating the natural limits of rehabilitation, helping to extend improvement well beyond the first six months, avoiding giving inconsistent or contradictory advice, and understanding the differences between physical and emotional recovery. In relation to effectively managing stress and other problems, topics covered include stress management, learning effective ways to judge success, avoiding working on too many things at one time, and expanding support systems. The final four topics, which are related to working effectively with rehabilitation professionals, include recognising and addressing gaps in the system of care, encouraging communication and asking questions, politely addressing disagreements, and resolving conflicting advice and information (Kreutzer et al., 2002).

The BIFI curriculum can be presented in a variety of ways. An approach suited to family therapy would be for the clinician to select a sub-set of topics, which can be arranged according to family goals. Focusing on one group of topics only may be most practical when therapy is limited to a small number of sessions (Kreutzer et al., 2002). Timeframes for therapy vary depending on client needs, although efficacy tests of the curriculum have been conducted using five two-hour sessions over 10 weeks (e.g., Kreutzer et. al., 2009; Kreutzer, Stejskal, Goodwin, Powell, & Arango-Lasprilla, 2010). Goals are collaboratively set with the family and clinician, and these can be re-examined regularly throughout therapy (Kreutzer et al., 2002).

In 2009, Kreutzer et al., (2009) published a preliminary investigation into the benefits of the BIFI for families where a mild, moderate or severe ABI had occurred. Families were provided with five 90 to 120 minute BIFI sessions over a 10-week period. Data were collected to assess a number of areas at pre-intervention, post-intervention, and three-month follow-up. The Family Needs Questionnaire (FNQ; Kreutzer, 1998) assessed family members’ perceived psychosocial and educational needs following brain injury. The FNQ also assessed the degree to which each of the perceived needs had been met. The Service Obstacles Scale (SOS; Marwitz & Kreutzer, 1996) was used to evaluate survivor and caregiver perceptions of the quality and accessibility of brain injury services. To assess family functioning, the Family Assessment Device (FAD; Epstein, Baldwin & Biship, 1983) was used. Psychological distress including somatisation, depression and anxiety was measured using the Brief Symptom Inventory-18 (BSI-18; Derogatis, 2000). Finally, global life satisfaction was measured using the Satisfaction with Life Scale (SWLS; Diener, 1985).

Fifty-three families participated in the study. The majority of brain injuries (87%)
were caused by trauma, 47% of which were classified as mild injuries, 13% were classified as moderate injuries, and 40% were classified as severe injuries. The majority of family members were female spouses, although other participants included siblings, and adult children.

Results indicated that family members felt more of their needs were met and perceived fewer obstacles to receiving services at post-treatment and three-month follow-up times (Kreutzer et al., 2009). However, no changes in family members’ satisfaction with life, psychological distress, or family functioning were identified. Despite the fact that this study failed to find statistically significant improvements in the above areas, qualitative data gathered post-intervention indicated that family members felt the BIFI assisted them to learn about the nature of brain injury, to enhance problem solving skills and communicate more effectively. Furthermore, all family members indicated that they would recommend the BIFI to others.

The following year, Kreutzer et al., (2010) reported a mixed methods evaluation of the intervention, and investigated its helpfulness and the degree to which session goals were attained for ABI survivors and their primary caregivers. Survivors and their caregivers were provided with five 120-minute BIFI sessions. At the conclusion of each session, participants completed a self-report ‘Learning Survey’, which comprised items that assessed perceived goal attainment (relating to session goals outlined at the start of each session), and perceived helpfulness of the session. Participants were also asked to record the most important things learned during each session. Lastly, a ‘Program Satisfaction Survey’ was completed after the final session, where participants rated overall programme helpfulness. Participants were asked to comment on the ways in which the programme was helpful to them and their family, and to indicate whether they would recommend the programme to others. Seventy-six ABI survivor and caregiver pairs were involved in the study. The majority of caregivers were female (70%) and married to the survivor (51%). Eighty five percent of brain injuries were a result of trauma, and the average time since injury was 30.2 months. No breakdown of injury severity was provided, although the mean GSC score at admission for trauma injuries was 9.6, which indicates that at least some survivors with mild injuries were likely to have been included.

Results from this study indicate that the BIFI was beneficial to families (Kreutzer et al., 2010). Data on the helpfulness of sessions indicated that participants found the topics included were relevant, and the strategies employed were effective. Furthermore, data relating to goal attainment was positive. More than 80% of caregivers and 75% of survivors
reported that all of their goals were met. Analysis of reported participant perspectives on the
most important things they learned provided further evidence that BIFI topics were relevant
and helped to achieve intervention goals.

**Multi-family group intervention (Charles, Butera-Prinzi & Perlesz, 2007).** This
pilot study evaluated a multi-family group intervention for six families where an adult had
sustained an ABI. The study included injuries of varying severities. The families attended 12
sessions facilitated by professionals, which were based on a model described earlier in the
“Family Reactions to TBI” section, which proposes that families negotiate through four key,
non-sequential tasks in the process of adaptation post-TBI. These tasks are grieving multiple
and complex losses, restructuring family roles and responsibilities, developing new identities,
and creating new meaning (Charles et al., 2007). Outcomes were assessed using quantitative
measures at pre-intervention, post-intervention, and three-month follow-up, as well as
qualitative data. Psychometric measures included the GHQ-28 (Goldenberg, 1978) to
measure depression, anxiety, somatic problems and social dysfunction, the Dyadic
Adjustment Scale (DAS; Spanier, 1976) to assess couple functioning, the FAD (Epstein et al.,
1983) to assess family functioning, and the Behaviour Assessment System for Children
(BASC; Reynolds & Kamphaus, 1992) to measure children’s behavioural and emotional
distress.

Measures of couple functioning reflected high amounts of dissatisfaction in marital
relationships across the study period. The exceptions were two ABI-survivors who reported
relationship satisfaction at follow-up, and one spouse who reported relationship satisfaction
post-intervention, but then reverted to reporting her relationship as unsatisfactory at follow-
up (Charles et al., 2007).

Measures of family functioning reflected a general pattern of high levels of family
dysfunction across the study period. The most notable exception to this pattern was that all
but one ABI survivor was satisfied with their family functioning at post-intervention. In
contrast, only one spouse reported being satisfied with their family functioning at this time
period. It is interesting to note that pre-intervention scores of all survivors reflected more
favourable perceptions of family functioning than their spouse’s scores (Charles et al., 2007).

Results for individual psychological wellbeing were mixed. While measure scores
across all three time periods were not included in the paper, the authors reported that at
follow-up, three of five partners and five of six survivors reported good psychological
wellbeing. Thus, 73% of the adult group reported that they were less psychologically
distressed that they had been prior to the intervention. In terms of children’s behaviour and emotional distress, children were found to be generally well functioning.

Families reported a number of benefits as a result of attending the multi-family group. Families described the process as providing “a context for mutual support and family understanding; a realisation that there were both shared and unique experiences for individuals and families; increased understanding and knowledge about brain injury; opportunities for discussion of difficult experiences; support in moving from blame to compassion; and fostering family re-organisation and adjustment following brain injury” (p. 67). Qualitative analysis also revealed themes in relation to issues that were discussed by survivors, their partners and children during group sessions. Survivors spoke about their loss of friendships, and appeared to gain reassurance from realising that other survivors had had similar experiences of loss. Partners discussed their mutual experiences of isolation, and one partner noted the loneliness she felt in dealing not only with the ‘physical realities’ of her partner’s injury, but also the emotional responses of her children. Some children spoke of the challenges they experienced in having a parent with an ABI, including coping with post-injury personality characteristics. Some parents with ABI spoke of the loss of connectedness with their children, and their difficulties in redefining the post-injury relationships with their children, and discovering ways to contribute as a parent. Another theme identified was that coming to group sessions allowed family members to increase their understanding about ABI and its effects. This in turn helped family members to better understand difficult behaviours as being related to the ABI.

The authors concluded that multi-family group work following ABI “provides a powerful healing context in which families can accept and come to terms with difficulties in family functioning and deterioration in marital relationships whilst acknowledging personal strengths, reducing shame, and normalising unique and shared experienced in on-going family adaptation post-ABI” (p. 73).

Family-to-Family Link Up programme (Butera-Prinzi, Charles, Heine, Rutherford, & Lattin, 2010). This Australian study assessed a pilot programme that linked together 46 families who had experienced ABI in order to provide mutual support, psycho-education and sharing of coping and problem solving strategies. Sessions of between 90 minutes and two hours were facilitated by a professional, and occurred just once or several times, depending on need and availability (Butera-Prinzi et al., 2010).
Results showed that family members were typically very satisfied with the programme, and 89% indicated that they would recommend it to other families. Family reflections on the outcomes of participating in the Link Up programme included themes of sharing and validation of common experiences, fostering empowerment and hope, gaining a sense of resourcing through shared experiences, giving to others, and greater compassion and understanding for themselves and the survivor.

The authors included a discussion of the issue of when to engage families post-injury. In this study, facilitators excluded families who they deemed to be ‘not ready’ (because they might find the process too confronting). However, some participating families commented that they might have found it helpful to be linked to another family earlier in the process. One facilitator remarked that “offering such a programme earlier in their journey may save families from complete despair” (p. 41). A family member of an ABI survivor also remarked “had we had this help early on, our situation could have been different, my family would have been together” (p. 41). The authors of this study conclude that the Family-to-Family Link Up programme is a useful addition to existing support services for families following ABI.

Community-based behaviour management and education for survivors and carers (Carnevale, Anselmi, Busichio, & Millis, 2002). In a USA-based study, Carnevale and colleagues (2002) explored the effectiveness of a behavioural management programme in reducing ratings of caregiver burden for severe ABI survivors and their caregivers. Twenty-seven survivors and their caregivers received ‘education only’, ‘education plus behaviour management’, or were allocated to a control group. The ‘education only’ group received information about brain injury and behaviour management strategies while the ‘education plus behaviour management’ group received the same educational input, as well as input from clinicians over an eight-week period, with guidance on how to implement specific behaviour-management strategies discussed in the educational sessions. Pairs in this group also received a behaviour-modification plan tailored to the specific needs of the family. The control group received no behavioral treatment for the study period but were offered treatment upon completion of the study. Caregiver burden was measured using an adapted version of the Maslach Burnout Inventory (MBI; Maslach, Jackson, & Leiter, 1996) and subscales of the Questionnaire on Resources and Stress (QRS; Holroyd, 1987).

In this study, no significant change in caregiver burden was found when controlling for initial burden severity (Carnevale et al., 2002). The authors suggest that the lack of
significant effect may be due to small sample size and/or insensitivity of the measures used to detect change.

**Distance education and support groups for carers (Brown et al., 1999).** This Canadian study compared outcomes of a face-to-face caregiver support group and a distance support-group for caregivers that utilized teleconference technology. Ninety-one caregivers of ABI survivors of all severities participated. Groups were facilitated by a professional and had a range of set topics relevant to brain injury and care giving.

In both types of group, statistically significant reductions in caregiver psychological distress were found. No significant change occurred in family functioning or caregiver burden for either group, although trends towards improvement were found. Both groups rated their experiences favourably, although telephone-based group participants reported slightly higher satisfaction with the intervention than did face-to-face group participants. The authors suggest that the anonymity and the convenience of the telephone service may have been beneficial.

**Community-based education for survivors and carers (Sinnakaruppan, Downey, & Morrison, 2005).** In their UK-based pilot study, Sinnakaruppan et al. evaluated the effects of a community-based education programme for moderate-to-severe TBI survivors and their family-member caregivers. The programme was delivered over eight weeks and provided information on memory, executive functions and emotions.

Compared to TBI survivors in a control group (N=18), survivors in the treatment group (N=23) showed significantly reduced anxiety, depression, somatic complaints, and social dysfunction. The survivor treatment group also achieved improved self-esteem and cognitive abilities. In the caregiver treatment group the only significant change was improvement on a measure of depression.

This study was one of the few studies to identify the themes of problems discussed by participants during the course of treatment. Themes that arose included fear of future injuries occurring to their loved ones, fear of seizures, and resentment about the impact on them in terms disruption to their own lives and lack of time for themselves. Survivors reported appreciating the reassurance gained from meeting others who had experienced similar or more severe problems than themselves, and felt that this improved their self-esteem.
Internet-based psycho-social intervention for spousal caregivers (Rotondi, Sinkule, & Spring, 2005). In a USA-based feasibility study, Rotondi and colleagues assessed outcomes for 17 family member caregivers who were given access to a website that provided information and an online support group with other participants and professionals. Results showed that the website was accessed frequently over the six-month study period, and was used to access both information and support. Caregivers reported feeling high levels of support, acceptance and understanding, and relatively low levels of stress, anger, loneliness or worry while using the website. However, psychometric tools were not used and consequently it is difficult to formally measure the impact of the intervention on caregiver wellbeing.

Provision of education information for caregivers (Morris, 2001). In a Scottish study, Morris (2001) investigated whether the provision of written information helped to reduce anxiety in 27 caregivers of TBI survivors of all severities. The booklet provided to caregivers included information on the nature of brain injury, common cognitive impairments (including advice on how to manage these), common emotional and behavioural changes (including advice on how to manage these), and self-care advice for the caregiver, including emotions that they might feel (e.g., anger, anxiety) and advice on how to help themselves. Caregivers also had the opportunity to ask questions.

All but one caregiver reported finding the book helpful, although there was no significant reduction in caregiver anxiety ratings. For caregivers who were caring for survivors who had been injured less than one year previously, there was a significant reduction in a measure of social dysfunction, although this reduction did not occur for caregivers who had cared for survivors who were more than one year post-injury.

Problem-solving training for family caregivers (Rivera, Elliot, Berry, & Grant, 2008). This randomized controlled study from the USA assessed outcomes for 33 caregivers who received comprehensive, tailored problem-solving training. The education-only control group of 34 caregivers received monthly telephone calls, where previously-mailed health-education materials were reviewed.

Recipients of the problem-solving training reported significant reductions in depression and health complaints over the 12-month study period. The authors note that these changes may be in part explained by the decrease that was also observed in dysfunctional
problem-solving styles for the treatment group. There were no significant changes in caregiver burden.

**Social work liaison programme for caregivers (Albert, Im, Brenner, Smith, & Waxman, 2002).** In this American study, researchers evaluated the usefulness of a social work liaison programme for 27 family caregivers after ABI survivors were discharged from hospital. Caregivers received education about brain injury and various social, emotional and cognitive issues that may result, as well as on-going support from a social worker prior to, and following discharge from hospital.

Compared to a historical comparison group who did not receive the intervention, those in the treatment group reported experiencing significantly less burden, as well as higher satisfaction and mastery in their care-giving role, and better quality of life. Analysis of telephone logs showed that contact with social workers was most frequently used for personal or family counselling. The need for counselling increased as time since discharge passed, which the authors concluded is evidence of the changing needs of caregivers over time.

**Summary of Family-focused Interventions**

A summary of research describing interventions that aim to cater for family member needs following brain injury has been provided. While the move towards more family-oriented approaches to rehabilitation is a welcome shift, the research in this field is in its infancy and further development and evaluation of potentially beneficial interventions is needed.

There is considerable variety in the format and type of interventions described. Some involved groups of families or caregivers together, while others took an individual family approach. Most interventions occurred face-to-face, although some researchers explored the possibility of providing interventions remotely, in an effort to reduce barriers to families accessing treatment. Education and support were key features in many of the interventions, and occurred to some degree in most of the studies. Interventions teaching practical skills such as behaviour management, problem solving and caregiver self-care were also described in the literature. While some services allowed the treatment to be tailored to individual family needs, many interventions were based on set treatment programmes, with apparently little opportunity for flexibility to address idiosyncratic needs of the participants.

While there appears to have been at least some benefit to participants in each of the studies, outcomes in terms of the study goals were often equivocal. Many studies did not
achieve statistically significant improvements in the areas they were hoping to affect, although this may have been at least partially due to small samples sizes.

The majority of interventions involved only the primary caregiver or primary caregiver and survivor. Other family members were typically not included. Given the importance that many writers in the field place on working systemically (see above), it seems that a helpful approach to interventions with families would be to include family members beyond the survivor and primary caregiver.

Although the literature is pointing to the need for family interventions in order to foster wellbeing in families and the individual members and to create an optimal social environment for functional rehabilitation of the survivor, unfortunately the provision of such family intervention is not common. The need for effective family-focused intervention underpins the research project presented in this thesis. The background of this study is outlined in the following sections, and provides an overview of rehabilitation services in Auckland, followed by the rationale for the present study.

**Current Rehabilitation Landscape and Research Rationale**

**Current Rehabilitation Following TBI in Auckland**

In New Zealand, rehabilitation after accident or assault is typically procured by private service providers, who are contracted and funded by the Accident Compensation Corporation (ACC), a government body responsible for accident insurance in New Zealand. While many rehabilitation needs for TBI survivors are well provided for by ACC, at the time of embarking on this project ACC funding rarely extended to family intervention, except in families with the most behaviourally challenging survivors. Over the previous three years ACC funding has extended to include family intervention where needed, although this is in the case of severe TBIs only.

Current practice in New Zealand following moderate to severe TBI is based on medical care in hospital during the acute phase of injury, followed by rehabilitation if required. A variety of rehabilitation services are available, ranging from intensive, residential rehabilitation, to community-based rehabilitation, which focuses on specific problems, rehabilitation programmes and support services. Those with mild injuries have access to concussion clinics in the community, where rehabilitation can be provided as required.

Residential rehabilitation is almost exclusively for people with severe TBI, and/or those who have complications relating to the TBI or other injuries. Residential rehabilitation
facilities are typically based on a model that provides for a small number of residents in privately owned ‘community houses’, with health-professional input and 24-hour supervision. At this level of rehabilitation, survivors typically receive support from inter-disciplinary teams including physiotherapists, occupational therapists, speech-language therapists, doctors, nurses, social workers, psychiatrists, and/or psychologists.

For survivors who are discharged from residential rehabilitation, or for individuals who return home directly from acute care in hospital, rehabilitation will occur in the community setting. This rehabilitation may include work with occupational therapists, physiotherapists, social workers or mental health professionals. For individuals who are identified as requiring individual psychological treatment, The New Zealand Guidelines Group (2006) recommend cognitive behaviour therapy, behavioural therapy, life review therapy, and practical help/problem solving.

In regards to the provision of family support, at the time of undertaking this research project there were very limited opportunities for intervention at the family level. However, as noted above, over the three years that this project was completed, ACC began to fund family therapy in cases where the injury is severe. The situation remains that no funded family input is available in cases where injuries are mild or moderate.

**Research Rationale and Study Aims**

The literature previously reviewed has shown that families can face profound difficulties when a family member sustains a TBI, and these difficulties can persist over years as families negotiate the numerous changes and adjustments that are thrust upon them as a result of the injury.

Many clinicians and researchers have advocated the use of family-focused interventions with TBI Families in order to help alleviate some of these difficulties. This is important for the wellbeing of all family members, as well as creating a supportive social environment to allow survivors to reach their optimal functional outcome and to prevent secondary psychosocial complications (Carnevale et al., 2002; Sander, 2007). The importance of optimal social environments is recognized in a report published by ACC, in which The New Zealand Guidelines Group (2006) states that effective rehabilitation for TBI should incorporate an approach that supports survivors to “…fulfill family roles and maintain personal, sexual and family relationships” (p. 70). Given that partners and other family members are an integral part of such a process, it seems appropriate that they should be included in rehabilitative interventions. Yet, typically, this does not happen in New Zealand.
Family-focused therapy is an approach that has been identified as potentially beneficial for TBI Families. Family Therapy has been defined as “bringing about change in a couple or family unit by psychological methods” (Laøri, 2003, p. 177). The present study aims to respond to the need for family-focused intervention by establishing a brief, small-scale service to provide family-focused therapy for TBI Families, with the view of potentially establishing a more permanent service for such families. This study is an exploratory one, with two therapists available over a limited period of time. Thus, although the service was small, it was hoped that this work would provide a valuable addition to the literature in this important area.

This study has four aims. These are:
1. To describe the problems that TBI Families in this study encountered,
2. To describe how such problems can be addressed in therapy,
3. To investigate the outcomes of family-focused therapy for TBI Families, and
4. To describe the challenges therapists experienced in establishing the service and delivering family-focused therapy for TBI Families.

The following chapters of this thesis include the Method (Chapter Two), Results (Chapters Three and Four), and Discussion (Chapter Five). Results relating to the first and second aims will be presented in Chapter Three. Results relating to the third aim will be addressed in Chapter Four, and Chapter Five includes a discussion of findings that relate to the fourth aim.
CHAPTER TWO

METHOD

Overview

This exploratory study was a mixed-method examination of the processes and outcomes associated with therapy for TBI Families. Family therapy research that employs both qualitative and quantitative approaches of inquiry has been advocated by writers in the field of family therapy, who argue that multiple methods “add to family therapy researchers’ ability to capture and reflect change” (Sprenkle & Piercy, 2005, p 8).

The need for more research exploring the processes and outcomes of family therapy following TBI has been described in Chapter One. In order for it to be of most use to clinicians working with this population, it must be designed in such a way that realistically represents clinical practice. Bowen, Yeates and Palmer (2010) identify a view among leading rehabilitation specialists that while research studies adopting a randomized control design are very relevant to evaluating treatments and interventions involving the provision of a single drug for patients with an isolated physical health problem, such a design may not be the best approach in regard to psychological rehabilitation treatment. Due to the complexity of TBI, there is increasingly a call for efficacy research where the methodology more accurately reflects the reality of clinical practice. Bowen, Yeats and Palmer point out that rehabilitation specialists are therefore beginning to broaden their approaches to research beyond the so-called ‘gold-standard’ of randomised control group studies. The authors highlight that because of the many complications resulting from long-term conditions themselves (such as the potential irreversible effects of the injuries and frequent co-morbidity with conditions such as epilepsy), there are considerable difficulties with conducting controlled research in rehabilitation settings following brain injury.

In a clinical and research landscape that has historically prioritized intervening at an individual level with TBI survivors, this study offered the possibility of shedding light on the experiences of family members, as well as the potential benefits and challenges of providing family-focused therapy after TBI. In addition, it was hoped that this research would provide guidance to clinicians who might in future work with TBI Families, on potential approaches to intervention.

Thus in respect of the four aims listed in the previous chapter, a number of specific research questions were developed. For the first aim, to describe the problems that TBI
Families encounter, the research questions were: (1) what are the therapy-goals identified by TBI Families who seek therapy, and (2) what are the common issues that arose for families during the course of therapy? Qualitative data from therapy transcripts were analyzed in order to address these questions. For the second aim, to describe how problems can be addressed in therapy, the research question was: (1) what interventions were used to target therapy goals and to address issues that arose during the course of therapy? Data from therapy transcripts as well as notes recorded by therapists in session were used to address this question. The research questions for the third aim, to investigate the outcomes of family-focused therapy for TBI Families, were: (1) do family members experience changes in family functioning following family-focused therapy, (2) do survivors and primary caregivers experience changes in levels of anxiety and depression following family-focused therapy, (3) does the primary caregiver experience changes in caregiver burden following family-focused therapy, (4) to what extent were therapy goals achieved, (5) how do family members describe the outcomes of participating in family-focused therapy, and (6) how satisfied were family members with the service? The questions arising from this third aim were addressed using qualitative data from feedback forms, therapy and follow-up session transcripts, as well as quantitative data from psychometric measures and feedback forms. Finally, research questions related to the fourth aim, to describe the challenges therapists experienced in establishing the service and delivering family-focused therapy for TBI Families, were (1) what were the therapists’ perceptions of the challenges associated with providing therapy for TBI Families, and (2) what were the therapists’ perceptions of challenges associated with establishing and operating the service? Data to address these questions was gathered by recording conversations between the two therapists.

Some acknowledgements about the therapy and research processes are required at this point. First, in this study the researchers were also the therapists. While this could be problematic in larger-scale studies, this was an exploratory study that did not intend to draw definitive conclusions. The reporting of clinical work as a researcher in small N studies is a necessary and acceptable practice in psychology (Mudford, McNeill, Walton, & Phillips, 2012) and in line with the scientist-practitioner model to which clinical psychology belongs. Thus, it was deemed to be acceptable for these dual-roles to occur in this exploratory study.

It is also important to acknowledge that because of the nature of therapy and the inherent processes involved, the therapists played a key role in guiding the content of conversations. We were required to continually make decisions about what to ask family members and what avenues of discussion to explore. These decisions are likely to have been
influenced by our assumptions, expectations, emotional and behavioural reactions, unconscious responses (Finlay, 1998), and theoretical perspectives. These are likely to have influenced the content of family discussions in therapy, therefore also influenced what is presented in this research.

It is also important to acknowledge the researcher’s influence in the data analysis process, and thus the construction of knowledge that has come from the present study. Similarly to the role the therapist plays in guiding content of discussion in therapy, as researcher, I was required to make judgements about what data was important and how to interpret such data. These decisions are likely to have been influenced by my own assumptions and experiences (Finlay, 1998; Thomas, 2006). As I had been involved as a co-therapists with the families in this study, I did not begin the process of analysis as a naïve investigator. I commenced the process of thematic analysis with a pre-established understanding of the data and potential themes of issues and outcomes within.

Method

Participants

Families included in the study met the following criteria:

- One family member had sustained a TBI of any severity (mild, moderate, severe);
- The survivor was older than 16 years of age at the time of injury;
- The family was experiencing difficulties that were perceived by family members to be a result of changes following the injury.

There were no restrictions on the time that must have elapsed since injury. There were also no strict requirements on which family members must participate in therapy. However, families were encouraged to include all family members who lived with the TBI survivor. In addition, any other family members who had regular interactions with the TBI survivor and would be considered a significant part of the family system were invited to participate.

Research participants were recruited through a variety of avenues. Initially, the study was advertised to clinicians working for one community-based rehabilitation agency that had clients with a range of injury severities. It was expected that this would result in a sufficient number of referrals. However, due to a very slow rate of referrals from this agency, the study was also advertised through two further community-based rehabilitation agencies, two residential rehabilitation services, the regional Brain Injury Association, three charitable trusts providing community-based support for TBI survivors, and all neuropsychologists working in the region.
Twenty-four family members from five families were recruited into the study, and 19 family members were involved for the duration of the study. This reduction in participant numbers was because in one case it emerged that five of the family members who attended the first session did not reside with the TBI survivor and that the issues experienced were primarily confined to the spousal subsystem. It was decided between the family and the therapists that it would be of most benefit for only the survivor and his spouse to attend regular sessions. The additional family members were invited back to attend the final session. Because they had not been involved in the whole therapy process they did not complete psychometric measures. Brief case descriptions of each family are provided in Chapter Three. Table 2.1 following provides demographic data for each family, with the survivor indicated in italics.

Severity of the TBI was established using the lowest Glasgow Coma Scale (GCS) score if available, and/or the length of post-traumatic amnesia (PTA), as indicated in medical notes. Injuries were categorized as mild if the lowest GCS score was between 13 and 15, or PTA period of 24 hours or less. Injuries were categorized as moderate if the lowest GCS score was between nine and 12, or PTA resolved within one to six days of injury. Severe TBI was indicated if the lowest GCS score was eight or below, or PTA lasted seven or more days. In one case neither the GCS nor the PTA was available, although medical records noted the injury as mild, so this categorization was used.

Therapy

Therapy sessions took place at a University Psychology Clinic. The lead therapist was a registered Clinical Psychologist with over 40 years of experience in family therapy, including working with families following TBI. He was also research supervisor to the primary researcher in this study. The second therapist was the primary researcher, who has experience working in a neuro-rehabilitation setting and volunteering for a brain-injury support service. Consultation with a Clinical Neuropsychologist, Associate Professor Suzanne Barker-Collo, who was also the secondary research supervisor to the primary researcher, occurred regularly for neuropsychology-related matters.

It was intended for therapy in this study to reflect clinical practice and thus therapy did not follow a standardised format. Due to the idiosyncratic nature of each family’s presentation, there was variation in the number and regularity of sessions attended. The number of appointments attended by families ranged between five and nine sessions.

Initially, the therapy team had intended to see families weekly, or fortnightly if
weekly was not possible. However, many of the families found attending at a regular time
difficult. There were frequently periods of up to four weeks between sessions, as well as
occasional periods of eight weeks between sessions for some families. Reasons for these gaps
were usually because of holidays, illness, or because of work or school commitments,
childcare problems, or other logistical difficulties.

Therapy with all families started with an assessment session, which lasted between 60
and 90 minutes. Family structure and roles were explored, and family members were asked to
describe what changes they had noticed in the survivor and the family since the TBI had
occurred. They were also asked to comment on what they would like help with (i.e., goals for
therapy). Perspectives were gained from the survivor and spouse, and also from children
where it was appropriate.

Formulations that drew upon a variety of theoretical models guided therapy. Thus,
there was also variation in the therapeutic approach taken across families. The service
established for this study benefited from a lead therapist who was experienced in therapy
using a variety of theoretical approaches, which made it possible for an eclectic approach that
was tailored to each family’s needs.

The therapeutic methods used are described more fully in Chapter Four but will be
briefly outlined here. Psychoeducation on brain injury and its various cognitive, emotional,
social, and behavioural outcomes was provided to all families. In addition, educating
survivors and family members on fatigue management was necessary for some families.
Behavioural interventions were common, especially where problem behaviours (in either the
survivor, or young children) were an issue. Interventions to improve communication were
used in some families. Techniques from a narrative approach (White & Epstein, 1990) were
commonly used, as well as techniques from family therapy.

A break-out room was available for instances where some family members were not
required. For instance, when discussing marital issues children could use the break-out room
to play and not be privy to therapy conversations.

When to end therapy was decided between the therapy team and family members.
Two months following the final therapy session families were invited back for a follow-up
session to check in, re-cap and reinforce progress made over therapy and to invite feedback
on their experiences in therapy. Three families attended the follow-up session. Two families
were not able to attend a follow-up session.
Table 2.1

Family Member and Injury Characteristics

<table>
<thead>
<tr>
<th>Family Members</th>
<th>Gender</th>
<th>Ethnicity</th>
<th>Age (yrs)</th>
<th>Highest Qualification</th>
<th>Severity of TBI</th>
<th>Time since TBI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family One</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>John</td>
<td>Male</td>
<td>NZ European</td>
<td>52</td>
<td>High school</td>
<td>Severe</td>
<td>1 year, 11 months</td>
</tr>
<tr>
<td>Susan</td>
<td>Female</td>
<td>NZ European</td>
<td>42</td>
<td>Tertiary</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family Two</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alistair</td>
<td>Male</td>
<td>NZ European</td>
<td>65</td>
<td>Trade</td>
<td>Moderate</td>
<td>6 years, 3 months</td>
</tr>
<tr>
<td>Leanne</td>
<td>Female</td>
<td>NZ European</td>
<td>58</td>
<td>Tertiary</td>
<td></td>
<td></td>
</tr>
<tr>
<td>James</td>
<td>Male</td>
<td>NZ European</td>
<td>19</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lisa</td>
<td>Female</td>
<td>NZ European</td>
<td>14</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family Three</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Amrit</td>
<td>Male</td>
<td>Sri Lankan</td>
<td>34</td>
<td>Trade</td>
<td>Mild</td>
<td>8 months</td>
</tr>
<tr>
<td>Preeti</td>
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<td>Indian</td>
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<td></td>
</tr>
<tr>
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<td>13</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Priva</td>
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<td></td>
<td>8</td>
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<td></td>
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<tr>
<td>Vishal</td>
<td>Male</td>
<td></td>
<td>2</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Family Four</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nisha</td>
<td>Female</td>
<td>Fijian Indian</td>
<td>42</td>
<td>Tertiary</td>
<td>Mild</td>
<td>3 years, 8 months</td>
</tr>
<tr>
<td>Ami</td>
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<td>44</td>
<td>Tertiary</td>
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<tr>
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<td></td>
<td></td>
</tr>
<tr>
<td>Vijay</td>
<td>Male</td>
<td></td>
<td>5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family Five</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kathryn</td>
<td>Female</td>
<td>NZ European</td>
<td>37</td>
<td>Tertiary</td>
<td>Mild</td>
<td>1 year, 10 months</td>
</tr>
<tr>
<td>Chris</td>
<td>Male</td>
<td>Samoan</td>
<td>39</td>
<td>Tertiary</td>
<td></td>
<td></td>
</tr>
<tr>
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<td>Female</td>
<td></td>
<td>6</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Luca</td>
<td>Male</td>
<td></td>
<td>5</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>
Measures

All measures were administered pre-intervention, post-intervention, and at two-month follow-up. These measures included the following.

**Family Assessment Device (FAD).** The Family Assessment Device (Epstein, Baldwin, & Bishop, 1983; Appendix D) is a commonly used measure of family functioning. As outlined in Chapter One, this self-report questionnaire assesses family member perceptions on the six dimensions of family functioning proposed in the McMaster Model of Family Functioning (Epstein et al., 1978). These dimensions are Problem Solving, Communication, Roles, Affective Responsiveness, Affective Involvement, Behaviour Control, and General Functioning (Ryan et al., 2005). Descriptions of each of these dimensions have been provided previously in Chapter One (pp. 13-14).

The FAD was designed to be completed by family members over the age of 12. It comprises 60 statements which family members score: strongly agree; agree; disagree, or strongly disagree. Endorsed responses are coded 1-4 and responses for each subscale are summed and divided by the number of items answered under the scale. This provides a score between 1 and 4 for each dimension, with higher scores indicating poorer functioning (Ryan et al., 2005). The present study reports scores for the General Functioning scale only, and uses a cut-off score for healthy/unhealthy functioning of 2.0 (Miller, Epstein, Bishop, & Keitner, 1985).

The FAD was developed in North America, although it has been translated into 23 different languages and has been widely used in other countries, indicating good cross-cultural validity (Keitner et al., 1990; Ryan et al., 2005). The measure also has been demonstrated to have adequate internal consistency and test-retest reliability, low correlations with social desirability, and successful discrimination between clinical and nonclinical groups (Akister & Stevenson-Hinde, 1991; Miller et al., 1985).

The FAD is a frequently used measure of family functioning in TBI populations. It has been used to examine and describe the way family functioning is impacted in TBI populations (e.g., Kolakowsky-Hayner & Kishore, 1999; Ponsford & Schönberger, 2010; Schönberger et al., 2010; Testa et al., 2006) as well as to assess the effectiveness family-focused therapeutic interventions for families who have experienced TBI (e.g., Charles, Butera-Prinzi, & Perlesz, 2007; Kreutzer et al., 2009; Stejskal, 2009).

**Hospital Anxiety and Depression Scale (HADS).** The Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983; Appendix E) is a widely used screening
instrument for clinically significant anxiety and depression. The HADS is a self-report questionnaire comprising of 14 items, of which seven assess depression and seven assess anxiety. Items are coded 0 - 3, with total scores for each subscale ranging from 0 to 21. Scores between 0 and 7 are considered in the ‘normal’ range, scores between 8 and 10 in the ‘mild range’, scores between 11 and 14 in the ‘moderate’ range, and scores between 15 and 21 considered in the ‘severe’ range (Snaith & Zigmond, 1994).

The HADS has been found to be a reliable and valid measure of depression and anxiety in both clinical and general populations. In their literature review of research on the HADS, Bjelland and colleagues concluded that the measure demonstrates good reliability and validity, with typical Chronbach’s alpha values between .8 and .9 for both the anxiety and depression subscales. This review also concluded that a cut of score of eight or above resulted in the optimal balance between sensitivity and specificity (Bjelland, Dahl, Haug, & Neckelmann, 2002).

The HADS has been used extensively in TBI research, including studies that describe the outcomes of TBI (e.g., Senathi-Raja, Ponsford, & Schonberger, 2010; Wood & Rutterford, 2006) as well as in research relating to interventions following TBI (e.g., Morris, 2001; Sinnakaruppan, Downey & Morrison, 2005).

**Revised 15 item Bakas Caregiver Outcome Scale (BCOS).** The Bakas Caregiver Outcome Scale (Bakas, Champion, Perkinds, Farran, & Williams, 2006; Appendix F) is a 15-item scale that was designed for use with primary caregivers of stroke survivors, to measure changes arising specifically from providing care for the survivor. It was selected for the present study because both stroke and TBI are types of acquired brain injury, and the challenges faced by caregivers of each population are likely to be similar. In addition, the BCOS also has the benefit of measuring positive changes associated with the care-giving role, rather than negative changes only.

Individuals respond to the 15 items on a seven-point Likert scale with two end anchor points, -3 (changed for the worse) to +3 (changed for the better). Total scores can range between 15 and 105 and lower scores indicate greater burden. The 15 items relate to self-esteem, physical health, time for family activities, ability to cope with stress, relationships with friends, future outlook, level of energy, emotional well-being, roles in life, time for social activities with friends, relationship with family, financial well-being, relationship with the survivor, physical functioning, and general health.
The BCOS has been shown to have good internal consistency (α= .90) and test-retest reliability (interclass coefficient = .66). The measure has good construct and criterion validity (Bakas et al., 2006).

**Client Satisfaction Questionnaire-8 (CSQ-8).** The Client Satisfaction Questionnaire-8 (Attkisson & Greenfield, 1983; Appendix G) assesses client satisfaction relating to clinical care and services. The CSQ-8 consists of eight items, each with four possible responses on a Likert scale. The CSQ-8 includes items such as: “How would you rate the quality of service you received?”, “To what extent has our service met your needs?”, “Have the services you received helped you to deal more effectively with your problems”, and “If you were to seek help again, would you come back to our service?” Each response is scored 1 to 4, with total scores ranging between 8 and 32. Higher scores indicate greater satisfaction.

Short-answer questions were added to the end of the CSQ-8 by the primary researcher to glean more detailed feedback. These questions were “What was most helpful about the service”, “What was least helpful about the service”, “Was there anything about the service that could have been better”, “Do you think that your experience would have been different if you had been involved in the service at another point in time after the injury (e.g., sooner, later) If so, how” and “Any other comments?”

**Procedure**

Ethical approval was granted by the University of Auckland Human Participants Ethics Committee (UAHPEC). All potential participants received a Participant Information Sheet that had been approved by UAHPEC (Appendix A) and were given the opportunity to discuss the study with the primary researcher if they wished. All participants aged 12 years and older signed a Consent Form (Appendix B), and all participants aged 11 years and younger signed an Assent Form (Appendix C). All TBI survivors had sufficient cognitive ability to understand the Participant Information Sheet and the Consent Form. Confidentiality of all information was assured. Family members were advised that they could withdraw from the process at any time, without giving a reason. All potential participants were advised that should they choose not to participate, or to withdraw their participation at any point, this would not have any effect on their normal care with the referrer or any other agency.

Referrers provided prospective participants with an information leaflet about the study. This information was given to either the TBI survivor, or to the primary caregiver.
depending on what was perceived as most appropriate by the referrer. Contact details for families were passed on to the research team with the written permission from the prospective participants. The primary researcher contacted the prospective participants by telephone to introduce the study, and answer any initial questions. A detailed Participant Information Sheet was emailed or posted to the family.

For families who chose to continue, a meeting took place in the family home between family members and the primary researcher. At this meeting a Participant Information Sheet was given to all family members who did not already have this. The therapy and research processes were described, and family members were given the opportunity to ask questions. This meeting took place in the family home for two reasons. First, it reduced the logistical burden on families by removing the need for them to travel. Second, it aimed to allow family members to ask questions and to decide about participation in an environment where the power differential between researcher and participants was reduced. All families were given the opportunity to advise the researcher at a later time whether they would participate, although all the families in this study consented at the time of the meeting. Consent and Assent forms were completed.

Therapy sessions occurred as described previously. All therapy sessions were recorded to DVD with every participant’s full consent. DVDs of therapy sessions were marked with family codes (i.e., Family One, Family Two, etc.) and the session date, and stored in a locked cupboard. Likewise, any other research documentation was coded in order to ensure the participants in question remained confidential. Family member codes were recorded on genograms that were kept in a locked drawer and were known by only the primary researcher.

Psychometric measures were completed at three time points (pre-intervention, post-intervention, two-month follow-up). At each time point the FAD was completed by all family members above age 12, the HADS was completed by all survivors and primary caregivers, and the BCOS was completed by the primary caregiver only. Pre-intervention questionnaires were completed at the initial meeting, which took place in the family home between one and four weeks before the commencement of therapy. Family members completed their questionnaires in private and were advised that their results would not be discussed with other family members, including in therapy sessions. Despite efforts to standardize the length of time between pre-intervention measures being administered and the commencement of therapy, there was some variation due to limitations with participant availability. Post-intervention measures were administered two to three weeks after the completion of therapy.
For four families, the post-intervention questionnaires were completed at a home visit by the primary researcher, two weeks following the conclusion of therapy. For one family (Family Five), the measures were completed and returned electronically, due to logistical difficulties of scheduling a time for the primary researcher to meet with the family. A delay in Family Five returning their forms electronically meant that the post-intervention measures in this instance were completed three weeks after the conclusion of therapy. In addition, the HADS for the survivor was incomplete and thus there is data missing for this part of the study for Family Five. Families were invited to a follow-up session approximately two months after the completion of therapy. At this session, as well as discussing family experiences in the two months prior, families were asked what they had found most helpful about therapy, and what (if anything) they would have liked to be different. Follow-up measures were completed at this session as well as the CSQ-8. Families Two and Five did not attend a follow-up session, so questionnaires were completed and returned by post.

Data Analysis

Due to the small number of participants in this study, meaningful statistical analysis of quantitative data was not possible. Therefore, in Chapter Four, quantitative data are presented in raw form, with some descriptive statistics. In addition, psychometric measure results over time are illustrated in graph format.

For analysis of qualitative data, a form of thematic analysis was used. Thematic analysis is a widely used method of inquiry for identifying, analyzing, and describing themes within data. ‘Themes’ represent patterns of meaning within the data set. It is the researcher’s role to determine what is counted as a theme, and therefore the researcher plays an active role in identifying and communicating meaning from the data (Braun & Clarke, 2006). It is therefore important that the inherent subjectivity in this method is acknowledged and addressed in the research process (Braun & Clarke, 2006; Finlay, 1998). While thematic analysis is a method that can be used in relation to a variety of theoretical and epistemological approaches, a realist theoretical approach (Smith, 1983) guided the present study. Within this framework, the researcher assumed that family member descriptions were an accurate reflection of their meaning and their experiences.

The process of thematic analysis assumed a data-driven, inductive approach, whereby the themes described stemmed from the data themselves. To conduct the analysis, the primary researcher transcribed therapy from audiovisual recordings of therapy sessions. While some researchers recommend verbatim transcription of all content for thematic
analysis (Braun & Clark, 2006) it was decided that an exhaustive transcription was not necessary for the present study. There were many parts of the sessions where the content of discussion was considered to be not relevant to the research questions and therefore unnecessary to transcribe fully. Examples would include conversations about how couples met, or specific details relating to weekend activities. In these instances, notes were made on the content of discussion without verbatim transcription.

Next, a thematic analysis was conducted to describe what issues arose for families in therapy dialogue, and to identify what families described as outcomes of coming to therapy. The stages of thematic analysis suggested by Braun and Clarke (2006) informed the process. Naturally, during the therapy process the therapists (who were also the researchers) began to notice patterns in the discussions with the families. Potential themes were discussed between the therapists (/researchers) and recorded. After re-reading the therapy transcripts, excerpts that that primary researcher deemed as meaningful were taken from the transcripts and coded into a series of topics related to the research questions (e.g., problems discussed by families, and outcomes of coming to therapy). An excerpt was deemed to be meaningful if it was perceived to be relevant to the aims of the study. Coded data were sorted into potential broader-level themes. Themes were identified based on whether they related to the research questions, and were not necessarily selected based on their prevalence in the data. Therefore, some themes represented issues that were present for just one family, while others were present across a number of, or all families.

Potential themes were reviewed and refined. Themes were considered as key themes if they captured the most important elements of what a family brought to the therapy dialogue. Lastly, themes were discussed between the researchers (/therapists).
CHAPTER THREE

CASE DESCRIPTIONS, ISSUES RAISED IN THERAPY
AND INTERVENTIONS USED

This chapter relates to Aim One (to describe the problems that TBI Families encounter), and Aim Two (to describe how such problems can be addressed in therapy). The chapter is presented in two main sections. In the first section, each family is briefly described, including an outline of the problems that they presented with and their specified goals for therapy. The second section describes the issue-based themes that arose in therapy, followed by a description of the interventions used to address these issues. All names and other identifiable characteristics have been altered and the way in which injuries were incurred have been omitted, in order to ensure confidentiality.

Case Descriptions and Therapy Goals

Family One

The TBI survivor in Family One was John, a 52-year-old New Zealand European man. John lived with his wife Susan, whom he had been married to for 20 years at the time of referral. John and Susan had two sons and a daughter all of whom were in late adolescence or early adulthood. All children had lived apart from John and Susan for some time. However, two months before therapy commenced their oldest son, Justin, had moved in temporarily with John and Susan. Justin had a seven-year-old daughter from a previous relationship who stayed at the weekend.

John had sustained a severe TBI 23 months prior to the referral. John’s GCS at the Emergency Department was eight out of 15, and his period of PTA was documented as 74 days. John was in hospital for six weeks and residential rehabilitation for five months. Upon discharge John returned to the home he shared with Susan.

Prior to his injury John had run a business with his cousin. He had not worked since his injury but intended to gradually return to his previous role. His partner Susan worked part-time in a professional role. There had been no change to her work circumstances as a result of John’s injury.

John attended the initial session with Susan, their three children, and John’s cousin. The family members reported that they had noticed changes in John’s personality and behaviour since his injury. His children and cousin reported that he had become more
negative and pessimistic since his injury. Susan described John as more irritable and angry. She said that prior to the TBI, John had been placid, easygoing, and rarely angry. However, since the injury she had been witness to frequent angry outbursts, which involved John speaking very loudly, saying nasty things about people, and cursing. His outbursts did not involve aggressive physical behaviour. The outbursts were almost always directed towards Susan, regardless of whether the trigger was related to her or not. This led Susan to describe home life as “walking on egg-shells” as she felt John could have an outburst at any time. Following an outburst John would calm down within a few minutes, and typically they would not discuss the event further. Neither John’s children nor his cousin had witnessed his angry outbursts.

Susan had also noticed a change in John’s motivation since the accident, and this was particularly evident in his approach to home maintenance. John reported taking pride in his property prior to the injury. He said he used to enjoy keeping the lawn mowed, garden neat and swimming pool clean. He was tidy in the home, well organised and used to cook often. Susan said that since the injury John rarely tended to the property and would let his garden become messy and his pool unclean. Indoors, he left his office in his mess and cooked less frequently, despite reporting that he was still a capable cook and enjoyed cooking. Susan said she would ask John many times to do these jobs before he would, and at times he would leave jobs only partially done.

When questioned about changes that he had observed in himself since the injury, John initially commented that he felt that he was approximately the same as his pre-morbid self. However, when the therapists questioned John further, he said that he was aware of the fact that his behaviour had changed (i.e., he knew that he had angry outbursts and did less around the house). However, John appeared to lack insight into the degree to which his behaviour, especially his angry outbursts, impacted on Susan.

After discussion with the family at the end of the first session, it was decided that only John and Susan would attend therapy sessions. This was because it was primarily Susan who experienced the impact of John’s injury. His children and cousin felt they were not impacted by the changes they had noted in John, and this was partially because they did not live with him. In addition, it was logistically difficult for the children and cousin to attend regular therapy sessions. However, all family members returned for the final session, so that they could be provided an overview of what had been covered in therapy and information on how they could best support John and Susan.
John and Susan were seen for a total of eight therapy sessions. They identified the following goals for therapy:

1. To reduce the number and severity of John’s outbursts,
2. To reduce Susan’s feeling of “walking on eggshells”,
3. To increase John’s motivation to do more activities around the house and property.

Family Two

The TBI survivor in Family Two was Alistair, a 65-year old New Zealand European man. Alistair had been married to his wife Leanne for 25 years. Together they had two children, James (aged 19 years) and Lisa (aged 14 years), both of whom lived in the family home.

Alistair sustained a moderate-TBI six and a half years prior to referral. Alistair’s GCS score at the accident scene was 10 out of 15. His documented LOC period was two to three minutes, and his PTA period was approximately three and a half hours. Alistair had a short hospital stay following his accident before being discharged back home the following day. Hospital staff had failed to identify that John had a cracked skull and bleeding on his brain. He received little post-injury care following the accident as a result of this oversight and it was weeks before the crack in his skull was identified.

Prior to the accident Alistair was successfully self-employed in a business related role, and Leanne worked part time in childcare. Due to difficulties he experienced as a result of the injury, Alistair had to alter the nature of his work, remaining self-employed but in a less demanding role. Following the accident Leanne began full time work in an office-based role, out of financial necessity.

Alistair attended the first session with Leanne and their two teenagers. In the six and a half years since Alistair sustained his moderate TBI, he and his family had experienced significant difficulties. Following his TBI Alistair became very easily angered and would regularly lose his temper, where he would yell and curse. While he was not physically violent, he would at times follow family members while yelling, which was frightening for some family members. Alistair’s anger was triggered by a variety of factors. Examples included his wife being late home from work, his teenage children being untidy or not doing what they were asked, his perceiving family members being tardy before coming to appointments, heavy traffic, raised voices, and every-day mistakes, such as dropping food on the floor.
Since Alistair’s brain injury the family rarely did activities together, as they reported it would inevitably result in conflict. Activities that they avoided included holidays, outings, and every-day activities, such as sharing meals.

Both Alistair and Leanne felt that the injury and resulting family discord had significantly affected his relationship with all family members. Leanne was particularly concerned at the impact of Alistair’s behaviour on their two children and this was her main motivation for her wanting the family to attend therapy.

Family Two were seen for a total of nine sessions. Typically, all four family members attended sessions. On one occasion only Alistair and Lisa attended because Leanne and James were ill. In another session Leanne and Alistair were seen separately to discuss parenting issues. Together, the family identified the following goals for therapy:

1. For Alistair to gain greater control of his temper – including finding an alternative to taking his temper out on the family; and
2. To reduce the impact of Alistair’s brain injury on the family.

Family Three

The TBI survivor in Family Three was Amrit, a 34-year old Sri Lankan man. Amrit had been married to his wife Preeti for 14 years at the time of referral. They had three children, aged 13 years, 8 years, and 2 years.

Amrit sustained a mild-TBI eight months prior to referral. Medical records were incomplete and no GCS was available. Amrit estimated his LOC to be approximately 5 minutes, and hospital staff reported his PTA period to be approximately 1.5 hours.

Amrit worked as a team leader in a busy warehouse. Following the injury he took two weeks leave and returned to work gradually over the following weeks. During therapy he was promoted, which meant he worked longer hours with more responsibility. His wife Preeti worked full-time in a retail-based role. There had been no change to her work circumstances following Amrit’s injury.

All family members attended the first session. They reported that in the eight months since sustaining his mild TBI, they had experienced a number of difficulties. Amrit was suffering from a number of post-concussive symptoms, which included persistent headaches, fatigue, sleep disturbance and irritability. Amrit slept poorly, and due to full-time work found it difficult to manage his fatigue. He therefore often felt tired and exhausted. This made it difficult to spend quality time with his wife and children. Amrit also described having a “short fuse”, which impacted his relationship with his family. He would lose his temper more
easily that before the accident, and there was frequent conflict between him and Preeti. They found it difficult to resolve conflict in a constructive manner. At times following an argument Amrit would get in his car and drive off for hours at a time. They occasionally had periods of not speaking to one another that extended days at a time. Both Amrit and Preeti agreed that they did not talk to each other about their relationship and it appeared that this lack of communication was contributing to their difficulties. Amrit said that his TBI had had a “huge impact” on his marriage, and the relationship appeared to be in a fragile condition when therapy commenced.

Amrit and Preeti were also concerned about his relationship with the children. While the older children (aged 11 and 8 years) used to confide in Amrit, both parents had noticed that they had become more distant with him since his injury. Amrit and Preeti attributed this to the children being more aware of his fatigue, and also his short fuse. The children were also witness to arguing between their parents.

Family Three were seen for a total of seven sessions. Amrit attended one session alone, as Preeti was unable to attend at short notice. There had been a significant gap since seeing these clients so the therapists decided to progress the session with Amrit alone. Because of the nature of their difficulties, much of the therapeutic work was in relation to the marital relationship, therefore four sessions were held without the children present. Amrit and Preeti identified the following goals for therapy:

1. For Amrit to become more in control of his angry “outbursts”;
2. For Amrit to better manage his fatigue/tiredness, including improving sleep;
3. For Amrit to participate more in the family, including spending more time with his children; and
4. For Amrit and Preeti to be able to enjoy an improved relationship, including dealing with conflict more effectively.

Family Four

The TBI survivor in Family Four was Nisha, a 42-year old Fijian-Indian woman. Nisha had been married to her husband Ami for 12 years. Together they had two children, aged 10 years and five years. Nisha sustained a mild TBI three years and eight months prior to referral. Nisha reported losing consciousness for approximately two or three seconds. She was examined at a local emergency clinic where according to a psychologist’s report, “serious injury was ruled out”. No GCS score or period of PTA was documented, although medical records described her injury as a mild TBI.
Nisha had worked as a dance coach prior to her injury. Following her injury she stopped working in her previous job as various post-concussive symptoms made this type of work untenable. Nisha doubted she would be able to return to dance teaching and was actively exploring alternative career options at the time therapy commenced. Her husband worked in a professional role and there had been no change to his work circumstances as a result of Nisha’s injury.

Nisha attended the first session with her husband and children. In the time since sustaining her mild TBI, Nisha had experienced troubling post-concussive symptoms. She suffered from memory problems, headaches, fatigue, and noise sensitivity. She also experienced some post-traumatic symptoms relating to the event that caused her injury, such as feeling anxious and hypervigilent when in environments similar to that where the injury occurred.

In many regards Nisha and her family had adapted well to the impact of her TBI. She and Ami had made a number of adjustments that had aided her recovery. She had resigned from her busy, noisy job. Some time after the injury she had gradually returned to less strenuous work (i.e., a voluntary role for a few hours per week). She took the opportunity to re-evaluate her career goals and at the time of referral was in the process of considering other career paths that she felt she would find more manageable than her previous job. She took regular rests and was effective at monitoring her activity to preserve energy for times of the day where it was most needed (e.g., when the children returned from school). Nisha and Ami had also made changes to their parenting since Nisha’s injury. Ami had become more involved with coordinating dinner and bed-time for the children, providing Nisha with the opportunity to rest at the end of the day. They had also raised the children to be mindful of Nisha’s noise sensitivity and as a result the children were good at playing quietly.

Although the family had adapted impressively in many ways, Nisha and Ami felt that they would benefit from the support of therapy to make further progress in adjusting to the injury. Nisha and Ami felt that because of Nisha’s fatigue and noise sensitivity they were not sharing in activities as a family as frequently as they would like. For instance, they did not eat dinner together or pray together, which was different to before the injury. Nisha also felt that it would benefit the children for them to understand more about the impact of her injury, which the family agreed should be called her “limitations”. She didn’t necessarily want the children to receive psychoeducation, but she felt that by attending the family sessions it would raise the family’s awareness of her limitations in a subtle manner.
Family Four were seen for a total of five sessions. Due to the nature of some discussions the children were present for only three of the five sessions. Nisha and Ami identified the following goals for therapy:

1. To increase their ability to do things as a family, such as meal times and prayer;
2. To educate their children as to Nisha’s “limitations”; and
3. For Nisha to be able to plan and act on returning to work.

Family Five

The TBI survivor in Family Five was Kathryn, a 37 year old New Zealand European woman. Kathryn had been married to Chris for 15 years at the time of referral. Together they had two children, aged seven years and five years.

Kathryn sustained a mild TBI, 22 months prior to commencement of therapy. No GCS score was available. A LOC period of around 30 seconds was recorded, and her PTA period was estimated to be approximately three hours. Kathryn had also sustained another mild TBI a number of years earlier, therefore this was her second TBI.

At the time she sustained her injury, Kathryn worked full-time as a school nurse. In the months following her injury she changed to a part-time office-based role, and was gradually returning to full-time capacity. Mid-way through the therapy she changed jobs again, and returned to full-time work as a school nurse. Her husband Chris was a mechanic. There had been no change to his work circumstances as a result of Kathryn’s injury.

Kathryn attended the first session with Chris and their two children. Kathryn and Chris reported that in the 22 months since her mild TBI, Kathryn had been experiencing a range of post-concussive symptoms. Amongst these were memory problems, noise sensitivity, sleep disturbance, fatigue, irritability and difficulty controlling anger. Kathryn and Chris had been struggling to adapt to the changes that had occurred in their family as a result of the TBI.

Prior to her injury, Kathryn had been gentle-mannered and the “peace-keeper” in the family. While Chris took an authoritarian approach to raising and disciplining their two young children, Kathryn’s approach was softer, and she described being the parent who would calm the situation if people became upset. She also reported that while she could be firm with the children, she would never become angry. Following her TBI, Kathryn felt that she was less tolerant with the children and became easily angered. At the start of therapy, she had angry outbursts towards the children, which she termed “losing it”. This occurred about once a week, and caused her great distress. Kathryn described these outbursts as “going from
zero to ten”, where she felt she suddenly became furious at small misdemeanors. “Losing it”
typically involved her yelling at the children and did not involve physical violence. In light of
their different approaches to parenting, Kathryn and Chris often disagreed on matters related
to parenting, and this was the source of frequent conflict between them. These differences
were present prior to Kathryn’s TBI, although since the injury they had intensified as Kathryn
felt less equipped to take the “peace-keeper” role she had been used to. She felt that Chris
needed to adapt his behaviour to better accommodate the changes that she had experienced as
a result of her TBI.

At the time therapy commenced, Kathryn and Chris were often in conflict with one
another and found it difficult to resolve this conflict in a constructive manner. Kathryn felt
that this was partly due to their different approaches to parenting. However she also felt that
Chris did not fully understand her injury and appreciate the extent of difficulties that she
experienced. Chris agreed that he did not understand why there had been such a change in
Kathryn, given the apparent mild nature of her injury.

Family Five were seen for a total of nine sessions. Kathryn and Chris attended all
sessions. Much of the therapeutic work was related to parenting and the marital sub-system,
so their children attended three only sessions. In light of these difficulties, Family Five’s
therapy goals were:

1. To reduce Kathryn “losing it” at her children;
2. To achieve a more harmonious household, including parenting agreement;
3. To improve Kathryn and Chris’ ability to resolve conflict; and
4. For Chris to achieve a greater understanding of Kathryn’s TBI.

Description of Issue-Related Themes, and Interventions

This section of the chapter aims to provide a description of the issues that TBI
Families described in therapy, and to outline the therapeutic interventions that were used in
response to these issues. Thematic analysis of therapy transcripts resulted in the following
issue-related themes being identified:

1. Difficulties experienced were unexpected;
2. Increased anger, irritation and outbursts;
3. Challenges within marital relationships;
4. Family discord;
5. Changes to parenting and parent/child relationships;
6. Lack of motivation;
7. Lack of understanding from others (from within and outside the family);
8. Grief and loss; and
9. Negative experiences with helping professions.

These themes will be discussed in more detail, illustrated by relevant quotes from family members. After each theme is described, an overview of the therapy interventions that were used will be provided.

**Theme: Difficulties Experienced were Unexpected**

An issue that was noted by all families where the injury was either mild or moderate was that they had not expected the nature and magnitude of difficulties that they experienced as a result of the TBI. In some cases they felt that they might have been better equipped to cope with the difficulties if they had been more aware of the possible problems they might encounter. For some, they wished professionals had been more informative about the possible medium to long-term effects of brain injury.

The spouse in Family Two expressed the way in which she expected things to improve, and suggested how things may have been different had she been aware of the extent of difficulties that the family may encounter:

> When he had the injury I thought things would get better over time... like a wound healing ... but when it's a brain injury it's like the wound gets bigger over time, and more things fall in and make it worse. In retrospect I would have addressed things differently years ago, to have the foresight to see how things may happen. That you don't have to hit rock bottom and have to crawl out. (Spouse, Family Two).

The survivor in Family Two expressed how he would have found it helpful to be told by professionals that he may not return to his premorbid level of functioning:

> I now appreciate that I won't ever be like I was pre-injury... it's just a shame that you spend so many bloody years, err, without them saying, “Hey, you're not going to return to how you were”... If you have a smack on the head, you never dream it will leave you like this. (Survivor, Family Two).

In two mild-TBI Families, members reported having no idea that the effects of concussion could be so debilitating. They reported receiving no information from
professionals about the effects of mild TBI. This lack of understanding led them to expect the survivors to quickly return to their pre-morbid capacities, which led survivors to feel misunderstood and unsupported. One spouse said:

*Part of the problem is that because Kathryn was always a strong person beforehand I just assumed that she would get back to ship-shape straight away... I assumed that it would all be normal.* (Spouse, Family Five).

**Interventions to address difficulties as unexpected.**

**Listening and validation.** Time was given to individuals to voice their frustrations and feelings were validated.

**Psychoeducation.** Psychoeducation about brain injury, common effects and the reasons for these was a key aspect of therapy with all families. This included reviewing existing neuropsychological reports and explaining the findings to families. Their experiences were normalised, but also the variable nature of outcomes and thus, the difficulty in predicting long-term outcomes, was highlighted. Potential reasons for why professionals may have not explained possible outcomes to family members were discussed (e.g., not wanting to alarm families unnecessarily due to the variable nature of TBI recovery).

**Theme: Irritability, Anger and Outbursts**

A very common issue for families was increased irritability and anger in the survivor. This was present to some degree in all families. Some families came to therapy with a goal to address this irritability and anger. For other families it was not a specific goal to address, but it arose in therapy as an issue that was affecting family relationships, to varying degrees.

Survivors described this problem in varying ways, and when talking about this issue, often referenced the change from their pre-morbid selves:

*I'd never just lose it and fly off the handle and now I do, regularly. It's better, it's improved but yeah I just lose my cool.* (Survivor, Family Five).

*It's so easy to push my buttons. I mean I'm fuming now because we were late, five minutes late.... It's like being goaded. You know, it's like when I hear [my children] argue, it suddenly flicks a switch..... It's so easy for me to just lose it.* (Survivor, Family Two).
Descriptions of irritability, anger and outbursts from non-injured family members paint a more detailed picture of what they experienced:

*Leaving hospital* he was just yelling and abusing and screaming and cursing at me, and started swearing and using the F-word 24/7. Prior to the accident he kicked people out of the house if they were going to use that word. It's now the most prolifically used word in our house. (Spouse, Family Two).

*When I say "outburst", he just talks very loudly. I know he is trying to express himself, I'm just not used to him being like that. But he says some horrible things! You know that he would never have said in the past.* (Spouse, Family One).

As would be expected, family members found these changes very difficult. The high amounts of angry communication often made home life very tense and family members wouldn’t know when the next angry outburst would occur. Not only did it affect the family dynamic and hurt feelings, but also it meant non-injured family members had to adapt their behaviour to avoid potential conflict. Some non-injured family members spoke about how the irritably and anger made them feel:

*It can be very, very hurtful, if he's having a dig at me about something. Very hurtful...I'm more on edge now, because I don't want to upset him* (Spouse, Family One).

Family members also had to adapt their behaviour and communication as a result of increased irritably, anger and outbursts. In some families, this meant deliberately avoiding time together, or deliberately avoiding conversation. In the two families where the injury sustained was moderate or severe, both partners referred to home life as “living on eggshells”. These spouses provide more description about how they have changed in response to increased irritably, anger and outbursts:

*... I feel like I'm tiptoeing around the joint* (Spouse, Family One).

*You have your guard up. You always have your guard up.* (Spouse, Family Two).
Interventions for addressing irritability, anger and outbursts.

Psychoeducation. Psychoeducation regarding emotional and behavioural changes following TBI was provided to each family. This information was tailored for each family, based on their particular difficulties and on information gained from medical and neuropsychological reports. For example, in one case where a neuropsychological report indicated deficits in executive function and medical reports described damage to the frontal lobes, therapists were able to explain these findings and relate this to the emotional and behaviour changes in the survivor. In cases where a mild injury had been sustained, the therapists provided information on post-concussion symptoms. For all but one family (Family One, Severe TBI), this was the first time they had received (or recalled receiving) such information.

Fatigue management. All survivors reported feeling more irritable when fatigued. Four survivors were already incorporating fatigue management strategies into their daily lives, however one mild-TBI survivor had no knowledge of the importance of fatigue management following TBI. He was encouraged to take a full lunch break from work (which he had not been doing previously), and to eat lunch and rest in a space away from the noise of his work canteen. He was also encouraged to take a short rest after arriving home in the evening before beginning family activities.

The same mild TBI survivor experienced significant sleep disturbance. Sleep hygiene concepts were explained to him and his spouse, and the therapists explored with the couple which techniques may be helpful to them.

The importance of fatigue management was reiterated to all families when discussing irritably, anger and outbursts. Non-injured family members were included in discussions about fatigue management, and together with the therapists explored ways in which they could support the survivors in their fatigue management strategies. Ideas included reducing noise when the survivor was taking a rest (e.g., taking small children to the park or for a walk), not calling out when arriving home in case the survivor was resting, and limiting background noise where possible (e.g., not having the radio on in the background).

Narrative techniques. Narrative interventions (White & Epstein, 1990) were used when discussing irritability, anger and outbursts with families. In the assessments families were asked to identify a name for the problem. For example, one family agreed on “outbursts”. Another family agreed to name the problem “losing it”. With agreed names in place, during conversations about the problem the therapists used externalizing language. For
example, when exploring the impacts of the problem on one spouse, the lead therapist asked, “in what ways have ‘outbursts’ affected you?” Externalizing the problem aims to help families see the problem as “a separate entity oppressing everyone in the family, including the [survivor]” (Nichols & Schwartz, 2001, p. 392).

Another narrative technique was to identify ‘unique outcomes’ (White & Epstein, 1990). Unique outcomes were times when the survivor had resisted the problem, or responded in a way that was different to the problematic behaviour. For example, survivors and their family members were invited to reflect upon whether there were times where they felt the survivor may have been heading towards an outburst, but it didn’t occur. Similarly, when there had been a reduction in the number of angry events, all family members were asked to consider what might have been different in that period. The following dialogue demonstrates one such exchange between the therapist and the survivor in Family One:

*Therapist: Have there been any outbursts in the last three weeks?*

*Survivor: No, I don’t think so.*

*Therapist: That’s different to usual, isn’t it?*

*Survivor: Yes.*

*Therapist: Well, it’s worth thinking about what’s different, why in three weeks there has been none of these, where as a couple of months ago they were happening several times a week. What would your explanation be?*

Information gleaned from these reflections was used to enhance strategies that had already been helpful in preventing irritation escalating into an outburst. For instance, one survivor recalled a time when he had been very irritable and instead of remaining in the situation, went to his bedroom for a rest, thus avoiding an angry exchange with family members. This was highlighted as a unique outcome and he was encouraged to do this more frequently.

**Behavioural techniques.** Behavioural techniques were used in an effort to reduce outbursts. Conducting a chain analysis of specific incidents helped survivors and their families to understand what events tended to trigger anger and lead irritation to anger and outbursts. When common triggers were identified, families were encouraged to reduce these where possible. Efforts to reduce triggers were suggested only in instances where it seemed reasonable for family members to make adaptations in order to be sensitive to the survivor’s difficulties. For example, it was suggested that family members refrain from yelling in the
company of a survivor who was very sensitive to noise as a result of his TBI. The purpose of this was to reduce easily avoidable triggers for his outburst, but also increase family members’ feelings of control around reducing outbursts. In contrast, family members were not encouraged to make adaptations in order to reduce triggers that seemed unreasonable, or which might increase family members feelings of ‘walking on eggshells’. For instance, the spouse in Family One who had regular outbursts directed towards her, caused by unpredictable events that were generally not related to her, was not advised to change her own behaviour in order to reduce these outbursts.

As well as understanding what events triggered anger and irritation, in some cases survivors were encouraged to notice subtle emotional and physiological changes that occurred in the build-up to an angry outburst, and take steps to de-escalate. Examples of de-escalation strategies included the survivors removing themselves from the situation, or counting to 10 before responding, sitting down, or writing thoughts and feelings down.

Some interventions were aimed at altering the behaviour of family members when the survivor was angry or irritable. In one family, when the survivor was communicating in a way that was upsetting for the spouse, she was encouraged to use a hand signal to provide an external cue to the survivor that his behaviour was upsetting. This external cue was intended to help him to become more aware of his behaviour and take steps to minimise his anger escalating further (as described above). In other cases, chain analysis revealed that when family members engaged in the content of what a survivor was saying in an angry outburst, this caused the anger to be maintained, or to escalate. In these cases family members were advised to avoid engaging in an argument, and instead ignore the outburst, or walk away.

**Improving communication.** Increasing open communication in relationships was used in an effort to reduce irritability, anger, and outbursts, and/or reduce the impact the problem had on family members. This is discussed in more detail in relation to the theme “challenges within marital relationships”.

**Theme: Challenges within Marital Relationships**

All couples experienced challenges to some degree in the marital relationship as a result of the TBI. A great deal of therapy undertaken with some families was effectively couples therapy to address relationship and parenting difficulties. In some cases, marital problems were present prior to the injury, and the difficulties had been exacerbated following the TBI. In other families, the challenges appear to have arisen only after the TBI.
Increased irritably, anger and outbursts was a significant challenge for many marital relationships. As described previously, spouses often felt on edge, and the constant uncertainty of how the survivor might respond in a given situation often resulted in a reduction in communication and sharing of experiences. This led to reduced connection and emotional intimacy in relationships.

_We don’t communicate... you don’t talk about your emotions, or your day, or your life. You just don’t... We deal with facts. You don't go into anything beyond facts, because it's not going to, it's going to be a disaster... we never talk about life, or “how was your day?” [He] wouldn't have a clue. He wouldn't know what my stresses in life are, he wouldn't have a clue! No idea at all. And probably I'm as bad._ (Spouse, Family Two).

While in some relationships the spouse reduced communication in order to cope with increased anger and irritation, in other families the couple engaged in reciprocal angry exchanges. The spouse of one mild TBI survivor described a typical response to her frustration at the survivor’s increased anger. She also highlighted how this pattern of exchange was different compared to their relationship before the TBI:

_I get angry, I get upset when he behaves in a certain way, when he's upset I don't know what it is that makes him angry, I don't know what it is. And when I ask him about it he just shuts me out and it makes me feel angry. And then I start yelling. I mean I don't yell at him but it makes me angry then it builds up and I'll yell at the kids, or you know. I don't focus properly.... we were able to talk about things before [the TBI]._ (Spouse, Family Three).

At times, frustration and anger between spouses led to complete communication breakdowns. More than one couple described periods of avoiding one another or not talking for various lengths of time.

_... Sometimes I get tired a bit too. It's like I can't, I don't want to deal with [his anger] too. Why should I put up with this? Because you know I have to deal with the kids too, I have to deal with him and his moods, and I just get tired and I get frustrated and I just shut him out. Cause if he shuts me out too I get twice as bad. What I mean by that_
is that I’ll completely shut him out, he won't talk and I won't talk either. (Spouse, Family Three).

While a high level of conflict was not an issue for all couples, communication could still be an issue. In one case, the spouse of a mild TBI survivor noted that he was often not aware when the survivor was having difficulties, as she did not highlight this to him. For instance, when discussing his reflections of a previous session where the survivor had shared her struggles with fatigue and low mood following a house move, the spouse said to her:

It's interesting to hear how after the house move it was quite a struggle for you to adjust, and when I come home I don't get that information, so you know, you're too tired to communicate and... the fact that you had taken a step back, that you got a bit depressed was quite surprising. (Spouse, Family Four).

A common change to marital relationships following TBI was spending less quality time together. This appeared to happen for a variety of reasons. In some cases fatigue impacted the survivors’ ability to participate in activities, especially in the evening when couples most frequently had time alone. In other cases, increased conflict meant that couples sometimes felt unmotivated to spend time together. Some couples reported that they were invited to fewer social engagements since the injury and this reduced the number of enjoyable occasions they could share together.

For one couple, the spouse spoke about how she felt they had less to talk about since the injury, as the survivor no longer worked and did little during his days. In this case, the problem was compounded by the survivor’s general apathy towards engaging in activities outside the home, including shared activities with his spouse.

To be honest I find it hard to find things to talk about because [I’ll say] “what have you been doing today?” [and he will say] “Not much” you know, and it's, there's not really a lot to chat about the two of us, like when he was working and he would bump into someone. You know, he would have things to tell me. (Spouse, Family One).

As noted above, the majority of spouses reported not ever receiving information about TBI and its sequelae. This lack of knowledge may have contributed to frustration, confusion
and anger experienced by some spouses in relation to the changes they experienced in the survivors.

**Interventions for challenges in marital relationships.**

*Psychoeducation.* Psychoeducation included information about TBI and its effects, tailored to individual couples and the idiosyncratic difficulties that they were experiencing. Often psychoeducation was provided within a single session, but it was also provided more briefly throughout therapy where relevant. For example, when discussing a pattern of conflict with one couple, the non-injured spouse was reminded that the mild TBI-survivor was experiencing difficulties (e.g., fatigue) that was likely to affect the quality of his interactions with her in the evening after a full day working.

*Improving communication.* Often, interventions to strengthen the marital subsystem involved facilitating communication between spouses. In some cases, this occurred spontaneously in therapy. For example, when discussing increased anger and outbursts in the survivor, the one spouse was encouraged to also talk about how outbursts made her feel, which she had not previously done with the survivor. In other cases, interventions were aimed explicitly at increasing or improving communication. One couple who had a high amount of conflict and would frequently argue without a resolution, agreed to take turns in discussions where one spouse could speak for three minutes without being interrupted, followed by the other spouse speaking uninterrupted for three minutes, and so on.

*Narrative techniques.* Narrative techniques of looking for ‘unique outcomes’ were used in some cases. For example, two couples that argued frequently without resolution were invited to reflect on whether there had been times when they had managed to resolve the conflict, and to identify what had been different about those interactions. This elevated successful strategies to their awareness and they were encouraged to use these again where possible.

*Improving amount and quality of time spent together.* Often, interventions involved encouraging couples to spend more time together alone. In some instances, it was suggested that couples arrange ‘date nights/days’, which were to be initiated and organised by each spouse alternately. Where couples felt that this would be difficult due to childcare and/or financial difficulties, suggestions were made for couples to take weekly evening walks, or even to take time together to talk or watch a movie when the children were in bed.
Theme: Family Discord

A number of families reported a higher amount of conflict in the family, and negative changes to family relationships following the TBI. This was a particular problem for one family with teenage children. Some conflict is not unusual for families in this stage of the family life cycle. However, the TBI and its effects on the survivor and family members appeared to contribute significantly to discord. In an early session when asked to describe how things were at home, one non-injured family member explained:

Quite simple, chaos. Just chaos…. it's just people who scream, yell, shout, hate, yell. I mean it's just... it is what it is. You stay away from people as much as you can, um, you know you say something to [the survivor] and then you go “oh why did I open my mouth”, you know? ... It's called survival. It's not home life. It's actually survival, and existence. There isn't a family home life as such. If we can do anything apart, great. But don't even try. We'll never go on holiday again, it's just too hard. (Spouse, Family Two).

The daughter in this family expressed her wish for more harmony in the family, noting the damage that she felt had been done to family relationships in the years since the TBI happened:

I just wish that life was more enjoyable, and that that people wouldn't get so upset and things wouldn't be so hard.... doing this stuff [therapy] is helpful, but I understand the damage is done. (Daughter, Family Two).

Interestingly, the survivor in this particular family was able to control his temper in the presence of others who were not family, even in situations that could objectively be considered as stressful. The survivor acknowledged that he tended to direct his anger and frustration towards his family members only:

I take the changes out on these people... it's these guys who suffer... I think the majority of the issues we have now are attributed to the way I treat my family now, and how my family feel alienated to me... Basically, this head injury has ruined my marriage, ruined my relationship and ruined my family, and it's no ones fault. ( Survivor, Family Two).
Interventions for addressing family discord.

Psychoeducation. As described previously in other sections, psychoeducation was also important for addressing family discord. Particular attention was given to aspects most relevant to the family, such as providing information on the effects of executive dysfunction. Having this information appeared to help the family members understand the mechanisms behind some of the problematic behaviour that the survivor displayed. Throughout therapy families were reminded of information relevant to the content of discussion. For instance, when discussing ways in which triggers for angry outbursts could be reduced, the therapists emphasised that an environment with low stimulation (e.g., reduced clutter, low levels of noise) would be most beneficial for the survivor.

Fatigue management. The importance of fatigue management, and advice on ways to manage fatigue, were provided to the survivor and discussed with all family members present. This included having regular rests, particularly when the survivor returned home from work. Time was taken to explain to family members the nature of fatigue that is usually experienced by TBI survivors. That is, TBI-related fatigue was differentiated from the type of tiredness non-brain-injured individuals might feel, in an effort to increase their understanding and empathy for the survivor.

Narrative techniques. Highlighting and emphasising an alternative story to the ‘problem saturated’ story (White & Epstein, 1990) of the family was used in some cases. For example, one family had described themselves in ways that indicated they felt they were entirely dysfunctional. The lead therapist highlighted an alternative story:

Survivor: For the family, it’s been downhill since the accident.
Therapist: Ok, but in fact ... in six years, you’ve [to the oldest offspring] managed to get through school, and done well enough to get to university and to be looking at a career, and you've [the youngest offspring] managed well enough to be at school and do so well at netball you have made a national team...

In another example, the lead therapist suggested an alternative story, in response to the family comparing themselves to other families that they felt were closer and more functional:

You compare yourselves to other families, but there is a lot of warmth and closeness ... the description that you give of what life is like at home, and of course the
description you give is biased towards the problems because of course that's what you do in a place like this, but you have a lot of connection to one another as well. There is a lot of warmth and that was noticeable when you first came. It’s just been a hugely difficult ordeal that you've had. I guess from where I sit, you’ve been very brave in dealing with what you have dealt with and still maintained relationships under this huge difficulty. (Lead Therapist).

An aspect of highlighting alternative stories was to normalise some of their difficulties in respect to their stage of the family life cycle. For instance, conflict between teenage children and parents about keeping bedrooms tidy is a common issue in non-TBI Families as well.

Another narrative technique was highlighting ‘unique outcomes’ and encouraging the family members to reflect upon what had contributed to the unique outcome and ways in which those differences could be enhanced. For instance, in one session a family reported that in the previous week they had been on a family outing that all experienced as enjoyable, for the first time in years. The therapist encouraged the family members to think about what had been different on that occasion, and to think of ways in which those factors could be replicated more frequently. Another example of conversation about unique outcomes occurred when in the week following, the survivor reported becoming less angry in response one of his typical triggers for anger. When asked to reflect on what was different he realised that he had been more able to think of the situation from the perspective of the other family member on that occasion. He was encouraged to continue to try to do this in order to manage his anger better.

**Behavioural techniques.** Some of the interventions used to improve family relations were behavioural in nature. Some of these were intended to reduce outbursts and anger, and are outlined in more detail in the ‘Irritability, Anger and Outbursts’ section.

**Increasing quality and time spent together.** Family members were encouraged to spend time together as a family, but also one-on-one between survivor and other family members, doing something mutually enjoyable. Time was taken to discuss ways in which this could happen.

**Theme: Changes Associated with Parenting and the Parent/Child Relationship**

A number of couples had experienced changes to their parenting following the brain injury. Some of these changes were discussed in the context of conversations about effective
adaptations that parenting subsystem had made. In other cases, changes were discussed because parents required assistance with parenting.

In one family where the survivor had sustained a mild TBI, the survivor and her spouse had made a number of adaptations to their parenting that allowed them to cope successfully with many of the challenges the family experienced. In this family there were two young children. The survivor’s brain injury was discussed openly in the family and children were aware of the ways in which the injury impacted on their mother (e.g., that she became tired easily and that she was sensitive to noise). Since the injury the children’s bedtime had been brought forward because the survivor went to bed earlier. The children were also instructed to play quietly when around their mother.

In this same family, the survivor felt that she was more easily irritated by her children than she had been before the injury. She described how she managed her increased irritation and subsequent responses to her children:

… I would get quite angry, you know with my tolerance and irritation, and I'd get quite annoyed with the kids and I'd have to really control myself in terms of managing that anger really, and having some insight into “well what is my anger about? It's not them, they're just being kids”. (Survivor, Family Four).

When asked what strategies she used to manage her response in such situations she cited techniques that she had learned from parenting books. She also indicated that she communicated openly about how she was feeling to her children:

... all the normal stuff from parent help-books. Count to ten, breathe and all that. Contextualize... I think that's the most difficult. You're annoyed, are you allowed to be that annoyed for the misdemeanor? Does the misdemeanor match the amount that you're annoyed?... and I'll say to the kids, “I'm really tired, don't be a nightmare today.” (Survivor, Family Four).

In other cases, parents were struggling to adapt to the changes brought about by the TBI. In Family Five experienced a significant change to parenting ability as a result of the injury, as described above. The survivor described herself as the “calm” parent prior to the injury, who would step in at times of conflict to placate the children and her spouse. However, following her TBI she found herself getting angry with the children, or “losing it”
more easily. This led to difficulty with parenting their two young children and frequent conflict between the parents.

The couple acknowledged that some of their parenting issues had been present prior to the injury. However, in the following exchange with a therapist, the survivor noted that these were exacerbated by the TBI:

Survivor (Family Five): [We had issues] around parenting but it was made so much worse by the brain injury.

Therapist: So the brain injury was like chucking a bomb in the middle?

Survivor (Family Five): Yeah definitely, because I carried so much, I held it all together.

Family Two also experienced a significant impact on the parenting subsystem. Prior to the accident the parents would regularly consult one another regarding parenting matters and hold equal parenting responsibility. Following the TBI, the non-injured spouse took on the majority of parenting responsibilities. She reported that since the TBI, the survivor was no longer able to “see the big picture” when it came to parenting matters. When asked about her approach to discussing parenting issues with the survivor, she responded:

[I’m] really selective, because he’ll lie awake at night. You know like say I was just saying something, for him it’s like he’s a dog with a bone, it’s not just a simple issue, which, you know, teenagers have issues, that will resolve and move on, for Alistair it would be overwhelming, overpowering, and it would take over his world, you know? But I would talk to him if it was something very significant, but not trivial stuff, unless I needed his help, (Spouse, Family Two).

The survivor expanded further on the fact that his spouse had taken over much of the parenting responsibility:

Yes. She does it all, she is the mother and the father. (Survivor, Family Two).

Another survivor spoke about the challenges he faced in parenting his three young children:
I found that after the accident, the kids don't listen what they're told to do and it really frustrates me, it frustrates Preeti so imagine how much more frustrated I feel! It's the same things over and over again. And when I come home from work I just don't have the mental or physical stamina to deal with it. (Survivor, Family Three).

Three survivors spoke about the way in which they felt their TBI had impacted on the quality of their relationship with their children. In one case, a mild TBI survivor felt considerable guilt that she had not been able to parent her younger child in her pre-school years with the same patience and energy that she had with the older child when he was the same age. Other parents spoke about how their interactions with children were different since the TBI. When asked how things were different with the children compared to before the TBI, one spouse said:

I think [the children] are a little bit more distant, they're more aware that Amrit is tired, whereas before they used to be all over him. (Spouse, Family Three).

Interventions for changes to parenting and the parent/child relationship.

Psychoeducation. In some cases, especially where young children were involved, psychoeducation on parenting techniques was provided. In some instances this was in the form of small suggestions made verbally, and in one case a book on parenting was loaned, along with resources on parenting after brain injury.

Strengthening the parental subsystem. In three cases, efforts were made to strengthen the parental subsystem, in order to present a ‘united front’ to children. In one case, parents were encouraged to discuss and agree on a set of rules for their children and consequences for breaking the rules. This was to be agreed upon as a parenting team, and then discussed with the children in order to set clear expectations and boundaries for behaviour. Parents were also encouraged to agree on what behaviours were unacceptable (therefore punished with “time-out”), what behaviours were not desirable (therefore best ignored) and what behaviour they wanted more of (therefore to be reinforced). Parents were encouraged to consult one another before parenting decisions were being made, to prevent children from taking advantage of a weakened parenting subsystem. Another intervention used with one family involved the parents taking time each day to provide feedback on one thing that they felt the other parent did that they admired or respected, and one thing that they themselves did well that day (in regard to parenting). This was intended to make parents
conscious of positive things so that they might build on strengths, in contrast to previous interactions about parenting generally being about what went wrong or what they did not like in the other.

**Changes to family routines.** Some parents were encouraged to consider changes to the family routines. For instance, in one family where the survivor felt significantly fatigued in the evening, it was suggested that getting the children to bed earlier, including turning the television off earlier in the evening, could be beneficial.

**Strengthening parent/child relationships.** All families were encouraged to spend more time together doing enjoyable activities with parents and children.

**Theme: Lack of Motivation**

In Family One, lack of motivation in the survivor caused difficulties. The non-injured spouse experienced frustration at her husband’s apathy towards previously enjoyed household tasks. Examples included not walking the dog, not cooking, and not gardening or mowing the lawns. Exploration of the nature of these difficulties revealed the problems appeared to be with initiating tasks, as well as having difficulty remaining on task until completion.

**Interventions for addressing lack of motivation.**

**Psychoeducation.** Psychoeducation was provided on executive dysfunction following TBI, including problems with motivation. This appeared to help the non-injured spouse understand that the survivor’s apathy was not laziness, and also to help the survivor understand his lack of motivation.

**Behavioural interventions.** A number of behavioural interventions were suggested. These included agreeing on specific tasks for the week, scheduling one activity for each day and writing these on a schedule, which was easily visible. The survivor and his partner were encouraged to discuss the scheduled daily task each morning. The survivor indicated that he did desire to do the tasks set, although when these interventions failed we suggested using an alarm to mark the start of his scheduled time for the task, and even having the spouse call him from work to remind him to start.

**Theme: Lack of Understanding from Others**

Some survivors talked about the fact that they had found others to lack understanding about the impact of their TBI, and two survivors suggested therapy goals relating to their
family members receiving information about TBI and its effects. Lack of understanding was a problem for both family members, and people outside of the family. This was evident in conversations with non-injured spouses about potential reasons for problematic behaviours in the survivor. For instance, when discussing possible causes for increased irritability in the survivor, one spouse said that she felt it had been “too long” after the accident for the TBI to be influencing the survivor in this way, as the injury had occurred eight months prior. In another family, the spouse of a mild-TBI survivor reflected on how his lack of understanding had impacted on the family:

*The impact [of the injury] has been on the family but it has I think been exacerbated by my lack of empathy for the injury because I thought she was stronger.... well she is strong, she is strong but I didn't appreciate the severity of the injury and the impact that it would have on her.* (Spouse, Family Five).

One spouse of a mild TBI survivor who generally did have good understanding and empathy for the survivor and the impacts of the injury, highlighted that even with understanding, it was easy to forget because TBI is not a visually evident disability:

*It would be good to put a plaster on her! Because you do, you think “why's she not doing this or that? And why is she not managing herself?” But maybe she forgets and I forget.... It's not a visual thing.* (Spouse, Family Four).

**Interventions for improving understanding from others.**

*Psychoeducation.* Naturally, psychoeducation was key in improving understanding in family members. As discussed above, psychoeducation was tailored to explain the specific challenges for survivors and the neuropsychological reasons for these. For instance, information about recovery rates and post-concussion syndrome following mild TBI was provided for the spouse who felt that eight months was “too long” for the TBI to be contributing to her husband’s difficulties.

*Exploring the survivor’s experiences.* For many families, conversations about the experiences of the survivor were rare outside of therapy. Active exploration of the experiences of the survivor served to elevate family member awareness of the challenges faced by the survivor, and to foster empathy for them. The ‘hidden’ nature of brain injury was discussed (i.e., that unlike a broken limb, it is usually not possible to see the extent of the
Theme: Grief and Loss

While it is likely that all survivors and family members had experienced some form of grief or loss, this was raised as an issue to explicitly discuss in therapy with only two families. In Family Four this was a central issue the survivor wished to discuss. She was an above-average functioning individual, who at the time of sustaining her mild TBI was employed in a challenging full-time job. In a report from the ACC assessor, it was noted that based on her performance on neuropsychological assessments she had lost 15% of her pre-morbid functioning. She noted that the neuropsychologist who had assessed her commented that because of her high level of pre-morbid functioning, she would feel this reduction more keenly than others with a lower level of pre-morbid functioning might.

For her, having an objective figure estimating the reduction in her functioning, as well as the realisation that she could not do things she had previously done, caused feelings of loss and grief. This sense of loss and grief was the focus of one session with the survivor and her husband. She explained to us her experience of loss, and the effect it had on her. She also talked about the challenge associated with talking about her loss:

... I know that when you have the incident in the first place, you know and you're thinking, “gosh I can't do these things”, that's the first time you start acknowledging the loss. And then you think about all the things you can't do, because you just can't. And then you get quite depressed. Now I was in that space, and I have been in that space periodically, you know getting quite despondent and all that sort of thing, and I couldn't get myself out of it. The only way I was going to get myself out of it was by getting on with things. So yeah, I also have a fear of examining it, because I'm thinking I don't want to go to a place where I can't then get out of myself.
(Survivor, Family Four).

Another survivor spoke about loss, but in the context of loss she felt for her children.

I feel so sad for what they've missed out on as well, with me, with the brain injury.
With how difficult it was when I was first injured, how difficult it was when I was first injured just to do anything with them. I feel like [the youngest child] has missed out
on a lot especially…. I just couldn't do it, especially in the first year I was just struggling with everything. It would drain me just to get up and get them to school and get home again. (Survivor, Family Five).

Interventions to address grief and loss.

Normalization and validation. Feelings of grief and loss were validated and normalized by therapists.

Narrative techniques. Having conversations that fostered development of alternative stories was used to help survivors with feelings of loss. For example, with the first survivor discussed in this section, the lead therapist drew out aspects of her as resilience:

Therapist: I think it's important for you and for the people around you to acknowledge there is a sense of loss... but there is another side to it.... how extraordinarily you have battled against the loss... you have been a ‘coper’ for sure, do you think?
Survivor: Yeah, definitely.

Another example of this approach was with the second survivor discussed in this section. She had developed a story around her children missing out and being disadvantaged by the impact of her TBI. While validating her feelings around this, the lead therapist also highlighted that children are very resilient, and that she is a very good mother despite her challenges. She reflected on this perspective and responded:

Yeah because I know that what they got from me not being 100% was better than what a lot of kids get from their parents. So I do get that. (Survivor, Family Five).

Theme: Negative Experiences with Helping Professionals

All five families described in therapy having negative experiences with the helping professions. Some of these difficulties were with medical staff, but the majority of were related to ACC processes and interactions with its staff.

One family described difficulties and dissatisfaction with processes in the hospital where the survivor was taken following the accident that caused the TBI. Despite the survivor being involved in a serious accident and losing consciousness, the family said that the TBI was not picked up initially by hospital staff. Later investigations revealed that he had
sustained a skull fracture and a significant haematoma on his brain. His behaviour was erratic and aggressive, and when the family reported this to medical staff their concerns were reportedly disregarded and the survivor was discharged from hospital. In the foyer of the hospital following discharge, the survivor collapsed. The spouse described what occurred in the days following when she tried to get help for her husband:

...it was just unbelievable, and then I'm saying 'help' and they say 'oh but [another department in another hospital] are handling him, but he's not bad enough to see them and I'm saying 'but this guy is crazy' and they're like 'oh well in three months he can go and see a specialist' ... and I screamed and yelled, so it was one month and not three months, before he actually saw a specialist. And in the mean time [the initial hospital] had him on every drug that they could have, and as soon as we saw the specialist she said 'oh throw that away, that away, that away, none of them are any good at all. (Spouse, Family Two).

Understandably, this was very distressing for the family at the time, and continued to be upsetting as they spoke about it in therapy. It raised questions about whether things may have been less difficult for them as a family in the wake of the accident, had they received more appropriate treatment.

A recurring theme among families was dissatisfaction with ACC staff and processes. Four of the five families experienced difficulties in this area. A common issue was ACC case managers being unresponsive or tardy in their communications. The spouse of one survivor explained her experience with trying to make contact with the ACC case manager:

I don't want to be a hassle but I'm thinking unless you are one of those annoying people who ring all the time, maybe you do get pushed aside. (Spouse, Family One).

Others described feeling like ACC case managers didn’t understand about TBI and its effects. This was raised in the context of discussions about the way in which ACC case managers pushed survivors to return to work sooner than they felt they were ready to. The spouse of one mild TBI survivor explained:

ACC were really pushing the employer to take him back, so yeah, ... I had an argument with the ACC manager. She said rugby players get injured all the time and
they start playing and I said "have you had a brain injury yourself? Do you understand what it is?" and she goes “yeah yeah I have” and I said “well you DON'T understand, and I don't want you talking to my husband, pressuring him to go to work because you don't understand anything” ... she was just pressuring him so much and saying "what are you doing at home, you should be at work, rugby players get injured, it's not a bit deal that you've got a brain injury". (Spouse, Family Three).

A mild TBI survivor talked about her experiences with the Occupational Therapists (OTs) contracted by ACC:

*I'm just constantly pushed by the OTs. I had to say to them, “I push myself hard enough! I need you to back off and actually support me”. (Survivor, Family Five).*

The spouse of one mild-TBI survivor commented about on how hard her and the survivor had found it to get access to a psychiatrist through ACC, when the survivor began to show signs of depression:

*ACC didn't want to approve most of the things, it was just really bad with ACC, yeah. Everything had to go through ACC for us, it was really difficult. (Spouse, Family Three).*

Finally, one mild TBI survivor remarked about her experience of health care professionals not paying her due regard with concerns related to her post-concussion symptoms:

*So when I go to the GP, or perhaps other health professionals, they'll be like “oh, so you're not feeling well again?” ... If you express significant concern only then will they, you know, refer.... So when I go to him, I see him working out whether or not it's a psychosomatic thing, you know that I'm being overly concerned about my injury... that I think I'm suffering from something I'm not. (Survivor, Family Four).*

**Interventions to address negative experiences with helping professionals.**

**Listening and validation.** Providing a space for their experiences and frustrations to be voiced was important for these families. From the therapists’ perspectives, listening to the
concerns and validation was the primary response when issues about negative experiences with the helping professions were raised.

**Advocacy.** For two families, therapists took the role of advocate, in supporting them to access information from ACC that they were entitled to but had not received (i.e., the survivor’s neuropsychological reports), and in another family, referring the survivor to an audiology service for assessment of her sensitivity to noise.

**Summary of Chapter**

This chapter has provided brief descriptions of the families involved in the study, including the goals they had for therapy. The chapter has also provided a description of the themes that were identified in therapy transcripts and which related to difficulties families discussed in sessions. The interventions used to address these issues were also described. The following chapter will provide an overview of therapy outcomes.
CHAPTER FOUR

THERAPY OUTCOMES

As previously explained, this was an exploratory study designed to investigate the usefulness of family-focused therapy for TBI Families, and thus, the potential value of establishing a more permanent service for such families. This chapter discusses the factors to be considered when evaluating its usefulness, including the outcomes for families, and family reflections on their experiences of therapy. This chapter is presented in three sections. The first section focuses on individual families, and describes the extent to which their therapy goals were achieved, as well as psychometric measure outcomes for each family member. The second section presents data from the Client Satisfaction Questionnaire-8 (CSQ-8; Attkisson & Greenfield, 2004), which asked family members for direct feedback on the service. In the third section, family reflections of participating in, and the outcomes of therapy, are described.

Family Goal Attainment and Measured Outcomes

In early sessions each family set therapy goals, which have been described previously. In this section, data on goal attainment is based on anecdotal information gleaned from discussions in therapy. Following this, data for each family member who completed psychometric measures is presented and discussed.

Family One

Goal attainment. As described in Chapter Three, John and Susan’s goals for therapy were: (1) to reduce the number and severity of John’s outbursts; (2) to reduce Susan’s feeling of “walking on eggshells”; and (3) to increases John’s motivation to do more activities around the house and property.

In relation to the first goal of reducing the number and severity of John’s outbursts, some reduction occurred over time, although John was continuing to have the occasional outburst at follow-up. At the start of therapy, John and Susan estimated that outbursts occurred approximately four or five times a week. Over the course of therapy the number of outbursts fluctuated between two a week, and one a month. The severity of outbursts also fluctuated. At the follow-up session (two months after the final therapy session), both John and Susan felt that outbursts were occurring less frequently than before therapy began.
However, when they did occur they were about the same intensity as they had been at the start of therapy.

In terms of the second goal to reduce Susan’s feeling of ‘walking on eggshells’, at follow-up she reported that she still felt this way, as the outbursts still occurred occasionally and she couldn’t predict when they would occur.

In terms of the third goal, to increase John’s motivation to do more around the house and property, the outcome was unclear. His motivation appeared to fluctuate over the course of therapy. At follow-up John said he felt like his motivation was better. In contrast, Susan felt that it was the same, or even slightly worse in the month prior (although she thought this was possibly due to the weather being very poor in the weeks prior to the follow-up session).

**Psychometric measure results.** Measures were administered to John and Susan pre-intervention, post-intervention, and approximately two months after therapy completion. Both John and Susan completed the Hospital Anxiety and Depression Scale (HADS) and the Family Assessment Device (FAD) and Susan also completed the Bakas Caregiving Outcome Scale (BCOS).

As can be seen in Figure 4.1, anxiety scores for John remained constant across all time periods. His scores fell in the ‘normal’ range and thus did not indicate presence of anxiety symptomology. In contrast, the pre-intervention anxiety score for Susan indicated ‘mild’ anxiety symptomology. Her score fell post-intervention to within the ‘normal’ range, but at two-month follow-up, her anxiety score returned to the ‘mild’ range.

![Figure 4.1. HADS anxiety scores for Family One.](image_url)
Figure 4.2 shows that depression scores for both John and Susan were in the ‘normal’ range across all time periods. John’s scores indicated an improvement (reduced score) between pre-intervention and post-intervention, with an increase of one point back towards baseline at follow-up. In contrast, Susan’s depression scores remained constant across all time periods.

![Graph showing HADS depression scores for Family One.]

*Figure 4.2. HADS depression scores for Family One.*

Results from the FAD show that John and Susan had very similar or identical General Functioning scores across the three time periods. Figure 4.3 shows that Susan reported slightly worse family functioning than John at pre-intervention, however post-intervention Susan’s score lowered to the cut-off score of 2.0, indicating a slight improvement in her perception of family functioning. This was maintained at follow-up. John’s general family functioning score remained constant at the 2.0 cut-off score across the study period. This indicates a mild level of family dysfunction.

![Graph showing FAD general functioning scores for Family One.]

*Figure 4.3. FAD general functioning scores for Family One.*
In terms of caregiver burden, Figure 4.4 shows that the Susan experienced less burden post-intervention compared to pre-intervention. However, the BCOS score returned to baseline at follow up, indicating higher caregiver burden.

![BCOS scores for Family One](image)

*Figure 4.4. BCOS scores for Family One*

A pattern of improvement between pre-intervention and post-intervention, followed by a trend towards baseline, can be observed in three of Susan’s psychometric tests. It is relevant to note that the week prior to administering the follow-up measures had been particularly difficult for John and Susan. Susan explained that the weather had been very poor and John had remained inside for most of the week, and she felt this had lowered his mood and made him “more grumpy than usual”. She said that this in turn had affected her mood and thus may have influenced her responses on psychometric measures at the time of follow-up.

**Family Two**

**Goal attainment.** As described in Chapter Three, Family Two’s therapy goals were: (1) for Alistair to gain greater control of his temper – including finding an alternative to taking his temper out on the family; and (2) to reduce the impact of Alistair’s brain injury on the family.

In terms of the first goal of Alistair gaining greater control of and finding new outlets for his temper, some progress was made over the course of therapy, although at follow-up the family felt that this was still a problem. Alistair felt that coming to therapy helped him to better understand the impact of his anger on his family so he had improved his efforts to control his temper. However, there were fluctuations in progress. In the fifth session Leanne felt that Alistair had been more rational and in control of his temper, and in session eight she
said she had noticed how Alistair had been making an effort to be more in control. In contrast, in other weeks Alistair had been less able to control his temper and his family noted the strain associated with this. At the follow up session Alistair and his family members reported that there had been improvement with some things, including his mood, although they were still experiencing some difficulties associated with his temper.

Because Alistair’s temper was an ongoing problem for the family, it still had impact on the family at the time of follow-up. However, therapy led to some positive outcomes that were not explicitly linked to the family’s initial goals, which will be described later in this chapter.

**Psychometric measure results.** Psychometric measures were administered to Family Two at pre-intervention, post-intervention, and approximately two months after therapy completion. All family members completed the FAD, Alistair and Leanne also completed the HADS, and as the primary caregiver, Leanne also filled out the BCOS.

As can be seen is Figure 4.5, pre-intervention anxiety scores for Alistair and Leanne were in the ‘moderate’ range. Alistair’s scores over time indicated a reduction in anxiety and lowered to the ‘mild’ range at follow-up. In contrast, while Leanne’s anxiety score fell post-intervention, it increased beyond her pre-intervention score at follow-up, which indicated that she continued to experience moderate levels of anxiety symptomology.

![Figure 4.5. HADS Anxiety Scores for Family Two](image)

Figure 4.5 shows that at pre-intervention, Leanne’s depression score was in the ‘moderate’ range, while Alistair’s score was in the ‘mild’ range. Both scores decreased at post-intervention, indicating that Alistair and Leanne were both experiencing fewer or less
severe depressive symptoms. Leanne’s score fell to the ‘mild’ range, while Alistair’s score was in the ‘normal’ range. Alistair’s depression score remained the same at follow-up, and Leanne’s score increased to the ‘moderate’ range. This indicated that Leanne experienced an increase in depressive symptomology, although her score was still lower than her pre-intervention score. Worth note is that Alistair was taking anti-depressant medication for the duration of the study, which may have affected his scores on the HADS.

![Graph showing HADS Depression Scores for Family Two](image)

*Figure 4.6. HADS Depression Scores for Family Two*

Figure 4.7 shows the FAD General Functioning scores for all family members. As can be seen, all family members scored above the 2.0 cut-off for ‘healthy’ family functioning throughout the study, indicating perceived dysfunction in the family’s general functioning. It is also evident that there were differences in how family members reported their family functioning. Throughout the study Leanne reported worse family functioning than other family members. Alistair and James had similar perceptions of family functioning, while Lisa reported the most favourable family functioning throughout the study period. These differences highlight the importance of exploring the perspectives of all family members. All family members reported an improvement in family functioning between pre- and post-intervention. However, all scores rose at follow-up to similar levels of family functioning reported pre-intervention.
As can be seen in figure 4.8, Leanne reported high levels of caregiver burden at pre-intervention. Her score improved considerably at post-intervention. However, the BCOS score fell at follow-up, indicating increased levels of caregiver burden, though this did not return to pre-intervention levels.

**Family Three**

**Goal attainment.** As described previously, in Family Three, Amrit and Preeti’s goals were: (2) for Amrit to become more in control of his angry “outbursts”; (2) for Amrit to better manage his fatigue including improving sleep; (3) for Amrit to participate more in the family, including spending more time with his children; and (4) for Amrit and Preeti to be able to enjoy an improved relationship, including dealing with conflict more effectively.
In terms of the first goal for Amrit to be more in control of his angry outbursts, there was a notable improvement over time in therapy. By the fourth session Amrit reported being less short-tempered, and in the fifth session said he was “not letting things get to [him]” so much. In the sixth session, Preeti reported that there had been no outbursts in the previous three months. The couple attributed this to them getting along better. However, in the week of the follow-up session Amrit and Preeti had had high levels of conflict and had not spoken for a number of days when they came to the session. Much of the session was spent addressing the current conflict and it was not possible to explore the frequency of Amrit’s angry outbursts in the two months since therapy ended.

The second goal was to better manage Amrit’s fatigue, including his sleep. Although sleep hygiene and fatigue management principles were discussed at length with Amrit and Preeti, unfortunately his sleep and fatigue did not improve over the period of therapy.

In relation to the third goal of Amrit participating more in the family, including spending more time with his children, although strategies for this were discussed there had not been any improvement by the end of therapy. Amrit cited being too busy with work and feeling fatigued in the evenings as the reason for lack of improvement in this area.

In relation to the fourth goal of Preeti and Amrit enjoying an improved relationship, including dealing with conflict more effectively, there was marked improvement over the course of therapy, although as noted above, the couple had been experiencing conflict in the week of their follow-up session that they had not been able to resolve. As a general observation by the therapists over the course of therapy, Preeti and Amrit were able to communicate more directly and more frequently. Preeti was being more understanding towards Amrit and the impacts of his TBI, and Amrit was less impatient and irritable with Preeti. In the final therapy session (two months before the follow-up session), the couple felt that their relationship had improved as a result of coming to therapy. This was not discussed in the follow-up session for reasons outlined earlier.

**Psychometric measure results.** Measures were administered to Amrit and Preeti and the oldest son, Ravi (aged 13 years). Amrit completed the HADS and the FAD, Preeti completed the HADS, FAD and BCOS, and Ravi completed the FAD only.

As can be seen in Figure 4.9, Amrit’s anxiety score was in the ‘severe’ range pre-intervention. His score dropped considerably at post-intervention, falling in the ‘mild’ range. At follow-up, Amrit’s score returned to the ‘severe range’. Preeti’s anxiety scores showed a similar pattern. Her pre-intervention score was in the ‘moderate’ range, but fell to the
‘normal’ range post-intervention. However, she reported greater anxiety symptomology at follow-up, with her score returning to the ‘moderate’ range.

Figure 4.9. HADS Anxiety Scores for Family Three

Figure 4.10 shows a similar pattern to figure 4.9, whereby both Amrit and Preeti’s depression scores dropped between pre- and post- intervention, but increased at follow-up. Amrit’s pre-intervention score was in the ‘moderate’ range, his post-intervention score was in the ‘mild’ range, and his follow-up score returned to the ‘moderate’ range. Preeti’s pre-intervention depression score was in the ‘mild’ range, fell to the ‘normal’ range at post-intervention, and then returned to the ‘mild’ range at follow-up.

Figure 4.10. HADS Depression Scores for Family Three

As figure 4.11 shows, all three family members who completed the FAD perceived an improvement in general family functioning between pre- and post- intervention. Interestingly, Preeti and their son Ravi had very similar perceptions of family functioning at pre- and post-intervention. Amrit’s scores in these two time periods indicated that his perception was of
unhealthier family functioning, but nevertheless showed a similar pattern of improvement between the two time periods. Post-intervention scores for all family members were near or on the 2.0 cut-off for healthy family functioning. However, the follow-up scores for all three members rose to indicate perceived worse family functioning, with Amrit’s perception of family functioning being the poorest of all three family members.

![Graph showing FAD General Functioning Scores for Family Three](image)

*Figure 4.11. FAD General Functioning Scores for Family Three*

As can be seen in figure 4.12, Preeti reported high levels of caregiver burden at pre-intervention. Her score improved considerably post-intervention. However, the BCOS score fell at follow-up, indicating increased levels of caregiver burden.

![Graph showing BCOS Scores for Family Three](image)

*Figure 4.12. BCOS Scores for Family Three*

**Family Four**

**Goal attainment.** As described previously, therapy goals for Family Four were: (1) to increase their ability to do things as a family, such as meal times and prayer; (2) to educate
their children as to Nisha’s “limitations”; and (3) for Nisha to be able to plan and act on returning to work.

In terms of the first goal of doing more as a family, both Nisha and Ami felt they were having more meals together by the follow-up session. The family had not started prayer time together. However, Nisha and Ami said they felt alright about this, as they felt it was helpful to make changes slowly.

In terms of the second goal of educating their children about Nisha’s “limitations”, at follow-up Nisha was pleased with the children’s involvement in the process and although the children did not attend every session, she felt that by coming and hearing the discussions about her limitations, it had raised their awareness and understanding and capacity to be empathetic. On occasions when the children did not attend sessions they were aware of where their parents were and Nisha felt that this helped them to understand that her head injury was something the family needed to be mindful of.

In terms of the third goal, over the course of therapy Nisha felt that she had become better prepared for return to work. At the follow-up session Nisha revealed that she had recently been offered two jobs. One was in a role that she was interested in although decided against this as it was almost full time and she felt that it would not be helpful for her stage of recovery, and would impact too greatly on the family. She had gained resolution about the direction of her career and had taken on a part time role in an area similar to where she was working at the time of her injury, although in a setting that would present fewer challenges in terms of her post-traumatic symptoms and noise sensitivity.

**Psychometric measure results.** In Family Four, measures were administered to Nisha and Ami only. Nisha completed the HADS and FAD, and Ami completed the HADS, the FAD, and the BCOS. As figure 4.13 shows, at pre-intervention Ami’s anxiety score fell in the ‘mild’ range, while Nisha’s score was in the ‘normal range’. At post-intervention Ami’s anxiety score reduced to fall in the ‘normal’ range alongside Nisha’s score. At follow-up both scores rose to the lower end of the ‘mild’ range.
As can be seen in Figure 4.14, depression scores for Ami were in the ‘normal’ range over all three time periods. Nisha’s score indicated ‘mild’ symptomology at pre-intervention, and this reduced into the normal range post-intervention. At follow-up her score had risen back to the ‘mild’ range.

The increase in Nisha’s depression and anxiety scores at follow-up may have been influenced by her return to work, and the subsequent increase in fatigue she felt. Indeed, in the follow-up session she reported enjoying her new job but finding it challenging at times, which led her to feel tired and at times to be irritable with her children. This may have also influenced Ami’s anxiety score, which also increased between post-intervention and follow-up.

In terms of general family functioning, Figure 4.15 shows that Nisha’s scores were under the 2.00 cut-off for ‘healthy’ family functioning at all three time periods. This indicates
that her perception of the general functioning of her family was considered ‘healthy’ compared to norms. Ami’s pre intervention score was slightly above the 2.0 cut off at pre-intervention, but fell at post-intervention and remained under the cut-off at follow-up. The changes in perception of family functioning for both Nisha and Ami mirror the same pattern across all time periods.

Figure 4.15. FAD General Functioning Scores for Family Four

Figure 4.16 shows caregiver burden scales for Ami. His scores indicated that he felt less caregiver burden between pre-intervention and post-intervention, although a slight increase in caregiver burden at follow-up. Again, this could have been related to Nisha’s recent return to work and resulting fatigue.

Figure 4.16. BCOS Scores for Family Four
Family Five

Goal attainment. Family Five’s therapy goals were: (1) to reduce Kathryn “losing it” at her children; (2) to achieve a more harmonious household, including parenting agreement; (3) to improve Kathryn and Chris’ ability to resolve conflict; and (4) for Chris to achieve a greater understanding of Kathryn’s TBI.

Goals were reviewed intermittently over the course of therapy. Because the family was unable to attend a follow-up session, unfortunately there was no information available on their goal attainment two-months post-therapy.

In terms of the first goal of reducing Kathryn’s “losing it”, at the start of therapy she estimated this was happening approximately once per week. By session seven Kathryn reported that it was no longer happening. She reported still finding the children more trying than she had before the injury, especially when she was tired, but reported feeling happier in general and attributed the reduction in “losing it” to her improved mood and enjoyment in life.

In terms of the second goal of achieving a more harmonious household, including parenting agreement, some progress was made over the course of therapy, although there remained some difficulties at the time therapy ended. There were noticeable fluctuations in reports of conflict across sessions. By session five there were improvements that indicated more harmony in the household, although there was a subsequent deterioration in session seven, followed by another improvement in later sessions.

In terms of the third goal of improving Kathryn and Chris’ ability to resolve conflict, over the course of therapy there had been instances where they had been able to do this more effectively, although it is something that they continued to work on at the time sessions ended.

Finally, Chris and Kathryn felt that coming to therapy had very much improved Chris’ understanding about Kathryn’s TBI. Chris stated that he felt his increased knowledge allowed him to be more understanding and empathetic towards Kathryn.

Psychometric measure results. In Family Five, measures were administered to Kathryn and Chris. Kathryn completed the HADS and FAD, and Chris completed the HADS, the FAD, and the BCOS. As can be seen from Figure 4.17, Kathryn’s anxiety score fell in the ‘severe’ range at time period one (pre-intervention). No data was available for time-period two (post-intervention). At time period three (follow-up), Kathryn’s anxiety score had fallen
to the ‘mild’ range. The same figure shows that Chris’ anxiety score was in the ‘mild’ range over all three time periods.

**Figure 4.17. HADS Anxiety Scores for Family Five**

Figure 4.18 shows that Kathryn’s depression score was in the ‘mild’ range at time period one (pre-intervention), and reduced to the ‘normal’ range at time period three (follow-up). No score for time period two (post-intervention) was available.

**Figure 4.18. HADS Depression Scores for Family Five**

In terms of family functioning, Figure 4.19 shows that there was considerable difference between Kathryn and Chris’ perceptions of family functioning as indicated by their scores in the General Functioning scale of the FAD. Kathryn’s scores indicated she had
a worse perception of family functioning than Chris did, across all three time periods. Chris’ score in the first time period (pre-intervention) was only slightly above the 2.0 cut-off for unhealthy family functioning. His scores in the second and third time periods indicate that his estimation of family functioning improved, and both scores fell in the ‘healthy’ range. In contrast, all three of Kathryn’s scores fell above the cut-off of 2.0, indicating unhealthy family functioning. There was a considerable improvement in her score between time period one and time period two, although at time period three her score increased slightly to indicate a negative shift in her perception of family functioning. Her score for time period three (follow-up) was however lower than her score for time period one, indicating that over the course of therapy and follow-up her perception of family functioning had improved.

![Figure 4.19. FAD General Functioning Scores for Family Five](image)

Figure 4.20 shows caregiver burden scales for Chris. His scores indicated that he felt less caregiver burden between pre-intervention and post-intervention, and a further reduction in caregiver burden between post-intervention and follow-up.
Client Satisfaction Questionnaire Results

The CSQ-8 (Attkisson & Greenfield, 2004; Appendix G) was sent to participants after the follow-up session. As well as the eight standard questions of the CSQ-8, five open-ended questions, tailored to the particular service were included. These questions were: (1) What was most helpful about the service? (2) What was least helpful about the service? (3) Was there anything about the service that you felt could have been better? (4) Do you think that your experience would have been different if you had been involved in the service at another point in time after the TBI (e.g., sooner, later) and if so, how? Lastly, (5) an opportunity to write any further comments.

Results from the CSQ-8 suggested that participants found participating in family-focused therapy worthwhile. As can be seen in Table 4.1, all respondents indicated that they would return to the service if they needed further help, and the majority felt certain about this. Similarly, all respondents indicated that they would recommend the service to a friend in need of similar help. Responses to other items indicated that participants were either ‘very’ or ‘mostly’ satisfied with the service they received and the amount of help they received. Half of the respondents indicated that the therapy helped ‘a great deal’ in dealing more effectively with their problems, and the remaining half indicated that it helped ‘somewhat’. While the majority of respondents indicated that most, or almost all of their needs had been met by the service, three of the twelve respondents indicated that ‘only a few’ of their needs had been met. One of these respondent noted on the questionnaire that this was because there were still ongoing problems with the survivor’s behaviour control. All respondents reported that they either ‘generally’ or ‘definitely’ got the kind of service they wanted. Finally, three quarters of
Table 4.1

Participant Responses to CSQ-8 Items

<table>
<thead>
<tr>
<th>Item</th>
<th>Response</th>
<th>% Responded</th>
</tr>
</thead>
<tbody>
<tr>
<td>How would you rate the quality of service you received?</td>
<td>Excellent.</td>
<td>75.00</td>
</tr>
<tr>
<td></td>
<td>Good.</td>
<td>25.00</td>
</tr>
<tr>
<td></td>
<td>Fair.</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Poor.</td>
<td>0</td>
</tr>
<tr>
<td>Did you get the kind of service you wanted?</td>
<td>No, definitely not.</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>No, not really.</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Yes, generally.</td>
<td>58.33</td>
</tr>
<tr>
<td></td>
<td>Yes, definitely.</td>
<td>41.67</td>
</tr>
<tr>
<td>To what extent has our service met your needs?</td>
<td>Almost all of my needs have been met.</td>
<td>16.67</td>
</tr>
<tr>
<td></td>
<td>Most of my needs have been met.</td>
<td>58.33</td>
</tr>
<tr>
<td></td>
<td>Only a few of my needs have been met.</td>
<td>25.00</td>
</tr>
<tr>
<td></td>
<td>None of my needs have been met.</td>
<td>0</td>
</tr>
<tr>
<td>If a friend were in need of similar help, would you recommend our service to him or her?</td>
<td>No, definitely not.</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>No, I don’t think so.</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Yes, I think so.</td>
<td>8.33</td>
</tr>
<tr>
<td></td>
<td>Yes, definitely</td>
<td>91.67</td>
</tr>
<tr>
<td>How satisfied were you with the amount of help you received?</td>
<td>Quite dissatisfied.</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Indifferent or mildly satisfied.</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Mostly satisfied.</td>
<td>50.00</td>
</tr>
<tr>
<td></td>
<td>Very satisfied.</td>
<td>50.00</td>
</tr>
<tr>
<td>Have the services you received helped you to deal more effectively with your problems?</td>
<td>Yes, they helped me a great deal.</td>
<td>50.00</td>
</tr>
<tr>
<td></td>
<td>Yes, they helped somewhat.</td>
<td>50.00</td>
</tr>
<tr>
<td></td>
<td>No, they really didn’t help.</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>No, they seemed to make things worse.</td>
<td>0</td>
</tr>
<tr>
<td>In an overall, general sense, how satisfied are you with the service you received?</td>
<td>Very satisfied.</td>
<td>58.33</td>
</tr>
<tr>
<td></td>
<td>Mostly satisfied.</td>
<td>41.67</td>
</tr>
<tr>
<td></td>
<td>Indifferent or mildly satisfied.</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Quite dissatisfied.</td>
<td>0</td>
</tr>
<tr>
<td>If you were to seek help again, would you come back to our service?</td>
<td>No, definitely not.</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>No, I don’t think so.</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Yes, I think so.</td>
<td>8.33</td>
</tr>
<tr>
<td></td>
<td>Yes, definitely</td>
<td>91.67</td>
</tr>
</tbody>
</table>

Respondents reported that they found the quality of service ‘excellent’, with the remainder indicating that they found it ‘good’.

In terms of understanding where survivors and family members felt things could have been improved, feedback gleaned from the open-ended written questions, as well as the feedback questions posed by the therapists in the follow-up sessions, were intended to enrich the data obtained from the CSQ-8. When asked in the follow-up session what, if anything, family members would have liked to be different, nobody responded with comments to this question. When asked in written form on the questionnaire attached to the CSQ-8, “what was
least helpful about the service?” most respondents remarked “nothing”. However, three people noted that the distance required for travel from their home or workplace was difficult. One survivor noted that therapy had not helped him to get a better sleep. When asked, “was there was anything that could have been better about the service?” almost all respondents said that in their opinion, there was not. One responded commented that she would have liked to hear more from the therapists about what other TBI Families experienced.

**Family Member Reflections on Therapy**

This section provides an overview of family member reflections about their experiences of participating in, and the outcomes of family-focused therapy. Qualitative data for this section were gathered from two sources: from spontaneous conversation in therapy sessions concerning their experiences of therapy and perceived outcomes; and from responses to questions posed by therapists in the follow-up session (the questions asked are provided in the method section). The comments discussed in this chapter are not necessarily related to the specific goal-attainment outcomes for individual families (which were described earlier in this chapter), but rather, general reflections and outcomes that were described by family members.

**Theme: Therapy Providing Space to Talk and Listen**

A number of individuals commented that coming to family-focused therapy allowed them the opportunity to talk as a family in a way that would not happen in the home environment.

*I think the benefit is that this is the only time we are actually together, even including the dinner table because that doesn't exist either.... It's been incredibly helpful just to have a space to air, and breathe, and cry and laugh or whatever, you know? It's fantastic.* (Spouse, Family Two).

*It's like anything, change is difficult to implement, you have to sustain it, you have to be on to it. And that's what is useful about coming here... it's that checking in with each other. “Where did we say we wanted to go? Are we on track?” You know, “what is it that we're not doing that means that we've gone off-track?”* (Survivor, Family Four).
For some families, open conversation was not happening in the home environment for fear of it escalating to conflict. Therapy provided a calm space with a third party (i.e., the therapists) to talk about issues in a constructive manner.

...if it was just us it would go wrong. But because you guys are here it's like, it can't go out of control, you know what I mean? No one can leave the room, no one can slam the door in someone's face, it has to be controlled, so it's a way of being able to get your point across and be listened to. (Daughter, Family Two).

I think the most helpful thing is that it gives you a chance to discuss things that you wouldn’t normally discuss at home. Like I normally wouldn't bring up things where there might be a possibility of conflict over it, and we don’t really discuss how we feel about anything we just sort of plod on through. So I've found that helpful. (Spouse, Family One).

To actually have discussions because I don't feel like we can without a third party present it just feels impossible to discuss things together. When you guys are here it happens and it's awesome and I feel like we leave and without someone else there to referee it just doesn't happen, it's not the same. (Survivor, Family Five).

Having the space to talk in this way allowed family members to understand other’s experiences and perspectives better.

I think an awareness of where other people are at had helped a lot. (Spouse, Family Two).

In one family, the survivor had appreciated the opportunity to have space to explore feelings of loss and grief. In the following comment, she reflected on the experience of having conversations in therapy about her sense of grief and loss:

If you don't acknowledge the loss, it doesn't mean it's not there. Just because you're not aware of it, or it's not coming to the fore, doesn't mean it's not there. So yeah that was a bit of "OK, there is this thing there that I didn't know was there!" Also, the level of talking, the level of conversation hadn't been given a space before. We've just been
very much 'get on with it' mode, 'coping strategies' mode,... but I suppose questioning the need for 'what happens when you don't acknowledge loss', I haven't really gone there. I have a logic that if you don't acknowledge the loss then you have other negative manifestations... I felt like I just scratched the surface of that area. (Survivor, Family Four).

While there were benefits of having space to talk about issues that may have not otherwise been discussed, it is not surprising that there were times when survivors or family members found the process challenging. The spouse in one family highlighted this, noting that although the process may have been challenging, she hoped that by opening up about their difficulties would be beneficial for the family members:

*I think it's probably been quite painful for the kids to actually sit down and actually have to address it, but the only way out is through, so I hope that that does help them get through it in a better way, rather than shelving it, hiding it, thinking it's normal.* (Spouse, Family Two).

While it was not something that was examined explicitly in this study, it was the impression of the therapists that communication improved at home in at least some of the families. This was particularly the case where specific interventions aimed at improving or increasing communication were included in the therapy. However, in at least one case it appeared that communication outside of therapy did not increase and the family still relied heavily on a third party to facilitate conversation. In this case, having a space created to talk in therapy was particularly important for the family, and suggested the need for longer-term involvement of external support.

**Theme: Survivor Gaining Increased Insight into the Effects of Their TBI**

In three cases, families noted that therapy had helped the survivor to gain increased insight into the effects of their TBI. In one family, at the start of therapy the survivor appeared to have little insight into the effects of his angry outbursts on those around him. While he was aware that he was more irritable and expressed anger more readily than before sustaining his TBI, he seemed less aware that it was very upsetting to his spouse and that it was affecting her own mood, behaviour and satisfaction in the relationship. Therapy created
an opportunity to discuss these difficulties in a way in which the couple reported they would not have at home. The spouse from this family commented:

... [it was helpful to make the survivor] realise that the outbursts aren't acceptable, and things like that, and having some help in dealing with the outbursts, possible remedies. (Spouse, Family One).

In another family, the survivor felt for the first time that he understood the magnitude of his short temper on his family. In therapy he highlighted the way in which he had been taking steps to reduce his outbursts after realising the effects of his behaviour on his family:

I've been lying down more in the afternoon because I've seen since meeting you two nice people the bloody damage that my [TBI] has done to our family.... what damage having a bloody accident can do to your family, you know, so that has caused me to try to be better. (Survivor, Family Two).

Of course, having insight into the effects of one’s TBI is not necessarily sufficient for behavioural change to occur without further rehabilitative efforts. However, where survivors were able to gain a better understanding of their limitations and problematic behaviours, as well as the ways in which these impact on family members, a stronger foundation of motivation to engage in further rehabilitative efforts appeared to develop.

In another family, where the TBI had been mild, coming to therapy and talking about the impacts of the injury had allowed the survivor and her spouse an opportunity to discuss and process some of the limitations she experienced. It was through this process that they both gained a better understanding of the effects of her injury. Her spouse remarked:

It's good that Nisha is getting insight into limitations, or what she can do, or awareness of where thoughts are coming from, or feelings. It's good to see that she gets insight into that, and I get awareness as well at the same time, it's been great. (Spouse, Family Four).

Theme: Increased Understanding From Others (Within and Beyond the Family)

Coming to therapy appeared to help others (both within and beyond the family) to better understand TBI and its impacts. It was common in families where the survivor had
sustained a mild TBI for spouses to have had received little or no information about mild TBI and/or post-concussion syndrome. In some instances, this meant that the family members had difficulty making sense of the changes in the survivor, given the apparent minor nature of their injury. In other instances, survivors felt that individuals beyond their family underestimated the impact of TBI and didn’t understand the ongoing nature of their difficulties.

Following a session that had been dedicated to psychoeducation and explanation of neuropsychological reports, one mild TBI survivor explained the way in which she felt having her condition explained to her spouse assisted in his understanding:

*I felt for Chris to see it in black and white, I felt like that helped a bit for him to understand... and a bit more about what I need... for me it felt like there was a bit of movement around that, and kind of for him understanding what it meant for me, to have someone clearly explain it. And I guess for me it was that clarity and what I'd been wanting him to understand, so it was really good. (Survivor, Family Five).*

In the same conversation, the spouse noted how he had found psychoeducation helpful, and suggested that his increased understanding of his partner’s TBI may have contributed to a recent positive change that the couple had observed in their relationship:

*It was a good explanation and I did understand it a lot more, and maybe that's what's contributing to this change. (Spouse, Family Five).*

Another mild TBI survivor spoke about how he felt his spouse had been more understanding of his injury and its impacts. This increased understanding was evident to him in a homework exercise that had been assigned to facilitate more effective communication between the couple. The intervention involved each spouse taking turns to speak to one another for three minutes each, rather than talking over each other in arguments. He spoke about how this had improved his relationship:

*I think that's helping quite a bit. Especially as she understands, it's good to know if she understands what I'm going through instead of thinking that this is how I am, but actually going, “why is he like this?” So if she just understands and gives me the benefit of the doubt to talk things over instead of just, “you can't talk”. Now one*
person has to talk then the other.... that's very good progress made. (Survivor, Family Three).

In another family, the survivor of a mild TBI felt that over time, people external to the family had forgotten about her TBI and lacked awareness that the difficulties she was experiencing were ongoing. In the course of therapy she commented that coming to family-focused therapy highlighted to others that she was still experiencing difficulties:

Sometimes when you interact with a professional because you've got something that they can offer you it elevates the reason that you're coming to see them. So if I'm able to say to someone “oh we're going to family therapy for head injury”, um, it enables them to say “oh are you still suffering?”. You know, and I'm like, “well it's something I have to live with, you know”. It keeps it, it makes it easier for me, it gives me permission to make some adjustments in my life as a result. (Survivor, Family Four).

**Theme: Gaining Increased Acceptance**

Some survivors and non-injured family members talked about how attending family-focused therapy had assisted them in gaining more acceptance of the limitations imposed on the survivor as a result of the injury, and the impacts on the family. This was particularly the case in families where the injury was moderate or severe, and the prospect of returning to pre-morbid functioning was unlikely. For example, in the course of therapy one survivor commented on this, and how it may have been helpful to have therapy sooner in his recovery process:

... it took me a long to come to terms with the fact that I'll never be the same. Now if I've come to terms with it I can at least try to improve what I've got. That's the thing. We should have been doing this [therapy] five years ago. (Survivor, Family Two).

In a follow-up session when asked about what had been gained from coming to therapy one child of a survivor spoke about how it helped her realise that she was not responsible for the happiness of her father and that it was helpful to let go of striving for that:

I think it's a permanent injury so it's not going to change but like, learning slowly adaptations to it.... and also just sort of coming to terms with it as well, like that day
you said to me I can’t actually change Dad like as much as I try. And um, all that effort sometimes I felt like I had to for some reason, personally. But being able to let go a bit has helped me I think. (Daughter, Family Two).

Theme: Having Professional Input

While all TBI survivors had received some professional input (e.g., psychology, occupational therapy) around the time of their injuries, for all but one survivor this had ceased and they were receiving no other ongoing professional input at the time of referral. Also, with the exception of one family, non-injured family members had not received any professional support to educate them or help support them following the injury. Some survivors and family members remarked how it had been helpful to have professional input as a family.

In a follow-up session one mild TBI survivor remarked how it was helpful to have the opportunity to discuss their family difficulties with someone outside of the family, and with a different perspective:

*It's good to talk to someone other than family, like I don’t talk to anyone apart from Preeti. It's good to see another person's perspective of what's happening. Because you always see things from a different perspective.* (Survivor, Family Three).

In a follow-up session when asked whether anything had been helpful, the spouse of one mild TBI survivor explained:

*The techniques when we do use them do help, and just talking about it, and having someone else understand what you go through also helps because we're so focused on ourselves and our own lives we don't know whether what we are doing is right or not or how we're doing it, and it helps when someone else looks in at us. So yeah it helps in that way.* (Spouse, Family Three).

One mild-TBI survivor commented that she found it helpful to receive feedback about other typical presentations following brain injury:

*You see a greater range of families, and it's useful for me to get that reflection from you. You can say, “oh that's common”.* (Survivor, Family Four).
When one survivor was asked what she found helpful in coming to terms with the loss that she had experienced from her injury she explained how she felt talking to psychologists helped her to feel understood:

*Coming here is quite useful... I go off and have my chats with the psychologist, and I'll feel ahh, somebody understands! I feel better. (Survivor, Family Four).*

**Summary of Chapter**

This chapter presented quantitative and qualitative data that described various outcomes of the family-focused therapy provided in this study. The chapter started with presenting information on each family’s goal attainment and psychometric measure results. Results from the CSQ-8 were presented, which provided information about family member satisfaction the service. Lastly, themes of family member reflections on therapy were described, with relevant quotes used to illustrate the way family members described their experiences of coming to family-focused therapy.
CHAPTER FIVE

DISCUSSION

This exploratory study was intended to examine the feasibility and usefulness of a family-focused therapy service for families where an adult had sustained a TBI. Five families were provided with family-focused therapy which drew upon a range of therapeutic approaches including psychoeducation, narrative techniques, behavioural interventions, and family therapy approaches.

There were four aims of this study. The first aim was to describe the issues that families in this study encountered. Writers have for some time been describing typical effects for families post-TBI, which included increased psychopathology, burden, and problematic family functioning (Hibbard et al., 1998; Kreutzer et al., 1994a). This study adds to the literature, and includes qualitative analysis of the issues families discussed over a series of therapy sessions. Such descriptions add richness to our understanding of the experiences of survivors and their families that go beyond that which psychometric measures alone are able to reveal. The second aim was to describe how these issues can be addressed in therapy. The third aim was to investigate the outcomes of family-focused therapy for families. Again, by including qualitative analysis of what families reported as the outcomes of therapy, we may gain a fuller understanding of the potential benefits for families than made possible by reliance on psychometric measures alone. Including qualitative data in therapy outcome studies has been advocated by other authors as providing important information to complement quantitative data (Kreutzer et al., 2010). The fourth and final aim was to describe challenges experienced by the therapists in family-focused therapy after TBI. This provides information for clinicians who may in future work with TBI Families, as well as identifying potentially important considerations for the running of a family-focused therapy service for this population.

Issues that Families Encountered After TBI

All families that participated in this study had experienced difficulties as a result of the TBI. These issues will be discussed below. However, first a brief discussion of how family members presented at pre-intervention will be provided, in relation to some key areas of difficulty that have been identified in the literature.
Problems with Anxiety, Depression, Family Functioning and Caregiver Burden

Consistent with the literature summarized in the first chapter, problems with anxiety, depression, unhealthy family functioning, and high levels of caregiver burden were present at pre-intervention. All caregivers and three survivors had clinically significant levels of anxiety, while three caregivers and four survivors had clinically significant levels of depression. These results are consistent with the literature that indicates high prevalence rates of anxiety and depression in TBI survivors (Hibbard et al., 1998; Morton & Wehman, 1995) and caregivers (Kreutzer et al., 1994b; Livingston et al., 1985; Marsh et al., 1998). All participants except one survivor had family functioning scores on the FAD that indicated a perception of problematic family functioning. A high level of unhealthy functioning has previously observed in TBI Families (Kreutzer et al., 1994a). These families had self-selected for family therapy, and therefore it could be expected that they would be family systems under strain. Interestingly, in some families, the family members had scores that indicated similar perceptions of general family functioning to other family members, while in other families there was considerable variation in scores between family members. This highlights the fact that individuals within families can each have quite different perceptions of family functioning. This was illustrated particularly in Family Two, where the spouse had consistently higher scores across all time periods in this study (indicating perceived unhealthier family functioning) when compared to other family members. In contrast, the youngest child in this family consistently had the lowest scores. Scores of caregiver burden in spouses across all families were elevated, which is consistent with findings from other studies (Carnevale et al., 2002; Livingston & Brooks, 1988).

While these problems of anxiety, depression, unhealthy family functioning and caregiver burden were common in families, it was the families’ therapy goals and the issues that they raised in therapy that were the specific targets of intervention in this study. It was hoped that by addressing these idiosyncratic family difficulties, scores on measures of psychopathology, family functioning and caregiver burden would improve as an outcome of therapy.

Themes of Issues Families Presented With

Previous literature has reported on common outcomes for families post-TBI. The present study adds to our understanding of the types of challenges families experience, by including experiences that families talked about during hours of conversations with the
therapists. This brings a richness to our understanding that is missed when considering psychometric results only.

A similarity amongst many families was that the nature and extent of difficulties experienced were unexpected by survivors and family members. A lack of understanding about TBI, and inaccurate beliefs in the general public about recovery has been reported in research (Swift & Wilson, 2001). Therefore, it might be expected that families would not have pre-morbid knowledge about TBI and its effects. However, the finding that families felt that their difficulties were unexpected raises the question of whether they received adequate information about brain injury and its typical sequelae from health professionals, after the injury had occurred. Just one family in this study recalled receiving such education. The survivor in the family who did recall receiving information (Family One) had the most severe injury and had spent time in a residential rehabilitation unit. This suggests that those families and survivors whose injuries do not call for such a high level of initial care may not be receiving appropriate information from professionals in community settings. However, it may also be the case that families did receive adequate information, but did not recall this. The need for families to receive information (particularly about behavioural and emotional changes that may occur) in order to better cope with these difficulties, has been advocated by writers in the field (Junque, Bruna, & Mataro, 1997). A challenge for professionals is to assess what information is appropriate for survivors and families to receive, and when to deliver it. The idiosyncratic nature of brain injury and associated outcomes means that professionals must strike a balance between providing enough information so that families feel well-informed, while not unnecessarily alarming families about possible adverse outcomes that may never eventuate.

Another theme that arose in therapy conversations was that some survivors felt that family members and people outside the family lacked understanding about the difficulties they experienced. This lack of understanding has been reported by TBI survivors elsewhere, particularly in relation to recovery timeframes, the types of problems that they encounter, and their capabilities (Swift & Wilson, 2001). It is likely that timely provision of information to families and other important people in survivors’ lives would reduce this problem, and increase understanding and empathy in non-injured individuals.

A very common difficulty experienced by families was increased levels of irritability, anger and outbursts in the survivor. That addressing these problems was a priority for families is not surprising. These emotional and behavioural consequences of TBI have been reported widely in TBI literature, and have been described as major contributing factors to
family stress and marital problems (Bowen et al., 2010; Kreutzer et al., 1992; Larøi, 2003; Wood, 2005), as well anxiety, depression (Perlesz, Kinsella, & Crowe, 2000) and burden (Brooks et al., 1987) in the partner of the survivor. All families in the present study denied violence. However, research shows that physical aggression does occur in families post-TBI (Butera-Prinzi & Perlesz, 2004; Charles et al., 2007) and thus therapists working in this area should be aware of this possibility. Increased irritability, anger and outbursts was an enormous overall source of tension in the families and a large amount of time in therapy was dedicated to interventions designed to manage anger and reduce the impact on family members.

Another theme identified in this study, that of challenges within the marital relationship, has also been reported by other authors (Perlesz et al., 1992; Wood & Yurdakul, 1997). In the present study, therapy discussions about marital relationships often related to coping with the effects on spouses of increased irritability in the survivor. This has been identified as a target for marital therapy post-TBI (Tyerman & King, 2008), and as a major factor in relationship breakdowns following TBI (Wood, Liossi, & Wood, 2005). In some instances, couples needed assistance with improving communication and developing productive conflict resolution strategies. These areas have also been identified as a common focus of intervention in couples after TBI (Tyerman & Booth, 2001).

In some families overt conflict was contained to the marital relationship, although for one family in particular there was a high level of discord between all family members. That all family members were included in therapy was particularly significant for this family, and having adolescent family members in attendance provided important insights into family dynamics and the experiences of family members. Such insights are highly likely to be missed in studies that include the survivor and caregiver only. Other studies have reported high levels of dysfunction as indicated by psychometric measures in TBI Families (Kreutzer et al., 1994a), although the present study added to this by providing rich, qualitative insights into family member experiences.

Reported changes associated with parenting, and impacts on the parent-child relationships were common. Difficulty adapting to parental role changes that occurred following the injury contributed to these parenting-related challenges for some families. Similar experiences have been described by other researchers (Pessar et al., 1993). Previous studies have also reported deterioration of relationships between brain injury survivors and their children (Butera-Prinzi & Perlesz, 2004; Charles et al., 2007; Pessar et al., 1993).
Therapy literature also indicates that this is an area that TBI Families often wish to address in therapy (Tyerman & Booth, 2001).

In one family lack of motivation in the survivor was a source of distress for the spouse. This is a commonly reported effect of TBI and has also been found to be challenging for family members in a number of studies (Butera-Prinzi & Perlesz, 2004; Ciurli et al., 2011).

Coping with grief and loss permeated the stories of the families in this study, although it was raised explicitly in only two cases. Coming to terms with losses and processing through grief have been identified as tasks that families must negotiate following TBI (Lezak, 1988; Perlesz et al., 1992) and professional input can aid families with this process (Rosenthal & Young, 1988)

Another theme that was common in therapy dialogue was that of negative experiences with professionals following the TBI. These negative experiences were generally in relation to ACC staff, and in two instances, medical staff. Complaints about ACC staff were most common from mild TBI survivors and their families, and related to feeling pressured to resume employment sooner than they felt able. In respect of return-to-work processes after mild TBI, there is an inevitable tension between ensuring that survivors do not become overly fatigued (thus hindering their recovery and potentially causing additional problems such as increased irritably with family members) and having mild TBI survivors return to regular activities in order to reduce the chance of secondary psychosocial problems such as depression, and to reduce the economic cost of their injury. In a 2004 Best-Practice Guideline report, ACC highlight its aim of reducing the economic impact of unemployment after TBI, as well as restoring quality of life for TBI survivors, by making return to employment a primary goal in the rehabilitation process provided by ACC in New Zealand (Larking, 2004). Advocacy on behalf of TBI survivors and their families is important in order to ensure that this focus on return to work is not enforced to the detriment of survivor wellbeing.

**How Problems Can Be Addressed in Therapy**

The second aim of this study was to describe how the problems families were experiencing could be addressed in therapy. A flexible approach to therapy was taken, which drew upon a variety of models that had been advocated by other writers previously. These included behavioural interventions, narrative therapy, systemic family therapy, and psychoeducation (Bowen et al., 2010; Larøi, 2003; Maitz & Sachs, 1995; Rosenthal & Young, 1988). This flexible, eclectic approach appeared to be suitable for the idiosyncratic
presentations of TBI Families, and provides support for the view of others, that such an approach is appropriate for working with TBI Families (Larøi, 2003; Perlesz et al., 1992).

Outcomes of Therapy

The third aim of this study was to investigate the outcomes of family-focused therapy for the families involved in this study. In terms of goal attainment over the course of therapy, there was improvement in relation to most of the goals that families set. However, in some cases goals were not obtained. An explanation for why this might be the case is that some goals set by families were possibly unrealistic, given the extent and duration of therapy. Another possible reason is that some goals were related to changing problem behaviours in the survivor that were likely caused by organic damage, thus less amenable to change than problem behaviours that do not have an underlying organic cause. For instance, in some cases irritability may be mediated by psychosocial factors and thus possible to target in therapy, whereas in other cases irritability may be more closely related to lesion characteristics and therefore less in the survivor’s control (Kim et al., 1999). It was necessary for therapists to regularly provide psychoeducation to families about the effects of TBI in order to allow family members to have realistic expectations about what degree of behaviour changes might be reasonable to expect from the survivor. It would be prudent for therapists working with TBI Families to be clear from the outset about the kind of goals for which family therapy might be appropriate.

Therapy outcomes were also assessed in relation to psychometric measure scores in areas typically reported to be problematic in TBI Families. A pattern in psychometric measure results can be observed across the majority of measure scores. Generally, scores improved between pre-intervention and post-intervention. While some improvements were maintained over time, typically scores showed a trend towards baseline in the follow-up time period. Gains made in therapy not being maintained upon discharge have been reported by other authors also (Perlesz & O'Loughlan, 1998; Tyerman & Booth, 2001). It may be that failure to maintain improvements was due to therapeutic intervention being too brief. The number of sessions attended by families in the present study ranged between five and nine sessions. In a previous study, which reported outcomes for 15 families who received an average of 8.4 family-therapy sessions, the authors reported a similar failure to maintain treatment effects over time in some areas, and concluded that a greater number of sessions may have led to more sustained improvements (Perlesz & O'Loughlan, 1998).
In the present study, another possible explanation for improvements not being maintained between therapy ending and follow-up could be the loss of opportunities for families to talk about their difficulties. Indeed, one of the positive outcomes of therapy that families in the present study described was having the space to talk about problems and discuss issues together, with the presence of a third party to facilitate these conversations. It is possible that having this space to talk played an important role in the improvement of psychometric scores over the course of therapy, and that when therapy ended the loss of this opportunity was reflected in lower psychometric scores.

Another source of information used to assess the outcomes of therapy was feedback from the client satisfaction questionnaires. Analysis of family member responses in the CSQ-8 indicated that families mostly found therapy helpful and all would recommend the service to other families. It appeared from the responses that there might have been some aspects of the service that could be improved. For instance when asked whether family members got the kind of service they wanted, just under half responded ‘yes, definitely’, while just over half responded ‘yes, generally’. Unfortunately, despite more than half of the respondents indicating that the service did not completely fulfill their needs, only one respondent provided qualitative feedback on what she would have liked to be different, noting that she would have liked to hear more about other survivors’ experiences. Therefore, it is difficult to know how the service could be improved for those individuals who responded that the service only ‘generally’ met their expectations. Of note, 91.67% of respondents reported that they would come back to the service if they needed help again, and the same percentage of respondents indicated that they would recommend the service to a friend if they were in need of similar help.

In order to explore in more detail the family’s experiences of participating in therapy, thematic analysis of therapy transcripts was conducted to identify what families considered were the outcomes of coming to therapy. The most commonly described outcome was that therapy created a space to talk and listen to one another in a way that would not typically happen in the home environment. The tendency for families to discuss issues only when in the security of therapy sessions has been described by other authors (Tyerman & Booth, 2001). Given that open communication is a factor in healthy family functioning (Ryan et al., 2005), as previously noted, having the opportunity to talk together in therapy may have been a factor in improving scores in family functioning between pre- and post-intervention. Also, as highlighted above, it is possible that having more opportunities for open communication improved scores on the HADS and BCOS.
Some families also referred to the way that talking about their experiences gave the survivor increased insight into the effects of their TBI. It has been recognised that TBI survivors may not always appreciate the impact of their condition on their family members (Bowen et al., 2010), and increasing their awareness of this can be helpful in motivating them to engage in therapeutic process in order to affect change (Alderman, 2004). However, Alderman points out that “there are obvious dangers in removing psychological barriers that have evolved in order to protect people from unpleasant, anxiety-provoking truths” (p. 284) and with increased awareness there may also come an increased risk of depression in the survivor. Thus, it seems important that if the survivor is to gain insight into the impact of his or her condition on family members, this should occur during a therapeutic process offering increased support, and hope for reducing this potential for depression.

Some survivors talked about the way in which coming to family-focused therapy helped facilitate greater understanding from others, both within and outside the family. Gaining increased understanding has also been described as an outcome in other family intervention research (Butera-Prinzi et al., 2010). The present study has identified that family members becoming more informed about TBI and its effects played an important role in this increased understanding, and this finding supports other author’s views that psychoeducation is a key intervention for families post-TBI (Cavallo & Kay, 2011; McAllister, 2011).

Another outcome that family members and survivors described was gaining increased acceptance of the survivor’s limitations as a result of the injury. The role of acceptance has been identified as a task that survivors and family members must negotiate (Perlesz et al., 1992). Bowen et al., (2010) allude to the importance of this process of acceptance, when they write that “as with many sudden changes to one’s life plan, the process of adjustment to brain injury involves discovering a way of changing the difficult relationship with the brain injury, in some ways, ‘forgiving’ the brain injury and accepting the interruption, identifying continuous threads of one’s identity from before and after the injury in order to integrate it into one’s life story” (p. 25). Thus it is possible that the experience of family-focused therapy, during which survivors and family members have an opportunity to work through these processes, may have facilitated this process of acceptance for some families. Interestingly, the two families where increased acceptance seemed to be a particularly important outcome were those where the injuries had occurred the greatest time prior (6 years 3 months, and 3 years 8 months).

Families also discussed the value they gained from having profession input. Having a service that prioritized exploring their collective experiences was validating for families. The
therapists in the present study would argue that this is particularly important in rehabilitation landscapes that tend primarily to acknowledge the difficulties experienced by the survivor but which create little opportunity for ‘brain-injured families’ to have therapeutic input.

**Challenges**

The final aim of this study was to consider the challenges associated with providing family-focused therapy service. The first part of addressing this question is to discuss the challenges the therapists experienced, from a clinical perspective. The second part of answering this question was to report what difficulties were associated with the establishment and running of the service.

As typical in most therapy, there were challenges related to the therapy process. The most common challenge faced was families not putting into practice the strategies or suggestions that were made. Interventions that were suggested to reduce outbursts, manage emotions, increase activity, improve relationships and assist with parenting were often not tried, or tried once but not practiced consistently. Thus, it was difficult for the therapists and families to know whether these interventions could have been helpful and whether they would have affected therapy outcomes. Fatigue was an issue that may have affected individual’s ability to try new strategies. For instance, often the only time available for parents to practice new tasks (e.g., giving each other praise) was in the evening. Many survivors felt too fatigued at this time of day and therefore lacked the personal resources to put new suggestions into place.

On many occasions, scheduled sessions were cancelled by families. Sessions were typically cancelled due to illness, difficulty getting childcare, or transport problems. As a result of cancellations, occasionally there were several weeks between sessions, which slowed the momentum of therapy and as a result, may have affected therapy outcomes.

A further challenge was that some of the relationship difficulties appeared to have been present prior to the TBI, and may have been longstanding. In some cases it may have been beneficial for couples to have access to marital therapy on an ongoing basis, beyond the duration of the present study.

There were a number of challenges encountered when establishing and maintaining the family therapy service. First, despite consistent feedback from TBI rehabilitation professionals that family focused therapy would benefit a high proportion of families, we struggled with low numbers of referrals. The service was advertised through many avenues, and professionals with direct contact with TBI survivors and their families were provided
with information on the study and encouraged to refer. However, as described previously, this effort resulted in only five referrals being made. There are a number of possible reasons for this. First, the nature of family therapy requires that a number of individuals attend sessions at the same time. For some families, it may have been considered too difficult to find a regular time for all family members to attend together. This problem was raised in feedback by one family, who commented that it was challenging for them to travel to the location for therapy, given they lived some distance away. The primary researcher is aware of at least two families who declined referral because the distance of travel would be too great.

It is possible that if a family-focused therapy service was attached to an already existing rehabilitation service, this would overcome some of the barriers mentioned above. Potential barriers for families attending family sessions together have been discussed by other authors. In their study discussing a family-to-family link up programme, Butera-Prinzi et al. (2010) state: “Despite the positive clinical outcomes, the high level of commitment required from families (typically involving 6-12 sessions over a 6-18 month period) may make Multi-Family Groups inaccessible, particularly for families who are overburdened or experiencing time or geographical constraints” (pg. 32). In recognition of the geographical constraints that can prevent families being able to access intervention, some research groups have explored alternative delivery methods such as internet or telephone-based treatments (Brown et al., 1999; Rotondi et al., 2005).

The question of readiness for this type of intervention must also be considered. It is possible that families may not be ready to engage in therapy too soon after the injury, as they may not yet realise or accept that they would benefit from help. As Lezak (1988) proposes in her six-stage model of adaption after TBI, families generally achieve a certain level of awareness about the chronicity of difficulties before they may be ready to seek out psychological help. Additionally, other writers have reported that often family members may “wait to see how [rehabilitation professionals] meet the needs of the person with the TBI before they are willing to acknowledge their own needs” (Tyerman & Booth, 2010; p. 64). In contrast, some families with very entrenched problems may feel hopeless and that it is too late to engage in therapy. Indeed, previous authors have highlighted that families with long histories of living with problematic behaviours might be reticent to engage in family therapy (Perlesz & O'Loughlan, 1998).

A final reason for the low number of referrals could possibly be because the therapy was to be provided in the context of research. This may have discouraged the participation of some families.
Another challenge experienced at a service-delivery level related to when sessions were held. Initially, it was planned to open the clinic for one working day of the week and have families attend throughout the day. In reality, families were reluctant to attend during working hours and therefore all sessions took place on week evenings or weekends. The therapy team aimed to be flexible for families, although whether this flexibility is feasible for a larger-scale service would need to be considered.

**Implications of the Study**

The present study has echoed results from research by others that shows that families often experience significant difficulties following TBI. This is true for families with injuries of all severities, as in the present study difficulties were reported in families with mild as well as moderate and severe injuries. It is also clear that families stand to gain from family-based interventions, and may do so in ways that were related to both specific pre-therapy goals, as well as in other, less pre-identified ways.

The question of timing in regards to therapeutic intervention for TBI Families is an important one. While the therapeutic needs of families may change as time since the injury passes, it seems important that family-focused support is available to families early in the adjustment process. This is evident from comments made by the survivor in Family Two in the present study, who stated: “It's a shame that this didn't happen years ago. This situation now is a bit like the ambulance at the bottom of the cliff.” Similar sentiments have been expressed by a survivor from another family intervention study, who remarked “had we had this help early on, our situation could have been different, my family would have been together” (Butera-Prinzi et al., 2010; p. 41).

Additionally, it appears that families may benefit from long-term support. This makes sense, as the often-chronic nature of TBI sequelae means that many of the challenges that families face are likely to remain over time. Indeed, some writers have suggested that follow-up appointments should be available to families and couples for years following the injury (Perlesz & O'Loughlan, 1998; Tyerman & Booth, 2001).

Of course, this raises a question about whether such ongoing support is feasible, especially within New Zealand’s current rehabilitation and funding contexts. To comment on the feasibility and likelihood of ongoing family-focused therapy funded by ACC is beyond the scope of this thesis. However, it is hoped that the present study has provided an insight into how some families in New Zealand struggle in the wake of TBI, and the ways in which providing support for these ‘brain injured families’ can have beneficial effects.
Limitations

The present study was exploratory in nature, with a small number of participating families. Therefore, the findings can not be generalized across TBI Families. Families who were referred for the study had either self-selected for therapy, or had already been identified by professionals as having difficulties as a result of the TBI. Therefore, the extent and nature of difficulties that families presented with should not be considered representative of all families where someone has sustained a TBI. Also, due to the small number of families participating, it was not possible to differentiate between the nature and extent of issues faced by families where the injury had been mild, versus moderate or severe.

The small number of participants made meaningful statistical analysis of standardized measure results impossible, and the follow-up period of two-months was relatively short. The reason for the short-follow-up time period in the present study was due to time constraints relating to the completion of this thesis. A different result may have been achieved had the follow-up period been longer. For example, it is possible that families may have still been impacted negatively in the two-month period by the discontinuation of therapy, and with further time they may have made positive adjustments leading to improved functioning, based partly on what they had learned from earlier therapy. Alternatively, psychometric scores may have declined further regardless of length of follow-up. In future research it seems desirable to have a longer follow-up period in order to investigate potential long-term impacts and/or reversals.

It was not possible to screen extensively for pre-morbid family or marital difficulties, and therefore some of the difficulties discussed in therapy may have been present despite the TBI and may have affected the outcomes of this study. It was not always possible to distinguish what factors led to improvements reported by the families. For instance, some improvements may have been due to spontaneous recovery of the brain, and therefore reduction in neurobehavioural sequelae. It was also not possible to control for support that families may have been receiving from sources outside the therapy team, which may have also influenced results.

There are a number of limitations associated with the fact that the therapy team was also the research team. For example, the second therapist administered the standardized measures, and was the return addressee for the feedback forms. Although participants were encouraged to respond accurately, it is possible that their responses may have been biased in order to provide a favourable impression of the service. Similarly, in the follow-up session, requests for feedback were made in person by the therapists and participants may have been
inclined to provide more favourable feedback, or withhold negative feedback. However, these challenges are typical of exploratory research and could not be avoided in the present study.

Future research

Results from this study suggest more research is warranted into the value and delivery of family-focused therapy following TBI. Future studies would benefit from a larger number of participants so that statistical analyses of psychometric results is possible, and longer follow-up timeframes than the present study. Given that families in the present study experienced benefits of family-focused therapy that were beyond the constructs measured by psychometric questionnaires, continuing the use of qualitative analysis in any such future studies would be beneficial. In regard to the difficulty with recruitment in the present study, future research should investigate potential ways in which such a service could be more accessible to families. This could include whether delivery of service in alternative settings (e.g., at home, or community centres in various locations), or even employing the use of technologies such as Skype. Larger-scale studies would also benefit from the use of therapists who are independent from the research team so as to reduce the potential for bias in family member feedback.

Conclusion

Although limited in its scope and aims, the present study has identified several important findings and thus offers a modest contribution to knowledge in this important area of practice. This study’s results have supported the findings reported in existing literature regarding adversities faced by TBI Families, and with the addition of qualitative accounts, it has added richness to our understanding of these experiences. It is one of few studies to describe family-focused therapy with TBI Families, and to report on outcomes. Again, by including qualitative data in the reporting of outcomes, it has revealed a number of benefits experienced by families that would not have been evident in psychometric scores alone. The fact that improvements on psychometric measure scores were not maintained at follow-up suggests that families may require more ongoing support compared with that provided in the present study. A number of possible areas for future research have also been suggested.

This thesis began by emphasizing that TBI can happen suddenly and without warning and may result in profound consequences for the survivor and family members alike. In light of the multiple and complex individual and family stressors, anything that can be done to
help such families living with the distress of TBI and its sequelae should surely be considered. This study has indicated that family-focused therapy is one such potentially beneficial intervention and it is hoped that this study will encourage the more widespread practice of family-focused therapy for survivors and their families.
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APPENDICES
Appendix A
Participant information Sheet
Hello, my name is Kessiah Hunt and I am completing a degree (Doctor of Clinical Psychology) in the Psychology Department at the University of Auckland. As part of my training to become a Clinical Psychologist I am conducting a research project that will provide family-focused therapy for families where a member has had a traumatic brain injury (TBI), and evaluate the effectiveness of the intervention.

As a family who has experienced a family member sustain a TBI, you are invited to participate. Similar research in other countries indicates that family-focused therapy can be helpful in helping to reduce the impact of difficulties that families commonly face after a TBI. This research is the first of its kind in New Zealand. We hope that the information gathered will be used to guide rehabilitation specialists in planning the most appropriate types of rehabilitation interventions for TBI survivors and their families in New Zealand.

**Why have we been chosen?**
You have been identified as a family who may benefit from family-focused therapy following the injury of a family member.

**Do we have to take part?**
As a family, your participation is entirely voluntary. If you choose not to take part, it will not affect the service you receive from any other healthcare providers. If you decide to participate, you have the right to (1) withdraw from the study at any time, without giving a reason; (2) withdraw your data from being used in the report up to three-months after therapy has ended.

**If we chose to take part, what is involved?**
Families who take part in this research will be asked to attend a course of family-focused therapy and to each complete a questionnaire and three points in time.

An initial meeting will be arranged between your family and one of the researchers. This can be at your home, or if you prefer, at the university. This meeting is to answer any questions you have about the study and for your family members to fill out a questionnaire, which will provide us with information about how things are for you before therapy starts. Different family members will be asked to complete slightly different questionnaires depending on their position (e.g. child, injured person, caregiver). The primary caregiver (i.e. the person who spends the most amount of time helping the injured person) will have the most questions to answer, and it will take around 30 minutes to complete. All together, this meeting will take approximately one hour.
Within a couple of weeks after the initial meeting, therapy will begin. Families who participate in the study will be provided a course of family-focused therapy, free of charge. Typically, this will be around six, hour long sessions, but depending on the needs of your family there might be slightly fewer sessions, or slightly more. The decision on when to end the therapy is made jointly between you and the therapists. Therapy sessions will be video recorded. This is so the researchers have an accurate record of what was covered in therapy, as it may be important to check details at a later date. Recordings are highly confidential and will not be shown to anyone outside of the therapy team. Even if you agree to be video recorded, you may choose to have the recorder turned off at any time.

A week after therapy has finished we will ask you to complete the questionnaires again. This provides us with information about how things have changed for you over the course of therapy. Again, different family members will be asked to complete slightly different questionnaires, depending on their position. The primary caregiver will have the most questions to answer, and it will take around 30 minutes to complete. Three months after therapy has finished we will go through the same process of completing questionnaires. This gives us information about how the process has impacted you beyond the course of treatment.

Where would therapy take place?
Therapy will take place at the University of Auckland Psychology Clinic, in Glen Innes. Financial assistance for transport costs is available if required.

Who is the therapist?
Therapy will be run through the University of Auckland Psychology Clinic and your therapist will be Professor Fred Seymour. Fred is a Clinical Psychologist and has over 30 years of experience working with families who are experiencing difficulties for a variety of reasons, including following TBI. Kessiah Hunt, a Doctor of Clinical Psychology student, will also be present in the therapy sessions and will provide information on TBI and its effects, where relevant. Kessiah is in her fifth year of study and has experience working for a brain injury charity in the UK and at Cavite ABI (brain injury rehabilitation service) in Auckland.

What happens to the results?
This research will be published as a doctoral thesis as part of the requirements of the Doctor of Clinical Psychology programme. There is also the possibility that the study will be published in an academic journal. The results of this research project will be available to you.

Will our involvement in this study be kept confidential?
All the information you provide on questionnaires and all the content of what is discussed in therapy will remain confidential. This means that the therapists will not tell anyone what is discussed in therapy sessions and when reporting results of the study it will be done in a way that does not identify you or your family (no names, specific occupations or details of how the injury was sustained will be reported).

An exception to the above is that if at any time the therapists become concerned for the safety of any individual(s), we have a professional obligation to notify the appropriate services. In this case, the process will be as transparent as possible and we will talk with the individual(s) involved first.

Storage of information
All information gathered in this study will be kept locked in secure storage within the University of Auckland premises. Data will be stored for six years following the completion of the research. After this period all data will be destroyed under secure conditions (electronic data will be deleted and paper documents and DVDs will be shredded).

What are the risks and benefits of participation?
As mentioned earlier, family-focused therapy can be helpful in alleviating difficulties that families commonly face after a TBI. As may be expected with any therapeutic intervention, some people may experience some discomfort talking about the issues that arise. In these instances our experienced therapist will provide support and guidance for the individuals concerned.

Thank you for making the time to read about, and consider taking part in this study. If you have any questions or would like to discuss participation, please contact Kessiah Hunt at the details below.
For any queries regarding ethical concerns you may contact the Chair, The University of Auckland Human Participants Ethics Committee, The University of Auckland, Office of the Vice Chancellor, Private Bag 92019, Auckland 1142. Telephone 09 373 7599 extn: 83711.

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 22 June 2011 for 3 years, Reference Number 2011/290
Appendix B
Consent Form
CONSENT FORM
This form will be held for a period of six years

Project Title: Family-Focused Therapy Following Traumatic Brain Injury
Principal Investigator: Kessiah Hunt

I have read the Participant Information Sheet, have understood the nature of the research and why I have been selected. I have had the opportunity to ask questions and have them answered to my satisfaction.

• I agree to take part in this research study.
• I understand that by consenting to this study, I am consenting to completing three questionnaires and participating in a course of family-focused therapy.
• I understand that participation is voluntary and I am free to withdraw at any time.
• I understand that I can withdraw data from being used in the report up to three months after therapy has ended.
• I understand that therapy sessions will be videotaped.
• I understand that no material, which could personally identify my family or me, will be used in any report on this study.
• I understand that data will be kept for six years, after which it will be destroyed.
• I am aware that our participation or non-participation will not affect any other service we receive from healthcare providers.
• I understand that I have the option of receiving a summary of the final report upon completion of the research project.
• I understand that therapy will be provided free of charge, and that financial assistance for transport costs is available if required.

Name: ...........................................................................
Signature: ................................................................. Date: ..............................

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 22 June 2011 3 years, Reference Number 2011/290
Appendix C
Assent Form
ASSENT FORM
This form will be held for a period of six years

Project Title: Family-Focused Therapy Following Traumatic Brain Injury
Principal Investigator: Kessiah Hunt

I have read the Participant Information Sheet and have had the details of the research explained to me. I have been able to ask questions about the study and understand I can ask more questions at any time.

• I agree to take part in this project.
• I know that by saying yes to doing this study I am agreeing to fill out three questionnaires and come along to some sessions with my family to see a psychologist.
• I know that what I say in the questionnaires might be mentioned in the report but no one will know that it was me that said it.
• I know that the fact I was in this project will be kept private from people other than my family.
• I know that the researchers will keep my questionnaires for six years, and then they will destroy them.
• I know that I can ask to get a summary of the results of this project.
• I know that therapy will be provided free of charge, and that financial assistance for transport costs is available if required.

Name: .................................................................
Signature: ........................................................... Date: ..............................................

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 22 June 2011 3 years, Reference Number 2011/290
Appendix D
Family Assessment Device
Family Assessment Device (FAD)

Identifier: ________________

Please respond to the items in terms of how you feel your family has been functioning in the past **two months**. Do not discuss your responses with your family member. We are interested in your personal view of your family.

<table>
<thead>
<tr>
<th></th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Planning family activities is difficult because we misunderstand each other.</td>
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<td>2. We resolve most everyday problems around the house.</td>
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<td>3. When someone is upset the others know why.</td>
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<td>4. When you ask someone to do something, you have to check they did it.</td>
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<td>5. If someone is in trouble, the others become too involved.</td>
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<td>6. In times of crisis we can turn to each other for support.</td>
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<td>7. We don’t know what to do when an emergency comes up.</td>
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<td>8. We sometimes run out of things we need.</td>
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<td>9. We are reluctant to show our affection for each other.</td>
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<td>10. We make sure members meet their family responsibilities.</td>
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<td>11. We cannot talk to each other about the sadness we feel.</td>
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<td>12. We usually act on our decisions regarding problems.</td>
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<td>13. You only get the interest of others when something is important to them.</td>
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<td>14. You can’t tell how a person is feeling from what they are saying.</td>
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<td>15. Family tasks don’t get spread around enough.</td>
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<td>16. Individuals are accepted for what they are.</td>
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<td>17. You can easily get away with breaking the rules.</td>
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<td>18. People come right out and say things instead of hinting at them.</td>
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<td>19. Some of us just don’t respond emotionally.</td>
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<td>20. We know what to do in an emergency.</td>
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<td>Statement</td>
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<td>21.</td>
<td>We avoid discussing our fears and concerns.</td>
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<td>22.</td>
<td>It is difficult to talk to each other about tender feelings.</td>
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<td>23.</td>
<td>We have trouble meeting our bills.</td>
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<td>24.</td>
<td>After our family tries to solve a problem, we usually discuss whether it worked or not.</td>
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<td>25.</td>
<td>We are too self-centered.</td>
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<td>26.</td>
<td>We can express feelings to each other.</td>
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<td>27.</td>
<td>We have no clear expectations around toilet habits.</td>
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<td>28.</td>
<td>WE do not show our love for each other.</td>
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<td>29.</td>
<td>We talk to people directly rather than through go-betweeners.</td>
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<tr>
<td>30.</td>
<td>Each of us has particular duties and responsibilities.</td>
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<tr>
<td>31.</td>
<td>There are lots of bad feelings in the family.</td>
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<td>32.</td>
<td>We have rules about hitting people.</td>
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<td>33.</td>
<td>We get involved with each other only when something interests us.</td>
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<td>34.</td>
<td>There’s little time to explore personal interests.</td>
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<td>35.</td>
<td>We often don’t say what we mean.</td>
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<td>36.</td>
<td>We feel accepted for what we are.</td>
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<td>37.</td>
<td>We show interest in each other when we can get something out of it personally.</td>
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<td>38.</td>
<td>We resolve most emotional upsets that come up.</td>
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<td>39.</td>
<td>Tenderness takes second place to other things in our family.</td>
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<td>40.</td>
<td>We discuss who is to do household jobs.</td>
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<td>41.</td>
<td>Making decisions is a problem for our family.</td>
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<td>42.</td>
<td>Our family shows interest in each other only when we can get something out of it.</td>
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<td>43.</td>
<td>We are frank with each other.</td>
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<td>44.</td>
<td>We don’t hold to any rules or standards.</td>
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<td>45.</td>
<td>If people are asked to do something, they need reminding.</td>
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<td>46.</td>
<td>We are able to make decisions about how to solve problems.</td>
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<td>47. If the rules are broken, we don’t know what to expect.</td>
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<td>48. Anything goes in our family.</td>
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<td>49. We express tenderness.</td>
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<td>50. We confront problems involving feelings.</td>
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<td>51. We don’t get along well together.</td>
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<tr>
<td>52. We don’t talk to each other when we are angry.</td>
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<td>53. We are generally dissatisfied with the family duties assigned to us.</td>
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<tr>
<td>54. Even though we mean well, we intrude too much into each other’s lives.</td>
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<tr>
<td>55. There are rules about dangerous situations.</td>
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<td>56. We confide in each other.</td>
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<tr>
<td>57. We cry openly.</td>
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<tr>
<td>58. We don’t have reasonable transport.</td>
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<tr>
<td>59. When we don’t like what someone has done, we tell them.</td>
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<tr>
<td>60. We try to think of different ways to solve problems.</td>
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</table>
Appendix E
Hospital Anxiety and Depression Scale
Hospital Anxiety and Depression Scale (HADS)

This part of the questionnaire will help the researchers to know how you are feeling. Please read every sentence. Place an “X” on the answer that best describes how you have been feeling during the **LAST WEEK**. You do not have to think too much to answer. In this part of the questionnaire, spontaneous answers are important.

1) I feel tense or ‘wound up’:
   - 3 Most of the time
   - 2 A lot of the time
   - 1 From time to time, occasionally
   - 0 Not at all

2) I still enjoy the things I used to enjoy:
   - 0 Definitely as much
   - 1 Not quite so much
   - 2 Only a little
   - 3 Hardly at all

3) I get a sort of frightened feeling as if something awful is about to happen:
   - 3 Very definitely and quite badly
   - 2 Yes, but not too badly
   - 1 A little, but it doesn’t worry me
   - 0 Not at all

4) I can laugh and see the funny side of things:
   - 0 As much as I always could
   - 1 Not quite so much now
   - 2 Definitely not so much now
   - 3 Not at all

5) Worrying thoughts go through my mind:
   - 3 A great deal of time
   - 2 A lot of the time
   - 1 From time to time, but not too often
   - 0 Only occasionally

6) I feel cheerful:
   - 3 Not at all
   - 2 Not often
   - 1 Sometimes
   - 0 Most of the time

7) I can sit at ease and feel relaxed:
   - 0 Definitely
   - 1 Usually
   - 2 Not often
   - 3 Not at all

8) I feel as I am slowed down:
   - 3 Nearly all the time
   - 2 Very often
   - 1 Sometimes
   - 0 Not at all

9) I get a sort of frightening feeling like ‘butterflies’ in the stomach:
   - 0 Not at all
   - 1 Occasionally
   - 2 Quite often
   - 3 Very often

10) I have lost interest in my appearance:
    - 3 Definitely
    - 2 I don’t take so much care as I should
    - 1 I may not take quite as much care
    - 0 I just take as much care as ever

11) I feel restless, as if I have to be on the move:
    - 3 Very much
    - 2 Quite a lot
    - 1 Not very much
    - 0 Not at all

12) I look forward with enjoyment to things:
    - 0 As much as I ever did
    - 1 Rather less than I used to
    - 2 Definitely less than I used to
    - 3 Hardly at all

13) I get sudden feelings of panic:
    - 3 Very often
    - 2 Quite often
    - 1 Not very often
    - 0 Not at all

14) I can enjoy a good book or radio or TV programme:
    - 0 Often
    - 1 Sometimes
    - 2 Not often
    - 3 Very seldom
Appendix F
Bakas Caergiving Outcome Scale
**Bakas Caregiver Outcome Scale**

This group of questions is about the possible changes in your life from providing care for the brain injury survivor. For each possible change listed, circle one number indicating the degree of change. The numbers indicating the degree of change range from -3 "Changed for the worse" to +3 "Changed for the best". The number 0 means "Did not change".

<table>
<thead>
<tr>
<th></th>
<th>Changed for the worse</th>
<th>Did not change</th>
<th>Changed for the best</th>
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</thead>
<tbody>
<tr>
<td>My self-esteem</td>
<td>-3</td>
<td>-2</td>
<td>-1</td>
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<td></td>
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<td>0</td>
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<td>+2</td>
<td>+3</td>
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<tr>
<td>My physical health</td>
<td>-3</td>
<td>-2</td>
<td>-1</td>
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<td>0</td>
<td>+1</td>
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<td>+2</td>
<td>+3</td>
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<tr>
<td>My time for family activities</td>
<td>-3</td>
<td>-2</td>
<td>-1</td>
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<tr>
<td>My ability to cope with stress</td>
<td>-3</td>
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<tr>
<td>My relationship with friends</td>
<td>-3</td>
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<td>My future outlook</td>
<td>-3</td>
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<td>My level of energy</td>
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<tr>
<td>My emotional well-being</td>
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<td>My roles in life</td>
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<td>My time for social activities with friends</td>
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<td>My relationship with my family</td>
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<td>0</td>
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<tr>
<td>My financial well-being</td>
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<td>0</td>
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</tr>
<tr>
<td></td>
<td></td>
<td>+2</td>
<td>+3</td>
</tr>
<tr>
<td>My relationship with the TBI survivor</td>
<td>-3</td>
<td>-2</td>
<td>-1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>0</td>
<td>+1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>+2</td>
<td>+3</td>
</tr>
<tr>
<td>My physical functioning</td>
<td>-3</td>
<td>-2</td>
<td>-1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>0</td>
<td>+1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>+2</td>
<td>+3</td>
</tr>
<tr>
<td>My general health</td>
<td>-3</td>
<td>-2</td>
<td>-1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>0</td>
<td>+1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>+2</td>
<td>+3</td>
</tr>
</tbody>
</table>
Appendix G
Client Satisfaction Questionnaire-8
With Additional Open Ended Questions
Client Satisfaction Questionnaire. Identifier:

1. How would you rate the quality of service you received?

<table>
<thead>
<tr>
<th>4/ Excellent</th>
<th>3/ Good</th>
<th>2/ Fair</th>
<th>1/ Poor</th>
</tr>
</thead>
</table>

2. Did you get the kind of service you wanted?

<table>
<thead>
<tr>
<th>1/ No, definitely not</th>
<th>2/ No, not really</th>
<th>3/ Yes, generally</th>
<th>4/ Yes, definitely</th>
</tr>
</thead>
</table>

3. To what extent has our service met your needs?

<table>
<thead>
<tr>
<th>4/ Almost all of my needs have been met</th>
<th>3/ Most of my needs have been met</th>
<th>2/ Only a few of my needs have been met</th>
<th>1/ None of my needs have been met</th>
</tr>
</thead>
</table>

4. If a friend were in need of similar help, would you recommend our service to him or her?

<table>
<thead>
<tr>
<th>1/ No, definitely not</th>
<th>2/ No, I don’t think so</th>
<th>3/ Yes, I think so</th>
<th>4/ Yes, definitely</th>
</tr>
</thead>
</table>

5. How satisfied were you with the amount of help you received?

<table>
<thead>
<tr>
<th>1/ Quite dissatisfied</th>
<th>2/ Indifferent or mildly dissatisfied</th>
<th>3/ Mostly satisfied</th>
<th>4/ Very satisfied</th>
</tr>
</thead>
</table>

6. Have the services you received helped you to deal more effectively with your problems?

<table>
<thead>
<tr>
<th>4/ Yes, the helped a great deal</th>
<th>3/ Yes, they helped somewhat</th>
<th>2/ No, they really didn’t help</th>
<th>1/ No, they seemed to make things worse</th>
</tr>
</thead>
</table>

7. In an overall, general senses, how satisfied are you with the service you received?

<table>
<thead>
<tr>
<th>4/ Very satisfied</th>
<th>3/ Mostly satisfied</th>
<th>2/ Indifferent or mildly satisfied</th>
<th>1/ Quite dissatisfied</th>
</tr>
</thead>
</table>

8. If you were to seek help again, would you come back to our service?

<table>
<thead>
<tr>
<th>1/ No, definitely not</th>
<th>2/ No, I don’t think so</th>
<th>3/ Yes, I think so</th>
<th>4/ Yes, definitely</th>
</tr>
</thead>
</table>
9. What was most helpful about the service?

10. What was least helpful about the service?

11. Was there anything about the service that you felt could have been better?

12. Do you think your experience would have been different if you had been involved in the service at another point in time after the injury (e.g., sooner, later)? If so, how?

13. Any other comments?

Thank you for your feedback.