

**A qualitative investigation of perceptions of stress and coping  
strategies employed by caregivers of individuals with a traumatic  
brain injury in Kwa-Zulu Natal:**

**A retrospective study.**

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March 2017

MASTERS THESIS

## **Abstract**

Traumatic brain injuries (TBI) are a major health and socio-economic concern which negatively impacts communities worldwide (Maas, Stocchetti & Bullock 2008; Udoh & Adeyemo, 2013). Although most traumatic brain injury survivors recover completely, approximately 10-15 % may continue to experience physical, cognitive and emotional disturbances well beyond the expected recovery period (Mokhosi & Grieve, 2004). In South Africa, access to care facilities and rehabilitation is costly and limited. Thus, the patient's family members are usually left to care for the patient at home (Webster, Taylor & Balchin, 2015). The process of adapting to the caregiver role as well as performing caregiver duties can be stressful for family members (Degeneffe, 2001). This is because the patient's accident is usually unexpected and performing caregiver duties or rehabilitation activities may also be unfamiliar (Chronister, 2010).

The aim of the present study was to investigate the experiences of caregivers of TBI patients to better understand which situations were perceived to be particularly stressful and which coping strategies were commonly adopted. Following a qualitative approach, semi-structured interviews were conducted with six participants. The findings of the present study were generally consistent with the findings of previous similar studies, with some unique contributions (Rawlins-Alderman, 2014; Verhaeghe, Defloor & Grypdonk 2005; Bond, Draeger, Mandleco & Donnelly, 2003; Minnes, Graffi, Nolte, Carlson & Harrick, 2000; Degeneffe, 2001). The caregiver stressors that were frequently reported included hospital experiences, sequelae of TBI, caregiver responsibilities, social networks, financial burden and limited resources. In attempt to better manage these stressors, the caregivers reportedly adopted both problem-focused and emotion-focused coping strategies. The outcomes of the current study may contribute towards positively supporting the caregiver experience and developing intervention programs that benefit both TBI survivors and their families in the future.

## **Acknowledgements**

This dissertation would not have been possible without the support of the following people:

My supervisor, Zethu Memela, thank you for your mentorship and for allowing me to conduct this research project under your supervision.

My family, partner and friends, your support has been unconditional and I am eternally grateful to have each of you in my life.

My colleagues from the University of Kwa-Zulu Natal and the Durban University of Technology have been a major support throughout completing my studies and internship. I would like to say thank you to each of you for all your support.

My participants, thank you for participating in this research project. Without each of your contributions this would not have been possible. I admire your perseverance despite all the challenges you have experienced. I endeavour to make a difference for the TBI community with the wealth of information you have provided.

This study received no sponsorship and was self-funded.

## Declaration

Submitted in fulfilment of the requirements for a Master of Social Science Counselling Psychology in the Discipline of Psychology, University of Kwa-Zulu Natal, Howard College, South Africa.

I, Julianne Hardman, declare that

1. The research reported in this thesis, except where otherwise indicated, is my original work.
2. This thesis has not been submitted for any degree or examination at any other university.
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## **Abbreviations**

KZN	Kwa-Zulu Natal
GCS	Glasgow Coma Scale
LOC	Loss of Consciousness
MVA	Motor Vehicle Accident
PTA	Post Traumatic Amnesia
TBI	Traumatic Brain Injury
RLAS	Ranch Los Amigo Scale
WPTAS	Westmead Post-Traumatic Amnesia Scale
ICU	Intensive Care Unit
RAF	Road Accident Fund

## **Chapter 1: Introduction**

Traumatic brain injury (TBI) affects more than 10 million people annually worldwide. The global prevalence of TBI suggests that it is a significant public health concern (Pretorius & Broodryk, 2013). Traffic accidents are one of the leading causes of TBI and in South Africa approximately 100 people are injured daily with 20 rendered permanently disabled. South Africa has one of the highest incidence rates of road traffic accidents in the world, with a mortality rate that is double the global average (Kaminer & Eagle, 2010).

Most existing research on the long-term sequelae or consequences of TBI has focused on changes in the domains of cognition, behaviour and personality (Bryant, O'Donnell, Cramer, McFarlane, Clark & Silove, 2010; Calvete & Lopez De Arroabe, 2012; Degeneffe, 2001; Kolakowsky-Hayner, Miner & Kreutzer, 2001). These changes have a significant impact, not only on the survivor, but also on the lives of their primary caregiver and family (Minnes et al., 2000). In South Africa, there are limited resources available for rehabilitation which means that the responsibility of caregiving and rehabilitation often falls on the family once the patient has been discharged from hospital. This is a major challenge considering most families are not well prepared for the responsibility of dealing with the consequences that often accompany a TBI (Webster et al., 2015).

Studies also illustrate that high levels of mental health problems are commonly experienced by caregivers of TBI patients. However, despite these findings, relatively few studies have investigated the coping strategies that caregivers of TBI survivors commonly adopt whilst adapting to their new role (Norup, Siert & Mortensen, 2013). In response, qualitative research that examines caregivers' adaptive and maladaptive responses as well as coping mechanisms would allow for a better understanding of caregiver's experiences and types of intervention required (Carnes & Quinn, 2005). The purpose of the present study was therefore to investigate the stressful experiences and coping strategies adopted by caregivers of TBI survivors in order to contribute towards enhancing informative intervention strategies in the future.

## **Background, Definitions and Context**

To contextualise the stressors associated with caring for a TBI patient and the coping strategies adopted by caregivers it is important to have a fundamental understanding of TBI and the challenges that often accompany this type of trauma. Thus, this section will include definitions, classification of TBI, epidemiology as well as factors involved in TBI health care and rehabilitation. The study's rationale, aims and objectives will also be reviewed.

### ***Definitions***

#### ***Traumatic Brain Injury***

A TBI is a non-degenerative and non-congenital insult to the brain that is caused by external mechanisms that leads to the temporary or permanent impairment of cognitive, psychological and physical functioning with associated reduced state of consciousness or coma (Dawodu, 2001). The external force causing damage to the brain is what distinguishes a TBI from other types of brain insults. It is important to note that as severity of the head injury increases, the extent of potential long term emotional, physical and cognitive impairments increases (Degeneffe, 2001).

#### ***Caregiver***

Each TBI case is unique and subsequently requires different types of care and support. TBI patients often require additional assistance from a caregiver (Degeneffe, 2001). By definition, a caregiver is a family member or a helper whom regularly cares for a sick, elderly or disabled citizen (Stevenson & Waite, 2011).

#### ***Stress***

Considering that the type and length of care required for TBI patients is diverse, it is not uncommon for caregivers to experience stress whilst adjusting to their new roles (Degeneffe, 2011). According to Coon and Mitterer (2010), stress refers to “the physical and mental condition that occurs when we adjust or adapt to the environment”(p.430). Stress is typically experienced when a person encounters stressors which are perceived to be difficult to manage or beyond their control. A stressor is any condition or event which challenges or threatens a person's wellbeing. The impact of these stressors is magnified when these stressors are sudden, intense, repeated, uncontrollable or unpredictable. If there is no supportive mediation

available, the person may experience shock and eventually burn out. For a caregiver, burn out may lead to the inability to perform their caregiving responsibilities effectively.

### ***Coping***

People handle stressful situations by coping. The way a person copes depends on the demands of the situation. Understanding the way people cope could provide information about the different ways people appraise traumatic events. Thus, researching coping strategies that are used to manage both short and long term stress caused by traumatic events is a relevant area of research regarding caregivers (Norup et al., 2013). This research would encourage caregivers to adopt the necessary coping strategies once they have learnt to identify sources of stress and the adaptive coping strategies that are most effective. It is also important to consider that there is a diverse range of coping mechanisms available and that the most effective coping strategy for a person would depend on their characteristics as well as the circumstances of their specific situation (Schlebusch, 1999).

### ***Classification and Mechanisms of Traumatic Brain Injury***

A TBI can be classified as an open or closed head injury (Rengachary & Ellenbogen, 2005). For example, an open head injury is caused by an external object penetrating the skull and meninges (Fuller & Goodman, 2001). Whereas, closed head injuries do not involve the penetration of the skull or meninges. Closed head injuries are usually caused by blunt force trauma leading to a more diffuse brain injury (Rengachary & Ellenbogen, 2005). The different types of traumatic brain injuries are explained in further detail in Table 1 below (Fuller & Goodman, 2001; Greenberg, 2001; Rengachary & Ellenbogen, 2005).

## Chapter 1: Table 1

### *Summary of Types of Traumatic Brain Injury*

Type	Description
Concussion	Altered state of consciousness without structural brain damage
Contusion	Sudden head deceleration causes the brain to impact against the skull thus bruising the brain tissue at the area of impact
Coup Contra-Coup Injury	The brain is thrust forwards impacting against the front skull, then the energy transferred causes the brain to thrust backwards in the opposite direction impacting the back of the skull
Diffuse Axonal Brain Injury	Widespread pin point bleeds due to multi-directional shearing forces that damage the axons during acceleration or deceleration
Subcutaneous Haematoma	Accumulation of blood between the skin and the skull
Extradural Haemorrhage	Accumulation of blood between the skull and the dura mater
Subdural Haemorrhage	Accumulation of blood between the dura mater and brain tissue
Subarachnoid Haemorrhage	Accumulation of blood within the arachnoid mater
Laceration	Tears in the brain tissue with bleeding and necrosis due to the penetration of a foreign body or skull fragments
Skull Fracture	There are different types of skull fractures, however this generally refers to a disruption of the skull and fragments of bone may penetrate the brain tissue exposing the brain and causing further damage

Evaluating the severity of TBI is important because each brain injury is unique and various factors may impact the severity of the TBI. The treatment of TBI is influenced by the type of TBI sustained and the conditions under which this occurred (Roa & Lyketsos, 2000).

According to Rengachary & Ellenbogen (2005), severity of the TBI may be evaluated using

the Glasgow Coma Scale (GCS), the duration of Loss of Consciousness (LOC) and the duration of Post-Traumatic Amnesia (PTA).

The Glasgow Coma Scale uses a point system to evaluate the patient's level of consciousness. Ocular, verbal and motor responses are compared to the GCS Table then calculated to obtain a total score out of 15. A comatose patient with a severe TBI on ventilation in the ICU would typically score a GCS of 3/15. Whereas, a healthy and fully functioning individual would obtain a score of 15/15 (Pollak, 2005). PTA is the time between sustaining a traumatic brain injury and resuming normal continuous memory which includes a state of altered consciousness (King, Crawford, Wenden, Moss, Wade & Caldwell, 1997). Following a head injury, the individual may lose consciousness for a few seconds or minutes followed by alterations in consciousness, for example confusion. This may occur despite there being minimal or no obvious intracranial pathology, for example in a concussion. Marshman, Jakabek, Hennessey, Quirk & Guazzo. (2013) state that the duration of PTA generally correlates with the severity of the TBI. According to Greenberg (2006), a mild TBI may be correlated with no LOC or LOC of less than five minutes, whereas a moderate TBI may be correlated with LOC of more than 5 minutes. Literature suggests that a prolonged LOC is correlated with a more severe head injury and that comatose patients are considered critical (Greenberg, 2006). However, the Ranch Los Amigo Scale (RLAS) may provide a more accurate assessment of the long-term impairments associated with TBI. This scale measures the patient's levels of awareness, cognition, behaviour and interaction with the environment (Warden, Labbate, Salazar, Nelson, Sheley, Staudenmeier & Martin, 1997).

### ***Epidemiology of Traumatic Brain Injury***

TBI accounts for more than a third of all trauma-related deaths worldwide (Mokhosi & Grieve, 2004). The efforts made by various organizations and the public health sector in first world countries have reduced the number of motor vehicle accidents (MVA) which lead to TBI. Furthermore, advances in medical technology and efficient emergency response have increased the survival rate of TBI patients. However, TBI remains a significant public health concern due to the high incidence and prevalence worldwide (Lefebvre, Pelchat, Swaine, Gelinas & Levert, 2005; Langlois, Rutland-Brown & Wald, 2006).

In a study conducted by Thornhill, Teasdale, Murray, McEwen, Roy & Penny (2000) it was estimated that the annual incidence of moderate to severe disability following a TBI worldwide was approximately 1 in every 10 000 cases, with five percent resulting in

moderate brain injury and three percent resulting in severe brain injury. Severe TBI was reported in 15 to 20 per 100 000 patients, with majority of patients being markedly physically and mentally disabled due to their TBI (Thornhill et al., 2000). Only rare cases of TBI resulted in a vegetative state, however this may be accounted for by under-reporting due to significant reductions in the patient's life span (WHO, 2015). According to Bowley & Boffard (2002), in 1990 approximately 5 000 000 people died from TBI and it is estimated that based on trends by the year 2020 approximately 8,4 000 000 people may die from fatal traffic accidents. Furthermore, it was suggested that injuries sustained in traffic accidents will likely become the third most common cause for disability in first world countries and the second most common cause for disability in other developing countries.

Similarly, Coco, Tossavainen, Jaaskelainen & Turunen (2013) reported that TBI accounts for approximately 8 000 000 disabled individuals worldwide. Estimates based on trauma unit consults, hospital admissions and death records indicate that at least 1,5 000 000 people sustain a TBI each year. In the United States it is estimated that approximately 3 000 000 people live with functional disabilities due to TBI (Livingston et al., 2010). It was also noted in Zimmer et al. (2008) that about half of all trauma-related deaths in developed countries are caused by TBI.

South Africa has a high incidence of trauma-related injuries and deaths, with mortality rates due to injuries being six times higher than the global average (Naidoo, 2013). Post-Apartheid South Africa has become associated with a high crime rate and traumatic events both locally and internationally. Thus, most people living in South Africa may have either experienced or witnessed a traumatic event (Smith, Lobban & O'Loughlin, 2013). Although the latest statistics relating to TBI in South Africa have not yet been released by Statistics SA, the National Health Laboratory Service estimated that the number of new TBI cases is 89 000 per year in South Africa.

It is estimated that the incidence of TBI is significantly higher than the global average with approximately 316 per 100 000 annually reported in Johannesburg during previous years (Mokhosi & Grieve, 2004). It was further estimated that of the total number of traumatic brain injuries, 10% of people died and 90% were hospitalized. Furthermore, from the 90% hospitalized, 80% were classified with a severe TBI, 10% with a moderate TBI and 10% with a mild TBI. Considering the above findings, it could be assumed that majority of TBI



survivors in South Africa would most likely experience permanent residual impairments and this would mean a subsequent continuous need for care (Mokhosi & Grieve, 2004).

A study conducted at a Hospital in Cape Town illustrated the impact of TBI in the paediatric population. The study involved 37 610 children with TBI sustained between 1991 and 2001. More than a third of these children were injured in traffic accidents and physical assaults. 17,9% of the children in the study were classified having a moderate to severe head injury (Adnams, 2010). These statistics are concerning, especially considering presumptive research conducted by Rawlins-Alderman (2014) estimated that there would likely be double the number of patients globally requiring long-term care by 2020.

### ***Health Care and Rehabilitation for Traumatic Brain Injury***

According to the World Health Organization, approximately 90% of patients reach the maximum recovery potential within 6-12 months. However, patients continue to recover for many years following the TBI (WHO, 2015). Trend analysis research indicates that there has been a decline in mortality due to severe head injuries from 50% in the 1970s to 36% in the 1980s and continues to gradually decrease (Degeneffe, 2001). This improvement has been attributed to the wider availability of emergency medical services as well as major advancements in medical science (Rengachary & Ellenbogen, 2005).

Care provided within the home environment by family members is a more modern concept. During the mid-1980s, hospitals would typically discharge TBI survivors once they had recovered physically, without taking into consideration any cognitive or emotional sequelae. However, in contemporary society, emphasis is placed on rehabilitation which involves re-training and re-educating individuals with disabilities to improve their daily functioning and quality of life. The ultimate goal of rehabilitation is to successfully re-integrate individuals with disabilities back into the community at their highest level of functioning possible and enable a satisfactory quality of life (Zillmer, Spiers & Culbertson 2008). Previous studies conducted in South Africa have found that patients, caregivers, healthcare professionals and the public may all have misconceptions regarding traumatic brain injuries and the rehabilitation required (Pretorius & Brookdryk, 2013). There are also limited resources and rehabilitation centres available for TBI patients in South Africa, thus it ultimately becomes the responsibility of a family member to perform caregiving duties. However, families are usually not equipped to manage the complex and long term sequelae associated with

traumatic brain injuries. This can make caregiving activities difficult which could negatively impact the patient's recovery and caregiver's wellbeing (Webster et al., 2015).

### **Rationale for the Study**

The purpose of the current study was to investigate caregiver experiences that were perceived to be stressful during the time of injury and also explore the coping strategies that were commonly adopted. By investigating caregiver stress and coping, the findings of this study would contribute towards a better understanding of caregiver experiences. This information could also be used to empower caregivers of TBI survivors as well as be collated with existing literature to inform intervention programs for TBI patients, their families and health care professionals working with the TBI community (Man, 2002).

### **Aims and Objectives**

The aim of the present study was two-fold. The first aim was to investigate the experiences of caregivers of TBI patients to gain a better understanding of the type of encounters that were perceived to be particularly stressful at the time. The second aim was to identify and explore the coping strategies that were commonly adopted by caregivers to cope with the stressors related to caring for a TBI patient.

The specific objectives of the present study were:

1. Identify and explore events that are perceived to be particularly stressful by caregivers
2. Explore coping strategies that are commonly adopted by caregivers to identify the most effective strategies which successfully address the stress associated with becoming a caregiver for a TBI patient.

### **Conclusion**

The incidence and prevalence of TBI is a significant public health concern in South Africa. Care and rehabilitation of TBI patients often becomes the responsibility of family members due to the limited resources available. However, these family members are usually not prepared for their new role, particularly the numerous stressors that may be encountered whilst performing caregiver duties. Through a qualitative investigation of caregiver experiences, the researcher explored the common stressors and coping strategies adopted. These detailed findings, along with existing literature, are needed to inform family members

and health care professionals about the experiences of caregivers attending to TBI survivors as well as inform future intervention strategies.

## **Chapter 2: Literature Review**

### **Introduction**

This chapter reviews the available literature on TBI related to caregiver stress as well as coping strategies. The beginning of this chapter supplies definitions and discusses considerations regarding the provision of care for TBI survivors by caregivers at home. This is followed by a basic understanding of stress and a more detailed exploration of the sources of stress encountered by caregivers. Finally, more specific coping strategies commonly adopted by caregivers will be reviewed.

### **Home Care Considerations**

Many traumatic brain injury survivors return home following hospitalization or rehabilitation. However, the patient and their family must consider the feasibility of living at home in a safe and happy environment. The requirements of the patient's current functional status, resources available to cope effectively as well as the quality of patient's existing relationship with the caregiver should all be considered (Zillmer et al., 2008). Although there is epidemiological data available regarding patients with TBI, there is little information published that describes the background of caregivers (Degeneffe, 2001). Caregiver responsibilities are unique in each case of TBI, however caregivers typically assist with activities of daily living and rehabilitation. This can be a difficult because the caregiver's skill competencies are often challenged. Their patterns of living and ways of interacting with the patient may also have had to change to accommodate the patient. Other common challenges encountered by caregivers include monitoring medication administration and managing problematic behaviours, which are issues that are usually unfamiliar to the family (Degeneffe, 2001).

### **Caregiver Stress**

Stress is experienced when a person perceives a discrepancy between the demands of a situation and their ability to cope effectively. Literature suggests that caregivers experience high levels of emotional distress including low mood, somatic complaints, anxiety, anger, fatigue and stress (Bond et al., 2003; Bryant et al., 2010). Similarly, Evans-Roberts, Weatherhead & Vaughan (2014) reported clinically significant levels of psychological distress in approximately a third of adults caring for a relative with a TBI. Caregivers are already experiencing day-to-day stressors when further responsibility is un-expectantly added which amplifies their levels of stress. This is because caring for a family member with a TBI

can have a variety of negative consequences, which remain present for several years. It also does not help that the severity of the patient's deficits can increase with time following the accident (Chronister, 2010). These high levels of stress are often endured for at least 10 to 15 years and research illustrates that family members of head injured patients are affected to the point that professional intervention is indicated many years following the trauma (Kelso, French & Fernandes, 2005).

Individuals are unique, therefore all have different perspectives of a similar situation and it cannot be assumed that a caregiver definitely experiences the patient's brain injury to be a source of major stress. However, literature does suggest that caregivers of a person with a disability are more vulnerable to the effects of stress when compared to the general population (Kelso et al., 2005). By virtue of the functions associated with the severity of the injury, each TBI is specific to each patient and thus the care required for each patient is unique. Caregiving for a TBI patient may be complex, especially with regards to the level of care needed, the duration of care and the degree of recovery achieved by each individual. This means that the amount of caregiver stress experienced is specific to each patient and their family or caregiver (Degeneffe, 2001).

### **Sources of Caregiver Stress**

According to Lefebvre et al. (2005), the onset of emotional distress is usually immediate, from the moment of notification about a loved ones' accident and often fluctuates throughout the recovery. Questions are raised about how the accident happened and this is often related to concerns about the patient's prognosis, which may be devastating. Initially it is difficult for family members to comprehend the significance of the trauma due to shock and health care professionals are often unable to predict outcomes for the future. It is this uncertainty which may cause distress and occasionally lead to conflicts with the health care team (Stulemeijer, Van Der Werf, Borm & Vos, 2008).

#### ***Conflicts with Health Care Professionals***

Conflicts with the team of doctors, nurses or rehab staff could contribute significantly to increased levels of stress experienced by family members (Siminoff, 2013; Verhaeghe et al., 2005). In a study conducted by Lefebvre et al. (2005), family members reported that ambiguity regarding the patient's prognosis at each stage of recovery was stressful. Not feeling included or supported appears to weaken the relationship between the family and the health care team which may be detrimental to the patient's recovery. Physicians reported that

the uncertainty, from their perspective, was regarding the short-term outcomes of their interventions due to the complexity of TBI cases (Stulemeijer et al., 2008). Physicians also reported that due to the uncertainty of the patient's prognosis during the early stages of severe TBI management, the health care team did not want to unnecessarily upset the family with a poor prognosis which could potentially improve or unintentionally encourage any false hope. Thus, providing basic information and only including the family in major decisions was considered the safest option. Health care professionals also emphasized the importance of providing information that is relevant to the patient's stage of recovery to prevent overwhelming the family, however this reasoning is not always understood by families and is often misinterpreted as being 'secretive' or 'unhelpful' (Lefebvre et al., 2005).

The same study also reported that family members perceived the 'human dimension' as frequently absent in the relationship between the patient and the health care team. This can have a negative impact on the patient's self-esteem being treated like an 'object' as well as negatively influence the family's opinions of and interactions with the health care team which can hinder collaborative rehabilitation in the future. From the physician's perspective, there are numerous barriers to forming a constructive relationship with families. These include disagreements regarding the orientation of interventions, conflicting internal family dynamics, unrealistic expectations, harassment of the physicians involved, breakdown of communication between family members and expressing no trust or gratitude despite the physician's dedication. However, this relationship can be strengthened when professionals acknowledge that family members are the experts on everyday life of the TBI survivor and provide support for the family by providing regular feedback, referrals for counselling and encouraging family involvement where appropriate.

Research by Coco et al. (2013) suggests that although nursing staff would like to chat to families and realize the importance of communication, this is often difficult due to the limited quiet places that are confidential where discussions can be held. This is most likely due to a minimal space in the wards and ICU as well as there being no designated rooms available for counselling. This is unfortunate because studies have illustrated the importance for families to have regular meetings with nursing staff and doctors in a confidential setting as this allows for sensitive, honest communication as well as the opportunity to discuss their experiences and receive feedback at their own pace.

### *Limited Availability of Services*

In a study conducted by Lefebvre et al. (2005), participants reported that there are minimal or no resources available to assist families of TBI patients in or near their areas of residence. Participants reported that there were only few rehabilitation centres available in the larger metropolitan areas and most of the rehabilitation centres focused on mental health problems, with no rehabilitation centres or other special services available in rural areas, which is often also the case in the South African context. This often leads to the cancellation of follow up appointments with physicians and then result in social isolation. It was also time consuming, costly and difficult for severe TBI patients to travel such a far distance to access resources (Dovey & Graffam, 1983). Paediatric TBI is a particularly important concern since these patients depend on their families and society for care. These children require special education systems, often live longer than their parents and thus with a potential to become a burden to extended family members or the community (Adnams, 2010). The provision of emergency medical services, for example ambulances, are also limited in South Africa. Delayed response times, insufficient staff and inadequate equipment for ambulances are common issues which are often to the detriment of critically ill patients (Calvello, Reynolds, Hirshon, Buckle, Moresky, O'Neil & Wallis, 2013; Scribante & Bhagwanjee, 2007). Thus, the provision of clinics, rehabilitation services with staff trained to deal with TBI cases as well as responsive emergency services in the more rural areas was recommended (Dovey & Graffam, 1983).

In comparison to many African countries, South Africa boasts numerous policies which address disability in general. The constitution based on civil rights makes provision for paediatric and adult intellectual disability. Within the relevant sectors, policies also make provision for social security grants, free primary health care and tax benefits. Furthermore, there is a health care policy regarding rehabilitation and the National Mental Healthcare Act addresses the rights of people that are intellectually disabled. The mainstream schooling system recently allowed for the inclusion of intellectually disabled children and should provide special education support. However, despite the existence of these comprehensive policies, assistance for cognitive impairments remain a low priority and the budget allocations do not allow for the extensive resources required which leads to only a few of these policies being effectively implemented (Adnams, 2010). Furthermore, except for the Road Accident Fund (RAF), the policies in South Africa do not directly address children or

adults whom have sustained a TBI nor do the policies include specific provisions for their health care, social and educational requirements.

### ***Family Adaptation***

Providing care for a family member who has sustained a TBI demands change and adaptation from family members. This may be a source of stress, depending on the family relationships and family dynamics before the patient's TBI (Carnes & Quinn, 2005). Caregivers not only have to deal with their own personal role changes but also deal with changes in dynamics of the family unit (Rawlins-Alderman, 2014). Family members provide the primary support system for the patient and daily living routines may have to be adapted to achieve balance in the novel situation (Florian, Katz & Lahav, 1989). Therefore, the entire family needs to redefine its structure, refocus its resources and commit to new individual roles whilst trying to maintain normal daily routines (Carnes & Quinn, 2005).

Previous research has found that 60% of families experienced significant changes to their previous family structure following the trauma (Carnes & Quinn, 2005). These findings suggested that families functioning well prior to the trauma were most affected. This was likely because the family structure and the role that each member plays were in place for many years prior to the trauma, thus this family system was suitable for each member and in accordance with their beliefs, goals and financial status. A family member sustaining a TBI can cause significant disruption and the family structure should be revised at each stage of the patient's recovery. These constant adaptations create stress that is compounded by the patient's rehabilitation which is continued at home with the assistance of the family (Carnes & Quinn, 2005).

There are differing views when it comes to the relationship between caring for a TBI patient and the levels of stress experienced by different family members. For example, Minnes et al. (2000) suggest that being a TBI survivors spouse or parent does not necessarily dictate a difference in the amount of stress experienced. However, other studies report that there is significantly more stress experienced when a spouse is the patient due to the major changes in relationship dynamics. This is because, with a spouse, there is likely to be an increase in parenting responsibilities and a possible loss of income for the household (Carnes & Quinn, 2005). At the same time, children are reported to experience significant distress when a parent is involved in a traumatic incident. Children of TBI survivors not only have a lesser functioning parent but also must compete for attention from the remaining fully functional



parent due to caregiver responsibilities. Siblings of TBI survivors are also more likely to experience stress, behavioural problems, depression and generally pessimistic attitudes (Degeneffe, 2001; Verhaege et al., 2005).

Transitions for people with a TBI and their families includes a number of stages that occur within a variable time span. These generally include the transition from the hospital to rehabilitation, from rehabilitation to home, attempting community re-integration, from dependency to autonomy or from the previous sense of self to a reconstructed identity. Research by Conneeley (2012) suggests that the most crucial transition is from the hospital or rehabilitation centre to the home environment. Although this may have been a much-anticipated milestone, this was reportedly a stressful transition due to the uncertainties involved. There is also minimal supplementary information available to the public about the recovery process after a TBI or when the information is provided, it is often in complex medical terminology which caused more confusion.

According to Man (2002), the participation of family members in a TBI survivor's rehabilitation is important and should be advocated by health care professionals. However, despite their dedication, the healthcare system often does not support the preparation of the family to deal with this process effectively. Many developing countries also do not have access to rehabilitation centres or there are lengthy waiting lists, which leads to a number of TBI patients being transferred to a care facility. This is because these patients cannot care for themselves and their families do not yet have a sufficient understanding of the patient's condition or their caregiver responsibilities (Zillmer et al., 2008). Furthermore, the recovery process is protracted and the current trend towards shorter in-patient rehabilitation increases the demand for effective community-based rehabilitation programs. However, these types of programs are not yet available or accessible in all communities (Conneeley, 2012).

### ***Financial Burden***

The majority of studies in the area of stress and coping following a TBI indicate that one of the greatest stressors for caregivers is the financial burden (Degeneffe, 2001). The financial burden starts to accumulate from the time of the accident. Literature suggests that household income is directly related to caregiver's perceived burden. This is because decreased household income often translates into limited access to resources for the family member with the TBI. Thus, caregiver duties and rehabilitation are often provided by a member of the

patient's family to the best of their ability within the home environment (Naborsi, Seacati & Rosenthal, 2002).

According to the council for medical schemes, it is the responsibility of the patient, guardian or caregiver to remain vigilant about the provisions specified by their medical aid in order to fully access the necessary benefits required. Many private healthcare practitioners do not charge medical aid rates, thus there may be additional costs which must be paid from the caregiver's income. Thus, the affordability of the patient's treatment may cause high levels of stress because in South Africa there are different types of medical aids each with varying plans and rates which means the full treatment costs may not be paid by medical aid and the family would remain liable for the rejected amounts or exclusions (SA Medical Sites, 2012). More than half of the caregivers in a study conducted by Carnes & Quinn (2005) reported having concerns about what their family member's insurance would or would not cover. The findings suggested that financial security was related to lower psychological distress and better family functioning. This suggests that financial status could be a significant contributing factor towards caregiver stress and adaptation.

There are various types of financial assistance that may be accessed in the form of grants. There are many types of grants that can be obtained from the Department of Social Welfare available in South Africa, for example The Disability Grant for adults 18-59 years old. A disadvantage of the current criteria is that if a family or individual is receiving a grant they may not receive a second type of grant or other financial assistance from the Government, despite their financial status. Furthermore, all Government grants in South Africa have the strict provisos that include or exclude applicants, for example the applicant must not be currently cared for by a state institution and the family must submit full medical reports confirming any disabilities (Department of Social Welfare, 2013).

Further assistance is offered to both public and private sectors by the RAF and the Compensation for Occupational Injuries Act, however these both require lengthily legal processes and disqualify any previous assistance being claimed from the Government, for example a social welfare grant ([www.raf.co.za](http://www.raf.co.za) and [www.labour.gov.za](http://www.labour.gov.za)). The South African Revenue Services (SARS) also offers certain tax allowances and deductions for patients and caregivers of patients with certain disabilities. However, this benefit is only compensated after the expenses have been paid at the end of each tax year ([www.sars.gov.za](http://www.sars.gov.za)). These applications can be stressful and costly for caregivers because the process involves compiling

paperwork from various health care providers and they may require additional professional assistance to achieve the maximum benefits, for example a lawyer. Compensation is also difficult to obtain because the patient's injuries must be constantly justified to the compensation agents for reimbursement (Lefebvre et al. 2005).

### ***Personality and Behavioural Changes***

Another major source of stress for caregivers is having to accept a family member that is now different to before the trauma and who may exhibit various emotional, cognitive and behavioural problems (Mokhosi & Grieve, 2004; Rawlins-Alderman, 2014). TBI can lead to various long term or permanent deficits. These changes can negatively impact on the survivor's ability to function independently and can increase emotional stress on family members (Langlois et al., 2006).

In a study conducted by Mokhosi & Grieve (2004), most of the TBI patients experienced functional changes in cognitive, motor, emotional and social domains. According to Greenberg (2001), the long-term complications following a TBI may include epilepsy, hydrocephalus, paraplegia, post concussive syndrome, post traumatic encephalopathy and Alzheimer's Disease. Epilepsy is a common sequelae following a TBI and patients are routinely prescribed anti-convulsant medication to prevent potential seizure activity. Statistics estimate that approximately 10% of closed head injuries and 40% of open head injuries will develop post-traumatic epilepsy. Physical impairments typically include hemiparesis, visual disturbances, speech deficits, muscle spasticity, alterations in sensation and incontinence (Degeneffe, 2001).

Literature suggests that the patient's initial physical disabilities are often less stressful for the caregiver when compared to the long-term cognitive, emotional and behavioural deficits that may develop with time (Verhaeghe et al., 2005). Especially because the sequelae of TBI typically include a combination of cognitive impairments, emotional disturbances, interpersonal difficulties and behavioural problems (Shotton, Simpson & Smith, 2007). Studies have illustrated that it is the nature of the deficit, rather than the severity of the injuries that determine that amount of stress experienced by the patient's caregivers (Verhaeghe et al., 2005).

The transition from the previous sense of self to a reconstructed identity is usually significant to the individual as well as their family (Conneeley, 2012). For example, depending on the type and location of the insult TBI often causes apathy which can influence the patient's

cognitive, emotional and behavioural functioning. Consequently, the apathy also impacts their motivation to recover and cope independently which means that caregivers may have to assist with many daily activities. Aggression is another common sequelae and causes significant stress for families constantly anticipating when and how to manage the next outburst (Coco et al., 2013).

Many TBI patients sustain poly-traumatic injuries – these individuals may have to make use of additional aids, for example a wheelchair or prosthetic limb. Others may have significant alterations in their physical appearance, for example deforming scarring or amputations (Rengachary & Ellenbogen, 2005). A person's identity is often defined by their occupation or hobbies and re-enforced by their physical appearance (Conneeley, 2012). The transition from the old self to the new self can be extremely difficult, especially when great value was placed on a type of activity that the patient is no longer able to perform. The impact of impairment on vocational duties is often acknowledged (Green, Davis, Karshmer, Marsh & Straight, 2005). In a study conducted by Conneeley (2012) it appears that societal attitudes and potential prejudice were perceived to be greater threats. Survivors reported that although it was disheartening not to be able to return to work, a shift in focus to being appreciative for a future with family and their family's support allowed for the realization that life will continue despite the disabilities.

The transition from dependency to a degree of autonomy involves a dynamic interaction between practitioners, caregivers and the individual concerned. Enabling opportunities for independence later in the rehabilitation process can be challenging for caregivers due to their anxiety of the patient not being able to cope or the occurrence of another trauma. The inherent want for caregivers to protect the patient from harm is a natural response, however encouraging empowerment is essential during the transition. Therefore, opportunities to practice independence within a supportive environment is crucial for successful and safe autonomous functioning for the patient and family in the future (Conneeley, 2012).

### ***Unrealistic Expectations***

The strain caused by learning about a loved one's traumatic injuries as well as the levels of stress and depression that may develop necessitates that family members usually require professional support. The emotional support provided involves knowing that help is available if required. Family members typically experience insecurity and fear because trying to understand the patient's condition can be challenging with minimal medical background.

These individuals are also experiencing shock because there was no prior warning to the accident and there is minimal time to prepare for the challenges ahead (Coco et al., 2013).

In a study conducted by Coco et al. (2013), majority of the families reported that too little support was received and too little preparation was discussed for the future. A number of family members also preferred to be prepared for the worst and wanted to be told when there is no hope for the patient anymore. Families often have unrealistic expectations of the patient's recovery which can also cause immense stress when not achieved. This can become detrimental because maintaining unrealistic expectations delays acceptance by the patient and their family of the likelihood that the injury may be permanent. This postpones making practical adjustments and planning appropriately for the patient's future (Mokhosi & Grieve, 2004).

### *Grief*

Research suggests that it is not a requirement to be a direct victim of trauma to develop acute stress disorder or post-traumatic stress disorder. These conditions and their associated symptoms may be present due to indirect traumatization, for example learning the details about a family members serious traffic accident (Kaminer & Eagle, 2010).

Family members of TBI patients often experience a similar type of grief to those whom have experienced the death of a family member. Kubler-Ross describes the psychological process of bereavement involving denial, anger, bargaining, depression and acceptance. The process may take many months to years for eventual acceptance and adjustment to the loss to be achieved (Evans-Roberts et al., 2014). Families should set their own pace when dealing with their grief and this must be respected by others (Coco et al., 2013).

Similarly, a study conducted by Calvete & Lopez de Arroyable in 2012 found that due to the major personality and behavioural changes that a TBI survivor may experience, families typically experience the emotional processes similar to the stages of grieving when a relative or friend passes away. However, the continued presence of the TBI survivor being grieved about interferes with the normal stages of grief. Thus, this is considered a loss that is ambiguous because the patient is still alive but different and this causes significant distress for the family. Especially in severe TBI cases, parents have reported experiencing what is referred to being 'partial death' because their child is still alive but not the child that was known before the accident (Conneeley, 2012).

Furthermore, family members of TBI patients often have to grieve alone, whilst isolated from their social network and hiding their feelings in order to protect their relative. There are also no traditional rituals to follow to encourage closure for the loss of the person the family knew prior to the accident. Whilst the patient's limited self-awareness and denial may serve to protect from depression, this may heighten the family's sense of loss (Evans-Roberts et al., 2014).

### ***Guilt***

A number of traumatic brain injuries are sustained whilst driving under the influence of alcohol or other recreational substances which may lead to family members feeling ashamed of their relatives' actions. Family members may also feel guilty when participating in self-care or leisurely activities whilst their relative is confined to a hospital bed or fighting for their life (Coco et al., 2013). Generating positive caring experiences and maintaining a perception that the situation is manageable appears to counteract feelings of guilt and sense of hopelessness in caregivers. Thus, social support networks and the health care team should reinforce activities that could enhance empowerment by instilling hope and encouraging any positive efforts made by the caregiver and the rest of the family (Man, 2002).

### ***Decreased Quality of Life***

After receiving medical treatment and rehabilitation, most TBI patients will be discharged and return home to their families. Thus, immediate family members often become the primary caregivers. Caregivers would typically help the TBI survivor with a variety of short and long term needs including self-care, emotional support and other daily activities. The extent of responsibility assumed by the caregiver is immense and often leads to emotional distress, illness and burnout. Previous studies suggest that caregivers of TBI patients are at high risk for experiencing decreased quality of life and lower levels of life satisfaction (Livingston, Kennedy, Marwits, Arango-Lasprilla, Rapport, Bushnik & Gary, 2010).

These researchers reviewed previous studies which found that caregivers of severe TBI cases presenting with significant neuro-behavioural disturbances were typically dissatisfied with their lives. Specifically, literature shows that significant personality changes in patients were associated with lower life satisfaction and increased likelihood for the development of depression in caregivers. Social support appears to be a moderator of life satisfaction because previous studies illustrate that caregivers with low levels of social support experienced significantly decreased quality of life. Appraisal of responsibilities and capabilities also

seems to mediate the levels of life satisfaction experienced by caregivers. Thus, a large number of caregivers report decreased quality of life which may negatively influence their caregiver experience as well as interfere with their ability to perform duties.

Rawlins-Alderman (2014) suggests that the anticipated amount of time for caregiving has a major impact on the caregiver. The transition to the role of caregiver as well as the length of the caregiving relationship have a significant influence on the caregiver's lifestyle. Studies have shown that people who become caregivers for patients with a TBI are at a greater risk for developing depression and hostility. This may be reflected in their acknowledgment of dislocation from their lives before the trauma due to caregiver responsibilities. It is also important to consider the age of the TBI survivor because a child or adolescent would probably require life-long care. This means that caregivers will be providing support to their family member during a period when their own requirements for additional support continue to increase and the caregiving role may be a life-long commitment.

### ***Social Isolation***

The TBI survivor's resulting disabilities can be demanding on the patient and their family, thus their social network typically decreases which makes the process of adaptation difficult for everyone involved (Lefebvre et al., 2005). Mokhosi & Grieve (2004) also found that social isolation is frequently observed in family members of traumatic brain injury survivors. This was usually because bed-bound patients require full time care and other patients would embarrass their family members in public or were irritable towards visitors. A few family members reported being isolated from extended family, especially when they stopped helping with caregiver responsibilities but were quick to criticize the caregivers' coping efforts which produced conflict and resentment. However, a number of families also reported that extended family and neighbours were supportive and helpful, showing their sense of community, also called 'Ubuntu' (Mokhosi & Grieve, 2004).

### **Caregiver Coping Strategies**

Research in the area of stress, coping and traumatic brain injury suggests that there is a need to understand that caregiving is a process which may create stress as well as gratification within the family (Norup et al., 2012). Family members assuming the primary caregiver role for their injured relative experience the most demands producing higher levels of stress and

major changes within the family system. To cope effectively with all of these demands and changes, caregivers adopt a variety of coping strategies to adapt better to the requirements of their impaired relative (Rawlins-Alderman, 2014). It is important to understand these strategies because, both clinical and research data suggest that the efficacy of coping can have a significant impact on the quality of the caregiving experience (Degeneffe, 2001).

### ***Support from Health Care Professionals***

Additional support for the family members is crucial, especially during the acute phase of hospitalization. Nursing staff often provide the main source of emotional support to the patient's family during this time by addressing any concerns they may have, which alleviates their insecurities, anxieties, hopelessness and helplessness. Research suggests that sharing their concerns and receiving encouraging statements may help family members cope better (Coco et al., 2013).

The capacity to gain access to and efficiently use support resources also differentiates coping strategies among families impacted by traumatic brain injury. Studies indicate that family members would prefer honest, accurate information as well as require guidance and support from health care professionals. Other studies have confirmed these requirements, with their findings that family members request accurate information regarding the patient's condition and prognosis as well as would like to be more involved in the patient's medical management (Degeneffe, 2001).

According to Rawlins-Alderman (2014), the sequelae of TBI create ambiguities for families that extend into the distant future, often with the expectation that the individual will be dependent on caregiving for the rest of their lives. Thus, families are introduced to caring for a relative with a disability without any prior knowledge or skills to provide the care required. Thus, guidance is required to provide support and reassurance that the provision of care is adequate and that their coping strategies are effective. Information is usually gathered from health care professionals regarding the extent of the disability and how to establish a caregiving process that supports positive adjustment to the disability (Rawlins-Alderman, 2014).

Health care professionals can enhance the family's involvement by providing knowledge, skills and engagement in partnerships with family members. Considering that requirements of people with TBI are varied, opportunities for partnerships between professionals and families are abundant and can benefit both parties. Professionals can benefit from the knowledge



family members possess about the patient and families can benefit from the years of experience possessed by the professionals. Information pamphlets and reading materials can assist family members to make more informed decisions regarding the medical treatment and rehabilitation of their relative with a traumatic brain injury (Degeneffe, 2001).

Without prior knowledge or experience, it is difficult for family members to anticipate the impact of a TBI on their relative's capabilities, particularly with regards to those abilities which have been altered by the TBI (Conneeley, 2012). Access to professional support lowers levels of anxiety and stress in caregivers because caregivers learn to be more confident in their ability to deal with challenges in the future. Being involved in the patient's rehabilitation allows caregivers to practice their skills and increases their insight into the implications of caring for a relative with a traumatic brain injury. This implies that opportunities to practice tasks relevant to the home environment is crucial for the caregiver to be better prepared and able to respond adequately to similar challenges in the future (Conneeley, 2012).

Social workers provide many of the necessary services to families of TBI survivors immediately following the injury as well as on a long-term basis following discharge. Immediate support usually involves counselling to facilitate adjusting to the reality of the trauma and the subsequent effects on the family system. Long-term services focus on supporting the transition from hospital to the home environment or a rehabilitation centre. It is important to note that despite social welfare services being available in countries abroad, the majority of care is ultimately provided by caregivers. And in developing countries long-term support is often not adequate or available, especially in rural areas (Degeneffe, 2001).

Minimal research has been conducted that focuses on interventions for the emotional support of family members by health care professionals. There is a major gap in the literature with regards to the description of successful interventions provided by health care professionals, for example maintaining hope or supportive counselling (Coco et al, 2013). According to Evans-Roberts et al. (2014), TBI is often under diagnosed because the immediate medical attention is towards other external injuries which can lead to failure of recognising neuropsychiatric sequelae in the future. This means that families could be deprived of psycho-education and emotional support which could lead to misunderstanding of their relative's behavioural and emotional disturbances. For example, family members may

perceive apathy to be intentional efforts of laziness rather than apathy (Evans-Roberts et al., 2014).

### ***Culture and Religion***

Culture may have a major influence on the way families interact with a family member with a TBI (Simpson, Mohur & Redman, 2000). In some cultures, TBI is associated with stigma and is considered to bring shame on the whole family often leading to social isolation. However, this may be successfully counteracted by health care professionals respecting the family's culture by explaining the condition using interpreters and including them in rehabilitation (Siminoff, 2012; Simpson et al., 2000). It is also important to note that the definition of a family may involve only the nuclear family unit or may involve the participation of other family members. Thus, the patient may be cared for by immediate family members or extended family members, for example a trustworthy aunt (Simpson et al., 2000).

Mokhosi & Grieve (2004) suggest that religious beliefs may also have a major impact on the way families perceive TBI. For example, in some African families, ancestors are considered to remain a part of the family in the form of guardians and keep the family safe from misfortune. However, although these religious interpretations are significant, the authors suggest that these beliefs may be attempts to explain situations that are difficult to comprehend and rather provide comfort. Attempts to attribute misfortune to external forces may be a coping mechanism which assist families to cope better with illness and other misfortunes. For example, in some African cultures, it is believed that misfortunes may be a form of punishment from a higher power for wrongful behaviour or neglecting to perform important rituals. It is also important to note that some behavioural sequelae of TBI may have been different interpretations from different cultures. Involving the family and sourcing their explanatory models of illness may not only provide clarification for behaviours, but may translate to respecting the family's culture and way of life. In some cases this may provide more psychological healing to the family and caregivers than therapy. (Mokhosi & Grieve, 2004).

### ***Family Demographics***

Families vary in their ability to cope with adjustment and differences in the efficacy of coping strategies are often functions of family characteristics from before the traumatic event. Highly functional families often have characteristics in common including cohesion, boundaries and communication. The occurrence of a TBI in a relative can place strain on the

family's coping resources. Families most negatively impacted by the presence of TBI are usually those deficient in adequate coping strategies prior to the trauma, thus these families are considered vulnerable. This is because their pre-existing vulnerable nature as well as having to deal with a family member with a TBI may stretch their resources to breaking point. These characteristics may influence a few situations, for example how family members react to the behaviour disturbances expressed by their injured relative (Degeneffe, 2001). According to Verhaeghe et al. (2005) younger families with minimal social support, financial constraints as well as pre-existing medical or psychiatric conditions are most vulnerable.

Research on coping styles and their relationship with family adaptation to TBI indicate that optimism, accessing resources and social support are all associated with positive family functioning. Positive appraisal and family tension management were also found to be predictors of constructive family adaptation. Families with balanced cohesion and open communication typically adapted better in stressful situations when compared to families with extreme cohesion and minimal communication between members (Degeneffe, 2001). Research on families with a disabled member indicate that communication often remains unclear or unresolved which leads to problems in family dynamics going unnoticed. Thus, deciding together on family rules can help stabilize the process of re-defining each member's role in the unit (Rawlins-Alderman, 2014).

### ***Social Support***

Social support refers to the alleviation of caregiver stress by providing assistance usually in the form of helping a family member or friend by participating in caregiver responsibilities or being a sympathetic listener. Support for caregivers from people external to the family usually includes friends and the health care team. Being involved in the rehabilitation process can allow family members to feel more empowered to assist their relative and family system whilst adjusting to the new situation. Caregivers often experience isolation from friends and family due to the patient's emotional and behavioural disturbances. Subsequently, support groups may become a major source of support. Although scarce in South Africa, research suggests that interacting with a TBI community can offer a range of services that may assist with reducing the stress associated with caregiving as well as improve the quality of life for

Literature suggests that although rehabilitation programs extensively consider the physical and functional disabilities, the emotional aspect of the experience for both the patient and their family are not always considered. A number of participants in the study conducted by

Conneeley (2012) reported that the psychologist played a vital role in the rehabilitation team by explaining the patient's condition in layman's terms as well as dealing with the family's emotional reactions. The psychologist also encouraged the family's existing coping strategies - for example returning to work, focusing on the immediate family, maintaining a normal routine and participating in social networks.

### *Self-Care*

Caregivers can only provide effective long-term support for their relative if self-care is a priority. However, encouraging the recognition and attempts to reduce stress can be challenging because caregivers have usually developed avoidant coping strategies before professional intervention is referred, for example denial. Most commonly, caregiver's lives are enmeshed with their relative's difficulties and these individuals have forgotten what it was like to consider their own well-being. Thus, these individuals struggle to understand that improving their own well-being can have a positive effect on the well-being of the patient and their family unit (Evans-Roberts et al., 2014).

Family members interviewed in previous studies have reported that making personal time for themselves helps to relieve some of the stress associated with being a caregiver. Personal time was perceived to be a 'mini break away' from caregiver responsibilities. Although many family members become the primary caregiver to individuals with a TBI, this commitment is often made with great personal sacrifice. Having self-care strategies in place is important in order for the caregiver to have both the physical and mental strength to provide effective caregiving and prevent burnout in the future (Rawlins-Alderman, 2014).

### *Denial and Avoidance*

Common coping mechanism adopted by caregivers of TBI patients are denial and avoidance. Denial is a psychological defence mechanism which protects against overwhelming feelings of pain or anxiety in adverse circumstances which cannot be avoided, for example disability. Families would like to believe that their relative is going to fully recover and return to their 'normal' former selves (Evans-Roberts et al., 2014).

Immediately following the trauma, families often demonstrate a number of grief reactions when attempting to accept the reality of the patient's injuries. Later grief reactions typically include anger, depression and anxiety. These reactions are similar to the death-related grieving model, however this is called "mobile mourning" as the person is still alive and the

issue is that they may never fully regain their pre-injury functional status and thus the family walks around “carrying” their grief, without any prospects of “closure”. Subsequently, the grieving process may be experienced repeatedly and family members may never accept the reality of the situation without professional intervention (Degeneffe, 2001). In the case of Mokhosi & Grieve’s study (2014) it was found that denial by family members was often prolonged by beliefs that patients may return to their former selves if allowed enough time or if the correct cultural rites were performed which sustains hope (Mokhosi & Grieve, 2004).

Norup et al. (2013) found that denial was the most frequent maladaptive coping strategy employed by caregivers and this was highly associated with anxiety and depression. Denial may serve to protect the caregiver during the acute phase of the trauma to avoid the pain of sudden loss, however in the long term this is considered maladaptive as this coping strategy often leads to more distress and decreased quality of life. Similarly, Evans-Roberts (2014) found that avoidant coping strategies are common among caregivers of TBI patients and that they have a negative impact on the caregiver’s psychological adjustment and wellbeing.

This researcher believes that although denial may promote hope and be a helpful coping strategy during the early stages of trauma, caregivers can only be fully functional and maintain resilience if a realistic appraisal of the injury and its consequences are accepted. However, successful adjustment to the patient’s limited functional abilities can be facilitated by gaining a better understanding of traumatic brain injury and the consequences thereof (Evans-Roberts, 2014). Realistic expectations regarding the nature of the TBI and potential sequelae are fundamental for successful rehabilitation. Studies illustrate that patients and families introduced to the likelihood of impairment from the head injury during the early stages are generally able to cope better, accept the patient’s disabilities and make any necessary adaptations (Mokhosi & Grieve, 2004).

### ***Positive Re-Framing and Acceptance***

Positive reframing and acceptance are emotion focused coping strategies that are associated with better outcomes for the patient and their family. Accepting or trying to find positive aspects are perceived as constructive ways of handling the new situation (Norup et al., 2013).

For caregivers of TBI patients to cope with feelings of powerlessness and losing control, literature suggests that active efforts towards empowerment has been found to be helpful. Empowerment is a multi-faceted construct which describes families including TBI survivors that are in control and trying to master their lives in a new context by making desirable

adaptations. Empowerment is assumed to counteract the powerlessness associated with head injuries, through positive subjective experiences and the objective acquisition of resources. Factors enhancing successful empowerment of families include recognising their powerless state, having realistic expectations, motivation to master adverse situations, flexibility to adjust, active planning and accepting support from others (Man, 2002).

Another study found that families tended to rely on social support and comparatively fewer families adopted avoidant coping strategies, for example denial or searching for meaning. Typically, caregivers tried to gain knowledge and skills to confidently deal with the sequelae of traumatic brain injury and maintained hope that their relative could be successfully rehabilitated. Families that adjusted well sought advice from other families caring for TBI survivors and attended support groups held at community centres (Man, 2002).

Gradually the caregiver and other family members begin to acknowledge that the sequelae of the traumatic brain injury may be permanent and start adjusting their situation to accommodate for caregiving requirements. This typically includes adaptations in family member roles and budgeting for the expenses involved. Some family members may perceive these changes to be catastrophic, whilst others may accept the changes and perceive the experience as encouraging cohesion in the family unit. Adapting to the injury is a continuous process and the caregiver's perception of change in the family dynamics may become more positive after gaining a better understanding of TBI and spending quality time with their injured relative. A few caregivers report that their caregiving experiences are rewarding and that their families are eternally grateful for their dedication. This is akin to the conversion of hardship into hope which is another coping strategy commonly adopted by caregivers. Rawlins-Alderman (2014) reported that participants in his study expressed that caregivers gave their best serving their relative and that providing the best care possible was rewarding.

## **Conclusion**

Research illustrates that family members of TBI survivors encounter numerous stressors whilst the patient is still in hospital as well as upon returning home. A few examples of common stressors mentioned in the literature included grief, financial burden, sequelae of traumatic brain injury, societal attitudes and conflicts with healthcare professionals. However, previous studies suggested that family members had adopted both positive and negative coping strategies in an attempt to deal with these stressors. Examples of coping

strategies commonly adopted were social support and positive re-framing. This review provided evidence for the notion that caring for a TBI survivor is challenging and that support is required to cope effectively. Thus, the literature re-iterated the relevance of identifying stressful situations encountered by caregivers of TBI survivors as well as distinguishing which coping strategies are commonly perceived to be helpful. The present study attempted to fulfil this requirement by qualitatively exploring caregiver's experiences according to the transactional model of stress and coping.

## Chapter 3: Theoretical Framework

### *The Transactional Model of Stress and Coping*

The initial theories regarding stress and coping were considered trait-oriented approaches where a particular type of pathology was attributed to a defensive coping style which was associated with a certain personality type (Lazarus & Folkman, 1984). However, the late 1970s revealed novel research which revised the concepts of stress and coping which suggested that these are continuous processes and change according to the demands of the situation or environment. Thus, the Transactional Model of Stress and Coping is considered a contextual process-oriented approach (Folkman, Lazarus, Dunkel-Schetter, DeLongis & Gruen, 1986). This model is a theory-based framework for evaluating the process of how a person copes with stressful situations, for example how a caregiver copes with caring for a family member with a TBI. This person-environment interaction is mediated by the person's perception of the stressful situation as well as their context and the resources available at their disposal, for example funds or social support (Kelso, French & Fernandez, 2005).

Stress is defined as a physiological or psychological demand on a person that is perceived to be adverse and difficult to manage (Coon & Mitterer, 2010). A person's perception of stress involves a dynamic interplay between the individual and their environment. The environment may be other individuals or the physical surroundings at any given time. The stressor may lead to hardship, distress or dysfunction (Lazarus & Folkman, 1984). The actions taken by a person to try manage these stressors from both a psychological and physiological perspective are referred to as coping (Folkman et al., 1986).

The theory discusses two important processes, namely cognitive appraisal and coping. These two processes are considered intermediaries in the relationship between the person and their environment during a stressful encounter. Cognitive appraisal is the conscious thought process whereby a person assesses their current situation and applies relevance in relation to their own wellbeing and how this may affect themselves as well as significant others in their life (Folkman et al., 1986). For example, hearing the news of a patient's serious car accident is typically a traumatic experience for their family.

Initially, primary appraisal occurs, taking into account the extent and way in which the situation is relevant to the individual concerned (Mitrousi et al., 2013). This may involve the assessment of factors such as physical harm or benefits, values, goals and self-esteem. This



primary appraisal places the situation into one of three categories - being irrelevant, benign-positive or stressful (Lazarus & Folkman, 1984). An irrelevant evaluation determines that the encounter is not significant and requires no further action on the part of the individual. A benign-positive appraisal occurs when the individual deems the situation to be in their favour, thus potentially benefiting the person, either immediately or in the future. Whereas, stress appraisals occur when a situation is deemed by the individual to be threatening to their wellbeing or to the wellbeing of significant others (Lazarus & Folkman, 1984).

Stress appraisals are further divided into threats, harm or challenges (Lazarus, 1993a). In the case of a threat, detriment may only be anticipated, however the implications of experiencing possible loss in the future generates major stress and feelings of vulnerability. Harm generally involves damage that has already occurred and requires immediate action in attempt to save the situation from further damage. However, challenges are demands that seem manageable but require the activation of coping mechanisms to achieve the desired outcome (Lazarus, 1993a). For instance, the acute phase of the patient's hospitalization is typically a traumatic and anxious period. Family members are usually not familiar with the hospital environment, are concerned about the patient's prognosis as well as wanting to know how they can help in the situation.

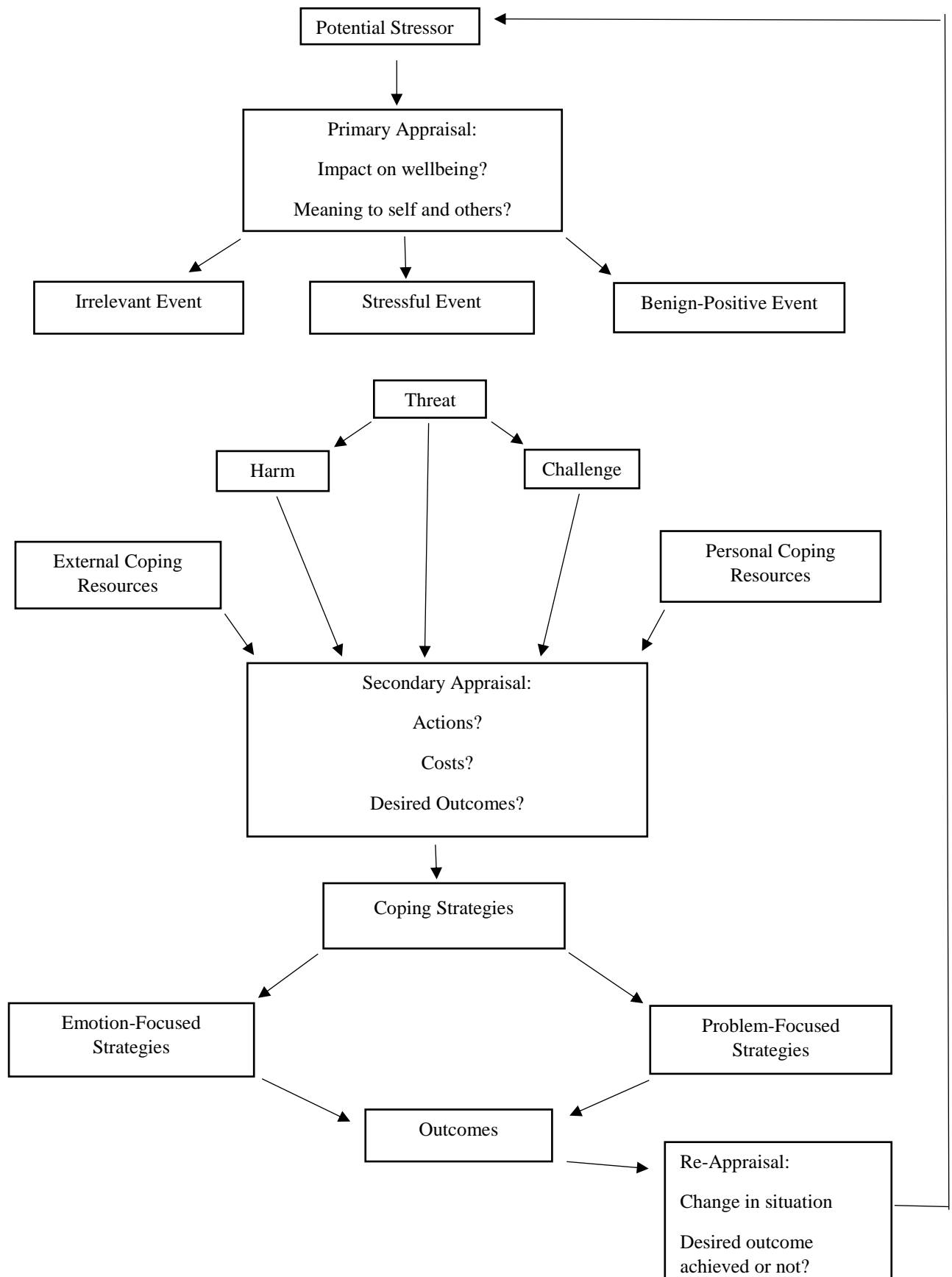
Primary appraisals lead to secondary appraisals, where a person will evaluate the possibilities of managing the situation in an effort to curb the negative effects or enhance the positive effects. The person will then further evaluate the situation in detail, which is essential for the formulation of coping strategies as well as other potential actions to be taken towards the desired outcomes (Mitrousi et al., 2013). Following the above processes, the individual would combine the two appraisals and determine the degree of stress and necessary reaction. In a perceived helpless situation, stress will greatly increase and can have potentially devastating effects. Despite the possibility of a resolution being found, the degree of commitment required to achieve the outcome may still be overwhelming. There are numerous mediating and pre-existing factors which influence appraisal and subsequent coping strategies. These may be physical, social or psychological, for example personality and culture. These factors can influence the level of importance to the individual and their choice regarding expectations and actions (Schlebusch, 1999).

Whether it is a positive or negative attempt, the effort made by the person in distress to try alleviate the situation is termed coping. Coping is also contextual and is therefore

significantly influenced by the individual's perception of the situation and the resources available at the time of crisis (Folkman et al., 1986). Essentially, the purpose of the coping process is to reduce the degree of stress being experienced by a person via targeting the source of stress whilst regulating the emotional component of the encounter. The coping strategies employed are attempts at increasing the ability of the individual to function effectively as well as successfully adapt to any new situations (Mitrousi et al., 2013). Coping involves a combination of problem-focused coping and emotion-focused coping strategies, with each style appearing at a particular time in the process of attempting to resolve the stressful situation. Problem-focused coping is an action taken in an effort to change a physical person-environment situation, for example altering living arrangements to accommodate for wheel-chair access. Alternatively, emotion-focused coping attempts to change the way the stressful situation is perceived or change its degree of relevance to the individual concerned, for example maintaining a positive attitude (Kelso et al., 2005).

According to Lazarus (1993b), when a stressful situation is perceived to be refractory to change then emotion-focused coping strategies will usually be adopted. However, problem-focused coping strategies are typically adopted when the situation is perceived to be controllable by actions. Considering situations are fluid, re-appraisals may be required numerous times upon learning more about the situation. These re-appraisals may contain both positive and/ or negative aspects in a situation that is constantly evolving and thus the individual may display different reactions in response (Lazarus, 1993a). To illustrate this, the re-appraisal of stressors and adjustment of coping strategies at each stage of the patient's recovery is a good example. For instance, the patient's admission to ICU may be a traumatic experience and thus caregivers may attend counselling or prayer groups to cope better, which are considered emotion-focused coping strategies. However, once discharged from hospital, the family may accompany the patient to their rehabilitation sessions to learn how to better assist the patient with daily activities; this is considered a problem-focused coping strategy.

The Transactional Model of Stress and Coping has also been explained via schematic representation, including all of the relevant constructs and processes involved (See Figure 1).



*Figure 1. Schematic Presentation: The Transactional Model of Stress and Coping by Lazarus and Folkman (1984)*

## **Chapter 4: Methodology**

### **Introduction**

This section will provide a general overview of the research methodology. The chapter begins with a description of the research design, sampling technique and participant characteristics. This is followed by a description of the data collection process and data analysis procedures used. The chapter closes with information regarding ethical considerations as well as the reliability and validity of the study

### **Research Design**

This was a qualitative study embedded within an interpretive social science paradigm. This is because the purpose of the present study was to gather data relating to the perspectives of the participants about the phenomenon of being the primary caregiver for a TBI survivor (Groenewald, 2004). A qualitative approach was decided to be most appropriate to gain insight into the lived experiences of caregivers. This is because a qualitative methodology enables the researcher to comprehensively examine a smaller number of specific cases (Neuman, 2011) and gain a more detailed understanding of the participants' personal perceptions of experiences within a specific context (English & Van Tonder, 2009). Furthermore, research suggests that it is difficult for individuals to accurately identify their stressors or coping strategies on a questionnaire. This supports that a qualitative methodology would be more appropriate to explore individual's stressors and coping strategies because these would be revealed during discussion (Shotton et al., 2007). Focus groups were also considered, however it would have been difficult to align groups with the patient's follow up appointments therefore this method of data collection was negated.

### **Sampling Technique**

The sample was selected using a non-probability sampling technique due to the qualitative nature of this study. In a non-probability sample, subjects are deliberately selected to represent specific features within the population (Ritchie & Lewis, 2003). Thus, purposive sampling was employed because this method involved selecting a small number of unique cases that were particularly informative (Neuman, 2011). This was consistent with the research objectives which were to comprehensively investigate the experiences of caregivers of traumatic brain injury survivors. A sample size of six participants volunteered. According to Baker et al. (2012), a smaller sample size of six to twelve subjects should provide valuable

information and may adequately represent difficult to access populations. Guest et al. (2006) also suggest that a sample size of four to six participants can provide a wealth of information, especially if the participants possess intricate knowledge about the topic being studied.

### *Participant Characteristics*

Family members that were the primary caregiver of a person who had sustained a moderate to severe traumatic brain injury at least 1 year prior to the study were identified. Participants were only included in this study if four criteria were met. Firstly, all participants had to be the primary caregiver of a traumatic brain injury survivor and spend majority of their time caring for their relative in the home environment. Secondly, these caregivers had to be a family member of the TBI survivor. Thirdly, the survivor’s traumatic brain injury had to have occurred at least one year prior to the interview process to allow for adequate rehabilitation to have occurred. Lastly, only English speaking participants could be included due to resource constraints and the researcher being only fluent in English.

A total of six participants were included. Five of the participants were female with their ages ranging between 27 and 58 (Mean = 42.5). One of the participants was a male aged 57 (See Table 2). All of the participants were able to communicate fluently in English. Majority of the participants reported that their home language was English (83%) and one participant reported being bilingual, i.e. fluent in both English and isiZulu (17%). The relationship of the participant to each TBI survivor included mother, daughter, sister and spouse. The number of years since the patient’s accident ranged between 1 and 9 years (Mean = 5 years).

Chapter 4: Table 2

#### *Summary of Participant Characteristics*

Participant Code	Age	Race	Home Language	Relationship to TBI Survivor	Years Since TBI
1	58	Indian	English	Wife	4 Years
2	33	Indian	English	Sister	4 Years
3	44	African	Bilingual	Mother	1 Year
4	27	Indian	English	Daughter	5 Years
5	57	White	English	Father	9 Years
6	55	White	English	Husband	1 Year

## **Data Collection**

The researcher contacted a Neurosurgeon practising in the private sector in Durban, Kwa-Zulu Natal to request their assistance with regards to potential participants. The potential participants were contacted by the Neurosurgeon to request their participation in the study and their permission was obtained. Thereafter, the researcher contacted the participants telephonically to schedule the interviews. Data was collected when patients were scheduled to attend follow up appointments with the Neurosurgeon. This was at the request of many patient's family members for convenience and affordability purposes. Arrangements were made to conduct the interviews in a spare consulting room at the practice to ensure privacy.

Semi-structured interviews were conducted for approximately 60 to 90 minutes with each of the six participants (See Appendix A and B) The interviews were all audio-recorded for transcription purposes with the participant's permission. The interviews began with welcoming the participants, a brief explanation of the research project and signing consent forms. General demographic questions were asked at the beginning followed by a number of open-ended questions regarding their experiences as caregivers.

Examples of the questions included:

1. What happened that caused your (family member/ spouse/ child) to sustain a traumatic brain injury?
2. What do you think caused you the most distress since your (family member) had the accident?
3. How did you manage these difficult situations?

The researcher also used probing questions to get further information when required. The interviews ended with the researcher thanking the participants and information for a local psychology clinic was provided in case further support was required.

## **Data Analysis**

The data was analysed using thematic analysis. This method involves organizing the data into categories based on similarities and examining the relationships between the ideas presented (Attride-Stirling, 2001; Neuman, 2010). The data analysis process followed the six phases of thematic analysis suggested by Braun and Clark (2006).

Phase One: The interviews were conducted and transcribed verbatim by the researcher (See Appendix D). The purpose of this process was for the researcher to become familiar with and fully immersed in the data that was collected.

Phase Two: Whilst reading the transcripts again, the researcher began noting interesting ideas and patterns within the data. These were highlighted, labelled on the side of the transcripts and documented to create a list of initial codes. This included a list of as many potential themes as possible that could be found in the data.

Phase Three: Next, the list of initial codes was arranged into potential themes. All the relevant coded data was then combined to form themes. The relationships between the initial codes, the themes and the different levels of each theme were also considered.

Phase Four: Eventually a list of main themes and sub-themes were identified and their correlating coded data was refined. The researcher located extract examples which meaningfully illustrated the theme or sub-theme being discussed. All of the interview extracts that were coded for each theme were then reviewed for coherency.

Phase Five: These themes and sub-themes were further refined and each theme was named per the most important aspect of the data being represented. The relevance of each theme in relation to the specific research questions were also considered.

Phase Six: Lastly, the complete analysis was comprehensively documented. The researcher compared the literature explored in the literature review with the findings of the present study and decided on two main themes within which the sub-themes would be discussed, namely caregiver stressors and caregiver coping strategies.

### **Reflexivity of the Researcher**

At the time of collecting the data for this project, the researcher was a 27-year-old female currently completing a Masters' degree in Counselling Psychology. For many years prior to studying Psychology, the researcher worked in various positions within the medical field including emergency medical services and radiology. Thus, was regularly exposed to many cases of TBI and interacting with their families. The challenges encountered by the family members of severe TBI patients was a personal area of interest for the researcher which is what informed the topic of the present study.

Reflexivity is commonly adopted in qualitative research and is typically used by the researcher to better understand their position in relation to the topic being studied as well as ensure accuracy when reporting the participants accounts (Lambert, Jomeen & McSherry, 2010). Morrow (2005) suggests researchers should acknowledge that by the nature of a qualitative research project, the data analysis process will involve a degree of subjectivity and this should be managed carefully to avoid researcher bias. The researcher engaged in introspection regarding any pre-conceived ideas or experiences regarding TBI to become aware of any existing assumptions or biases. For example, the researcher realised from reviewing the literature that not all TBI caregiver experiences were negative and that caregivers often have positive experiences despite all the hardships involved.

During the interviews the researcher often reflected the participant's thoughts and probed further to ensure clarification of the information provided. The interviews were transcribed verbatim by the researcher and member checks were offered to avoid incorrect interpretation of the data collected. Attending regular supervision sessions also allowed the supervisor to challenge the researcher regarding any possible biases or incorrect interpretations. The accounts provided by participants should be considered interpretations of their experience within a given time frame and within a specific socio-economic context (Day, 2012). Thus, the researcher attempted to contextualise the present study by describing the location and participant characteristics.

Day (2012) suggests that the researcher should pay attention to the emotional interactions which occur during interviews and these findings should be noted in the data collected. Emotional interactions are often shifts in power between the researcher and participant. The researcher holds the power to formulate interpretations based on the participants' accounts. Whereas, participants have the power to challenge the researcher by refusing consent, redirecting questions or confronting the researcher during the interview. All participants in the present study provided consent to participate in the interviews. However, there were a few occasions during the interviews when a participant would deflect a question or change the topic of conversation. This was respected by the researcher, especially considering the sensitive material being discussed.

### **Ethical Considerations**

Ethical approval to conduct this study was obtained from the Humanities and Social Sciences Research Ethics Committee at the University of Kwa-Zulu Natal (Protocol Reference



Number: HSS/0473/016M). Fully informed consent was obtained and a consent form was signed prior to data collection. Within the consent form the interview process was explained to the participants and it was re-iterated that they may refuse to participate without any penalty or withdraw at any stage of the interview should they decide. It was explained to the participants that all of the information discussed would remain confidential and that their identity would remain anonymous. Although personal information was required for the demographic section of the interview, the researcher ensured that the participants would not be identifiable by assigning a number to each individual and only the researcher and their supervisor had access to the data obtained. The documented data was kept under secure conditions and any electronic data was password protected. It was not anticipated that any of the participants would experience significant emotional distress during the interviews because the study was simply exploring the caregiver's experiences at their own pace and as a counselling psychology student, the researcher was trained to conduct emotional containment. However, arrangements were made with the UKZN Psychology Clinic for participants to receive counselling if required. The researcher did not encounter the need or request to refer any participants during the study.

### **Credibility, Transferability and Dependability**

The reliability and validity of findings are of paramount importance in all studies, irrespective of the chosen methodology (Van der Walt & Van Rensburg, 2008). Although different to quantitative procedures, the qualitative approach also embraces the fundamental principles of reliability and validity through the concepts of credibility, transferability and dependability (Shenton, 2004).

In qualitative research methodology, credibility refers to the consistency of the participant's accounts as well as the researcher's ability to record information in a way that accurately reflects the participant's accounts (Shenton, 2004). The findings of the study should only include accurate reflections of the participant's experiences from their personal point of view. To achieve credibility, the researcher should implement procedures to ensure that the findings are credible to the participants as well as the readers (Van der Walt & Van Rensburg, 2008). Prior to starting the interviews, it was explained to all participants that they may refuse to participate or may discontinue the interview at any time without having to provide a reason. This explanation ensured that data collection only involved participants that genuinely wanted to participate in the study (Shenton, 2004). The independent status of the researcher

and confidentiality of the data provided was explained to all participants. This allowed participants to contribute their personal experiences without the concern of any negative feedback becoming public. The researcher also attended regular supervision sessions and conducted a pilot interview with a peer external to the study for any constructive criticism to be noted. The researcher conducted member checks by transcribing the interviews verbatim as well as offering all participants the opportunity to review the interview transcripts and amend any findings which were not being accurately reported.

Transferability refers to the degree to which the findings of this study can be applied to other situations (Shenton, 2004). A comprehensive review of the literature regarding the experiences of TBI caregivers was discussed to provide sufficient context for the study. The epidemiology of TBI in South Africa, the influence of culture and a description of the participants are all examples of the researcher's efforts to contextualise the study (Shenton, 2004). Furthermore, the researcher reported the common themes with related sub-themes mentioned by the participants and these were transcribed verbatim by the researcher to provide cumulative evidence for the findings presented (Neuman, 2011).

For the study to be dependable, it should be "consistent, reasonably stable over time and across researchers" (Van der Walt & Van Rensburg, 2008, p.163). This means that the study should be able to be replicated by another researcher using comparable methods with a group of comparable participants and should produce comparable findings (Van Der Walt & Van Rensburg, 2008). To achieve dependability, the researcher developed consistent procedures for conducting the interviews and analysing the data collected. The researcher followed a supervisor reviewed interview schedule to maintain uniformity of data collection. The research design and data collection process were also explained in detail to allow for potential replication in the future.

### **Conclusion**

In summary, a qualitative methodology was used to conduct this study. Six participants were selected using purposive sampling and semi-structured interviews were conducted for 60-90 minutes. The data was collected and then explored using thematic analysis. Any issues relating to ethics, validity and reliability of the study were also addressed.

## **Chapter 5: Results**

### **Introduction**

This chapter presents a summary of the findings of the data collected. In keeping with the qualitative paradigm, “thick descriptive data” will be used to substantiate the findings. From the semi-structured interviews, it was found that although there were differences in the severity of injuries and duration of caregiving, there were a number of themes that were commonly reported by all participants. Thematic analysis was used to identify the main themes that can be found in Table 3 and Table 4. Each main theme consisted of sub-themes that were considered either to be stressors or coping strategies that were associated with the caregiving experience.

## Chapter 5: Table 3

### *Themes related to Caregiver Stressors*

Themes	Sub-Themes
Hospital Experiences	Hearing the News Hospital Environment Prognosis Health Care Professionals
Sequelae of TBI	Personality Changes Physical Disabilities
Caregiver Responsibilities	Burnout Changes in Relationship Dynamics Guilt Concerns about the Future
Social Networks	Interference & Assumptions Lack of Public Awareness Societal Attitudes
Financial Burden	Medical Aid IOD Medical Bills Transport Costs
Limited Resources	Delayed Ambulance Load Shedding

### *Caregiver Stressors*

Six main themes emerged from the data analysis process in relation to situations that caregivers deemed to be particularly stressful. The caregiver stressors discussed included hospital experiences, sequelae of TBI, caregiver responsibilities, social networks, financial burden and limited resources. These will be discussed in further detail below with excerpts from the participant interviews to illustrate each theme.

### *Hospital Experiences*

#### *Hearing the News*

All participants reported that hearing the news about their family member's accident was traumatic. Majority of the participants reported that their family member's TBI was caused by a motor vehicle accident or by being a pedestrian crossing the road. Other

participants reported that their family member sustained a TBI whilst at work, whilst playing sport or were assaulted. The participants generally heard the news about their relative's accident from other family members, friends, school or health care professionals that made contact telephonically. The news was usually a vague description of what had happened to their family member, that the injuries were serious and requesting their presence at the hospital. All of the participants said that this news was unexpected and difficult to process in the moment.

Participant two found out about her brother's accident from a family member by answering her husband's cell phone: *"His phone rang again while he was in the bathroom so I like jumped over the bed and picked up the phone and before I could say anything he says you know what, you need to tell as many people as you can to come here because it's so dark and we don't know which is the bodies and which is the bags... I started screaming."*

All participants reported that the sudden nature of hearing the news about their family member's serious accident as well as the happenings on the day of the accident were traumatising and shocking. The following quote illustrates how traumatising this was for the participants: *"I drove from work and as I was driving another call came through, no she's not there she's at a different hospital... as I was driving I heard on the radio, the news at twelve just said a bus accident happened, one child died... so when I got to the hospital and I couldn't see her with the other kids my mind started racing and I thought maybe she's one of the dead ones... the nurses had to calm me down, eventually one of them found that she was transferred from this hospital to another hospital because of her injuries, already that told me this is bad."* (Participant Three)

One of the participants found his wife upon returning home: *"I found her lying outside... it's hard to describe the feeling or what I went through... people in casualty were asking me what had happened but I couldn't say, I couldn't speak..."* (Participant Six) He explained that it was shocking to discover his wife in that condition and he did not know what to do at the time. In hindsight, he was of the opinion that immediate debriefing might have been beneficial but he is currently attending psychotherapy to deal with the trauma.

### *Hospital Environment*

According to the participants, the hospital environment itself was stressful for caregivers. Seeing a family member injured in an unfamiliar setting connected to hospital equipment and surrounded by other critically ill patients was particularly stressful. For instance, participant three described seeing her daughter lying in the ICU bed: *“She had that scary neck brace, that thick plastic one and she was lying there all bloody and dirty... she was connected to this thing and it was making a clicking sound and you’re thinking, oh god what’s happening now.”* Another participant described the trauma of witnessing the death of a patient in ICU: *“There was one drop, like a tear, rolled down his eye but during the whole three days since the accident he never responded... my cousin starting crying, I was so out of it I didn’t even realise this boy had died in front on me.”* (Participant Two)

Two of the participants reported being worried about when their family member wakes up from a coma. There were concerns regarding whether or not to tell the patient about the accident, anxiously anticipating possible sequelae of the TBI as well as how to handle the patient’s reaction. One of the mothers described the day her daughter woke up: *“But then I was still a bit anxious because you don’t know after a head operation... is her memory back, does she remember things... so the first time I talked to her I was like, do you know who I am?”* (Participant Three) Another participant describes their anticipation building up to the day their family member woke up: *“I asked the doctor if he wakes up what do I tell him... we agreed on tell him he’s in hospital, tell him he met an accident, but don’t give him full details because we don’t know how it will affect him.”* (Participant Two)

### *Prognosis*

Uncertainty regarding the patient’s prognosis appeared to be a major stressor for all the caregivers. This excerpt illustrates a participant’s uncertainty regarding her son’s prognosis: *“You don’t know if he is going to make it, cause they would literally say he’s in God’s hands, we don’t know... we used to go home every night not knowing.”* (Participant Five)

Another major concern was the number of injuries and how these may all influenced the patient’s recovery. This was illustrated by a parent’s description of her daughter’s surgeries: *“They had to wait until they had done the head op to go again to do that... they only took her completely out of the induced coma after she went to theatre for the sides... because the other thing was the lungs were also bruised and swollen.”* (Participant Three)

### *Negative Experiences with Health Care Professionals*

Negative interactions with healthcare professionals being a source of stress was a recurrent theme throughout the data. Participants reported negative exchanges with nursing staff, for instance participant three recalled being angry towards the nurses in response to the perceived neglect of her injured daughter's basic needs: *"I fought with the nurses... one day I got there and they hadn't bathed her, they hadn't changed her nappy, she was in a terrible state... I was very angry. I mean she is lying there helpless."*

Another participant witnessed her brother being spoken to badly by the nursing staff: *"We had a very bad experience with the hospital because the nurses, a few of them, were very bad people... I was told that ward was the neuro ICU, that they would know how these people behave... but they never wanted to believe how bad my brother's condition really was... I know he wasn't behaving right but he was ill... when he asked for more water she said why don't you get up and get it yourself."* (Participant Two) Despite being concerned about their family member's wellbeing, the participants commented that these complaints were not reported to management due to fear of the patient being victimized.

While participants often expressed satisfaction with their primary surgeon and general practitioners, a few participants reported dissatisfaction with referral practitioners. For instance, participant two recalled being dissatisfied with the psychiatrist's short consultation: *"So we called in the Psychiatrist, who hardly spent more than fifteen minutes with the patient but yet diagnosed this patient."* Another participant felt that the Neurologist could have been more compassionate: *"You see not all Doctors were like our Doctor... they didn't want to talk much, they don't want to talk to you... they must talk to the person, tell them what's happening... not just do like all clinically, like cold and distant."* (Participant One)

### ***Sequelae of TBI***

All participants reported various sequelae that have been experienced following their family members TBI involving physical, emotional and cognitive deficits. All participants reported significant personality changes and physical limitations to be stressors, thus these shall be discussed further below.

Participant one described feeling like their family had been granted a “grace period” before the long-term sequelae of her husband’s TBI became apparent: *“When he came out of hospital he was recovering and everything seemed to be normal... it was like a euphoria, everything was getting better and better... but then other things started coming in now, like he had that very bad seizure... it was like just a one-year grace period.”*

Three of the participants also mentioned that their family members suffer from seizures since the accident, illustrating that this is a common sequela amongst TBI survivors.

Two of the participants reported that their children experienced academic difficulties since sustaining a TBI. A common depiction of this was that their children were achieving lower grades in their school work compared to before the accident. For instance, participant three described her daughter’s academic difficulties since sustaining the TBI: *“Before the head injury she would just read something once and remember... Now she has to re-read her notes a few times and just do well enough to pass.”*

### *Personality Changes*

Personality changes resulting from the patient’s TBI appeared to be a major source of stress for caregivers. Adjusting to a family member who seemed different to their former selves before the accident was described to be a stressful process for caregivers. Certain personality changes were considered more stressful than others. Anger outbursts, demanding behaviour, unpredictable behaviour, inappropriate behaviour and depression were deemed to be particularly stressful. The following excerpts illustrate caregiver’s responses to the various personality changes in their relative:

*“There’s definitely a huge personality difference, he becomes angry very quickly and he can change just instantly from happy to suddenly having an angry outburst... which can be very upsetting when he does... he was an absolute angel of a child up till then.”*

(Participant Five).

*“We took him home in that state... not understanding, not knowing sometimes who he is, it was scary... He had to get re-adjusted to everything... sometimes you want to get frustrated... like we didn’t understand, we didn’t know how to deal with him... like can I shout at him and not feel bad, but you don’t want to shout at him because you know it’s not his fault.”* (Participant Four).



*“Then the depression was the main thing... we are still battling with that, even now... I think nobody warned us about that, maybe if they did they didn’t tell us how bad it becomes... her character changed.”* (Participant Three).

It was evident in all participant’s discussions that personality changes were among the most stressful sequelae to accept and manage when you are the primary caregiver of a TBI survivor.

### *Physical Disabilities*

According to the participants, witnessing the physical disabilities that their family members have suffered impacted their interactions with each other and was perceived to be a source of stress for caregivers. The physical challenges that were perceived to be particularly stressful included seizures, hemiparesis, tremors, unbalanced gait and being wheel chair bound.

Participant four explained how her father being completely reliant on a wheel chair influenced the family’s living arrangements to accommodate him: *“We used to live with my mum’s parents with my dad. Thereafter he got sick but it was becoming too cramped for him, we couldn’t carry him up and down the stairs all the time... but now that we got a flat we had to change our living arrangements. Also, we had to find something that suits dad... cause now we have a wheel chair, so we’ll like wheel him from the room to the lounge to interact with us.”*

In line with physical changes, one of the participants explained that their family member had to receive brain surgery a few years later to better control a tremor: *“In 2010 he went in for a brain op, deep brain stimulation, he has a neuro-stimulator in his chest... he was the first patient in the world to get this for trauma, it’s definitely helped him... I mean that was an 11-hour op where he was awake the whole time... just not knowing again, you didn’t know if he was going to come out paralyzed or blind... he’s due to go in for the replacement stimulator next year...”* (Participant Five)

Pain and sexual related problems were also mentioned as a source of stress. This not only affects the patient but the caregiver as well, in particular, where the spouse is the person providing care. Participant one explained how the relationship between her and her husband has changed since the TBI. According to her, a decreased level of intimacy has changed the dynamic of their relationship: *“The intimacy side had stopped... because I*

*was afraid to put him under pressure and then he had that urology problem so that has really changed our lives.” (Participant 1)*

### ***Caregiver Responsibilities***

Participants reported that their perceptions of adjusting to the role of caregiver was stressful. This would often result in them being sick and even needing hospitalization. The stress of having to be constantly available for the patient led to self-neglect and burn out.

#### *Neglecting Self-Care*

The stress involved in caregiving for a relative often leads to burn out. Three of the participants were admitted to hospital at various stages of their family member’s recovery for burn out. Participant two, like a few others, suggested that she often neglected her own self-care in favour of being there for her brother in the hospital: *“In those first three days I sat in the hospital... I don’t remember bathing, I don’t remember eating, I couldn’t sleep... but I remember sitting there in the hospital refusing to move.”* Participant five attributed their Lupus diagnosis to the stress of adapting to becoming a caregiver: *“Still to this day I have a sleeping problem... I ended up in hospital, I went down to 35kgs from the stress and I ended up getting an auto-immune disease from all this, Lupus.”*

#### *Changes in Relationship Dynamics*

All participants reported that the additional responsibilities involved in caregiving are stressful and that often roles have to be adapted or reversed when accommodating for caregiver duties. For example, participant four mentioned how having a baby will be impacted by having to manage their father’s TBI: *“Once baby comes, we know now we will have more to deal with... I think we will just try work around having a baby at home... maybe our routines will change a little bit but it would be us having to work around him, we can’t change dad’s routine.”* The participant explained that despite the additional caregiver responsibilities being stressful, there is a role reversal occurring where it is now the daughter’s obligation to care for her father.

## *Guilt*

Two participants mentioned feeling guilty about not always being present whilst their family member was in hospital because of returning to work or resting at home.

Participant one explains how other people's comments led to feelings of guilt: *"I thought to myself not everyone will understand... I could sit at home or I could just sit all day at his bedside... still to this day I feel guilty, maybe I should've taken leave from work... people would say I'm surprised, your husbands in hospital and you're at work, I felt like people were judging me."*

## *Making Medical Decisions for the Patient*

Participants reportedly felt immensely responsible for their family member's wellbeing when signing consent documents with the hospitals and health care professionals. The participants explained that this was a major decision and that there was little time to deliberate in these type of emergency situations. Participant two recalls signing consent for a brother's emergency surgery: *"Then the vascular surgeon here saw to him and asked me to sign and it was the first time I like had to really sign documents too... so now I'm thinking if he dies I'm the one that signed for it, and if I don't sign for it, what will happen."* The participants all mentioned feelings of guilt and having "what if" thoughts about the surgery not being successful or blaming themselves for signing the consent if the patient died.

## *Concerns about the future*

Participants that were parents expressed concerns about their child's future, especially in relation to their child not being able to meet a partner or have a career. This was evident in participant five's dialogue: *"For us as folks it's very hard for us knowing that he's never going really have a proper career and be able to have a normal life, like meet a girl and get married and have children... so it's a worry for us about his future."* Another major concern for both sets of parents was what would happen to their children in the event of one or both parents either not being able to be a caregiver anymore due to illness or passing away.

## *Social Networks*

Although social networks were a major source of support for all participants, a few of them referred to instances where friends or other family members were perceived to be insensitive. In addition to this, lack of public awareness about people with TBI and negative attitudes towards people with disabilities in general was a source of additional unwanted stress.

### *Interference and Assumptions*

Two of the participants experienced disagreements with friends and extended family regarding visiting rights as well as concealing the details about their family member's accident. All participants were advised by health care professionals to minimise the number of visitors whilst their family member was in ICU due to potentially interrupting the patient's quiet environment and increasing the risk of infection. However, for participant one, this decision was not appreciated by others: *"I didn't want people visiting him in ICU because I know people carry infections and he didn't know who was visiting him anyway... some people didn't understand that, they were angry with me."*

Another participant's extended family ignored instructions to not discuss the accident with the patient in case this caused emotional distress: *"We told them don't talk too much and if he asks questions say you don't know otherwise rather don't go in... then these two people went in, one being my cousin, they were there for very long... we could see his bed from the entrance and he was having like fits, something stressed him out... a couple of visits later I found out that they told him."* Participant two was also confronted with offensive assumptions by others regarding the details of the accident: *"It's very sad because some people, even in the seriousness of things, can be very nasty... I walked out the ICU door and a family member of mine got up to come towards me, I was crying hysterically... I said they might cut his leg off and she said but maybe that's what he deserves because he must have been speeding."* She elaborated that this was upsetting because in crisis situations people expect their friends and family to provide support, not criticize the patient and make unfounded assumptions.

### *Lack of Awareness and Societal Attitudes*

Participants commented on society's lack of awareness regarding TBI. They noted a general lack of educational materials and awareness campaigns both in health care centres

as well as the media. This may impact or contribute towards the misconceptions of TBI survivors. This was articulated as follows:

*“I think it’s not really publicly known, I think there should be more public awareness... and also like what people undergo, like the personality changes, so that society can understand when they are looking at someone like that don’t just say that person is mental, don’t just assume... it actually irritates me when I hear people say that now because I know more about it.”* (Participant Four)

Furthermore, lack of awareness makes it difficult for caregivers to reintegrate the patient and themselves back into the community: *“Sometimes, even till this day, like when we take him out or he behaves in an inappropriate manner, people don’t understand him... it’s difficult to cope with society, to fit in sometimes with him, it’s difficult to try and make people understand also.”* (Participant Four)

There was further agreement that there is a general perception in society that if a person is not physically disabled then the disability is not severe or doesn’t exist, which is often the case with a number of TBI survivors who usually present as neurotypical whilst trying to deal with cognitive challenges and personality changes: *“People have this perception that if you can walk, you’re alive, you can talk, you’re fine, but they don’t see all the emotional things.”* (Participant One)

### ***Financial Burden***

All participants reported that financial burden was a major source of stress. The financial burden was mainly accumulated by injury on duty or medical aid not covering all the costs involved in the patient’s treatment plan. Another expense was paying for transportation to visit their family member whilst in hospital or attend follow-up appointments once discharged. The participants also discussed a lack of support from their family member’s employers and the Workman’s Compensation Fund regarding claims and medical boarding, this was especially stressful when the patient was the breadwinner in the family. These challenges were explained in the following manner:

*“We were on a hospital plan, that was draining, it was quite tough... I mean when you going to a therapist at eight hundred rand a pop... but to be quite honest you know how your brain changes, you start saying we will pay anything, it’s amazing how your priorities change.”* (Participant Five)

*“The municipality paid the IOD bills, like the hospital bills, but we still had to pay for transportation to get him to the hospital and back and to visit, for physio sessions and some Neurologist wasn’t on the IOD network so we were paying cash for visits.”*  
(Participant Four)

*“My dad was like the sole provider at home and I just started work at the time and my brother was still in school... it was really difficult to trying to get people to help, because we couldn’t afford a caregiver for like every day or every month.”* (Participant Four)

*“We had no assistance from the Municipality what-so-ever... We actually received a notice that we had to visit his occupational health doctor only two years after his injury, at that time it was already too late, they had decided to pension him off instead of medical boarding... there were things he could’ve claimed for that he didn’t... for us that was absolutely devastating, because the financial side of it was really difficult at some points.”* (Participant Four)

*“Medical aid was a nightmare... getting through to people, the lack of communication was terrible... like with the bills I had to pay cash and then the onus is on you to submit, then two weeks later they’ll say they didn’t get it, it was very frustrating.”* (Participant One)

There were also two instances where caregivers felt that administrative staff were insensitive with regards to the manner in which financial matters were dealt with:

*“You’ve just been called, your daughter has been in a terrible accident and all people want is your medical aid card or signatures for money, I mean I hadn’t even seen my daughter yet... I do understand they need the medical aid or money but the way it’s done is just very distasteful, just give me some time to calm down.”* (Participant 3)

### *Limited Resources*

Limited resources were another major source of aggravation, especially during the acute phase. Participants complained about the delayed response time of emergency services as well as the fact that some areas did not have enough ambulances. This was also mentioned as a stressful encounter for family members:

*“There was still no ambulance, no police, nothing and I already got from Bluff to you could say the airport... I remember saying but there are two ambulances and there’s three patients... they took the other chap and put him in the normal place and they took my brother and lay him on the bench seat.”* (Participant Two)

Interrupted electricity service, colloquially known as “load shedding” appears to have impacted the treatment provided in emergency departments:

*“There was load shedding on that day... this is what they told me, yes, they did a CAT scan and they checked the upper spine but they couldn’t do all the other bones to check for broken bones because there was load shedding.”* Participant three explained that this was perceived to be stressful as the patient could have had other injuries that would have been neglected, which is not the level of service expected from a private hospital. This also indicates that some hospitals, albeit private, do not always have back-up generators available, as would be expected where critical services are being offered.

Chapter 5: Table 4

#### *Themes related to Caregiver Coping Strategies*

Themes	Sub-Themes
Problem-Focused Coping	Health Care Professionals
	Routine
	Social Support
	Research and Experience
Emotion-Focused Coping	Optimism and Humour
	Acceptance
	Religion

## Caregiver Coping Strategies

Two main themes emerged from the data analysis in relation to the coping strategies employed by caregivers. All participants employed both problem-focused and emotion-focused coping strategies. The problem-focused coping strategies frequently discussed included support from health care professionals, returning to normalcy, social support, research and learning from prior experience. Optimism, religion and acceptance were the emotion-focused coping strategies most commonly mentioned.

### *Problem Focused Coping*

All participants made active attempts to improve their situation and relied on others for support including advice from health care professionals, maintaining a routine, seeking social support, researching on the internet and learning from experience.

#### *Support from Healthcare Professionals*

The participants perceived their Doctor to be competent based on the consistent feedback, compassion, dedication and explanations at each stage of the patient's recovery. Interactions with the Doctor was one of the most commonly discussed coping strategies and was perceived to be a form of reassurance. This was demonstrated in a quote from participant two:

*"I used to wait for Doctor every single chance I got... I knew this Doctor stays in hospital very late and is very very dedicated to his work... even though he said the same thing to me every single day, to know that it is the Doctor talking to me made me feel better, he would tell me very calm and patiently and I think that's what I appreciated."*

Of importance, here was the Doctor's communicated 'presence' as well as patience irrespective of the content of the engagement. This was perceived by the caregivers as therapeutic.

The importance of the doctors communicating in layman's terms, without the use of medical jargon, was perceived to be respectful towards the caregivers: *"The Doctor told us what had happened, he was very thorough, he even drew stuff for us to explain to us*



*the severity of the injuries... he gave it to us, you know like it is, he didn't hide anything and he answered all my questions... I really appreciated that.*" (Participant Three)

*"Every time I saw Doctor, he was positive and he inspired you to go home and not, I was losing faith, I thought this is it you know, she's never going to be, she's brain damaged, she's never going to come right...but of all the times I did see him, he encouraged us, the physio was very positive, so that type of re-affirming and reassuring helped."* (Participant Six)

The presence of a crisis counsellor was also mentioned as a valuable source of support especially during the acute phase which was most uncertain for caregivers: *"She explained to me what happened and ja they were still stabilizing... she told me she is a counsellor and that she helps people in crisis situations... she played a very vital role at that time because at least she gave me information."* (Participant Three) Participant one felt that their family would've also benefited from psychological support: *"The sad thing is, you know, is that I asked him, do you want to see a psychologist... he said no he doesn't want to see a psychologist, he's never believed in all that... but I believe that maybe if he did speak to a psychologist, he would have coped... and maybe if I can take that credit, I was like his psychologist, the support, but it was hard."*

For a few participants, watching the nursing staff interact with their relative was informative:

*"And the nurses at that time in the ward, I think they understood him a little better than we did, or they knew how to cope with him better because when he used to shout or say inappropriate things and we used to be like shhh... the nurse would say no, like it's OK or leave him he doesn't understand... I think we took something away from the nurses, that maybe they taught us this is the way you should react or better handle the situation."* A number of the participants also commended the nursing staff on their helpful advice and the compassionate care given to their family member.

The above examples illustrate the degree of support required from health care professionals for caregivers to cope effectively as well as how important it is to caregivers to be provided with information to improve their understanding and prepare for adjusting to their caregiver responsibilities.

### *Routine*

All participants mentioned that trying their best to keep to their usual routine helped them cope better and allowed them space to be themselves.

Half of the participants said that returning to work was recommended because this kept them preoccupied rather than worrying about their family member in the hospital. The support from colleagues was also appreciated: *“Being at work helped me because it kept me occupied... I told myself when I’m at the hospital I’m at the hospital, but when I’m teaching the children are my responsibility.”* (Participant One)

Two of the participants also discussed how creating a routine for responsibilities made this easier for both the patient and caregiver: *“Building a routine actually helps us with the day to day activities... it actually makes it easier for us as well... so by him having his specific times, we know there’s a time allocation... he also knows and reminds us.”* (Participant Four)

The importance of self-care and having time alone to reflect on their situation was mentioned by the participants:

*“Some people, obviously meaning good, they wanna come and stay with you, so I told them ok guys, please I don’t want anyone coming to stay with me except my aunt... I need my alone time, whether I need to cry or pray or just sit there on my own, because you know all the time when the people are there you need to keep it together... it’s better to have your own space.”* (Participant Three)

### *Social Support*

Although sharing their experiences with others was helpful, the findings suggest that caregivers appreciated concrete assistance. Examples of this included neighbours delivering a meal or sharing visiting hours at the hospital. Verifying decisions with other family members regarding the patient’s treatment or surgery was also deemed important.

Individuals within the family unit would often rely on each other for both emotional and physical support: *“I think we used each other to cope... because we had each other, we always had people around us though.”* (Participant Four)

The significance of support from friends and other social settings was discussed by the participants: *“We had a lot of people that supported my husband and I... people and faith,*

*you must also have faith... you must have a support system, you can't do it all alone."*

(Participant One)

*"On weekends family would invite me around to their places and I also had a good group of friends, so that support was vital... It's nice to talk about it, what you feel, what you're experiencing, you know."* (Participant six)

### *Research and Experience*

All participants mentioned researching TBI and found that the more they understood about their family member's condition, the better they were able to cope with their caregiver duties. Sharing information and materials from and with other caregivers as well as health care professionals was reportedly helpful to the participants. This was illustrated in the comments below:

*"Now I'm reading more about traumatic brain injury because at the neuropsychologist they give her pamphlets for her to read and understand, she knows, I think she knows more than me... so that I think is very crucial for anyone, they've really helped all of us."*

(Participant Three)

*"We always did research and got involved and found out more, I think that helped a lot... I think that people are well informed it's easier for them to cope with these kinds of situations... I wish we had the proper information and someone who experienced this before to assist us, I think that would go a long way."* (Participant Four)

Although researching TBI and caregiver advice was helpful in most instances, caregivers were cautious about using the internet for research because this often contains graphic and extreme case studies which can be distressing. Thus, they relied more on health care professionals for advice and learning from their own experiences: *"I think now after five years, we sort of expect certain things, we know how to plan for these situations... I'm not saying that we will always be one step ahead but at least we know what ground to cover as opposed to five years ago, not knowing what to do."* (Participant Four)

### ***Emotion Focused Coping***

Although the participants all acknowledged the significance of physical attempts to improve their situation and asking other for help, a few participants mentioned that the way a person perceives their situation can also impact their ability to cope with caregiver

duties. This means that staying positive and trying to accept what has happened often helped caregivers to cope better.

### *Optimism and Humour*

Maintaining a positive outlook helped most caregivers to cope better and reduced tension in stressful situations. The use of humour was mentioned as a coping strategy: *“I like humour, I try and use humour in my life, you know with all that happens... sometimes she laughs at me, sometimes I will say, what’s wrong with you did you hit your head or something and she will laugh and say ma it’s too soon for that, too soon and we laugh, because we watch Trevor Noah.”* (Participant Three)

Optimism being used as a coping strategy is illustrated in the comments below:

*“I’m now so thankful for every day, maybe if this didn’t happen I wouldn’t be so appreciative of life in general and of the people around us... it’s the quality of life not the quantity of possessions you have... I can genuinely say, genuinely with all sincerity, our lives have improved because of our closeness, the communication and knowing what we almost lost.”* (Participant One)

*“When she was lucid again and knew what was going on she was very positive, so yeah it’s been great to get her home... she’s not the woman that was beforehand, really depressed, didn’t want to do anything, now she’s happy... I mean she is now the girl that I married... I mean I’ve also had to learn how to do more around the house... things I’ve never had to do in all my life, I mean she’s always done them... so it’s made me a better person too I think.”* (Participant Six)

Half of the participants felt that keeping their hopes high and being grateful for any progress the patient made got them through difficult times, for example one participant explained how the Physiotherapist visits gave their family hope: *“I know that the Doctor asked for a physio to see to him, but now I’m thinking but he must be going to survive because why would the Doctor ask, maybe the Doctor knows he is going to live and doesn’t want to tell us because just in case he dies...”* (Participant Two)

*“It was so difficult to see him like that, but it was also progress.”* (Participant Five)

The participant further explained that being empathetic towards other people’s reactions was helpful when experiencing social isolation:

*“but you’ve also got to be fair to other people, people react differently and it doesn’t mean that they don’t care... I mean we used to see that when we used to push him in his wheel chair, you would see good friends coming towards you and next minute they would go into a shop... they just didn’t know how to deal with it, so it’s not bad on their side, they actually just didn’t know how to handle it.” (Participant Five)*

### *Acceptance*

Achieving a level of acceptance was reported to be valuable after many years of trying to make sense of what happened and how to cope with all the adjustments following their family member’s accident. This is illustrated in the following comments:

*“you know it almost gets to a stage where we say almost every day it’s a brain injury, you almost come to accept that he’ll do stuff, he does stuff differently, he is his own, it’s just different... as hard as it is, it is what it is... and we have this for the rest of our lives as much as he does.” (Participant Five)*

*“I always maintained this and I often tell him this, your accident does not define you because I have never wanted a before and after scenario for us... so I never let it come to that because we are still the same people, it’s just that our circumstances have changed.” (Participant One)*

### *Religion*

The most commonly mentioned emotional coping strategy was religion or faith. All six participants felt that praying for their family member was comforting and that the situation was “in God’s hands” or beyond their control. Caregivers also appreciated others praying for their family members and believed that more prayers would increase the chances of a miraculous recovery;

*“you’re thinking oh my god is my daughter going to survive this, it’s very stressful... so I think for me, prayer kept me going, just praying and knowing that other people are praying for her, praying for us...” (Participant Three)*

*“I said he can pray for him, and he prayed for my brother for a very long time ... he came out and we were talking and he said don’t worry he will be ok, I prayed to Jesus... it was very reassuring.” (Participant Two)*

These findings suggest that both problem focused coping and emotion focused coping each contribute in their own way towards the patient and their family experiencing a positive adjustment to the stressful situations encountered following the accident. It appears that these efforts continue to change according to the caregiver's requirements at each stage of the recovery process and can have a major impact on the outcomes for both the patient and their family.

### **Conclusion**

The present study involved semi-structured interviews with six participants. Six themes related to caregiver stressors were identified via thematic analysis. These themes included hospital experiences, sequelae of TBI, caregiver responsibilities, social networks, financial burden and limited resources (Refer to Table 3). Two themes were identified related to caregiver coping strategies including problem-focused coping and emotion-focused coping (Refer to Table 4).

## **Chapter 6: Discussion**

### **Introduction**

The aim of this study was to investigate the perceptions of stress and coping strategies adopted by the caregivers of TBI survivors. These stressors and methods of coping were investigated by discussing the caregiver's experiences. Previous studies suggest that caring for a TBI survivor is a challenging endeavour and includes many stressful situations. However, research has also found that there are numerous different resources available to assist families to mediate levels of stress as well as cope better with adjusting to the role of caregiver (Degeneffe, 2001; Minnes et al., 2000; Rawlins-Alderman et al., 2014; Shotton et al., 2007; Verhaeghe et al., 2005; Webster et al., 2015). Similar findings emerged in the present study, with family members reporting a number of stressors associated with the role of being a caregiver. However, the participants also acknowledged resources that enhanced their ability to manage these challenges and positively adjust to their new lifestyle. The previous chapter identified the themes and sub-themes which emerged from the data, including both stressors and coping strategies. The Transactional Model of Stress and Coping (Lazarus & Folkman, 1984) will be used to interpret these themes to contextualise the stressors commonly encountered by caregivers and the coping strategies adopted which will be discussed in this section.

### **Caregiver Stressors**

According to Lazarus and Folkman (1984), stress is the physical or psychological demand encountered by a person which is perceived to be unavoidable or challenging to achieve. The model assumes that stress is a dynamic person-situation encounter that depends on the dynamic relationship between a person and their environment. Primary appraisal involves the initial evaluation of the stressor being either irrelevant, benign-positive or stressful. There were no irrelevant or benign positive situations mentioned by the participants, thus only stressful situations will be discussed. A situation is appraised to be stressful when it is perceived to be threatening to the wellbeing of the individual concerned or significant others in their life. These stressors are considered detrimental involving threats of either loss or harm and challenges to the individual, their significant others or environment. Examples of threats, harm, loss and challenges were discussed by all participants, making reference to their current situation as well as concerns about the future.

### *Hospital Experiences*

All participants reported that hearing about their family member's accident was a traumatic experience, irrespective of the way in which this information was delivered. Although the participants were not directly involved in the trauma, learning about a family member's accident can be indirectly traumatising for caregivers. A number of the participants reported post-traumatic symptoms, for example hyperarousal and nightmares (Herman, 1997). The hospital environment also caused a significant amount of stress for caregivers, particularly with reference to the trauma unit and intensive care unit equipment. The literature suggests that families of TBI patients are often overwhelmed when their relative is admitted to the ICU. This is usually due to concerns about the patient's critical status, the unexpected occurrence of the accident, the patient's fluctuating condition and the possibility of losing a loved one (Bond et al., 2003).

Uncertainty contributed significantly to family members stress, especially in relation to not knowing what to expect when the patient awakens, being uncertain of the patient's prognosis and what to expect regarding their recovery. Previous studies have found that uncertainty is common for both the family and health care team because it is difficult to predict the prognosis and effectiveness of any interventions due to the complexity of TBI cases (Stulemeijer et al., 2008). Participants also reported dissatisfaction with the treatment being provided by nursing staff and referral physicians. The complaints were usually related to the caregiver's perceptions of nurses being neglectful of basic duties or doctors displaying poor bedside manner. Similar findings were presented in a study conducted by Lefebvre et al. (2005) where participants reported dissatisfaction with nursing staff and doctors treating the patient with minimal compassion and this made the participants concerned about the quality of care being provided.

### *Sequelae of TBI*

Traumatic brain injury survivors are often called 'the walking wounded' because a number of these individuals appear physically normal, however suffer a number of neuropsychiatric sequelae leading to lifestyle limitations (Rao & Lyketsos, 2000). All of the participants in this study discussed the patient's personality changes in relation to how these were difficult to manage and accept. The most commonly mentioned changes in personality included anger outbursts, inappropriate behaviour, demanding behaviour, unpredictable behaviour and depression.



According to the review conducted by Rao & Lyketsos (2000), a number of neuro-psychiatric sequelae may be experienced by TBI survivors including cognitive deficits, mood disorders, anxiety disorders, psychosis and apathy. The authors elaborate that mood disorders are commonly diagnosed in TBI survivors, with depression occurring in approximately 25% of TBI cases. Similarly, Bryant et al. (2010) found that the most commonly reported psychiatric disorders following a TBI were depression, generalised anxiety disorder, posttraumatic stress disorder and agoraphobia. From a cognitive perspective, the patient may present with impairments in memory, attention, concentration, problem solving, abstract reasoning, planning, information processing and organization (Degeneffe, 2001). A number of studies have documented the stress and decreased quality of life experienced by caregivers whilst trying to adjust to the broad spectrum of personality changes demonstrated by TBI survivors (Calvete et al., 2012; Conneeley, 2012; Evans-Roberts et al., 2014; Lefebvre et al., 2005; Livingston et al., 2010; Minnes et al., 2000; Webster et al., 2015).

Although the personality changes were reported to be significantly more stressful, the participants also reported challenges related to their family member's physical disabilities including hemiparesis, epilepsy, unbalanced gait, tremor and being wheel chair bound. It has been documented that these disabilities have a restricting impact on the patient's independence as well as limits any dynamic engagement with their family and community (Webster et al., 2015).

### ***Caregiver Responsibilities***

The responsibility that accompanies caring for an injured family member was an area that was emotional for caregivers to discuss, often evoking feelings of fear and guilt. The participants mentioned two instances where guilt was experienced. This included the times when they had to make life decisions for the family member in the form of signing consent documents as well as when they had to take a break from visiting the hospital. Caregivers in this study felt guilty that their relative was confined to ICU whilst they could enjoy life (Coco et al., 2013). This is in line with a study conducted by Kelso et al. (2005) where they also found that all medical and treatment decisions generally became the responsibility of the primary caregiver which caused a significant amount of stress for the individual concerned.

A study conducted by Rawlins-Alderman (2014) found high rate of burn out amongst caregivers of TBI survivors. Similarly, more than half of the participants in the present study experienced burn out and were either admitted to hospital or diagnosed with a stress-related illness. Evans-Roberts et al. (2014) also mention that high levels of emotional distress among caregivers are often associated with somatic complaints, fatigue, stress and burn out. This is understandable, considering previous studies investigating the relationship between trauma and the human body revealed that biological disruption is commonly associated with traumatic experiences and high levels of stress. This is because the body assumes survival mode when experiencing stressful conditions. Thus, the flight-or-fight centres of the brain are activated and other body systems are halted. If this stress response continues for a protracted period, the body may not be able to return efficiently to prior functioning and the individual may develop immune-related illness (Wastell, 2005).

Carnes and Quinn (2005) discuss the stress associated with parents concerns about their child's future. Following a TBI, parents often have to negotiate issues of independence and dependence at each stage of recovery as well as make compromises in their own lives. A similar concern was expressed by a parent in the present study with regards to their son's TBI sequelae preventing him from having a relationship or career. This was apparently distressing for both parents and continues to be a concern, especially in relation to their child's wellbeing if for some reason both of them are unable to provide support in the future.

The stress caused by changes in relationship dynamics following a family member's TBI are well documented in the literature (Carnes & Quinn, 2005; Conneeley, 2012; Kelso et al, 2005; Rawlins-Alderman, 2014). Previous research suggests that approximately 60% of families' initiate alterations to the unit's structure when a family member sustains a traumatic brain injury. This is usually in a collective effort to provide additional assistance to the injured relative. This is typically a stressful transition because it requires extensive compromise from all members of the family unit (Carnes & Quinn, 2005). The participants in this study reported similar experiences, for example experiencing role reversal being a child caring for their disabled parent.

### ***Social Networks***

Although social support was greatly appreciated, all participants in the present study reported examples of interference from extended family members which caused great distress for the caregiver involved. The instances mentioned in the present study involved extended family members divulging the traumatic details of the accident to the patient, relatives arguing about restricted visitation as well as insensitive comments. This was similar to a study conducted by Siminoff (2013) which also discussed how family members may intrude on the clinical encounter as well as negatively impact the relationship between the patient and their physician. Although this can cause a significant amount of distress for the patient or their caregiver, it is also important to acknowledge that illness is a biological and socio-cultural process in which families may be able to contribute valuable information and support (Siminoff, 2013).

Most of the participants in this study reported experiencing stigma, particularly in relation to social reintegration. Within the context of disability, labelling involves the recognition that certain personality or physical traits are different from the norms and are considered adverse. A negative reaction to these differences often leads to a pronounced sense of 'otherness' and stigma is experienced. Similar to individuals with disabilities, caregivers often encounter stigma in their community which can lead to increased stress and social isolation (Green et al., 2005). A few examples of the ways in which stigma was experienced by the participants were discussed in the current study. The lack of awareness regarding traumatic brain injuries as well as how this contributed towards the negative way the public typically perceive and interact with TBI survivors was concerning to majority of the participants in this study.

### ***Financial Burden***

A study conducted by Carnes & Quinn (2005) confirmed that the financial burden associated with the care of TBI patients is stressful for caregivers. The study found that financial security had a major influence on the caregiver's level of psychological distress and most of the participants discussed concerns regarding the patient's insurance coverage. Similarly, the excerpts offered by the participants in this study demonstrated that financial burden and dealing with insurances are a major source of stress for caregivers. The findings also demonstrate that how administrative staff deal with financial

matters is impressionable and is often associated with caregiver's general perception of the hospital.

The difference between the accounts paid by medical aid or injury on duty and the amounts rejected were the main contribution to financial burden for caregivers in this study. In South Africa, rehabilitation is expensive in the private sector and medical aids that provide full coverage typically cost thousands of rand per month. Thus, majority of the population can only afford to belong to basic medical aid plans and must pay for the outstanding accounts not settled. These costs can accumulate quickly, considering a session of physiotherapy costs approximately R400 and patients often require continued rehabilitation from variety of professionals (Dovey & Graffam, 1983). The present study revealed that it was not only the costs involved that were a major source of stress, but also the way in which administrative staff dealt with issues of finance. Participants expressed their discontent about administrative staff being too abrupt and were often insensitive towards the level of trauma being experienced by the family.

With regards to IOD, a participant in this study explained that not all service providers are contracted to injury on duty and thus the family had to pay additional accounts.

Consequently, the restricted services covered by injury on duty had a major influence on their family member's recovery and meant that the family had to personally pay for many medical bills. Although some rehabilitation services may be available in both the private and public sector, the cost of transporting the patient to sessions can be prohibitive (Dovey & Graffam, 1983). The cost of transport to visit the patient in hospital as well as attending follow up appointments was also mentioned by a participant in the current study. Furthermore, this participant's family did not receive any assistance from their family member's previous employment with regards to claiming from the compensation fund or with the process of medical boarding. The challenges associated with compensation were also briefly discussed by Lefebvre et al. (2005).

### ***Limited Resources***

The participants in the current study discussed the ways in which resources are limited in Kwa-Zulu Natal, particularly in relation to the availability of emergency services and disruption of electricity services. The findings of this study suggest that the limited availability of ambulances and the prolonged response of emergency services are concerning. This is especially concerning considering that ineffective transportation of a

critically injured patient increases their morbidity and mortality. A study conducted by Scribante & Bhagwanjee (2007) in Cape Town reported similar findings, with a significant number of critical patients being transferred to hospital using ill equipped and inadequately staffed ambulance services.

The present study also revealed how the interrupted supply of electricity can negatively impact the provision of health care services in hospitals, especially in relation to emergency services which are reliant on high voltages of electricity or advanced technology. Although there are a few studies investigating the negative impact of load shedding on the country's economy, the researcher could not locate any formal publications regarding the impact of load shedding on the provision of medical services. The only information available was a FAQ document found on the Eskom website which makes reference to 'customers with special needs'. Eskom recommended that customers requiring medical support equipment should speak to their physician about what arrangements could be made in case of no electricity, for example obtaining back-up batteries for equipment or additional oxygen cylinders. ([www.eskom.co.za](http://www.eskom.co.za)).

### **Caregiver Coping Strategies**

According to Lazarus and Folkman (1984), the process of coping involves two key components namely problem-focused or emotion-focused coping methods (Minnes et al., 2000). Problem-focused coping strategies refer to attempts at reducing or managing the stressor by changing the situation. Attempts at regulating the emotional responses to a stressful situation are called emotion-focused coping strategies (Louw & Edwards, 1993). However, it is important to note that some strategies may serve more than a single function. Problem-focused and emotion-focused coping strategies may intersect or may be simultaneously adopted. This means that the findings below should be interpreted with caution (Lazarus, 1993; Norup et al., 2013).

#### ***Problem-Focused Coping Strategies***

Problem-focused coping strategies are attempts at actively managing the problem. These typically include asking for practical assistance from others, learning a new skill, planning better or seeking information (Kelso et al., 2005). The caregivers in the present study mentioned a number of problem-focused coping strategies, for example seeking advice from the health care team and researching TBI to better their understanding of the patient's condition.

### *Support from Healthcare Professionals*

The most commonly discussed coping strategy was interactions with the patient's primary physician and this was perceived by all participants to be a form of reassurance. The participants all appreciated the physician's compassion and regular feedback sessions. Previous research suggests that family members appreciate support and direction from the health care team (Degeneffe, 2001; Man, 2002). Similar to the study conducted by Coco et al. (2013), the participants in the current study also reported that the competency of nursing staff caring for their relative was reassuring. Participants in both studies also reported that support from nursing staff helps families to deal with numerous concerns related to the patient's care following discharge.

Debriefing provided by crisis counsellors was also perceived to be helpful by participants, primarily because this provided a source of feedback regarding the patient's condition and what to expect at each stage of the patient's stabilization in the emergency room. This is typical of a crisis intervention which usually involves counselling to provide extra support and reassure the family that help is available to reduce anxiety and feelings of helplessness in a traumatic situation (Brammer & Shostrom, 1977). Only two of the participants received crisis counselling, however both mentioned that this was a major source of support during the acute phase of the trauma. Participants that did not receive counselling expressed that this may have been helpful and felt that their injured relative may have benefitted from therapy to better deal with issues of adjustment in the long term. This may have been valuable for caregivers and their families, considering the purpose of counselling or therapy is to assist clients with problem situations that are causing emotional distress and enhance their coping strategies to better deal with potential problems in the future (Egan, 2010).

### *Routine*

Majority of the participants reported that trying to re-instate a degree of normalcy back into their lives was helpful. This was most commonly in the form of returning to work or creating a routine for caregiver duties. In a study conducted by Lefebvre et al. (2005), caregivers reported that going back to work, keeping busy and following a routine helped to alleviate stress as well as restructure daily activities. Having 'alone time' was also important to caregivers for self-care and to be able to mentally process the changes that were rapidly occurring in their lives. Rawlins-Alderman (2014) found that having

personal time relieved a degree of stress associated with being a caregiver as well as allowed for the recuperation of the caregiver's mental and physical capacities.

### *Social Support*

Social support refers to the help provided by friends and family which alleviates a degree of the stress associated with the burden of being a caregiver. Examples of social support include assisting with caregiver responsibilities and offering advice (Degeneffe, 2001). Previous studies suggest that social support can significantly decrease or eliminate the negative impact of stress (Louw & Edwards, 1993). The literature suggests that social support is the most common coping strategy employed by caregivers of TBI survivors (Carnes & Quinn, 2005; Conneeley, 2012; Degeneffe, 2001; Kelso et al., 2005; Man, 2002; Verhaeghe et al., 2005). All participants in the present study discussed the importance of social support, however this assistance was mostly in the form of delivering meals or taking turns to visit their relative in hospital. Participants also appreciated being able to ask their family's advice when signing consent or discussing treatment options on their relative's behalf.

### *Research and Experience*

Similar to the findings in Kelso et al. (2005), participants in the present study also reported that their resources accumulated with time and consequently they felt better able to deal with the patient's disabilities. These findings imply that caregivers require time to learn how to deal with challenges through trial and error as well as gradually adapt to their changed lifestyle (Kelso et al., 2005).

Research suggests that professionals can enhance caregiver's feelings of empowerment by providing information about TBI and involving the family in their relative's rehabilitation. The provision of educational materials about TBI ensures that families are able to make informed decisions regarding their relative's treatment and rehabilitation (Degeneffe, 2001). Furthermore, in a study conducted by Webster et al. (2015) families reported that verbal information was inadequate because caregivers would prefer to review the information at their own pace and later share this information with the rest of the family. Families also reported that written information was preferred because the patient's needs are constantly changing at each stage of recovery. Thus, families often had to review the information again or find more relevant information from other sources (Webster et al., 2015). All participants in the current study also reported that researching

traumatic brain injury was helpful. This was because the more caregivers understood about the condition, the better they could cope with the patient's sequelae and their caregiver duties. A lack of information may also lead to families misunderstanding the patient's emotional or behavioural sequelae, for example blaming apathy on being intentionally lazy (Evans-Roberts et al., 2014). However, a participant in the current study also cautioned caregivers against searching the internet rather than consulting with the health care team. Although the internet contains a plethora of information relating to traumatic brain injury, this information is not specific to each individual's context and often contains extreme examples which can be upsetting. Participants expressed that advice from another caregiver in a similar situation would have been appreciated. This was the reason most commonly offered by participants in previous studies for joining support groups because caregivers can share advice and support each other during hardship (Degeneffe, 2001).

### ***Emotion-Focused Coping Strategies***

#### *Optimism and Humour*

In a study conducted by Norup et al. (2013) positive re-framing and acceptance were considered emotion-focused strategies and were both associated with better adjustment in families of TBI survivors. Similar to the findings of the present study, Rawlins-Alderman (2014) found that most participants reported that being a caregiver included positive experiences and that it was rewarding to contribute towards a loved one's recovery. In the present study, more than half of the participants reported that maintaining hope and a positive attitude were helpful coping strategies. Studies suggest that laughter and humour are positive ways of relieving or avoiding stressful situations (Louw & Edwards, 1993).

#### *Acceptance*

Accepting the altered situation or trying to find the positive in a negative situation are both associated with better outcomes for the patient and their family (Norup et al., 2013). Rawlins-Alderman (2014) suggests that the more time caregivers spend re-connecting with their injured family member, the better their sequelae can be understood and accepted. The quicker the family can accept that the sequelae are permanent, the better the family can adjust to meeting caregiver demands and initiating the necessary changes in family dynamics.



### *Religion*

Religion was the most emphasised coping strategy reported by participants in the present study. This is likely because faith is a frequently reported emotion-focused coping strategy. All participants reported that praying and having faith in their relative's ability to recover were of utmost importance. This may be because praying allows for mental relaxation and the responsibility for the patient's healing is shifted onto a 'higher power' capable of performing 'miracles' (Verhaeghe et al., 2005).

### **Conclusion**

This chapter discussed the findings of the present study in relation to the existing literature that was reviewed. The chapter was informed by the theoretical framework of the Transactional Model of Stress and Coping. The stressors and coping strategies of the present study were generally consistent with the findings of prior TBI caregiver studies, with a few unique contributions.

## **Chapter 7: Conclusion**

### **Limitations and Recommendations**

In the present study, the generalizability of the findings may be questionable because of the small sample size and data was collected from family members that volunteered to participate. It is also important to note that the findings of this study are specific to the context of private hospital patients in Durban, Kwa-Zulu Natal. Thus, caregivers in other parts of the country may provide different views of their experiences which may emanate from differences in culture and socio-economic status. This could limit the comparison or application of findings across different cultures as well as other countries. Furthermore, the findings were at risk of elite bias because the researcher only interviewed participants from private hospitals and therefore could not provide a broader understanding of the topic, for example participants from public hospitals were not included. However, the purpose of qualitative research is not to generalize the findings but rather to provide rich and detailed data relating to a specific issue (Myers & Newman, 2007). Lastly, the participant's experiences were explored retrospectively and at varying time spans following their family member's accident. The preferred methodology for the study would have been longitudinal to investigate causal relationships and have supplementary confirmation of the findings. However, this was unfortunately not possible in the current study due to time constraints.

Determining the needs of caregivers of TBI survivors is important for health care professionals to consider when trying to empower caregivers to better cope with the stressors encountered (Bond et al., 2003). Although the findings of this qualitative study contribute towards a better understanding of caregiver experiences within the context of TBI, further research is essential to provide sufficient information and develop effective intervention programs (Kelso et al., 2005; Man, 2002). Considering the participants of the present study were a convenience sample from Kwa-Zulu Natal, it would be valuable to replicate this study both in different contexts as well as with a larger more representative sample.

Further inquiry into the reactions and responses of families from different cultures when a family member sustains a TBI is required (Simpson et al., 2000). This would be valuable because each culture has their own prescribed ways of dealing with trauma and the information would be useful to those providing support. This would also be helpful to

tailor make interventions to include families' cultural and other requirements (Coco et al., 2013). Despite the recent increase in involvement of family members in patient's treatment and rehabilitation, research regarding the influence of the family on patient's health care decisions remains limited (Kolakowsky-Hayner et al., 2001; Siminoff, 2013). More information on this topic would be valuable, especially considering the major impact of family involvement reported by caregivers in this study.

Although reported in the 'participant characteristics' section, the present study did not investigate any relationships between caregiver stress or coping and any demographic characteristics. The present study also did not consider the impact of the severity of the TBI or the impact of the time elapsed since the TBI was sustained. This information may be useful to better understand if and in what way the demographics of caregivers, the severity of the TBI and the time frame since sustaining a TBI could either positively or negatively impact the caregiver experience.

### **Implications and Conclusion**

The purpose of the present study was to investigate the experiences of caregivers of TBI survivors in Kwa-Zulu Natal. These experiences included the stressful situations encountered by caregivers as well as the resources employed to cope with the caregiver role. The present study supports the findings within existing literature that sequelae of TBI, hospital experiences, caregiver responsibilities, lack of public awareness and financial burden were stressful situations frequently encountered by caregivers. However, unique findings that emerged from the present study included interference and negative assumptions by extended family members which often caused emotional distress for caregivers. Limited resources with regards to insufficient and delayed emergency services as well as interrupted electricity supply were also reported to be major stressors for caregivers in Kwa-Zulu Natal. From the caregiver's perspective, inadequate or interrupted resources meant that their critical family member's treatment was being delayed which was distressing.

With regards to the way caregivers coped with the above stressful situations, the present study found that both problem-focused and emotion-focused coping strategies were adopted. Although there were a few complaints relating to health care professionals, their support was considered very helpful by caregivers in the present study which is consistent with previous studies. Previous studies as well as the caregivers in the present study

suggest that creating a routine, conducting research on TBI and caregiver duties as well as learning from experience in the caregiver role were all helpful coping strategies. The present study's findings that social support was a valuable resource for caregivers is consistent with prior research projects. Religion was the most frequently discussed coping strategy in the present study, with faith and prayer being common coping strategies reported in previous studies. Trying to stay positive and being grateful for any progress made by the patient were strategies commonly reported by caregivers in the present study. Eventually accepting the altered situation and positively adapting to the caregiver role were also coping strategies reported by caregivers. These were all coping strategies confirmed in the existing literature and previous studies regarding TBI caregiver experiences.

The findings of the present study suggest that interventions in the form of psycho-education regarding the sequelae of TBI and how to better manage these sequelae would be appreciated by caregivers of TBI survivors. The caregivers in the present study appreciated the support of a crisis counsellor during the acute phase of the patient's hospitalization and recommended that this be offered to all families dealing with a traumatic event. It was also suggested by caregivers in the present study that counselling or support groups would be beneficial to share their experiences with others as well as receive advice on adapting to the caregiver role. Caregivers emphasised that the relationship between themselves and the health care professionals involved in the patient's treatment plan was important to them. Thus, the support and guidance provided by health care professionals was considered a valuable coping strategy and should be encouraged. Furthermore, the caregivers in the present study appreciated being invited to participate in the patient's rehabilitation sessions, which could be considered by other health care professionals to make families feel more included. Finally, the outcomes of this study could be used as a basis for other studies regarding the experiences of TBI survivors and their families. The more studies that are conducted will increase the knowledge available for interventions and programs to be enhanced that will benefit both TBI patients and their families in the future.

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# Appendix A

## Consent Form

Dear Participant

### Informed Consent Letter

My name is Julianne Hardman. I am a Master of Social Science Counselling Psychology candidate studying at the University of Kwa-Zulu Natal, Howard College Campus, Durban.

The topic of my dissertation is: A qualitative investigation of perceptions of stress and coping strategies employed by caregivers of individuals with a traumatic brain injury in Kwa-Zulu Natal: A retrospective study.

The purpose of the study is to interview caregivers of patients that have suffered a traumatic brain injury in order to examine which events were perceived to be particularly stressful, which coping mechanisms were adopted and which of these were considered helpful. The findings of this study could empower current and future caregivers by identifying which situations are stressful and methods that would assist caregivers to cope better, thus ultimately ensuring better outcomes for the patients and adaptive family functioning following the trauma.

Please carefully note the following:

- Your confidentiality is guaranteed. The information you provide as well as your personal particulars will not be mentioned, rather these will be reported by numerical reference.
- The interview may last for approximately 1 hour and may be segmented depending on your preference.
- Any information provided by yourself cannot and will not be used against you by any means, this information will be used for research purposes only.
- The data obtained will be stored under secure conditions and destroyed once 5 years have lapsed.
- You have the choice to participate, not to participate or to stop participating at any stage during the interview.
- You will not under any circumstances be penalized for choosing not to participate in the study.
- Your involvement is for academic purposes only and there are no financial benefits involved.
- If you are willing to be interviewed, kindly indicate (by ticking as applicable) if you are or are not willing to allow the interview to be recorded.

Equipment	Willing	Not Willing
Audio Recording Device		

Should you require any further information, I may be contacted at:

Email: [jujuhardma@yahoo.com](mailto:jujuhardma@yahoo.com)

Tel: 072 425 6715

My supervisor is Ms N Memela at the University of Kwa-Zulu Natal, Howard College Campus in the School of Psychology.

Email: [memelan@ukzn.ac.za](mailto:memelan@ukzn.ac.za)

Tel: 031 260 7428

You may also contact the research office via:

P Mohun

HSSREC Research Office

Email: mohump@ukzn.ac.za

Tel: 031 260 4557

Thank you for taking the time to consider your participation in this study.

Should you require any further support following this interview, arrangements can be made for you to receive counselling at the UKZN Psychology Clinic at Howard College Campus in Durban Central.

UKZN Psychology Clinic Contact Details: 031 260 2612

#### Declaration

I \_\_\_\_\_ (Participant Full Name) hereby confirm that I understand the contents of this document as well as the nature of this research project and I consent to participating in this research project.

I also understand that I am at liberty to withdraw from this research project at any time if I should desire.

Participant Signature:

\_\_\_\_\_

Researcher Signature:

\_\_\_\_\_

Date:

\_\_\_\_\_

## **Appendix B**

### **Interview Schedule**

#### **Question 1**

Enquire about specifications:

- Participant's gender and age
- TBI patient's gender and age
- Relationship to the TBI patient
- How long ago was the accident?
- How did the accident happen?
- Injuries sustained

#### **Question 2**

The questions to be answered should be answered in relation to your experiences from the time of the accident to date.

The past few years must have been a difficult time for you and your family. Would you mind telling me what you think caused you the most distress during your relative's accident and the recovery process involved?

#### **Question 3**

How did you manage these difficult situations?

#### **Probes:**

Which of the above strategies did you experience to be most helpful and why?

In retrospect, do you think there is anything you would've done differently?

#### **Points to remember:**

Thank you for participating in this study and should you have any further queries please don't hesitate to contact me.

All participants to be provided with a copy of signed consent form, researcher details and UKZN Psychology Clinic contact number.

# Appendix C

## Ethical Clearance Letter



27 May 2016

Ms Julianne Hardman 210505184  
School of Applied Human Sciences - Psychology  
Howard College Campus

Dear Ms Hardman

Protocol reference number: HSS/0473/016M  
Project title: A qualitative investigation of perceptions of stress and coping strategies employed by caregivers of individuals with a traumatic brain injury in KwaZulu Natal: A retrospective study.

### Expedited Approval

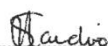
In response to your application dated 28 April 2016, the Humanities & Social Sciences Research Ethics Committee has considered the abovementioned application and the protocol have been granted **FULL APPROVAL**.

Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach and Methods must be reviewed and approved through the amendment/modification prior to its implementation. In case you have further queries, please quote the above reference number. Please note: Research data should be securely stored in the discipline/department for a period of 5 years.

The ethical clearance certificate is only valid for a period of 3 years from the date of issue. Thereafter Recertification must be applied for on an annual basis.

I take this opportunity of wishing you everything of the best with your study.

Yours faithfully

  
.....  
Dr Shamila Naidoo (Deputy Chair)

/px

cc Supervisor: Ms NC Memela  
cc Academic Leader Research: Dr Jean Steyn  
cc School Administrator: Ms Ayanda Ntuli

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Humanities & Social Sciences Research Ethics Committee

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## Appendix D

### Interview Protocol

#### Participant 1

I: Interviewer / Researcher

P: Participant

I: Thank you for consenting to participate in my research project. Basically I am just going start off with some very basic straightforward questions, um, about your partner and yourself etc. Is that ok?

P: Nods

I: Thank you. Your relationship to the patient, what is that?

P: The patient is my husband.

I: And how long ago was the accident?

P: It was the 12<sup>th</sup> October 2012.

I: You remember it to the day. And how did the accident occur? Do you know about it?

P: He was playing golf and he was using a golf cart but because of his golf partners but he loves walking. He never use a golf cart, very seldom. And then he fell off the golf cart, it was on the 12<sup>th</sup> hole and he also walked it. So his companions went out with him and then, um, he wanted to walk to it and his companions found him on the floor.

I: Oh my word!

P: And only after he had the surgery here did Dr \*\*\* confirm that the nature of the injury and the indent that it was could be a golf ball.

I: Okay. So they reckon that it might have been a golf ball that could have hit him. And according to your own understanding of the injuries that he sustained, what were those at the time?

P: What? What the doctors said?

I: Yes. Like what you heard from the doctor and your understanding of his injuries.

P: I didn't understand because it's what the doctor said, but I appreciate the doctor, you know, he explained, he didn't use medical jargon he used very plain language. He didn't say it was a fracture. He called it he used a name that it is fragmented it was a fragment of bone in the brain and he did give me a lot of detail but in layman's terms so that I could understand.

I: It is difficult when doctors speak sometimes because we can't understand what is going on when they use complex terms.

P: Yes Yes

I: So that was a good thing. Okay, and, um, have there been any long term problems that your husband has experienced following this injury.

P: Yes, um, One of his, um side effects of that injury was a stroke of the left hand side. His left arm and left leg but it was immediate. And we only realised it was a stroke when he was in hospital again. But then through intensive Physiotherapy he was able to walk in hospital and, of course, doctor recommends that he goes to rehab and he went to Entabeni.

I: Okay, the Rehab Centre?

P: Yes. But to date already he can walk but the gait has been effected. But I would know, you know, because his walk is not the same and also he cannot clasp his left hand so driving is a challenge and holding things and the sad thing is that, I think the saddest thing, is that after this we had 2 grandchildren and he doesn't think that he is fit to carry them.

I: I am sorry to hear that.

P: He is nervous about just carrying them

I: Especially a little baby I would imagine

P: And the last is just 2 months old so he quickly just hands her to me. So he is scared, like you know, like he is going to drop them.

I: Shame but congratulations though on your grandchildren. So, Thank you for all that info, I know it is was straight forward questions there. The next few questions are going to be more me hearing from you about your experiences, okay? So I need for you to explain for me, in your understanding at the time of what took place and we are going to talk about some of the stressful things and you can answer it from the day that this happened right up until today, any of the stressful experiences that you experienced yourself or that the patient experienced or anyone else in your family, um, you know what was the most stressful things that occurred at that time.

P: Well a lot of time has passed now from 2012 so I can't always recollect accurately but at the time of his accident, the stress was, the first stress was "is he going to be normal" because that the doctor couldn't give any guarantees so that was my first worry as such you know that when he comes out is he going to be the same person, it was compounded by the stroke. The brain issue was one thing and then there was stroke so that was definitely a worry. But, um, it wasn't like something that I was upset about because I worked from day to day with him in hospital and I was grateful for every progress that he made. Doctor said he would recover after 72 hours but within 24 hours he knew that I was there. So I was grateful for every little improvement.

Okay, but at the back of my mind it was always there, whether the stroke was going to cause him to be completely, what's this, um, functional or is the brain injured forever. But I am a very positive person and I have a lot of faith but I am also human so um I was worried about that and from time to time and remember he was hospitalised for 45 days including the rehab. Here it was just one month. But the doctor kept giving us, you know, positive feedback but there was one incident when he got that lung infection here and he got very sick again. So they called me quickly and I came here and the doctor rushed him into surgery to do a scan and apparently he was being very very, what's the word, difficult with the nurses. But then later I found what happened, so the doctor told me what happened that it is characteristic of patients that have brain injuries so I know this means that the patient has a relapse. That night that he told me when we were at his bedside and he couldn't cough and they were not attending to him and also I saw a lot of things actually in the care that really let me down but I couldn't say anything because I was afraid that they might ill treat him you know, like things like his food was there and ice cold and after that he can't walk much so he just start eating, so where must I go warm it now at that time of day? So, so I saw compassion but as I

said also lack of but I didn't hold it against them. But I know he had the best care and what I assume was possible. Oh ja, when I really was troubled, very, very troubled, was the same incident but I went back to the ward he was very, very highly sedated because probably the doctor thought it was some sort of a relapse or something. In the night when I came he wasn't awake at all and I thought I am not going to see him again. And I actually said I said no he will live and what the fear I had was he had been overmedicated. I would never had known what was it. That was very painful.

I: Did he come right after that?

P: He was fine after that and then I was so patient with him as he was very, very snappy you know and what was hard for me was always accommodating him and accommodating the injury. Like I always had to take a step back, you know. And it is frustrating and of course we waited long for Entabeni and we put him in Shifa and oh that ward! But what killed me was those times where it was a whole day screaming match but I would let it pass and let it pass.

I: It's almost like it's just happening and happening quickly.

P: It's like I was busy with my life and it was so long a day, he's always been a hands on person he's always been gardening and making cupboards, but I'm just telling you that. But, sorry I'm jumping but I was glad I was at work, it made the whole day pass, people would say but why are you here? She told me you just can leave, but then being at work, it helped, it helped me because he came here a few times and now he is another person and he always said no one must know about his injury he hates that people know. I really appreciate my colleagues for their support. I felt like at work I was here at work and soon as my day went out I was at the hospital, so I became like a robot. It was October and now it was November and I could not neglect those children. It gave me a lot of motivation, my class children. Their parents will not understand, Im their English educator so we finished the poetry, I would have had to sit at home otherwise and worry. I also cannot just sit at his bedside. I also had feelings of guilt – people would say but he is still in hospital. I felt guilty, I still feel guilty that I should have maybe just sat at the hospital. And at church, after church I would be back at the hospital, I think maybe people just expected me to break down, you know. The other people said you know what that was what upset people. But I realised I was not the only person going through that or other bad things. I don't expect people now to bend over backwards for me.

I: You are a very strong person.

P: My last duty at work was the Matric Farewell but it helps you, it drives you. While I'm in hospital, I'm in hospital, but those children are also my responsibility at school.

I: Do you think that helped you to cope?

P: Definitely, definitely. A lot of people feel that that's why my husband didn't go to work. But he wanted to go to work. On the personal side we were living alone, but my brother came to stay with me. For the driving at night, going to work was okay, but the night was lonely and scary. So he drove me every day to Entabeni and Shifa. He took leave just to help us. So he also became my friend to help me to make decisions. And when he came out of hospital, my brother and sisters just got on my nerves, just got on my nerves so much, all the sympathy and nagging. They would just be on the phone wanting to know how he is now, but I had just got home, for god's sake. But the church helped, my pastor, because while he was having the surgery they just filled up all the waiting rooms. I don't know how they got there but they were there. The Pastor made sure someone was always visiting me. But I didn't want people visiting him in ICU, because of the germs and things and he didn't know anyway on the machines. The family were angry with me. My husband only had his

Mother and one sister at the time. But she thought she knew better, she didn't understand. I said I don't want you to come again. My sister is a nurse; she works in a Neuro ward in the States. But she prepared me. When he came out I was walking on eggshells, because of the Epilepsy.

I: Has he got epilepsy now?

P: Yes he has it. He came out like he was essentially normal but then the other things started coming. He went back to work and it was like euphoria. Everything was getting better and better and then he had a very bad seizure at work and he fell on the floor and then the doctor explained about the lesions. We had had a one year grace period and then the bubble burst. They did tests, MRI scan and then everything was fine and then that burning pain came in about 2013/2014. And he says it makes him feel like hell. Our communication now, it's improved at last but the physical side, the intimacy side has stopped. I was scared to put pressure on him and then he had that urology problem, so that really just changed our lives. And when he was in hospital the hardest thing was some people thought we would get divorced. It was hard to not have that other person there, even though before when we were home it' like you are not seeing him, but you know he is showering or getting dressed, you know they are there. I told him in rehab the thing I miss most is seeing you getting dressed in the morning. You were always dressed smart for work. And he would only come at quarter to five but now he didn't come anymore. I had all these things and he didn't come home. Those silly things that happen and make you think. So it's not like it's the big things, it's the small things. I was thankful that if maybe this didn't happen I wouldn't be so appreciative of people, it's the quality of life not the quantity that matters.

I: It's such a negative experience but there is still so much you have managed to learn and you're still so positive.

P: I can genuinely say with all sincerity our life has improved by knowing what we almost lost. There was a time I was very afraid when he used to lose his temper and people say but you have to excuse him because he has a brain injury. People don't understand. Our family, mostly they understand.

I: Were there any other ways or types of support systems that helped you?

P: For me it was prayer, he wasn't very close to God but he admits that he was in God's hands. I asked him if he wanted to see a Psychologist but he said he didn't want to he doesn't believe in it. But I think he should have, we could have together. He may have coped better. If I can take the credit maybe I was his Psychologist. We've always had a very stress free life, we never chased after things and possessions. We lived a very simple life. Oh we were talking about support, I mentioned my family, my Pastor, the church, the doctors and professionals and, oh, our family doctor, our GP and I appreciate him because he always listened. And what I like about him is he says you can always ask if you are not sure. But I can't say that people didn't support us, because we didn't reach out much. Maybe they were there. But they were very understanding when we did ask. We didn't reach out because I always told him this – your accident does not define you. I never wanted a before and after scenario. I never wanted that.

I: That is very insightful that not comparing a before and after scenario helped you to cope.

P: Yes, it definitely helped. He was the same person, still is. Just the situation and circumstances changed. He always used to talk about it and tell his children and then one day he said I don't want to talk about it anymore. My neighbours have been very supportive, very, very helpful. I was coming to the hospital and I told my maid to just pray and she told the neighbours and so we had a lot of people who were very supportive.

I: So do you think that was the most helpful? Having faith?

P: Yes, people and faith. You must have faith. You must have support, you can't do it alone.

I: I know this is a horrible question to ask, but is there anything, some advice you would give to someone else who, may heaven forbid have to go through a similar situation?

P: Yes there was a very young man and he fell down the stairs and had a very bad brain injury and I could see what was happening to him. I could see. He did mention oh my wife doesn't understand. I asked if I can phone his wife and talk to her. He said yes. I didn't phone her yet because I saw a change in him but I gave him my number hoping she would phone me but she didn't do it yet. Maybe I should just phone and ask?

P: So already there are other people at church so I help them, not preaching to them, especially not the patients, the other person living with them.

I: So what kind of things have you helped them with or advised?

P: I tell them to be patient, you must be more understanding, and every day is not the same. They do and say things that you don't like it's not because they do it deliberately.

I: That is hard for people to understand but it is true.

P: When he came out of hospital I told him you don't have to be this model person now, because everybody has been so supportive and kind. Just be yourself, you are the same person.

I: That must have been a great help to him. Your support would have helped his healing.

P: Oh the other thing I didn't say was that medical aid was a nightmare. Getting through to those people, it was terrible. The lack of communication and at the time it was very difficult.

I: What were some of the difficulties?

P: Oh like paying an account. I know we live in the age of technology, with the bills they say I have to pay cash and the onus is on you to submit. So I would photocopy, give the doctors codes and then we didn't get it through, and again, and again. Then the medical aid only paid so much and then we had to foot the bills.

I: He had quite a big procedure so they would have been a lot of bills. How did you cope financially?

P: The finance was okay but the stressful part was that he wanted to know everything and he would get into a frenzy. Like why do you have to do that, why don't they pay for that. So I had to divulge to him but I wanted to keep him stress free.

I: We spoke about the healthcare and the nurses but in retrospect was there anything that the health care people could have done differently to make it easier?

P: I was happy that he had very good specialists and caregivers and other than those couple of incidences I wouldn't like to complain.

I: And at the Rehab?

P: The doctor was very understanding and explained what was going on. The Nurses were fine but I think it made him appreciate life because he could see there is always other people who are worse.

I: Is there anything I might have left out that might have been significant?

P: I can't think of anything now, time has passed.

I: Is there anything in the past 6 months that has changed?

P: I just feel that he could be more appreciative of life in general and be grateful to God that he is well. I would like for him to give back. Like in church he could visit the sick and encourage the sick. Nothing like heavy stuff. But he is a very generous person.

I: And his treatment that he is still on now?

P: It is still a very sad part for me, because in hospital they told me to bring all his medication so that we can see what he has been having. And I checked what medication he was on and I had to phone the doctor and ask what medication, chronic and so on, was he on and he said 'nothing' he was such a fit person. So probably that helped him.

I: Is he just on the epilepsy meds now or are there others that he has to take?

P: Yes, but talking about the medical professions, you see not all Doctors were like our Doctor. He didn't like this one person, they didn't talk much, they didn't want to talk to you, I feel that they mustn't think that the patient is brain dead. They must talk to the person and tell them what is happening. Not do it all like clinically, like cold and distant. Our main doctor was so compassionate.

P: He still has pain, that debilitating pain but you wouldn't know. Only he knows. And now he doesn't like socialising. But it will come right.

I: Thank you so much you have really given me a great insight.

P: People have this perception that if you can walk you're alive, you can talk, go back to work you are fine. But they don't see all the emotional things that mentally you may be different. I was the one who saw it all. But you have to be grateful that the faith kept us going. If people can see a scar or in a wheelchair they are more understanding. We always took care to prepare for when we can't work and now that we don't have responsibilities we can afford to maybe travel but his health is so bad that is very sad for me. He says I must go alone, but I don't want to. I went to Johannesburg with my daughter and people were like so you left him alone, why is he alone? That was very annoying. So I also learnt that after he had epilepsy, it was horrible. I fear that if something happens I will be blamed and would blame myself too. But he has to be a person, and have faith that nothing will happen. You can't live in fear.

I: Thank you so much. You are such a positive person.