

# **Traumatic brain injury caregivers' experiences: An exploratory study in the Western Cape**

by

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## **Declaration**

By submitting this thesis electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the authorship owner thereof and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

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## Abstract

Family caregivers play a large role in the lives of traumatic brain injury (TBI) survivors. This study explored the experiences of family members who care for TBI survivors in the Western Cape. Emphasis was placed on the challenges and resources that were associated with the caregiving role. A qualitative exploratory research design was implemented, whereby thematic analysis was utilised to examine the semi-structured interviews that were conducted with 12 female family caregivers of TBI survivors. Several challenges emerged, namely trauma, consequences of a TBI, responsibilities, lack of support, unawareness, financial burden, emotional challenges and coping. Several resources were also identified, namely the road to recovery, social support, financial resource and coping. These findings suggest that although caregivers who care for a family member who sustained a TBI face several challenges through the caregiving task, these individuals have a number of resources that help them to cope. Interventions that focus on psycho-education have been identified as an important need amongst the participants of this study. In addition, the need for support groups were highlighted as an important way in which many of the challenges that these caregivers experience could be addressed. Caregivers also expressed a need for more active involvement of health care professionals with regard to the provision of guidance, empathy and information. It seems as if the caregivers view the relationship between themselves and the health care professionals involved in the treatment of their family member who sustained a TBI as very important. It was however evident from the findings of this study that the caregivers are generally not satisfied with the quality of the interaction between the health care professionals and themselves. This study's findings serve as a basis for future research studies on the experiences of family caregivers of TBI survivors in the Western Cape.

## Opsomming

Gesinsversorgers speel 'n groot rol in die lewens van oorlewendes van traumatiese breinbeserings (TBB). Hierdie studie het die ervarings van gesinsversorgers van TBB-oorlewendes in die Wes-Kaap verken. Die fokus is op die uitdagings en hulpbronne wat geassosieer word met die versorgingsrol. 'n Kwalitatiewe ontwerp is geïmplementeer, waarby tematiese analise gebruik is om die semigestruktureerde onderhouds van 12 vroulike gesinsversorgers van TBB-oorlewendes te bestudeer. Verskeie uitdagings het na vore gekom, naamlik trauma, gevolge van TBB, verantwoordelikhede, gebrek aan ondersteuning, onbewustheid, finansiële las, emosionele uitdagings en hantering. Die hulpbronne wat geïdentifiseer is, het die pad na herstel, sosiale ondersteuning, finansiële hulpbron en hantering ingesluit. Intervensies wat fokus op psigo-opvoeding is geïdentifiseer as 'n belangrike behoefte onder die deelnemers aan die studie. Hierbenewens is ook 'n behoefte aan ondersteuningsgroepe uitgelig as 'n belangrike wyse om die vele uitdagings wat hierdie versorgers ervaar aan te pak. Die versorgers het ook 'n behoefte ervaar aan meer aktiewe betrokkenheid van gesondheidskundiges ten opsigte van die voorsiening van leiding, empatie en inligting. Dit blyk dat versorgers die verhouding tussen hulself en die gesondheidskundiges betrokke by hul gesinslid met die TBB as belangrik beskou. Desnietemin blyk dit duidelik uit die bevindinge van hierdie studie dat versorgers oor die algemeen nie tevrede is met die kwaliteit van die interaksie tussen die gesondheidskundiges en hulself nie. Die bevindinge van hierdie studie dien as basis vir toekomstige navorsing oor die ervarings van gesinsversorgers van TBB-oorlewendes in die Wes-Kaap.

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## Chapter 1 : Introduction

### 1.1 Introduction

Family caregivers play a large role in the lives of the dependent individuals that they care for. As a result of the caregiving role, these family caregivers can face many challenges (Ketzeback, 2012) which could have an impact on their physical, psychological and social well-being (Marsh, Kersel, Havill & Sleigh, 2002). Depending on the severity of the injury, TBI survivors may require long-term rehabilitation and caregiving (Ketzeback, 2012) which in many cases become the responsibility of the family members of the TBI survivors (Jumisko, Lexell & Söderberg, 2007). Caring for a family member who sustained a TBI involves many challenging experiences (Arango-Lasprilla et al., 2010; Gan, Gargaro, Brandys, Gerber & Boschen, 2010; Jumisko et al., 2007) and can be difficult to adapt to.

Several previous studies have been conducted on caregivers' experiences with traumatic brain injury (TBI) survivors (Arango-Lasprilla et al., 2010; Chronister, Chan, Sasson-Gelman & Chiu, 2010; Gan et al., 2010; Jumisko et al., 2007; Kreutzer et al., 2009; Lefebvre, Cloutier & Levert, 2008; Livingston et al., 2010; Rotondi, Sinkule, Balzer, Harris & Moldovan, 2007). However, caregivers in the South African context might face unique challenges and utilise resources that are distinctive to the South African population. In South Africa there is a need for community-based and home-based caregivers due to the lack of hospital beds, health care professionals and the high cost of health care institutions (The Western Cape Department of Health, 2003). With these limited health care resources and access to existing resources that are not always guaranteed (Western Cape Department of Health, 2003), it is inevitable that family members will need to take on the caregiving role in the lives of family members' that sustain TBIs. There also seems to be many of these caregivers when considered that an estimated 89 000 new cases of TBIs occur in South Africa each year (National Health Laboratory Service, 2012). Consequently this is an

important topic worthy of research. However, to my knowledge no research that focusses on family caregivers' experiences in the context of TBIs in South Africa, and particularly the Western Cape, has been conducted.

In addition, most prior research on this topic generally seems to focus on the challenging experiences of family caregivers of TBI survivors (Arango-Lasprilla et al., 2010; Ergh, Rapport, Coleman & Hanks, 2002; Jumisko et al., 2007; Marsh et al., 2002; Rotondi et al., 2007) with little attention given to the resources available that help family caregivers to cope with the caregiving role. While the challenges that family caregivers face can be burdensome, there are resources that may help family caregivers cope better with their role as caregiver and the challenges associated with caregiving (Gan et al., 2010). The aim of this study was, therefore, not only to focus on the unique challenging experiences of family caregivers within the South African context, but also to explore the resources that help these caregivers to cope with the role of caring for a family member who sustained a TBI.

## 1.2 **Key terminology**

### Caregiver

A caregiver can be defined as “a family member or paid helper who regularly looks after a sick, elderly, or disabled person” (Stevenson & Waite, 2011, p. 214). In this study the term caregiver will refer to someone who cares for a family member who sustained and survived a TBI.

### Primary caregiver

In a case where more than one caregiver cares for a chronically ill or disabled individual, the primary caregiver will be the caregiver that spends the most time caring for the individual with the disability. In this study, the primary caregiver refers to the family

member who assumes the majority of the caregiving roles in the TBI survivor's life.

Caregiver and primary caregiver will be used interchangeably throughout this study.

#### Traumatic brain injury (TBI)

A TBI can be defined as “a nondegenerative, noncongenital insult to the brain from an external mechanical force, possibly leading to permanent or temporary impairment of cognitive, physical, and psychosocial functions, with an associated diminished or altered state of consciousness” (Dawodu, 2011, p.1).

#### TBI survivor

A TBI survivor refers to an individual who sustained and survived a TBI.

#### Challenges

A challenge includes any task or situation that is demanding or taxing for an individual (Stevenson & Waite, 2011). For the purpose of this study, challenges will include those experiences family caregivers perceived as difficult to deal with.

#### Resources

Anything that can aid or help an individual in adverse circumstances and/or any type of asset that an individual has in supply or stock can be regarded as a resource (Stevenson & Waite, 2011). For the purpose of this study, resources involve the experiences, support and assistance that family caregivers perceive as helpful in the caregiving role.

### 1.3 **Presentation of research**

A review of the literature associated with family caregiving in the context of TBI will follow in Chapter 2. This review will include caregivers' role in society, caregivers in the context of TBI, an overview and relevant information about TBI, the challenges that caregivers of TBI survivors face, as well as the resources that caregivers report as helpful in

this role. The theoretical framework used to interpret and conceptualise the data will also be discussed in this chapter.

In chapter 3, I will expand on the research methodology used in this study. The rationale and relevance of this study, the research question and aims of this study will also be discussed. This will be followed by a description of the research design, the sample and the procedure used for collecting data. Lastly, the data analysis process, trustworthiness and ethical considerations will conclude the chapter.

In chapter 4, the research findings of this study will be reported and presented. The themes that emerged from the thematic analysis of the semi-structured interviews will be reported in this chapter.

Lastly, in chapter 5, the study will be concluded with a discussion of the findings of this study through the lens of Bronfenbrenner's ecological systems theory. Limitations and recommendations for future research on this topic will also be discussed.

## **Chapter 2 : Literature Review**

### **2.1 Introduction**

In this chapter, the role of the family caregiver in society will first be discussed. This discussion will be followed by an overview of traumatic brain injury and the family caregiver's role and experiences in the context of traumatic brain injury (TBI) survivors. These experiences will be considered with specific focus on the challenges faced by family caregivers of TBI survivors and the resources that help them cope with their caregiving role. Finally, this chapter will conclude with a description of Bronfenbrenner's ecological systems theory as a framework for the interpretation and contextualization of this study.

### **2.2 Caregivers' role in society**

Many studies around the world have been conducted on caregivers of individuals who need care (Bevans & Sternberg, 2012; Dillenburger & McKerr, 2010; Mhaule & Ntswane-Lebang, 2009; Pereira & Botelho, 2011). A caregiver can be defined as "a family member or paid helper who regularly looks after a sick, elderly, or disabled person" (Stevenson & Waite, 2011, p. 214). This means that a significant amount of the caregiver's time is used to take care of the person who cannot take care of him- or herself independently. The caregiver can also be a family member of the individual who does not necessarily get paid to do so.

It is important to note the distinction between formal (paid) caregivers or helpers and informal caregivers (Bevans & Sternberg, 2012; Pereira & Botelho, 2011). Formal caregivers refer to any person or professional who receives payment in order to take care of dependent individuals in the home or in another setting where care is provided (Family Caregivers Alliance, 2013). In contrast, informal caregivers are unpaid individuals who could include family members, spouses, friends or neighbours of the dependent individuals (Family Caregivers Alliance, 2013). In many cases a formal caregiver is too expensive to employ or

too difficult to gain access to. Often an informal caregiver is assisted by a formal caregiver. For the purpose of this study, caregivers will refer to the informal caregivers which are related to the dependent individuals they care for.

Caregivers' family members or spouses may need care due to a chronically ill, frail, or a disabling condition. Examples of these conditions may include HIV and AIDS (Uys, 2002), Alzheimer's Disease (Navab, Negarandeh & Peyrovi, 2011), learning disabilities (Dillenburger & McKerr, 2010), Traumatic Brain Injuries (Arango-Lasprilla, et al., 2010), Cancer (Bevans & Sternberg, 2012), Huntington's disease (Skirton, Williams, Barnette & Paulsen, 2010), Down Syndrome (Dillenburger & McKerr, 2010), Strokes (Dillenburger & McKerr, 2010), Autism Spectrum Disorders (Dillenburger & McKerr, 2010) and Schizophrenia (Mhaule & Ntswane-Lebang, 2009).

When such a significant change in the health of a family member occurs, resulting in a need for assistance, another family member may take on the role of caregiver. This family member will consequently be the primary caregiver for the dependent family member, spouse or child with the chronic condition (Carnes & Quinn, 2005; Livingston et al., 2010).

Bronfenbrenner (1979) refers to this change in roles as an ecological transition. An ecological transition, "occurs whenever a person's position in the ecological environment is altered as a result of a change in role, setting, or both" (Bronfenbrenner, 1979, p.5). This is a difficult task in itself and completely changes the function of the family member in the family. Depending on the specific condition of the dependent individual, caregivers have specific roles to play. According to Pereira and Botelho (2011), caregiving involves "acknowledging that one (the caregiver) takes care of someone else's life" (p. 2453). This is an enormous responsibility to take on and demands many hours of the caregiver's time.

Caregivers' roles consist of various types of support for their family members (Kreutzer et al., 2009; Smeets, van Heugten, Geboers, Visser-Meily & Schepers, 2012).

Caregivers generally help their dependent family members with daily tasks, making appointments, managing finances, managing medication, arranging socialization and recreational activities (Kreutzer et al., 2009). Other examples also include supervising and assisting their family member with bathing, meal preparation and feeding (Ketzeback, 2012; Kreutzer et al., 2009). These roles can place a significant amount of burden on the caregiver because of the crucial role they play in their dependent family members' lives (Chiou, Chang, Chen & Wang, 2009).

The roles that caregivers take on can become a source of stress and make life more challenging to cope with. Researchers of a recent case study on caregiving in the context of cancer, have found that the challenges faced by caregivers include restricted finances, lack of social support, uncertainty of the future and health of the patient, taking care of cleaning, transporting the patient to and from the hospital and preparing meals (Bevans & Sternberg, 2012).

Similar challenges were also found as stressors for other caregivers caring for family members or spouses with other conditions and/or disabilities (Dillenburger & McKerr, 2010). These conditions include Down syndrome, learning disabilities, Autism Spectrum Disorder, Cohen's Syndrome, cerebral palsy, muscular dystrophy and stroke (Dillenburger & McKerr, 2010). The tasks that are associated with the caregiving role seem to place a large amount of emotional distress on caregivers. The effects of these tasks on caregivers are evident across different diagnosed conditions in their family members.

Together with the challenges that caregivers face, specific resources have also been reported. These resources or support help caregivers to cope better with the caregiving role. Examples of resources include support groups, respite care, psycho-education, social support, and close relationships (Gan et al., 2010). Social support has been identified as a particularly

important factor that contributes positively to the caregivers' well-being (Dillenburg & McKerr, 2010).

To my knowledge very little published literature is available on the experience of caregivers in the South African context. Only two studies that relate to this topic could be found (Mavundla, Toth & Mphelane, 2009; Mhaule & Ntswane-Lebang, 2009). Challenges that caregivers do face in the context of Schizophrenia have been reported by Mhaule and Ntswane-Lebang (2009). These challenges include the stigma attached to the illness, lack in support structures and resources, presence of poverty, psychiatric patients not taking their medication or taking it incorrectly, self-care problems and cultural beliefs. A significant cultural belief which could impact the caregiving role negatively is the belief that witchcraft is to blame for mental illness (Mavundla et al., 2009; Mhaule & Ntswane-Lebang, 2009). Misconceptions about the illness may prevent the patient from receiving adequate care and therefore potentially prolong the consequences that the illness has for the patient and the caregiver.

Similar findings about caregiving in the context of mental illness in a rural community have also been reported by Mavundla et al. (2009). Stigmatization and ostracism were experienced by both caregivers and their family members resulting in social isolation (Mavundla et al., 2009). Certain supports were also found inefficient, such as social workers and health care professionals lacking knowledge of mental illness (Mavundla et al., 2009). Family members also did not always take their medication correctly (Mavundla et al., 2009). Other challenges reported were financial demands, unemployment and providing physical needs for family members (Mavundla et al., 2009). These challenges placed an increased burden on the caregivers in these specific studies conducted in South Africa.

To my knowledge, resources in the context of South African caregiving roles are not researched as much as the challenges that are faced. Even though the study conducted by

Mavundla et al. (2009), was based on neutral questioning in the interviews, the participants generally reported that their experiences were negative and challenging. The study conducted by Mhaule and Ntswane-Lebang (2009) also presented with mainly negative experiences and highlighted the challenges caregivers face in a South African context. It is important to conduct research that not only focusses on the negative experiences and the challenges faced by caregivers in a South African context, but also on the positive experiences and the resources that help caregivers to cope (Gan et al., 2010). By exploring these resources, investigators become informed about the support that caregivers find useful in alleviating burden in the caregiving role. Future interventions may incorporate these resources to help caregivers to cope with their caregiving task. This study will therefore focus not only on the challenges that the caregivers face, but also on the resources that help these caregivers to cope with their situation.

### **2.3 Caregivers in the context of traumatic brain-injured family members**

The focus of this study is on the challenges faced and the resources utilised by individuals caring for a family member who sustained a TBI. Caregivers with family members who sustained a traumatic brain injury (TBI) have particularly been found to face many challenges in the caregiving role (Arango-Lasprilla et al., 2010; Gan et al., 2010; Jumisko et al., 2007). To understand the specific context of these family members' condition, I will start with an overview of a TBI. This will include defining a TBI, a description of causes and types of head injuries, TBI diagnosis, consequences of the injury as well as the prevalence of TBIs.

## Overview of traumatic brain injury

A TBI can be defined as “a nondegenerative, noncongenital insult to the brain from an external mechanical force, possibly leading to permanent or temporary impairment of cognitive, physical, and psychosocial functions, with an associated diminished or altered state of consciousness” (Dawodu, 2011, p.1). Due to the complexity of the brain and the vital functions it controls in every individual’s survival and daily life, injury to the brain can be fatal and extremely disabling. The consequences of brain damage can also be severe and impact the functionality of such family members, making them dependent on their caregivers.

When a family member sustains a TBI, it is usually associated with a traumatic impact to the brain. The most common causes of TBIs include motor vehicle accidents (MVAs), falls and violence (Adekoya, Thurman, White & Webb, 2002). Classifications of TBIs related to the cause of the TBI include penetrating head injuries and closed head injuries. A penetrating head injury is any injury to the brain that results from an object that physically pierces through the skull and the meninges of the brain (Degeneffe, 2001). Meninges are the protective layers of tissue and fluid surrounding the brain (Degeneffe, 2001). Objects that could potentially cause penetrating head injuries include knives, scissors, glass and bullets. A closed head injury occurs when the injury has been sustained from an external force, but the meninges are not penetrated (Degeneffe, 2001). The skull might be fractured in the family member who presents with a closed head injury (Degeneffe, 2001). Closed head injuries could include concussion and whiplash which could be the result of a fall or MVA.

The diagnosis of the TBI sustained by the family member consists of classifying the severity of the injury as either mild, moderate or severe. The severity of the TBI is generally measured with the Glasgow Coma Scale (GCS). This scale was developed by Teasdale and Jennett (1974) and measures three independent aspects of behaviour including motor

responsiveness, verbal performance and eye opening. If a patient has a GCS score of 8 or below, the score represents a severe TBI, a score of 9 to 12 indicates a moderate TBI and, lastly, a score of 13 to 15 indicates a mild TBI (Sbordone, Saul & Pursich, 2007). A lower score therefore indicates a more severe TBI.

The consequences of sustaining a TBI can vary from individual to individual. According to Grieve (2002), a TBI is not just a head injury, but involves damage and functional deficits of the brain. The family members who sustain a TBI can present with a variety of physiological, psychological and neurobehavioural problems (Kreutzer et al., 2009; Trevena & Cameron, 2011). Often a TBI is referred to as the *silent epidemic* (Faul, Xu, Wald, & Coronado, 2010; Sudarsanan, Chaudhary, Pawar & Srivastava, 2007) because these complications associated with a TBI are not always visible to others (Faul et al., 2010).

Physiological problems that may arise after sustaining a TBI may include seizures, headaches, sleep disturbances and dizziness (Trevena & Cameron, 2011). Psychological problems that could occur include anxiety, depression, personality changes and psychosis (Trevena & Cameron, 2011). Neurobehavioural problems associated with TBIs may include cognitive problems (Riggio & Wong, 2009) such as deficits in memory, including retrograde and anterograde amnesia (Zillmer, Spiers & Culbertson, 2008), changes that affect thinking processes, sensation, language and/or emotions (Faul et al., 2010), personality changes and psychiatric disorders (Riggio & Wong, 2009). The implications and consequences of a TBI are therefore complex because it affects an individual's ability to function like before.

Due to the consequences of sustaining a TBI, family members will most likely need intensive rehabilitation. TBI rehabilitation often range from months to a few years and may sometimes last up to a lifetime (Rotondi et al., 2007). This means the TBI survivor will need continuing care after being discharged from the hospital (Livingston et al., 2010). This is where the primary family caregiver plays a significant role. To emphasise the great demand

for family members to be caregivers of TBI survivors, it is important to consider the prevalence of TBIs.

TBIs are regarded as a global public health problem. Research has shown that TBIs annually affect an estimated 10 million people worldwide (Hyder, Wunderlich, Puvanachandra, Gururaj & Kobusingye, 2007). In the United States alone, 1.7 million individuals sustain TBIs each year (Faul et al., 2010). Thirty thousand people die due to a TBI annually and 125 000 people survive and live with disabilities as a result of TBI each year in India (Sudarsanan et al., 2007). In South Africa, the National Health Laboratory Service reported that 89 000 new cases of TBIs are diagnosed per year (National Health Laboratory Service, 2012). These statistics suggest that TBI is not only a significant public health problem worldwide, but in South Africa as well. It also emphasises the need for caregivers, because the more TBI cases, the more family members are needed to become caregivers to these patients.

Many previous studies have been conducted on family caregivers and TBIs (Arango-Lasprilla et al., 2010; Chronister et al., 2010; Davis et al., 2009; Ergh et al., 2002; Gan et al., 2010; Hanks, Rapport & Vangel, 2007; Jumisko et al., 2007; Kreutzer et al., 2009; Lefebvre et al., 2008; Livingston et al., 2010; Marsh et al., 2002; Phelan et al., 2011; Rotondi et al., 2007; Rivera, Elliott, Berry, Grant & Oswald, 2007; Sander, Clark, Atchison & Rueda, 2009; Vangel, Rapport & Hanks, 2011; Verhaeghe, Defloor & Grypdonck, 2005). However, to my knowledge no studies have been conducted on family caregivers and TBI in a South African context and in the Western Cape specifically.

There is therefore paucity in research on this specific topic in South Africa. The number of new cases in South Africa indicates that it is a relevant condition to investigate. It also suggests that long-term caregivers will be needed for many of these new cases, especially when they are severe TBI cases. There are also a number of problems in South

Africa's health care system which may contribute to the need for caregivers of TBI survivors. These problems include a shortage of hospital beds, lack in health care staff in the public sector, lack of resources for treatment and medication and high cost of institutional care (Western Cape Department of Health, 2003). It is therefore evident that the South African health care system is not able to assist in long-term rehabilitation for many of these TBI survivors. This in turn results in the need for family members to take on the caregiving role. These challenges emphasise why it is important to conduct this study which focusses on the challenges faced by and the resources utilised by caregivers of TBI survivors in a South African context.

#### **2.4 Caregivers' challenges and resources in the context of TBI**

For the purpose of this study, the experiences of TBI caregivers will broadly be divided into two categories. The first category includes all the challenging experiences that these caregivers face. An example of a challenging experience can be managing the psychological and physical consequences of the TBI presenting in the family member. The challenges can therefore be any difficult or challenging experience that relates to the caregiving role.

The second category includes all the resources and the experiences that the caregiver finds to be helpful in the caregiving role. These experiences aid the caregivers to cope better with their role. An example of a resource could be the social support structure of the caregiver. This structure can help the caregiver cope better and alleviate burden. Throughout this study reference will be made to the experiences of the caregivers as it relates to the challenges that they face and the resources that help them to cope with the caregiving role.

## **Challenges faced by caregivers of TBI survivors**

There are many challenges associated with the caregiving role in the context of TBI survivors. These challenges can have a negative impact on the caregiver in many ways (Arango-Lasprilla et al., 2010; Ergh et al., 2002). Challenges can place a higher burden on the caregiver and make the caregivers' lives less enjoyable. It can also impact negatively on their adjustment to caregiving and contribute to a difficulty to maintain and continue with this role. Challenges that caregivers may experience include financial strain, insufficient time for the caregiver, the impact of the consequences of sustaining a TBI, lack of information, lack of understanding from others, emotional distress, stress and ineffective coping strategies.

### **Financial strain**

Due to the financial strain of TBI care, the financial demands often become the responsibility of the caregiver, sometimes without them even having a choice. Financial pressure has been reported amongst caregivers of TBI survivors as an enormous challenge in the caregiving role (Jumisko et al., 2007; Marsh et al., 2002; Rotondi et al., 2007). Examples of financial demands that caregivers of TBI survivors face include paying for treatments, the loss of employment due to their caregiving role, a reduction in hours worked due to lack of time available and/or re-entering employment in a lower-paying job (Rotondi et al., 2007). This can place a higher burden on the caregiver, especially when the TBI survivor is completely dependent on him/her.

### **Insufficient time for the caregiver**

Taking on the role of family caregiver is also very time-consuming. Family caregivers seem to struggle with finding enough time for their careers and professional life after taking on this role. Time is valuable when caregivers have a career and professional life of their own and it can be challenging to balance work with the caregiving role. Reorganizing one's own

time after the TBI survivor has been discharged from the hospital, has led many caregivers to re-evaluate their professional careers (Lefebvre et al., 2008). Many caregivers have to take leave and in some cases, caregivers even have to choose between following a career and providing care for a family member who sustained a TBI (Lefebvre et al., 2008). The family caregivers' lives can therefore be altered by their family members' TBI in such a way that the caregiver may feel pressured to give up more than just their time for their family member. Giving up a large part of one's own life and livelihood can be a great burden to bear for the family caregiver.

The lack in time available to caregivers can also affect their social lives. Due to the increased amount of time spent taking care of the TBI survivor, the caregiver's time becomes limited and less time is spent on social interaction. In many cases the TBI survivor is the family caregiver's spouse or partner. When the caregivers' spouses or partners sustain a TBI, the psychological and physical consequences can affect the type of relationship they now have with their TBI family members. Some caregivers report feeling a sense of loss of their partner, relationship and intimacy with the TBI survivor (Braine, 2011).

Other relationships can also be affected and it can become challenging to maintain relationships when caregivers have less time for themselves and their own social needs (Ergh et al., 2002; Jumisko et al., 2007; Marsh et al., 2002). Often caregivers provide care to family members other than their spouse, such as a son, a daughter, or a parent. Some caregivers have even lost their spouses due to spending too much time with the family member with the TBI (Lefebvre et al., 2008).

Caregivers generally tend to choose to take care of the individual who sustained a TBI, rather than spending time on their own, because they feel that those with TBIs are worse off than themselves (Jumisko et al., 2007). Therefore a sense of guilt can also keep caregivers from maintaining and seeking social support elsewhere, even if they have a need for it.

Caregivers' time for relaxation, holidays, rest and fun are also limited. Research suggests that after a period of 10 years of caring for a TBI survivor, caregivers tend to spend less time and lower quality of leisure activities than before the injury occurred (Lefebvre et al., 2008). This may be due to the increased time spent with their family member or having less energy for other things. Other research shows that as early as six months after caring for an individual who sustained a TBI, caregivers had less time for themselves and their social adjustment was impaired (Marsh et al., 2002).

Insufficient time for caregivers' privacy can also affect the caregivers' experience. When family caregivers are always on stand-by for their loved ones (Jumisko et al., 2007), it isn't surprising that caregivers report a decrease in their own personal space and less privacy (Marsh et al., 2002). Living with the TBI family member can impact caregivers' privacy and freedom, especially when the caregiver needs to monitor him or her constantly. The lack of time family caregivers' deal with can also contribute to the feelings of fatigue that have been reported by family caregivers of TBI survivors (Jumisko et al., 2007).

### **The impact of the consequences of sustaining a TBI**

Sustaining a TBI can leave the patient with a variety of short- and long-term neurobehavioural consequences. Managing these consequences can place a large burden on the caregiver of the TBI survivor. Caregivers have reported that the degree of the neurobehavioural consequences of a TBI, make their lives more difficult (Livingston et al., 2010) and this could increase stress (Ergh et al., 2002). Specific examples of the neurobehavioural consequences that TBI caregivers have reported as stressful include aggressiveness (Braine, 2011; Lefebvre et al., 2008), impulsivity (Lefebvre et al., 2008; McAllister, 2008), cognitive problems (Gan et al., 2010), personality changes (Gan et al., 2010; McAllister, 2008), social problems (Gan et al., 2010), forgetfulness (Braine, 2011), slowness in carrying out tasks (Braine, 2011), apathy (Braine, 2011; McAllister, 2008) and

repetition (Braine, 2011). These changes in behaviour and functioning can place further burden on the caregiver. Some caregivers have even reported a sense of loss or grief and feel that they almost had to get to know the TBI survivor again (Jumisko et al., 2007). The consequences and unpredictability of the TBI survivor's behaviour and personality changes can become a major source of stress for the caregiver.

### **Lack of information about consequences**

When considering the consequences of TBI it is evident that the lack of information about these consequences and how to manage it has also been identified as a significant challenge for caregivers. The lack in information and education on where caregivers can access support services for these patients, where to find caregiver support groups, and who to contact for assistance are also significant challenges. Once the TBI survivor has been discharged from hospital, the caregiver is the one who has to cope with and manage the TBI survivor's symptoms. This can be a daunting experience for the caregiver, especially when information on available resources and what to expect in the long term, are almost non-existing (Lefebvre et al., 2008). Rotondi et al. (2007) found that caregivers do not get sufficient information during the recovery process. Insufficient information can lead to uncertainty, which is a very common feeling that caregivers of TBIs have reported (Jumisko et al., 2007).

Caregivers have also expressed a need for a directory to inform individuals of accessible services targeted at TBI survivors and their family members (Rotondi et al., 2007) so that they could have an idea of what resources are in place for them to utilise. The lack of information can leave a caregiver confused, unsure and unarmed to effectively cope with the role of caregiver.

### **Lack of understanding from others**

Caregivers also have a need for the lay public to be educated about TBIs.

Stigmatization and marginalization of caregivers and TBI survivors can be the result of the lay public's lack of knowledge about TBIs (Gan et al., 2010). A caregiver who feels stigmatized by a family member's condition can go into social isolation (Phelan et al., 2011). Isolation can also occur in family caregivers and their TBI family members as a result of these outsiders' lack of knowledge and understanding of TBIs and the implications associated with it (Gan et al., 2010; Phelan et al., 2011). It has been reported by caregivers to be difficult to maintain social relationships when others do not understand the TBI survivors' sequelae (Lefebvre et al., 2008). Many caregivers have also reported loneliness due to others' lack of understanding (Braine, 2011; Jumisko et al., 2007).

### **Emotional distress**

The consequences of a TBI can also lead to negative emotions for caregivers. Specific consequences of sustaining a TBI include passive changes, lack of motivation, apathy, active changes, inappropriate remarks, profanity, irritability, emotional lability, aggression and unpredictability in behaviour in the TBI survivor (Braine, 2011). These changes in behaviour in the TBI survivor can lead to negative emotions in the caregivers, such as feelings of upset, sadness, frustration and helplessness (Braine, 2011). These negative emotions could also negatively impact the caregivers' psychological health and satisfaction with life.

Many caregivers also report a sense of feeling stuck and a loss of freedom to do the things they once could (Braine, 2011). Concerns about the future and uncertainty have also been reported (Braine, 2011; Gan et al., 2010). Caregivers often worry about the future of their family member and can feel like they are not in control of the situation. These negative feelings and emotions can impact the caregivers' mental health and physical wellbeing.

## **Stress**

Caregivers have also reported that a large amount of energy is needed every day to look after the family member with a TBI (Lefebvre et al., 2008). This could also affect caregivers' mental and physical health and could lead to burnout and exhaustion. Caregivers have reported experiencing chronic fatigue and feeling overwhelmed with the caregiving role (Gan et al., 2010). Often TBI survivors continue to be dependent on the caregiver many years after sustaining a TBI and this could lead to stress and exhaustion within the caregivers and their families (Lefebvre et al., 2008).

The caregiving role also takes its toll on the physical and psychological well-being of the caregiver. Caregivers have been found to present with clinically significant anxiety symptoms and sleeping problems (Marsh et al., 2002). Feelings of anger, frustration, guilt, anxiety, fear, embarrassment and lack of acceptance have also been reported by caregivers (Braine, 2011). Anger towards others who treat the TBI survivor unfairly has been specifically reported by caregivers (Jumisko et al., 2007). High levels of stress (Gan et al., 2010; Rotondi et al., 2007) and lack of time have also been reported (Gan et al., 2010) as stressors that negatively affect caregivers' psychological well-being.

## **Ineffective coping strategies**

The way in which caregivers cope can also negatively impact their experiences of the caregiving role. According to Lazarus and Folkman (1984, 1987) two specific coping strategies can be used by individuals to cope with personal and environmental stressors. One of these includes emotion-focussed coping strategies. Emotion-focussed coping strategies involve managing emotional distress by focussing on the emotions rather than the problem being experienced (Lazarus & Folkman, 1987). Examples of ineffective emotion-focussed coping strategies may include avoidance of the stressor, self-blame and distancing. Escape-avoidance coping strategies specifically have been found to relate to increased distress in TBI

caregivers (Davis et al., 2009). Therefore the type and the way in which a coping strategy is used could negatively impact the caregiver's experience in the caregiving role.

### **Lack of resources**

Resources can be described as anything that can aid or help an individual in adverse circumstances and/or can be any type of asset which an individual has supply or stock of (Stevenson & Waite, 2011). For a caregiver, resources can consist of anything that can make the role of caregiver easier, more effective and/or enjoyable. However, a lack of resources can make TBI caregivers' roles challenging and increase stress in TBI caregivers (Lefebvre et al., 2008). According to Smeets et al. (2012) the results of many caregiver studies have emphasised the need for interventions specifically focussed on caregivers' well-being. Caregivers who express a need for resources and time away from their caregiving duties generally also have a relatively high subjective burden (Smeets et al., 2012). TBI caregivers have also reported that all the problems that are faced when taking care of a TBI survivor, are intensified by a lack in available resources in the long term (Lefebvre et al., 2008). It is therefore a great need to have available resources after the TBI survivor has been discharged from the hospital, in order to serve as on-going support throughout the rehabilitation and caregiving process.

A study conducted by Gan et al. (2010) identified several resources that caregivers reported a need for, including respite care, home-based care, government funding for programs, access and information services, long-term continuity of care and community support services. These services have been reported by caregivers of TBI survivors as services which could decrease the burden of the caregiving role by giving caregivers more time for themselves, more specialized care for their affected family member and by empowering the caregivers through psycho-education programs and other support services in

the long term. Therefore a lack in these resources could place a significant amount of stress and responsibility on caregivers.

Many caregivers also expressed that they were in need of support networks or social support groups so that they could communicate with people who understood what they were going through (Rotondi et al., 2007). Family counselling is another support need that has been found to be lacking for caregivers, TBI survivors and their families (Gan et al., 2010). The support from health care professionals also seems to be limited, because many caregivers reported that health care professionals paid insufficient attention to their needs (Jumisko et al., 2007).

It is evident from the literature that the challenges that caregivers of TBI survivors face could include financial strain, insufficient time, consequences of a TBI, lack of information, lack of knowledge by others, emotional distress, stress and a lack in resources. Caregivers of TBI survivors therefore have many challenging experiences and lack resources which can make it difficult to cope in this role. The next section consists of a discussion of the resources that help the caregivers to cope better with these challenges.

### **Resources utilised by caregivers of TBI survivors**

Caregivers of TBI survivors have reported specific resources that help them with the caregiving role. These resources can help with the many challenges that caregivers face by alleviating the burden of these individuals. Resources that could help caregivers include social support, respite care, information, effective coping strategies and the caregivers' attitude.

### **Social support**

An important resource that can help with the burden that caregivers of TBI survivors face is social support (Gan et al., 2010; Jumisko et al., 2007). It can potentially decrease the burden and stress associated with the caregiving role (Davis et al., 2009; Hanks et al., 2007). Social support can come in the form of relationships with family and friends, relationships with a spouse or significant other and any other support that is gained through clubs, groups and religion.

Specific examples of social support that have been reported to help caregivers, include support groups (Jumisko et al., 2007) and talking to other family members (Gan et al., 2010). Support groups are a way for caregivers to express their feelings and thoughts, and caregivers have been reported to find comfort in knowing that they are not alone (Gan et al., 2010). Caregivers can often feel alone, socially isolated (Gan et al., 2010; Phelan et al., 2011) and misunderstood by outsiders (Lefebvre et al., 2008). Social support is therefore an important resource that could help caregivers to feel better understood and more connected, if they maintain healthy relationships. Social support can also offer the family caregivers the opportunity to attend to their own social needs.

### **Respite care**

A specific type of support that could give the family caregiver more time for themselves and therefore more time to focus on their social needs includes respite care. Respite care can be defined as care “being delivered within the home, through a day program, or in an outside facility” (Gan et al., 2010). This is especially important for caregivers of TBI survivors who have to spend a vast amount of time taking care of their family member. Respite care can give caregivers time to focus on their careers, relationships and other leisure activities.

Recent studies have found a great need for respite care services in caregivers of TBI survivors (Gan et al., 2010; Rotondi et al., 2007). Home-based care is a specific form of respite care and is convenient because the caregiver does not need to take the TBI survivor somewhere else, which could be a problem for some caregivers and their family members because of challenges such as transport problems or problems with mobility.

Government funding and information on accessing different forms of respite care are also essential in alleviating caregiver burden. Without information on where to find support care, the caregiver might not even know that support is available. Without access to or availability of respite care, the caregiver may not be able to find time to look after themselves, go to work and do the things that they once had time for. It seems that more time for caregivers away from the caregiving role and time to nurture their own personal needs, make a positive contribution to the caregiving experience (Gan et al., 2010). Specific services that meet this need include respite services in the form of home-based therapy for TBI survivors and also services including individuals that attend to the TBI survivor (Gan et al., 2010). These services have been found to alleviate burden in caregivers (Gan et al., 2010) and can alleviate the burden of attending to the TBI survivor during the day, giving the caregivers time for themselves and their own activities.

### **Information**

Information can be an important resource for TBI caregivers. Many caregivers have sought out information from libraries, the Internet and brochures (Braine, 2011). Information can come in the form of psycho-education programs, information leaflets, support groups and information that is given by health care professionals. Caregivers have also reported that a better understanding of the neurobehavioural consequences of a TBI helps them to know what to do and how to respond when certain behaviours occur (Rotondi et al., 2007). This could help with the challenge of the consequences of sustaining a TBI and help decrease the

stress associated with uncertainty about what to expect. Knowing what to expect and also how one can manage the consequences of sustaining a TBI, can help the family caregivers manage their time according to the TBI survivors and their needs. Knowledge could give the family caregivers the power that they felt they lost when they took on the caregiving role.

Training and psychological education for family caregivers has also been found to alleviate burden and help caregivers to cope better with their roles. When Sander et al. (2009) conducted an intervention study on web-based training for caregivers of TBI survivors, they reported that caregivers found learning how to cope with the TBI sequelae to be a beneficial effect of their training sessions. Psycho-education programs play a large role in the long term due to certain problems that might only manifest later in the rehabilitation process (Sander et al., 2009).

### **Effective coping strategies**

The types of coping strategies used by caregivers can also help them alleviate stress in the caregiving role. Depending on the way a coping strategy is used, it can also have a positive outcome to the stressful situation. As mentioned in the section on challenges that caregivers of TBI survivors experience, the emotion-focussed coping strategy, as described by Lazarus and Folkman (1984, 1987), includes managing emotional distress by focussing on the emotions rather than the problem. Some TBI caregivers have reported that they keep a diary and journal to write down their emotions and feelings (Braine, 2011) and this helps them to alleviate some of the tension.

Lazarus and Folkman (1984, 1987) also identified another coping strategy referred to as problem-focussed coping strategies. Problem-focussed coping strategies involve behaviours that emphasise changing stressful situations (Davis et al., 2009). Examples of problem-focussed coping strategies involve planning ahead of time and seeking information about the problem being faced (Davis et al., 2009). The way in which caregivers cope can

therefore affect their experiences as caregivers in a positive way. According to Smeets et al. (2012) interventions aiming to target mastery and coping skills for both caregivers and patients are necessary to improve the functioning of caregivers.

### **Caregivers' attitude**

For some caregivers, helping the TBI survivors with their rehabilitation was a learning experience (Lefebvre et al., 2008). This can be seen as a positive way of viewing their situation. A positive attitude can also aid the caregiver and in a way make the experience more meaningful. Some family caregivers have also reported that stronger bonds and better communication resulted after the family member sustained a TBI (Lefebvre et al., 2008).

The love and compassion (natural love) that the family caregivers feel towards the TBI survivors has also been found as valuable to their coping (Jumisko et al., 2007). These positive feelings help them to find meaning in what they are doing for their loved ones. Gratitude, pride and pleasure have also been expressed by caregivers of TBI survivors (Jumisko et al., 2007). These positive experiences suggest that the caregiving role is not only a burden, but can have positive outcomes as well.

There are therefore several resources that could help caregivers of TBI survivors with the caregiving role. The literature suggests that social support, respite care, information, specific coping strategies and the caregiver's attitude can all contribute to a more positive experience of caregiving for these caregivers.

## 2.5 Caregivers' challenges and resources in a South African context

To my knowledge, no published research exists on the challenging experiences as well as the resources utilised by the caregivers of TBI survivors in a South African context. Most of the caregiver literature in South Africa relate to conditions such as HIV and AIDS, Alzheimer's disease, cancer and mental illness. This study therefore focusses on the challenges faced by caregivers and the resources that help family caregivers as it relates to providing care for a TBI survivor in South Africa, and specifically in the Western Cape.

## 2.6 Theoretical framework: Bronfenbrenner's ecological systems theory

The ecological systemic approach of Bronfenbrenner (1979) will be used to understand the challenges faced by caregivers of TBI survivors as well as the resources that help them to cope with this role. According to Bronfenbrenner (1979) each person is surrounded by an ecological environment which can be viewed as a set of nested structures, each containing another. He uses the metaphor of Russian dolls with its different structures that fit within each other (Bronfenbrenner, 1979). Therefore the setting or surroundings of a person can be viewed as layered and these layers are divided into four levels or subsystems: the microsystem, mesosystem, exosystem and macrosystem (Bronfenbrenner, 1979).

The microsystem "is a pattern of activities, roles, and interpersonal relations experienced by the developing person in a given setting with particular physical and material characteristics" (Bronfenbrenner, 1979, p. 22). This is the innermost layer of the "Russian doll" which is the direct surroundings of the developing person (Bronfenbrenner, 1979). For a family caregiver such surroundings may include interactions within the home (with the TBI survivor) or at their workplace (with co-workers). These settings therefore involve the family caregivers' direct exposure to these specific environments (Bronfenbrenner, 1979). Whatever happens within the home of that individual, for example, occurs in the individual's immediate

environment and therefore occurs in the individual's microsystem. An individual therefore can also have multiple microsystems or direct environments.

The mesosystem involves "...looking beyond single settings to the relationship between them" (Bronfenbrenner, 1979, p. 3). The mesosystem can therefore be explained as involving the relationships between the various microsystems or immediate environments of the individual. This is the second layer of the "Russian doll". Bronfenbrenner (1979) defines a mesosystem as comprising "the interrelations among two or more settings in which the developing person actively participates (such as, for a child, the relations among home, school, and neighbourhood peer group; for an adult, among family, work, and social life)" (p. 25). It is therefore the entire interconnected system of microsystems of an individual's environment. For family caregivers this could include the relationship between their microsystems. An example of this level would be the relationship between the TBI survivor and his or her doctor.

The exosystem includes the "events occurring in settings in which the person is not even present" (Bronfenbrenner, 1979, p. 3). These settings may indirectly impact, or be impacted by the individuals' direct surroundings. According to Bronfenbrenner (1979), "(a)n exosystem refers to one or more settings that do not involve the developing person as an active participant, but in which events occur that affect, or are affected by, what happens in the setting containing the developing person" (p. 25). This means that the individual does not directly have contact to this surrounding that can impact the individual. An example of an exosystem in the context of a family caregiver is the employment status (environment) of a TBI survivor. The employment status of the TBI survivor indirectly affects the family caregiver, because unemployment of the TBI survivor means more financial burden on the family caregiver. The exosystem is the third level of the metaphorical "Russian doll".

The fourth level of the “Russian doll” is referred to as the macrosystem. According to Bronfenbrenner (1979) the macrosystem refers to “consistencies, in the form and content of lower-order systems (micro-, meso-, and exo-) that exist, or could exist, at the level of the subculture or the culture as a whole, along with any belief systems or ideology underlying such consistencies” (p. 25). Therefore similarities within the micro-, meso-, and exosystem in a specific environment (cultural, political, economical and societal) and the belief systems form part of the macrosystem. In the context of family caregivers of TBI survivors, the macrosystem could include the economic environment of the family caregivers (socio-economic status, living conditions, access to health care and access to sanitation). It could also include the societal environment of TBI family caregivers which could include beliefs and misconceptions about TBIs, support services available and stigmatization or marginalization of caregivers.

It is important to note that there is an interaction between each system which has an impact on the individual, in this case the family caregiver. In the context of family caregivers and TBI survivors, Bronfenbrenner’s ecosystemic theory (1979) could serve as a framework to identify and understand the challenges faced and the resources that help caregivers to cope.

## 2.7 Summary

In this chapter, the literature on primary family caregivers of TBI survivors was reviewed. The caregivers’ role in society was discussed, followed by an overview of traumatic brain injury and family caregivers’ experiences in the context of traumatic brain injury. The discussion of the experiences of family caregivers of TBI survivors consisted of the challenges faced by the caregivers and the resources that help them to cope with their caregiving role. This was followed by a description of research on this topic within the South African context. Finally, Bronfenbrenner’s ecological systems theory (1979) was discussed as

the theoretical framework that will be used to understand the results of this study. The next chapter consists of a discussion of the methodology used in this study.

## **Chapter 3 : Methodology**

### **3.1 Introduction**

In this chapter, an overview of the research methodology of this study will be discussed. First, the rationale and relevance of this study will be given. This will be followed by the research question and aims of this study. Furthermore a description of the research design, the sample and the procedure used for collecting data will follow. The data analysis process and trustworthiness of this study will also be discussed. Lastly, the ethical considerations of the current study will be highlighted.

### **3.2 Rationale for this study**

It is evident from the literature reviewed that caregivers of TBI survivors experience a great responsibility. These caregivers face many challenges in this role, which could affect physical, psychological and social well-being (Marsh et al., 2002). There does, however, also seem to be resources that could make the caregiving role easier to cope with. Several previous studies have been conducted on caregivers' experiences with TBI survivors (Arango-Lasprilla et al., 2010; Chronister et al., 2010; Gan et al., 2010; Jumisko et al., 2007; Kreutzer et al., 2009; Lefebvre et al., 2008; Livingston et al., 2010; Rotondi et al., 2007). However, to my knowledge no published studies of this nature exist within the South African context.

In South Africa, TBIs are a public health concern with an estimated 89 000 new TBI cases occurring each year (National Health Laboratory Service, 2012). Many of these TBI survivors need long-term rehabilitation and care. Unfortunately, in South Africa there are limited health care resources and access to existing resources are not always guaranteed (Western Cape Department of Health, 2003). Consequently many TBI survivors who need long-term rehabilitation will not necessarily receive the care that they need. It is therefore

likely that family members take on the caregiving role of TBI survivors. This study aims to investigate the challenges that these caregivers face as well as the resources that help them to cope with their caregiving role.

The findings of this study could be used to understand the unique challenges that caregivers face in a South African context, specifically in the Western Cape area. The resources that these caregivers find helpful in coping with their caregiving role could also serve as a general guide for what could be done to alleviate the burden of caregivers in the Western Cape.

### 3.3 **Research question**

The research question for this study was formulated as follows:

What are the experiences of family members caring for traumatic brain injury survivors in the Western Cape?

### 3.4 **Aims and objectives of this study**

The aim of the current study was to explore the experiences of family members caring for a TBI survivor. The caregiver experiences were investigated with regard to the following broad objectives:

1. What are the challenges faced by the primary caregivers of TBI survivors?
2. What are the resources employed by caregivers of TBI survivors that help them to cope with their caregiving task?

### 3.5 Research design

This study was an exploratory, qualitative study. A qualitative approach was chosen as the most appropriate methodology to explore the experiences of caregivers of TBI survivors, because it enables the researcher to make an in-depth inquiry and to incorporate complex and rich insights from individuals' personal experiences (Coenen, Basedow-Rajwicz, König, Kesselring & Cieza, 2011).

### 3.6 Participants

A purposefully selected sample of caregivers, taking care of their family members who sustained a TBI, was selected for this study. Individual semi-structured interviews with 12 caregivers were conducted. Data collection was discontinued after 12 interviews, because data saturation was reached. The point of data saturation is reached when the themes that occurred in previous interviews start to reoccur and no new information is obtained through data collection (Bowen, 2008). According to Crabtree and Miller (1999), five to eight participants are usually enough to provide rich information for qualitative research. Guest, Bunce and Johnson (2006), also suggests that conducting 12 interviews is sufficient in a group of participants who are relatively homogenous.

Participants were only included in this study if the following two inclusion criteria were met. Firstly, all the participants had to be caregivers of a TBI survivor. This means that a fairly large amount of these caregivers' time is allocated to caring for the TBI survivor. Secondly, these caregivers had to be a family member or spouse of the TBI survivor.

A total of 12 participants were included in this study. All of these participants were female and their ages ranged between 47 and 69 (mean = 57) years of age (see Table 3.1). More than half of the participants (58.3%) reported their home-language as Afrikaans. The relationship of the TBI survivor to each participant included that of daughters (58.3%), sons

(25%), a husband (8.3%) and a granddaughter (8.3%). The duration of time since the family member sustained the TBI ranged between 1 to 10 years (mean = 4 years).

Table 3.1

## Participant characteristics

Participant Code	Age	Race	Home Language	Relationship of TBI survivor	Years since TBI was sustained
1	69	coloured	Afrikaans	Granddaughter	4
2	59	white	English	Daughter	7
3	50	coloured	Afrikaans	Daughter	2
4	64	coloured	Bilingual	Daughter	1
5	56	white	Afrikaans	Son	3
6	59	white	English	Daughter	3
7	56	white	English	Daughter	10
8	65	coloured	Afrikaans	Son	4
9	47	coloured	Afrikaans	Son	1
10	47	white	English	Daughter	3
11	59	coloured	Afrikaans	Daughter	3
12	48	coloured	Afrikaans	Husband	1

*Note.* Bilingual Home Language = Afrikaans and English; Relationship of TBI survivor = the capacity in which the TBI survivor is related to the caregiver. Daughter therefore refers to the caregiver's daughter as the TBI survivor.

The majority of the participants came from low socio-economic circumstances and did not have the financial means to care for another individual. The means and/or access to transportation also seemed to be a specific issue for participants. This became evident after many participants either arrived late for their interview or could not attend the interview due to problems/access to transportation.

### 3.7 Data collection

Data was collected through the Western Cape Rehabilitation Centre (WCRC) at Lentegeur Psychiatric Hospital. A meeting with a clinical psychologist was organised by my supervisor and me to discuss the objective and procedures of the study. The clinical psychologist at the WCRC contacted potential participants to ask if they would like to take part in this study. The clinical psychologist obtained consent from the potential participants to provide us with their contact details. Only thereafter my supervisor and I contacted participants telephonically to schedule interviews. Interviews were conducted at a place where it suited the participants best. Most of the interviews were conducted at the WCRC when participants brought their family members for their check-ups or to visit them in hospital. This ensured that participants did not need to make additional plans for transport. The clinical psychologist at the WCRC assisted with providing rooms to ensure that the interviews could be conducted privately in the hospital.

Semi-structured interviews were conducted, lasting from 60 – 90 minutes each (see Appendices A and B). With the permission of the participants, the interviews were voice recorded for transcription purposes. The interviews commenced with the welcoming of the participants as well as signing of the informed consent forms. Questions regarding general demographic information were asked in order to understand the context of the participant (see

Appendices A and B). These questions were followed by a number of open-ended questions regarding their experiences of the caregiving role.

Examples of these questions include:

- 1) What exactly happened to your family member or spouse that he or she sustained a TBI?
- 2) What has your experience been like since your family member's injury?
- 3) What do you find the most difficult to cope with? What do you struggle with the most?
- 4) Are there any factors that you feel help you cope better with your caregiving role?

Probing questions were also used. The interviews ended with me thanking the participants for taking the time to talk to me. Information on a monthly support group was also made available to participants if they were interested.

### **3.8 Data analysis**

The method that was used to analyse the data was thematic analysis. This method involves the interpretation of data through identification, analysis and reporting of themes or patterns within the data set (Braun & Clarke, 2006). Using Braun and Clarke (2006) as model, the process ran as follows: First the data was transcribed while I started to familiarise myself with the data. I then also made notes to make the coding process easier. Secondly, I identified codes within the data set. Thirdly the search for themes within the data set began. The next process involved reviewing and refining the themes and codes so that nothing was left out. The software program ATLAS.ti was used to help with the data analysis process (ATLAS.ti, 7.1.3). This software was helpful in the identification of codes and managing these codes into specific themes. The fifth process was then started in which the defining and naming of themes and subthemes took place. Lastly a report was written to explain and

further discuss each theme in general as well as in comparison to each theme (Braun & Clarke, 2006).

### 3.9 **Trustworthiness**

In qualitative research, it is imperative to establish and increase rigour and trustworthiness of qualitative work (Guba, 1981; Sharts-Hopko, 2002). Guba (1981) identified four criteria that contribute to trustworthiness. These criteria consist of credibility, transferability, dependability and confirmability. Specific strategies, related to these criteria can be used throughout the research process to increase the trustworthiness of qualitative work (Krefting, 1991; Sharts-Hopko, 2002). These criteria and the associated strategies that were used in this study will be discussed.

#### **Dependability**

Dependability refers to the consistency of the research findings (Guba, 1981) and can be compared to the evaluation of reliability in quantitative research (Krefting, 1991). In this study, a dense description (Krefting, 1991) of the research methodology used was given and contributed to the dependability of this study. This enhanced the potential for replication of this study. Peer examination (Krefting, 1991) was also implemented in this study. Colleagues serving on the Departmental Ethics and Screening Committee (DESC) of Stellenbosch University's Department of Psychology screened the research plan of this study. The research plan was also screened and approved by the Health Research Ethics Committee (HREC) of Stellenbosch University's Faculty of Medicine and Health Sciences. Through the entire process of this research study, I was also monitored by my supervisor and we also consulted on a regular basis to discuss procedures and findings throughout the process.

### **Confirmability**

Confirmability refers to the suitability of the information that the researcher has reported (Sharts-Hopko, 2002) and whether it is a true representation of the research. I made use of reflexivity in this study which contributes to confirmability (Krefting, 1991).

Reflexivity entails being aware of and discussing how my attitudes, beliefs and values can influence the data collection and analysis (Forman, Creswell, Damschroder, Kowalski & Krein, 2008; Sharts-Hopko, 2002).

By reflecting, I became aware that I am a 24-year-old white female student, interviewing participants ranging between ages 47 and 69, with different levels of education and a different race from my own. A few participants also mentioned their faith in this study. I continued to keep in mind that my beliefs and values should not influence the interview process. Regular meetings with my supervisor contributed to this awareness. I have also had previous experience with counselling which assisted me in having an approach of warmth, non-judgement and unconditional positive regard towards participants in this study. As a student, I gained valuable skills and knowledge about these participants in their contexts.

### **Credibility**

Credibility refers to the truthfulness of findings (Sharts-Hopko, 2002) and can be compared to the internal validity of quantitative research (Krefting, 1991). One strategy that contributes to the credibility of this study is the length of time that I spent with the subject matter, the participants and the data (Long & Johnson, 2000; Sharts-Hopko, 2002). This strategy can be referred to as *prolonged engagement* (Lincoln & Guba, 1985). I have been engaged with this subject matter for more than two years. I also spent between 60-90 minutes with each participant in each interview and analysed the data myself. I was therefore completely immersed in the research, data collection and analysis. I also made use of the strategy referred to as member checking (Krefting, 1991). During interviews I made use of

this strategy by asking the participants to clarify or explain what they meant in order to ensure that I was interpreting their experiences correctly. Peer examination and self-reflection are also strategies that contribute to the truthfulness of research findings.

### **Transferability**

In order to generalise or transfer the findings of a qualitative study, it is important to evaluate whether a study's findings can be generalised to other contexts or with other study members (Lincoln & Guba, 1985). In this study, thick description of participants and the research setting and context were provided to allow others to assess how transferable the findings are. According to Lincoln and Guba (1985), it is the researcher's obligation to provide a sufficient database to allow conclusions about transferability to be made by others; it is not the responsibility of the researcher to deliver an index of transferability in qualitative research.

#### **3.10 Ethical considerations**

Ethical approval to conduct this study was obtained from the Health Research Ethics Committee at Stellenbosch University (Ethics reference number: S12/06/155). Informed consent was also obtained from each participant before the data collection could proceed (see Appendices C and D). In this informed consent form, the interview process was explained to each participant, and it was reiterated that they each had the right to withdraw from participation whenever they wanted to do so. They were also informed that they reserved the right to refuse to answer any questions. It was also explained that all participants' information would be kept confidential. Although personal information was required for the demographic part of the interview, the primary researcher made sure that in no way would the participants be identifiable nor would this information be made public. Confidentiality was maintained and only my supervisor and I had access to the data. The data set was also locked away in a

safe place and stored electronically with a password protecting access from anyone other than my supervisor and me.

This study did not hold any foreseeable risks. It merely asked questions about the caregiver's experience. The primary researcher did not anticipate that the participants in this study would experience emotional distress and/or discomfort during the interview to the extent where referral for counselling would be needed. Even though the primary researcher did not deem it necessary to refer any of the 12 participants, a procedure was in place to refer emotionally distressed participants to a counselling psychologist. Participants also had the option to take part in this study in Afrikaans or English as both languages were provided for (see Appendices A, B, C and D).

### 3.11 Summary

The research methodology used in this study was discussed in this chapter. This discussion started with the rationale of the study regarding challenges and resources that caregivers experience in the context of TBI. The relevance of this topic in the South African context was also described. This was followed by the research question and aims of the study, focussing specifically on the experiences (challenges and resources) of family caregivers of TBI survivors in the Western Cape area. The research design was briefly outlined, describing this study as an exploratory, qualitative study. Participant characteristics were described thereafter, followed by the procedure for data collection involving two different institutions. Furthermore, the procedure for analysing the data and thematic analysis was described. Finally, trustworthiness and ethical considerations of this study were discussed. The next chapter consist of the results of this study.

## **Chapter 4 : Results**

In this chapter, the findings of this study will be discussed. From the semi-structured interviews conducted with the participants of this study, it emerged that despite differences in the duration of being a caregiver, there were several themes that appeared to be common across the experiences of participants. The key themes that were identified through the process of thematic analysis can be found in Table 4.1. Each theme consists of various subthemes that could be considered as challenges and/or resources that were associated with the role of caregiving. It is vital to note that these themes are not displayed or discussed in any particular order of significance.

**Table 4.1**

Challenges and resources: Themes that emerged via thematic analysis

	Themes	Sub-themes
Challenges	Trauma	Hearing the news Experiences in hospital Interaction with health care professionals
	Consequences of a TBI	Personality changes Lack of independence Memory problems Speech problems
	Responsibilities	Helping with daily tasks Monitoring the TBI survivor Sacrifices
	Lack of support	Lack of support groups Lack of opportunities
	Unawareness	Lack of knowledge Others' lack of understanding
	Financial burden	Financial situation of participants Financial situation of survivors Medical aid Finances for transport
	Emotional challenges	Anger Grief
	Coping	
Resources	Road to recovery	Progress of patient Independence Health care professionals
	Social support	Support from family Support from friends Support from community Connecting with other caregivers Support groups
	Financial Resource	Road Accident Fund
	Coping	Self-care Taking a break Attitude Faith Gratitude Patience

## 4.1 Challenges

With regard to the challenges that caregivers face, eight key themes emerged from the data analysis. The key themes consist of trauma, consequences of a TBI, responsibilities, lack of support, unawareness, financial burden, emotional challenges and coping. Each of these themes and the associated subthemes will be discussed in the next section.

### Trauma

All of the participants reported that they experienced trauma when their family member sustained a TBI after a traumatic accident. The majority of participants reported that their family member's TBI was caused by a motor vehicle accident. This included family members as passengers in a motor vehicle or as a pedestrian crossing the road. Three participants reported that their family member sustained a TBI after falling, one family member fell from a moving train, one fell as a result of falling during a fire and another family member while working. The accident that caused their family member to sustain a TBI was a traumatic experience for the participants. Participants reported that hearing the news and their experiences in the hospital was particularly traumatic.

### Hearing the news

Most of the participants received the news of their family member's accident through family, friends or health care professionals that contacted them telephonically. This news involved very vague descriptions of what happened to their family member and how serious their injuries were. One participant said she received a phone call from her son about her other son's accident: "My seun wat bel en gesê het Mammie, Brandon<sup>1</sup> was in 'n ongeluk maar ons weet nie hoe erg, ek weet nog nie hoe erg dit is nie sê hy. Ek gaan vir Mammie

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<sup>1</sup> Note. Names in the participants' extracts were replaced with pseudonyms throughout

terugbel” (P8<sup>2</sup>). Another participant received text messages from several people during a meeting with a colleague that they are urgently trying to get hold of her. She phoned her one friend back: “So I phoned and she's screaming and they said come. I went to the accident scene” (P10).

The sudden nature of hearing the news of a family member who was in a serious accident as well as the day of the accident left most of the participants traumatised and shocked. The following quote emphasises how traumatic this experience was for the participants: “See that very day of the accident was like I said very traumatic... So yes that to me was the most traumatic experience of my whole life. I've never been in a situation like that” (P4). After hearing the news of their family member's injury, most of the participants were left with a sense of shock.

### **Experiences in hospital**

Participants reported a number of challenges relating to their experiences at hospital when they visited their family member. Challenges included seeing their family member in the hospital after the accident, lack of hospital beds and the type of care received in public hospitals.

Most of the participants reported that it was traumatic to see their family member in the hospital after the accident. One participant's experience was, “...’n mens het maar geskrik, want dit is net pype en goed” (P5). Another participant shared her experience, evident in the following extract:

Sal ek nou sien Ryan lyk soos ’n, so te sê dooie mens en almal die klomp masjiene op hom en ek het self geskrik wat Ryan nou so lyk wat ek daar kom...En vir my was dit ’n bietjie baie hectic wat ek hom nou daar sien lê. (P9)

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<sup>2</sup> Note. P8 = coding for participants; P = Participant; 8 = number of participant

It is evident from the results that the impact on the participants on hearing the news about the accident and seeing their family member in hospital were immense. They experienced it as extremely traumatic.

Several participants reported that there was a lack of open hospital beds when their family member needed to be transferred to another hospital or rehabilitation centre. Participant 12 reported that one hospital transferred her husband to another hospital without checking whether there was an open bed for him: “Vir een of ander rede het Tygerberg hom oorgeplaas Hottentots-Holland Hospitaal toe en toe is daar nie ’n bed vir hom nie toe moes hy die aand huis toe kom” (P12).

Participant 5 decided to check for herself if there was in fact an open hospital bed for her son after being told by the doctor he was being transferred. This participant reported that when she got there she was told the following: “Toe sê hy vir my maar daar is nie ’n bed nie, daar is nie ’n opening nie” (P5).

Several participants also reported experiencing disappointment in the type of care their family member received in the hospital. One participant felt angry due to the following situation her family member was in:

Op daai stadium het ek gedink ag nee wat ek wil nie eers met hulle praat nie, ek was eintlik baie vies vir hulle. En ek was kwaad omdat sy boude gebrand het, want jy kom daar en jy sê byvoorbeeld vir hulle jy weet hy het gepoo en dan moet jy wag en wag jy weet... En toe brand sy boude weet en toe is ek baie kwaad en sy privaat dele het gebrand en so aan en weet dan ek weet nie, ek is net ek het vir hulle gesê ek sal beter na hom kan kyk, verstaan jy? (P5)

Similarly, another participant reported that her family member was not bathed during her initial hospital stay: “Sy was nie gebad gewees daar in die hospitaal nie, toe sy nou uit die bad uit kom toe voel sy nou sy is reg” (P1).

### **Interaction with health care professionals**

Another participant felt that the health care professionals did not listen to her and her daughter: “That has been the biggest problem with our experience is that the medical profession do not listen... I was called neurotic, and she was called a drama queen” (P2).

One participant also reported that her daughter was discharged from the hospital five days following her accident after sustaining a severe TBI: “The final words of the neurosurgeon to me were take her home she’ll be absolutely fine” (P7).

Several participants experienced that a lack of interest, support and empathy from health care professions in the hospital contributed to their challenging experiences. Participant 6 suggested what she would have found beneficial: “When we were at the hospital to have somebody possibly who could say you know this is my field and I’m here for you if you need me. Here’s my card contact me” (P6). Another participant reported feeling the same way:

It would have taken a lot less of a toll on me if I had some back-up and not necessarily even ja just somebody to talk to, somebody to say you know what it’s ok. This is the next step in the process you know. (P7)

The participants expressed a great need for guidance about the process from the health care professionals.

### **Consequences of a TBI**

All of the participants reported that the consequences that followed the TBI that their family members suffered from were a challenging experience. One participant demonstrated this challenging experience as follows: “Each stage brought its own problems. Just when you think you’re over one hurdle, there is a different hurdle” (P2). Specific challenging consequences reported by participants included personality changes, lack of independence,

memory problems and speech problems. Other less common but challenging consequences perceived by participants included epileptic fits, controlling behaviour as well as problems with concentration, attention, studying and eyesight. Problems with toilet practices, problems with walking, eating, swallowing, spasticity, lack in motivation of the family member, difficulty with executing tasks and weight gain were also amongst these less common challenges. Only the most prevalent challenges will be discussed in more detail.

### **Personality changes**

Most of the participants reported that they perceived a significant change in personality in their family member after sustaining a TBI. Participants reported that their family members were different from how they were before the accident. This was a significant challenge and difficult to adjust to for the participants. The changes in personality are demonstrated by the following quotes:

“Ek meen John was ’n baie liefdevolle kind en hy is nie nou meer so nie” (P5).

“Hy het eintlik heeltemal ’n ander mens geword... So dit was, ek dink dit was vir ons al drie die grootste aanpassing” (P12).

“We had the stage where she would swear and for the first time for me it was like you know geez that’s not my child” (P6).

Specific personality changes that were experienced as challenging by the participants included child-like behaviour, demanding behaviour, anger outbursts, unpredictable and inappropriate behaviour.

Almost half of the participants reported that the TBI survivor was acting like a child for a while after sustaining a TBI and this was challenging. Examples of this perceived child-like behaviour are evident in the following quote:

Her language wasn't the language of a three-year-old but she was mommy don't leave the room, mommy I'm frightened, mommy don't leave me but in like a child would talk in a little frightened voice, it was like having a new-born baby you know. When they cry you get up you feed them you change the nappies you put them back to bed. (P7)

Another personality change that several participants reported involved the TBI survivor being very demanding. A participant describes her experience as:

Things must go a certain way and if they don't then all hell breaks loose... so she'll have a list of things every day and she'll BBM me, she'll sometimes BBM me 50 times in a day and if I don't respond then she gets upset you know. (P10)

Another participant experienced the same demanding attitude from her family member: "... daai tipe van manier as sy nou voel sy wil nou 'n ding hê, dis amper so te sê sy is demanding, sy wil hom nou net hê en klaar" (P3). It is evident that the participants find this type of demanding behaviour as challenging because it can often be difficult to manage and often contribute to emotional distress.

Several participants reported that the anger outbursts, which are a common consequence of sustaining a TBI, are extremely challenging. This involved getting angry quickly, working themselves up into a panic state and experiencing significant anger and aggression to the point of damaging property. One participant experienced rage towards her by her daughter as expressed in the follow extract:

Probably the first year after the accident Sally got really angry with me because to her it appeared that I was making it all about me. I was devastated because Alexander was killed I was devastated and because of that she developed an absolute rage towards me I mean spectacular beyond belief. (P7)

Another participant reported anger outbursts and described it in the following way: “Her anger outbursts used to be so terrible that we actually didn’t know quite how to handle it” (P6).

One participant struggled with unpredictable rage outbursts that her son experienced:

Hy het al baie vir ons almal jy weet aan die nek gegryp... ek dink dit is daai woedebuie wat hulle ook so sterk maak, maar ons was al eintlik al baie keer bang vir hom gewees en dan nou natuurlik my twee kleinkinders ook, hy knou hulle verskriklik af. (P5)

This specific participant also admitted that, due to the unpredictable nature of these rage outbursts, she would never leave her grandchildren alone with him. She could not trust him.

Half of the participants reported that their family member who sustained a TBI often presented with unpredictable and sometimes even inappropriate behaviour. These behaviours include mood swings: “Sy chop en change man” (P11), hiding property from others in the home and then forgetting about it and also sending pictures of their genitals to other people. Participant 5 reported: “Maar nou ’n paar keer ook het hy byvoorbeeld foto’s van sy privaatdele al afgeneem en vir meisies gestuur”. Due to the perceived unpredictable nature of several TBI survivors’ behaviour, participants often found it difficult to manage or control.

It is evident that participants experienced the personality changes that manifested in many different ways in their family members as challenging to manage.

## **Lack of independence**

Most caregivers expressed their family members' inability to function independently as a challenge. This was the case irrespective of whether their family members were in the early stages of recovery or whether it was after several years of recovery. Many caregivers reported that their family members were unable even to do the most basic tasks in the early stages of recovery. These included going to the toilet, swallowing, eating, walking, speaking, writing, executing small tasks and being left alone without supervision. A grandmother had the following to say: "Jy is 24 uur van die dag is jy besig met haar" (P1). Another participant explained the tasks that her family member needed help with:

[She]... needs to be fed. If something itches you need to scratch it for her. Like she'll say my head is itching so can you please scratch it, whatever. We need to feed her we need to dress her we need to do everything for her... We need to do everything from A to Z for her, there's nothing that she can do for herself. (P4)

A similar challenge was reported by participant 5 who reported that her son would say that he would eat later, and then she would realise that he had not eaten all day. She said that he is dependent on her and she needs to look after him otherwise he won't eat at all.

The lack of independence of their family members also affected participants' daily lives, limiting them to do the things that they could do before the accident. One participant experienced the following:

In fact it's more restrictions on our lives because if we want to go out we've got to make sure who's going to be here with Barbara. Don't like to leave her alone because still the whole security issue. She can't move very fast. She can't shout out loud so she wouldn't be able to alert anybody if there was a security problem. (P6)

## Memory problems

Another one of the major consequences of sustaining a TBI that the participants perceived as challenging was memory problems: “Hy vergeet baie gou” (P9). Some memory problems that were perceived by caregivers included problems with remembering faces, going blank when seeing someone, and problems with short-term memory. Perceived problems with remembering things from before the accident as well as during the TBI survivor’s hospital stay were reported by caregivers as illustrated by the following extract: “After the accident she’s lost a section of memory from before the accident and she’s lost quite a big section after the accident” (P7).

Another participant reported that her daughter had experienced memory loss after the accident:

She got home now, her memory had been wiped out, we can't work out exactly how long, but she didn't know that she was at university, she didn't know that she had a boyfriend... And when she came to this house, she had never seen it before. (P2)

Another participant spoke about how difficult it was to have to tell her granddaughter that her two children died in the fire that caused her fall of which she had no memory. “Hulle het gesê sy gaan miskien alles onthou, toe vra sy waar is hulle, nou sê haar ma vir haar, hoekom is hulle nie hier nie, en toe sê haar ma toe... Ek hardloop toe daar uit” (P1).

The participants also experienced forgetfulness as a challenging consequence of a TBI:

“She forgets things you know. She's always leaving her glasses, or leaving her school bag or leaving ... sort of like an old person you know” (P10);

“Maar sy is net vergeetagtig” (P11).

## Speech problems

More than half of participants reported that their family members could not speak and communicate with them after the accident. Participants' family members therefore had to learn to speak all over again:

Nothing set us up for what was to follow, and how traumatic getting her to be able to speak again, was" (P2).

"When she came out of the coma she couldn't talk for a while... they basically had to teach her how to speak again" (P4).

It was therefore difficult for participants to communicate with their family member and participants struggled to understand what their family members wanted to say:

"She used to write messages to us" (P6);

"Ek het lateraan die ABC op 'n plakkaatjie gesit en dan sê vir hom hy moet vir my druk wat hy wil sê" (P5).

Teaching family members to speak again was also reported by participants as a challenge in their caregiving role: "The speech has just taken it's been, it's taken a lot of hard work" (P6).

It is evident from this section that the consequences of sustaining a TBI, was challenging to manage.

## **Responsibilities**

Due to the severe consequences of family member's TBIs, participants reported that they had to take responsibility for helping their family member with a number of tasks and they had various responsibilities. Several participants reported that helping their family member with daily tasks, as well as monitoring them, was challenging. Participants also experienced sacrificing certain aspects of their lives in order to take care of their family member.

### **Helping with daily tasks**

Several participants reported that their family members needed help with very basic tasks on a daily basis: "We need to do everything for her" (P4). Participants reported that these daily tasks included feeding, bathing and dressing their family member as well as helping their family member with going to the toilet and changing their family member's diapers.

A few participants reported that at some point their family member could not feed themselves:

"We need to feed her" (P4);

"She couldn't feed herself" (P7).

Participants reported that bathing their family member was a particularly challenging task. One participant reported: "So dis nou net die badstorie wat nou vir my 'n bietjie baie ongemaklik is, want ons het mos nou nie 'n shower in nie" (P3). Another participant reported that she needed to bath her granddaughter twice a day: "Sy moet elke dag gebad word, want dan moet ek aande weer vir haar want sy, omdat sy so sweet moet ek weer vir haar bad" (P1).

Participant 6 reported how difficult a task it was to bath her daughter: “You know and getting her in and out of the bath you know. You got this dead weight”.

Several participants also reported that their family members’ needed help with getting dressed. This is demonstrated by the following quotes:

“We need to dress her” (P4);

“She couldn’t dress herself” (P7).

One major challenge that a few caregivers experienced included helping the family member with going to the toilet. Participant 1 reported the following about helping her granddaughter go to the toilet: “So elke dag moet sy opelyf kry nou as ek met daardie goed werk dan wil ek nie hê sy moet praat nie”. Another participant reported how she needed to plan in advance for others to change her daughter’s diaper: “I need to see that there’s always someone to come and change the nappy” (P4). Other participants also reported needing to wipe their family members after using the toilet:

“... maar eerste moes ek hom kom...afvee” (P5);

“She couldn’t go to the toilet and wipe herself” (P7).

Changing family members’ diapers was also reported by participants as a challenging experience: “Sy was op nappy gewees” (P3). One participant reported the following “I was so scared that the nappy stage would always be like that” (P6).

It is evident that participants found helping their family members with basic daily tasks was challenging and difficult to adapt to. Particularly challenging daily tasks included bathing family members, helping with going to the toilet and changing diapers.

### **Monitoring the TBI survivor**

Most participants reported that they needed to monitor their family member on a daily basis. Participants reported the following:

“Daar moet altyd iemand by hom wees jy kan hom nooit alleen los nie” (P5);

“I couldn’t leave her alone initially” (P10).

Specific tasks that participants’ family members needed monitoring for included eating and taking medication:

“Om te kyk nou of die appel wat hy eet hy moet nie te ’n groot stuk afbyt nie, want as hy dit insluk dan sluk hy dit in sonder om te kou en so” (P9);

“Ek moet kyk laat hy pille drink” (P5).

One participant reported that she monitored her family member by spending extra time breaking her family member’s food into smaller pieces: “So jy moet eintlik dit in klein stukkies breek vir haar” (P1).

One participant reported monitoring her family member during the night in the early stages of recovery “I did 24 hour duty and slept on her bed... because she kept on getting up in the middle of the night and deciding it was time to go to school or wondering the house” (P7). Another participant reported monitoring her son in the following way: “Ek borsel maar so elke tweede, derde dag of een keer ’n week borsel ek sy tande net baie mooi” (P5).

### **Sacrifices**

A few participants reported that they had to put their careers on hold in order to focus on their family member’s recovery after the accident. Participant 2 reported the following: “I just stopped working. I told everyone who phoned [place of work] that we weren’t available for the period, I mean, that went on for about three or four months”. Another participant

spoke about how she wanted to work but couldn't due to her son's injury: "Ek sal eintlik daarvan hou om te werk, maar wat doen 'n mens dan met John" (P5).

Participant 5 also reported that she moved away from her support system to be closer to a rehabilitation facility for her son: "Ek voel toe op daai stadium my support groep is eintlik meer in Oos-Londen...jou sosiale lewe ly daaronder" (P5).

Several participants reported a lack in appreciation from others and their family member for the sacrifices that they had made for their family member. Participant 7 reported that her daughter's memory loss contributed to a lack of appreciation for what she had sacrificed for her daughter. The following quote demonstrates what this participant said to her daughter: "You don't remember. For three weeks I slept on your floor every night because you wondered in the night. You don't remember and she would just shriek at me and scream at me".

Participant 4 sacrificed attending church during the week due to her caregiving role: "Like during the week I can't go to church anymore at night". Another participant reported staying up late to give her daughter medicine and waking up early again to give it to her again and then leaving for work:

I made sure I didn't go to sleep before 12 because I had to be awake to put this thing in which made me very nervous using this thing. I got used to it so 12 o'clock I'd give her medication, sitting her down then I'd go to bed and I'd set my alarm for 05:30 so by 06:00 I'd be wide awake so I could do the medication again and then I'd get ready and go to work. So that's what it was like in the beginning. (P6)

Many participants also reported that they took care of their family member first before thinking about themselves. One participant reported the following: "... me not realising I needed to take care of myself because all my attention was focussed on her you know... the fact that I don't have anybody to help me you know" (P7).

It is evident that the participants find the responsibilities that relate to the daily life, personal care and supervision of their family members that they care for as extremely challenging. Participants also sacrificed aspects of their life for their family member's recovery.

### **Lack of support**

Several participants reported that a lack of support contributed to the challenges that they faced in the caregiving role: "I think caregivers don't have enough support" (P2). Lack of support reported by participants included lack of support groups and lack of opportunities for the TBI survivor.

#### **Lack of support groups**

Several participants reported a lack in existing support groups for brain injury survivors and their caregivers. Participant 2 reported the following: "One of the worst things, that was what I looked for, I looked for support groups for brain injury, I couldn't find it". Another participant had a similar experience: "Ek het nog nooit enige support groep gekry of gegaan of enige iets nie" (P5).

Two participants reported eventually finding a support group. One participant reported her devastation after finding a support group contact number, but unfortunately not getting an answer: "So I had tried phoning and I remembered the day I tried and there was no answer, I cried" (P2). The other participant reported that she attended a support group meeting and found it unhelpful:

It wasn't run properly. You would go in there and they would, the survivors and the carers would talk about their terrible injury over and over again and you wouldn't get anything out of it, nothing. They would just say the same old thing over and over again. That's what that whole meeting was, it was depressing, very depressing. (P6)

It was evident from the interviews that the participants expressed a great need for support in the form of support groups.

### **Lack of opportunities**

A few participants also reported that there was a need for facilities to take in TBI survivors to work or study and to be taken into consideration: “Ek dink daar moet darem ’n plek wees wat ’n mens vir hulle kan explain sy is ’n breinpatiënt en laat hulle nie vir jou daai volle geld moet charge as sy dit nou nie maak nie” (P3).

### **Unawareness**

Several participants reported that a lack in knowledge and awareness was experienced as a challenge. This unawareness related in particular to the participants’ knowledge about TBIs. It also included the lack of understanding from others about the situation of the participants and the family member that they cared for.

### **Lack of knowledge**

Several participants reported that they did not know what to expect during the recovery stage of their family member. One participant reported the following: “We didn’t know how long anything was going to take” (P2). Another participant reported not knowing how to manage the consequences of her daughter’s TBI: “We actually didn’t know quite how to handle it” (P6).

Several participants also reported that they were not referred to any other professionals or services at the hospital before their family member was discharged. Participant 7 reported the following after hearing from other caregivers about therapies that helped their child: “Is that how it was supposed to work? Nobody told me you know...you just accept it. I mean it sounds remarkably naive but I didn’t know anything about it”.

Another participant reported the following about her daughter and not having anyone to turn to or ask for help: “There was nobody there who could tell us” (P6).

### **Others’ lack of understanding**

Several participants reported that other individuals, such as friends and family, did not understand what they were going through. Other people also did not understand the severity of their family member’s condition. A participant reported the following:

It is one of those situations where nobody understands what it’s like unless they’ve been in it. So I think a lot of the time I used to think well it’s no good speaking to so and so because they’re not going to know what I’m talking about. You know if I needed to speak to somebody I needed to speak to somebody who’d been in this situation. (P7)

Dis moeilik om vir ander mense te verduidelik, want soos ek sê almal wat hom ken sê ‘jinne maar jy het darem gevorder’ en ‘nee wat hy is alright’ maar ek dink nie mense verstaan regtig as hulle nie in die bootjie is nie. (P5)

Several participants also reported that their family member’s lack of visible injuries or disability made others unaware of the severity of their family member’s brain injury: “Dan sal hy sê nie maar hy gaan nou coach swat en dan dink jy jinne dan mense dink seker ek is van my kop af as ek vir hulle sê dat hy kan nie gaan swot nie” (P5).

Another participant experienced her family’s lack of understanding as challenging due to the way others treated her husband. This is demonstrated by the following quote: “Ander mense, sy familie byvoorbeeld, en mense buitekant die huis nog altyd, almal buitekant die huis en mense beskou hom amper asof hy half, jy weet vertraag is. En hulle behandel hom asof hy half vertraag is” (P12).

It is evident that the lack of knowledge of the participants and the lack of understanding of others contribute to the challenges that the participants face.

### **Financial burden**

Most of the participants reported that financial burden was a significant challenge that contributed to distress in the caregiving role. Participants reported that their financial situation, the financial situation of their family member, medical aid and finances for transport were particularly challenging.

### **Financial situation of participants**

Several participants reported that they struggled financially and that the caregiving role made their financial situation challenging.

“Op die huidige oomblik is ons geldjies nou bietjie scraps” (P3);

“Op hierdie stadium het ek nie geld vir ’n stokperdjie nie en ja ek gaan nêrens nie” (P5);

“Somtyds dan sê ek vir hom ek het nie geld gehet om vir jou iets lekker te bring nie maar solank ek hier is vir jou” (P9).

Another participant reported the impact of her family member’s TBI on her finances: “I’ve never recovered financially” (P2). Participant 11 also reported that her income was their only income and that financially it was challenging: “Daai en enigste difficulty is nou net die income wat ek kry, is al net my income”. Another participant reported that it was financially difficult due to her and her husband being pensioners: “Ons twee is nou net pensionarisse” (P1).

### **Financial situation of survivors**

One participant reported that her daughter received a basic salary from the company she used to work for, but it was still not enough to cover all her expenses.

We've paid up her Ackermans account, we've paid up her Woolworths then we discovered that she had a credit card and we sort of somehow paid that up and now it's basically just a loan that she has with Capitec. Then there is basically no money for food. (P4)

Another participant reported that the social grant that her granddaughter receives per month did not cover the full expense of her family member's diapers for the month: "En daai kiembie, en sy kry toelae van die Staat vir 'n duisend tweehonderd en ons betaal 'n duisend vierhonderd. Dan moet ons nou van ons geld bysit" (P1).

### **Medical aid**

Several participants reported challenges with regard to medical aid cover. The participants either could not afford medical aid cover or they experienced problems with their medical aid.

Several participants reported that not having medical aid cover was financially challenging.

Hy is nie op mediese fonds nie so daar lê nog rekeninge op rekeninge wat betaal moet word. So finansieel het dit ons nogal letterlik 'n knou toe gedek. (P12)

Ons het nie 'n mediese fonds gehad nie. En so begin hulle toe nou maar pressure op jou sit verstaan jy, want toe wou hulle begin geld hê die ergste was is dat jy nou nog onder pressure kry oor die geld ook verstaan jy, jy kan nie net jou aandag aan jou kind gee nie nou het jy nou nog daai worry by van hoe moet jy hierdie hospitaalrekenings ook betaal. (P5)

One participant reported that although she has a good medical aid cover, which is expensive, it does not cover alternative therapies as demonstrated by the following quote:

Fortunately we had a very good medical aid, uhm, which as you know is expensive, so it's not for nothing, but because medicine had been, had let us down, we looked to every alternative therapy that was possible. And that wasn't covered by medical aid.

(P2)

Another participant also has medical aid, but it did not cover a carer for her daughter:

But even so medical aid doesn't pay the carer, we've got to pay for that. So every month we've got to fork out for the carer and Barbara needs somebody with her and there's a number of things that medical aid doesn't pay for that we have paid for. So yes we started dipping into our savings and it's not easy you know. (P6)

Participant 6 also reported that her husband had to fight with the medical aid because he knew what his daughter's rights were: "He was fighting for medical aid and you know they're pretty nasty. You're not a person, you're just a number" (P6).

It is evident that the participants of this study found medical aid-related matters particularly challenging.

### **Finances for transport**

Several participants reported that they experienced transportation as a major financial challenge: "Baie gesukkel met vervoer" (P3) and "ons het mos nou nie vervoer nie" (P1). To highlight the extent of this challenge, many of the participants arrived between 15 and 90 minutes late for their interview with me, or they did not arrive at all, and/or we needed to re-schedule their interviews. This was all due to problems with transportation and therefore emphasizes the impact of this challenge.

One participant reported that her son-in-law helped her with transport: “He had to take leave today to bring me here” (P4). Another participant reported that she struggled to afford the taxi fare to go and see her son in the hospital: “Ek het so hier en daar taxi fare gekry laat ek net elke dag by die hospitaal moet gewees het” (P9).

It is evident that participants experience significant financial burden in the caregiving role. These challenges related particularly to their own financial situation as well as their family member’s financial situation which included a lack of income and social grants that did not cover all the expenses of the TBI survivor. Whether the participants had access to medical aid cover or not, this added to the challenging experiences of the participants. Last, but definitely not least, the participants also reported that problems with transportation contributed to their financial challenges.

### **Emotional challenges**

Most participants reported that they experienced several emotional challenges that made coping with the caregiving role difficult. The emotional challenges reported included anger and grief.

Two of the participants reported the following:

“En mense besef nie hoe moeilik dit is om uiteintlik hier deur te kom” (P12);

“When it's a young person, the parents are thrown into this turmoil, where you've got to focus on so much” (P2).

## Anger

Several participants experienced anger towards others during the early stages of their family member's recovery. One participant reported the following: "Daar is ook 'n sielkundige wat met my wou praat en ek het toe met haar gepraat, maar ek was soos in opstandig toe. En toe ek was eintlik baie lelik met daai mense ek het hulle, want toe is ek kwaad, verstaan jy" (P5). Another participant reported feeling angry and decided to express it in a journal: "I would be angry about certain things and I would write it in there" (P6).

Another participant reported that she struggled to cope with the caregiving role and the trauma associated with the accident. She reported the following about a counsellor's reluctance to let her join a group therapy session: "I was so angry and I was so aggressive that she thought that I wasn't going to fit into a group situation because I had this absolute rage in me as to why did this happen to my child" (P7). Participant 9 felt angry towards her family's lack of appreciation and respect for what she had been doing for her son: "Ek kan nie help nie hulle het my kom hard maak" (P9).

## Grief

Some of the participants reported that they went through a grief process after they realised that their family member in many instances changed completely after sustaining a TBI. A participant expressed that it was traumatic and that her child was actually dead after sustaining a TBI, saying: "Want daai kind wat jy geken het is eintlik dood. So dit is maar baie traumaties" (P5).

Another caregiver summarised losing her daughter and the grief process that she experienced:

So we have lost our daughter... what I realised now is that we had to grieve. It was a grieving that we were doing and it was very different. It's not different it's like losing a child. It's that same grief. It's a living grief. (P6)

In addition to grieving for their family member who sustained a TBI, some of the participants reported that they were also affected by the loss of other individuals who were part of the same accident. One of the participants reported that she and her family were not only traumatised by her daughter's injury, but by the death of her daughter's fiancé in the same car accident:

I think I had post-traumatic stress disorder or some sort of post-traumatic something from the stress of the accident, from losing Alex which I was absolutely devastated by because he and I were very close... I was so angry you know and I think I also probably needed some grief counselling as well. I think that would have made a difference. (P7)

Another participant who currently cares for her granddaughter, who sustained a TBI due to a fire, reported that even though her granddaughter survived, the fire killed seven other family members and acquaintances, including two of her great-grandchildren.

### **Coping**

Participants reported that they struggled to cope in the caregiving role. Their struggle is demonstrated by the following extracts:

“Party dae voel dit ek kan nie, ek kan nie verder nie” (P1).

“Daar is sommige dae wat dit, wat ek dink vandag is die hele besigheid besig om my onder te kry. Dan soms is jy emosioneel, soms is jy opvlieënd en jy weet dan is ek ook maar op my agterpote” (P12).

Several participants reported that it was difficult to cope due to being the only person there for their family member. One participant reported the following: “Although the therapists were helpful, they are there for a half an hour and then you’re on your own again” (P2).

Another participant felt like she was thrown into the deep end when her husband had to come home from the hospital:

Ek is bang hy gaan seerkry en hy is nog van balans af en ek mean ek het letterlik heel nag regop gesit... sê ek vir hulle dit is nou wat gebeur as ’n mens, almal gaan aan met hulle lewens en jy sit uiteintlik met dit. (P12)

One participant reported that she was in a vulnerable state after everything that happened to her daughter and ended up in a motor vehicle accident herself: “I was coming home 11 o’clock at night, drinking, on my phone something had to trigger and I drove into a tree, not on purpose it was an accident” (P10).

Participants reported using various ways of coping. Some unhealthy coping strategies that participants employed included drinking, using medication and smoking.

Participant 7 reported turning to alcohol as a way of coping in this role:

I drank and I actually drank to the point... I hadn’t always been a heavy drinker, the accident and the aftermath of that is what took me over the edge and so I actually ended up being a full-blown alcoholic and brought into treatment. (P7)

Participant 10 reported that a family member gave her medication to help her cope in the early stages of her daughter’s recovery:

She gave me Ativan. And sleeping tablets so I used Stilnox at night, I would just knock myself out and then during the day I would just take the Ativans and I think, I can't remember if it was an anti-depressant so it probably was from the divorce or

whatever and so I would just take Ativans and then I would remember that I forgot to take it if I were to start crying... I mean I was a wreck emotionally. I was a total wreck. I wouldn't have survived without the Ativans.

One participant also reported that she coped by taking a smoke break: “Ek rook mos nou, nou rook ek.” (P11)

It is evident from the latter section that the trauma related to sustaining a TBI, the consequences of a TBI, numerous new and additional responsibilities, a lack of support, unawareness, financial burden, emotional challenges and coping all contribute to the challenging experiences of these participants. In the next section, the results with regards to the resources that participants utilise will be discussed.

#### 4.2 Resources

It was evident from the data analysis that, although the participants faced various challenges that related to their role as primary caregiver, four key themes that relate to the resources that caregivers experience as helpful in the caregiving role emerged from the data analysis. These themes include the road to recovery of their family member, social support, financial resource and resources for coping. Each of these themes and the associated subthemes will be discussed in the next section.

##### **Road to recovery**

Three subthemes emerged as part of the caregivers' experiences of the TBI survivors' road to recovery. Participants reported that the progress that they perceived in their family member, the independence gained by the TBI survivor over time and the assistance and support of health care professionals with the rehabilitation of their family members was incredibly helpful.

## Progress of patient

Many participants reported that they observed progress in their family member's condition and a change in the symptoms that the patient initially presented with.

“’n Mens kan sien daar is baie verbetering, regtig” (P3);

“It was getting better, I could see it was getting better, I could see she was getting stronger” (P2);

“Everything that was done for her showed. She's here now I think all of it did. It was very slow progress, very slow” (P6);

“Ek dink nogal hy toon vir my nogal baie, baie goeie vordering” (P12).

The participants generally reported that they observed the progress of their family members with optimism. Progress with speech, emotional maturity, mobility, anger outbursts, and ceasing wearing diapers were reported as progress in family members. This progress gave participants hope.

Changes in speech were reported to be one of the most prominent changes. Several participants reported that their family member eventually stopped talking in a child-like manner after waking up from their coma. One participant reported: “Probably in a couple of weeks that grew off and she went back to talking in a normal voice” (P7).

Changes in emotional maturity were also noted by a number of the participants. One participant reported: “It took her a long time to get back to handling things on an emotional level as an adult” (P7).

Many participants also reported that their family member made good progress with regard to mobility. One participant reported the following: “Hy het mooi gerecover by die huis ja, maar nog nie soos normaal nie, maar hy het mooi gerecover om ’n bietjie te geloop

het ook dan loop hy na sy ouma toe sonder die wheelchair, sonder die stok” (P9).

Participant 4 reported how her daughter did not need as much help to sit anymore:

At first she couldn't, we first had to tie her up, but now we don't really have to because she don't fall over anymore. She can sit up yes but not for long periods. Obviously we put her in a one-seater couch so basically it's got support on both sides yes. So ja she doesn't need anything else. (P4)

Another participant reported that her daughter's anger outbursts improved over time: “Not so bad now because Barbara's not so bad anymore you know she still gets angry but not as often and the anger doesn't last as long and she's over it very quickly” (P6).

Several participants also reported that they were told by health care professionals that their family member would not be able to do certain things. Most of these participants also reported that their family members progressed better than health care professionals expected:

I mean she's a walking miracle because they didn't expect it. What they expected, firstly they didn't expect her to live and secondly they didn't expect her to get past the stage where she would need a carer 24/7 or where she would just be lying in a bed. They didn't think she would ever get past that and she is now you know, she walks with crutches but she kept through she will hold onto furniture. (P6)

Another participant had a similar experience reporting the health care professionals' reaction to her daughter's swift recovery:

Die Sondag toe ek vir haar terugneem na 'n tyd toe sê ek laat iets van haar binne-in die rystoel en sy stoot die rystoel self, toe kon hulle nie glo dat dit die kind is wat nou so met die rystoel nou in die hand daar aankom nie. (P3)

Many participants also reported that their family member did not need to wear diapers anymore: “Sy is af van die nappies af.” (P3) Several participants also reported that their family member did not have any more visible injuries. This is demonstrated by the following quote: “Now she is at that point where you would not say that there is anything wrong with her” (P2).

A number of the participants reported that the change in the symptoms and their family member’s progress gave them hope for the future of their family member. One participant reported the following:

There was hope. She wasn't physically impaired to a degree that traumatised me. I could see she was getting stronger, I could see that I at least I thought, that she wasn't gonna be left with that limp hand and leg, she was like that, initially, everything gave me hope. (P2)

### **Independence**

Several participants reported that their wish for their family member was to become independent again. One participant reported that seven years after the accident “she got a little part-time job” (P2). Participant 7 reported that her daughter was living independently ten years after her accident:

She had a devastating head injury you know. She drives, she lives independently. She has a boyfriend. She works. She does pole dancing, she does Pilates. She is president of our local lines club; she’s a member of Heads Up. She shouldn’t be doing any of that with the head injury she had. (P7)

Another participant reported that three years after her daughter's accident she wasn't as dependent as she was at the earlier stages of recovery:

Barbara doesn't need anybody to look after her anymore she looks after herself, we don't have to. She gets up and goes to have a bath she washes her hair she puts her make up on. She does everything we don't have to do anything for her. There's healing all the time but it's slower. (P6)

Participant 10 reported that her daughter was back in school within a year: "Oh gosh. You know she's absolutely a normal functioning human being and then at the end of the year after the therapy finished she went back to school" (P10).

Even though several participants reported that their family member was not completely independent, a number of the participants reported that there were small steps for their family member towards becoming more independent and they found this encouraging. One participant reported: "Ek hoef nie meer vir hom aan te trek en te stort nie. Want dit kan hy darem nou al self doen" (P5). Another participant reported a similar experience: "Hy is eintlik baie fine op sy eie... hy sal soggens opstaan en hy sal gaan stap 'n entjie en terugkom. En hy kan self toilet gebruik, hy begin leer om nou self aan te trek" (P12).

### **Health care professionals**

A number of participants reported that they found the variety of services that were offered by health care professionals very helpful. Some of these services included physiotherapy, speech therapy and occupational therapy.

Participant 3 reported that her daughter's occupational therapist invested a lot of time in her daughter's recovery:

Hulle was nou die mense wat vir my altyd deur die dag gekommunikeer het en my altyd gebel het en gevra het hoe het sy vandag gedoen en die tipe ding. Ons het baie

kontak met mekaar gehad. Hulle het regtig vir my lekker by gestaan veral Kara, die meisietjie. Sy was baie goed vir Adele gewees, regtig, eintlik hulle almal, maar sy het meer tyd, meer ingesit vir Adele sal ek maar nou sê.

Another participant reported how helpful physiotherapists and speech therapists were in her daughter's recovery. She noted that they did not always get the credit they deserved: "We came to realise that the most helpful professions are the ones that probably don't get the recognition, like the speech therapists, and the physiotherapists, and are the people who are side-lined" (P2).

Participant 6 reported that her daughter recovered well and that the following services contributed to her recovery: "She had physio-, occupational and neuro- speech therapy" (P6).

Several participants also reported that you should not be afraid to ask questions about what doctors are doing: "If you doubt sometimes what a doctor's doing, ask questions don't be scared to ask" (P6).

### **Social support**

Most of the participants reported that social support from various sources was particularly helpful in coping with the caregiving role: "Ek dink dit was maar net seker ondersteuning van almal rondom ons wat ons maar gehelp het om daardeur te kom" (P12); "There was my sister, my niece, my nephew who were there constantly, my eldest daughter and her husband. There was my husband, our friends" (P6). The most important sources of social support seemed to include the participants' support from family, friends, their community, connecting with other caregivers and support groups.

## Support from family

Most participants reported that their family was a particularly important resource and supported them in their caregiving role. Family members that supported participants included the participants' siblings, children and grandchildren.

“Familie het ons ook bygestaan” (P3);

“’n Mens kry baie ondersteuning van die res van die familie” (P12).

Several participants reported that remaining close and communicating with family members helped them cope with the caregiving role. One participant reported the following as a resource:

Ek dink die feit dat ons as ’n gesin dinge saam gedoen het en ek baie met my dogters gepraat het en gesels het en dat ons drie goed gedeel het mekaar... ons was altyd maar ’n baie hegte gesin, ons vier so ons het maar so ver as moontlik probeer om dit altyd maar so stewig as moontlik te hou die, die hegte gesinsband. (P12)

Another participant reported a similar experience demonstrated in the following quote:

We are a very caring family... that's basically a family thing of us all rallying around and wanting to do the best for her... my son-in-law had to take leave today to bring me here... I think it's just having a family that's very close, help me through this. (P4)

Several participants reported that their siblings were a great resource in their caregiving role. One participant reported the following about her sister:

My sister was invaluable, and she was the one who would give me a break, she would come to visit, while I went to Pick n Pay... I have an amazing sister, who was the one who stepped in, that was very very worthwhile, and helpful. (P2)

Another participant reported how her sister helped her when her son was in the hospital:

My oudste suster het vir my baie gehelp in daardie tyd, want sy het baie by my gestaan en sy het taxi fare of trein fare gegee en sy sal vir hulp met, eerder sy kom deur na my toe of ek moet vir haar wat Ryan nou hier kom lê het dan sal... sy bly in die Mitchells Plain dan vat sy taxi uit Mitchells Plain hientoe, sy het altyd vir Ryan kos gebring, sy sal altyd vir Ryan iets lekker gebring het, altyd sy was daar gewees as 'n mens vandag taxi fare gegee het dan sal sy my altyd sê daar is 'n R50 of 'n R100 vir môre, ek sal miskien nie môre of oormôre saam jou weer hier by Ryan wees nie maar daar is jou taxi fare vir jou uit, dan is sy die een wat vir my taxi fare gee. (P9)

Several participants reported that their children helped with managing the caregiving role. One participant reported the following:

Die kinders het baie saam met my gekom na hom toe en gehelp met hom toe hy nou huis toe kom en so aan. Hulle het maar altyd, ons doen maar altyd alles so saam... en hulle het nogal almal, ek dink almal het maar nou net gehelp om die taak ligter te maak. (P12)

Another participant reported the following about her children helping:

Ja it's a group and also a family thing because I have seven children. Her brothers is involved with them, her sisters is involved, very much involved. Like her brother will say why must we go out when you wash her I see that all the time I take her to the toilet I pull down her panty and I put her on the toilet, so those kind of things yes. She's got three brothers and they are all very much involved in things. (P4)

A few participants also reported that their grandchildren would help them with their roles as the caregiver. One participant reported the following about her daughter's children: "The children, we alternate with the children that each one get a chance to do something for her" (P4).

### **Support from friends**

Another important social support resource that participants reported, included support from friends. It is demonstrated in the following quote:

My husband and I we've got a fabulous group of friends, we call them our core friends. There's about 12 of us, 14 of us very good friends... my husband's best friend, and my best friend, they are a couple, every weekend he'd be there sitting with my husband holding his hand. Just there not saying anything just sitting there and his wife is a good friend of mine and I remember she just tried to feed me because I just stopped eating. I just couldn't swallow anything and it was just for three weeks. (P6)

Another participant reported that her son's friends were a great support for her in the caregiving role:

My son's friends all stepped in you know I've been trying to lift her into the bath or something one of his great big friends would come along and say I'll do it and she was completely unfussed that she had no clothes on or anything and inhibition went out the window with her so you know we did have a lot of support in that respect so ja but friends definitely played a big part. (P7)

Participant 4 reported how the support of her church friends helped her: "Having friends that can pray with me because I don't have any other friends I only have church friends".

## Support from community

Several participants reported that members in their community also supported them in their caregiving role. One participant reported that her community helped raise funds for her son's hospital bills:

Die eerste week het hulle 'n 5 km-stap vir hom gereël en dit is 'n groot ding om te reël ek meen dit is ambulans en ook sekere punte jy weet sulke dinge en goed. En daar het so baie mense opgedaag dat hulle nie voorbereid was vir dit nie. Daai een dag het hulle vyf en tagtig duisend rand ingesamel vir hom. Want die mense het, hulle het nie net hulle kaartjies gekoop nie hulle het donasies ook gegee. Dit was iets verskriklik weet jy regtig ek meen die kinders wat dit gereël het, het T-shirts met sy naam op en sy gesig op en.. .dit was 'n groot storie. (P5)

Several participants also reported that their communities helped them by bringing them meals during the initial weeks after their family member's accident.

It is a small community and everybody knows everybody else, so I had people that I've never seen before ringing my doorbell and bringing me meals. Total strangers rang my doorbell and said we've heard about your daughter, literally people I've never seen before say we've heard about your daughter we've brought you frozen lasagne, we cooked this for you... For about two weeks after the accident I just had random people arriving with me also it's bizarre. Absolutely it was fabulous I never had to cook. I would just take something out of the deep freezer and bun it in the microwave. (P7)

Another participant reported a similar experience: "I must say for two months a lot of people would drop off food which was amazing, I didn't cook for two months" (P10).

One participant also reported that serving in her church was a helpful resource: “Ek is baie betrokke by ons in die kerk, juis nou na sy siekte en het ons nou baie, ek baie betrokke geraak in die kerk so ek is by onse kerk op onse kerkraad” (P12).

### **Connecting with other caregivers**

Another form of social support that was noted by the participants included connecting with other caregivers and sharing experiences. One participant reported how she met someone through family members and they shared their experiences with each other. Participant 12 reported that she learnt how to approach her husband’s inability to properly dress himself:

Juis as gevolg van daai vrou tjie wat vir my gesê het nee sy, sy het hom gelos as hy, sy het nie omgee, ek was aanvanklik het ek baie, was ek baie bekommerd oor wat gaan mense sê, ek wou nie hê mense moet dink hy is onversorg of. (P12)

### **Support groups**

A few participants reported that attending a support group with other caregivers was a valuable source of support. One participant reported taking away the following from attending a support group;

I’ve got to have her weaned off her antidepressants. So that’s something that I’ve taken away from that meeting and that’s what you need. Somewhere where you can go with not even a problem, but saying I want to query this and everybody can chat about it. (P6)

Another participant described the value of attending a support group in the following way:

Somebody else understands what it's like to get a phone call to say your daughter's been badly injured. Somebody else knows what it's like to sit next to a bed in ICU when your child is hooked up to monitors and on a ventilator and being fed through a tube and you know that's enough to freak anybody out but for somebody else to say you know what I know what that feels like to sit at that bed. I know how scary that is. I've been in that place. That is the biggest benefit of the group. (P7)

Several participants reported that they learnt how valuable support was in the caregiving role. Participant 7 reported the following:

I would definitely get support for myself next time. That would be the biggest thing. I would definitely get support for myself, it's imperative as a carer that you have backup for yourself whether it's a church group or a friend or somebody outside your family somebody in your family is too close. (P7)

Another participant reported the following after being asked what advice she would give other caregivers that just found out about their family member: "Firstly ask them if they've got support. How much family support do they have you know people who they know because they need to call in or get in as much support as they got as they can get" (P6).

Another participant reported that a practical way of helping a caregiver with support includes helping the caregiver figure out what help he/she needs from family and friends and then asking for it:

What I would do, if I were asked to help someone who was struggling, or drowning, or overwhelmed, I would ask them for all the family phone numbers, and I would ask who was available, or set up a roster, or because people who can't ask, will find it difficult to ask, but it's not always that people aren't willing to, they just don't know

what to do. So, I would say the most helpful thing anyone in a crisis like this can be, is helpful, friends, really close friends, and family. (P2)

It is evident that the participants experienced support resources which helped them with their family member's progress and on a social level. Social support however, was reported as the most significant resource by participants in helping them with the caregiving role.

### **Financial resource**

A significant financial resource reported by participants whose relative's TBI was a result of a motor vehicle accident included the Road Accident Fund.

#### **Road Accident Fund (RAF)**

Most of the participants whose family members were in motor vehicle accidents reported that the Road Accident Fund (RAF) served as a significant financial resource.

“They started directing the bills to the Road Accident Fund so we don't pay anything at the moment. Everything is going into the Road Accident Funds claim” (P4);

“Al die rekening word betaal deur die prokureurs en die dinge” (P3);

“So financially we were okay and she did get a pay from the Road Accident Fund somewhere in the region of about R350 000” (P7);

“The Road Accident Fund has agreed to pay 50% all her medical expenses related to the accident for life and they've said in her report she needs the therapy for life”

(P10).

## Coping

Several participants made use of various strategies to help them cope with the caregiving role. These strategies included taking care of themselves, taking a break, their attitude, their faith, being grateful and having patience.

### Self-care

A number of participants reported that looking after themselves was an important resource for coping with the caregiving role. The participants achieved this in several ways. It varied from keeping themselves busy to returning to work and taking a break. One participant reported that keeping herself busy was helpful when her husband sustained his TBI: “Ek dink die feit dat ek besig gebly het, ek het eintlik ’n redelike besige lewe” (P12).

Returning to work was also reported by a few participants as a resource. One participant reported that going back to work gave her structure and normality in a traumatic time in her life: “Actually working is a good thing. It was the consistency and normalness (P2).

A few participants also reported that caregivers should not listen to negative talk and others who do not understand what you are going through. Participant 6 reported the following:

Don't listen to negative talk. We had a lot of negative talk out there. People, just people who thought they knew. I'm not talking about doctors and that people, who thought they knew everything and if somebody phones you and you don't like the person put the phone down, don't worry it doesn't matter. If you don't like that person you actually don't have to deal with that. (P6)

## Taking a break

Several participants also reported that taking a break away from their family member helped them to cope in the caregiving role. One participant reported the following about going away for a couple of days:

Desembermaand toe voel ek maar nou net, ek sê vir die pa toe, ek wil 'n bietjie weggaan, toe boek ek vir my 'n treinkaartjie, kry toe die 2de Januarie, kry ek toe plek op die trein, toe gaan ek 'n bietjie Joburg toe vir die week. Twee dae was vir my genoeg daar onder gewees. (P3)

Another participant reported that getting a break from the rest of her family helped her cope: “Om net so 'n bietjie iets op my eie te gaan doen of... weg te kom van die res van die gesin” (P12).

One participant reported that she would take a walk when she was having a bad day: As ek 'n slegte dag het dan sal ek stap, ja dan stap ek sommer op dorpie toe of ek stap hier oor na die kerk toe en ek gaan gesels met haar by die kantoor of so, 'n bietjie stoom afblaas en so. (P1)

One participant reported that she realised that she needed to take care of herself as well after going into treatment for alcoholism:

I think going into treatment made me realise that I needed to take care of myself in order to be able to take care of everybody else yes definitely and I think you know I can look back now and I can see where I went wrong. (P7)

This participant also reported the value of counselling as a resource in the caregiving role: “I had a lot of therapy and I found that incredibly helpful and I think I probably didn't particularly need anybody to give me advice. I just needed somebody to listen to me and somebody that I can phone” (P7).

One participant reported that spending time with her dogs was a way of breaking away from reality:

So like walking my dogs, I used to walk every single day, now and then Mary would come with me, uhm and then when this happened, and she was in hospital in and out for all those months, I still took an hour out to walk my dogs, but the rest of the day and night I was at that hospital, and they weren't gonna keep me away. But I still walked my dogs, and then when she came home, we, that was the thing that gave me joy, to see my animals happy and, and I could do that with her. (P2)

### **Attitude**

Several participants reported that a positive attitude helped them to make the caregiving role more bearable. One participant reported the following about her attitude:

Ek dink dis seker maar net 'n mens se ingesteldheid ook. Ek wou nie hê my lewe moes ingrypend verander, ek wil nie hê dit moes nou, dit moes iets wees wat nou vir jou 'n struikelblok is nie. Dit moes net iets wees waarmee net nog iets wees waarmee ek nou nog moet cope. (P12)

Another participant reported adopting the following attitude: "Ek sê altyd as 'n mens goed is vir mense dan is mense goed vir jou, reg? Maar ek maak niks, waar swarigheid is, ek gooi die swarigheid agter dan sê ek net oh just go behind my back" (P11).

Several participants also reported that they did not want others or themselves to cry around their family member with the TBI. One participant reported how she approached and handled her daughter's hospital stay:

I wouldn't allow anybody at Barbara's bedside who started crying. You better get out. I did a lot of crying then but I would do it in the little waiting room and here at home but when we got to Barbara, we had to be upbeat and we had to talk all the time. (P6)

Several participants also reported that they would celebrate progress in their family member. One participant reported the following about celebrating and being positive about her daughter's progress:

Everything that happened was like wow there's something else you can do. Look you're getting better this is awesome. Wow you can do that, you're brilliant, you're fantastic. You know I'm so proud of you. Look what you can do you can tie your shoelaces. What's going to be next? And we just treated it like that we never looked at she can't do this we looked at when is she going to be able to do this. (P7)

### **Faith**

Most of the participants reported that their faith helped them to cope with the caregiving role

“Dis ook maar net met ondersteuning en geloof en dat, kyk daar is 'n stadium waar jy maar net moet sê dis maar nou maar net geloof wat jou gaan deurdra.” (P12)

“Vat ons wat Christian is, want ons sê Hy is goed vir ons en Hy voorsien ons behoeftes” (P1).

One participant reported the following about having faith even though doctors gave them news that was challenging to deal with:

Toe die dokter vir ons sê maar sy is nou al hoe lankal in 'n koma en sy vorder nie.

Toe staan ek en hy by die bed toe sê ek vir hom, man die dokters doen ook maar net hulle werk, maar hulle is nie die Here nie. (P3)

Another participant reported a similar experience of her interaction with the doctor and how she remained faithful:

Three times the doctor said to us that she's not going to make it and every time I just had to tell my children whose report do you believe, God's report or the doctor's report? Because remember this is what the doctor says but God can overwrite it and you know there she is a living testimony of what God can do and I always thank God.

(P4)

Most participants also reported that praying helped them to cope during this time:

“Ek sal altyd net vra vir die genade as ek so frustrated voel en ek voel bedruk sal ek altyd sê die Here moet vir my kalmte in my hart gee of so” (P9); “Die gebed het baie gehelp, gebede wat uitgegaan het vir haar” (P3).

One participant reported asking friends on Facebook to pray for her daughter:

For me being a Christian and I had to take my stand in the Lord and I know a lot of people from here to Nigeria and everywhere people were just praying for her because I've put it on Facebook and they so many times wanted to know how is her condition now and then they praise God with me. So this is all the work of God yes. Within a week of praying for her with a prayer shawl she opened her eyes. (P4)

Another participant reported how she prayed in thanks after her daughter woke up:

“As sy wakker skrik ek sak amper in, ek gaan daar, ek sit sommer net daar wat ek inkom toe sê ek oh dank die Here, ek sê ja Allah Shukran sy is wakker” (P11).

## **Gratitude**

Most participants reported being grateful for how far their family members have come and progressed. According to the participants, they learnt to count their blessings. Participant 2 reported the following:

So I also have a gratitude list... I think what also helps me is, I sit and count the things that I'm grateful for. I think if I just had to focus on the things that have gone wrong, I would be much more demented than what I am.

The gratefulness experienced by the participants of this study is also evident in the following three excerpts:

“So ja it's just been such a miracle, she really is. It's been amazing” (P6);

“I see other people and I see the state that their children are in I think how did I get so lucky that she came back completely” (P7);

I've learnt to be so grateful for how far we've come and how blessed she is to be as well as she is. My gosh, I mean she could be outside sitting in a wheelchair in a corner and that was their prognosis. They were wrong and they have to cover their bases, because of what... they don't know. (P10)

## **Patience**

Most participants reported that they learnt to have patience with their family member:

“n Mens moet baie patience hê” (P1);

A lot of patience because sometimes I also feel like strangling her you know because remember she's also got a will of her own and a mind of her own and all that and with the brain not being fully healed it's sometimes very difficult but for that you need a lot of love and a lot of patience. (P4)

Jy moet maar baie geduld hê ek sal vir jou sê my geduld is beproef, want jy moet baie dinge herhaal, ek meen hy kan nie meer as... hy kan nie meer as twee opdragte op 'n slag uitvoer nie, as jy vir hom 'n opdrag gee van gaan was jou gesig en trek aan en kom af onder toe en drink jou pil, jou kos is in die mikrogolf sal hy dit nooit kan alles doen nie. (P5)

#### 4.3 **Summary**

In this chapter, the findings of this study were reported. Several themes and subthemes emerged from the semi-structured interviews that were conducted with the participants of this study. These themes included several challenges faced by the participants. Eight key themes were identified, namely trauma, consequences of a TBI, responsibilities, lack of support, unawareness, financial burden, emotional challenges and coping. Several themes related to the resources that the participants utilised to cope with the caregiving role also emerged from the data analysis. The four key themes that emerged regarding resources that participants experienced included the road to recovery, social support, financial resources and coping. The results will be discussed, interpreted and integrated with existing literature in the next and final chapter.

## Chapter 5 : Discussion

This study aimed to examine the experiences of the primary caregivers who are responsible for caring for a family member who sustained a TBI. These experiences were investigated by exploring the challenges and the resources primary caregivers encountered through the caregiving role. Several studies have found that caring for an individual who sustained a TBI consists of many challenges for the caregiver, but also include important resources that help these individuals to cope with the caregiving task (Arango-Lasprilla et al., 2010; Davis et al., 2009; Ergh et al., 2002; Gan et al., 2010; Jumisko et al., 2007; Lefebvre et al., 2008). Such findings also emerged in this study and most participants considered the resources that aided them in their day-to-day coping with the caregiving task as vital to overcome and to cope with the challenges that accompany such an enormous responsibility. The components of Bronfenbrenner's ecological systems theory (Bronfenbrenner, 1979) will be used to interpret the results and contextualise the discussion.

The first level of Bronfenbrenner's ecological systems theory is the microsystem, which represents an individual's immediate environment where intimate, direct interactions with people occur (Bronfenbrenner, 1979). This would include the relationships between the caregiver and the TBI survivor, his/her family, friends and neighbours. The second level is the mesosystem, which refers to the more than one link between the microsystems in which the individual participated (Bronfenbrenner, 1979). An example of this level would be the relationship between the TBI survivor and their doctors. The third level, namely the exosystem includes those structures (from micro- and mesosystem) where the individual is not actively involved. An example of this level for caregivers would be the employment status of the TBI survivor. Lastly, there is the macrosystem, which is the broadest level of development and includes laws, policy making, values and culture (Bronfenbrenner, 1979).

In the context of caregivers of TBI survivors, financial assistance from the Road Accident Fund and medical aid will be considered as part of this level.

From the four levels of development, namely the micro-, meso-, exo- and macrosystem, that Bronfenbrenner identified, only the micro- and macrosystem were applicable to this study. Due to this study's focus on the primary caregivers' experiences, and therefore participants' immediate environment and interactions, most of the challenges and resources emerged within the microsystem of these individuals. Themes associated with the microsystem include trauma, consequences of a TBI, responsibilities, lack of support, unawareness, financial burden, emotional challenges, coping, road to recovery, social support and coping resources while the themes associated with the macrosystem include trauma, financial burden, financial resource and medical aid.

It should be noted that no challenges or resources were identified as belonging to the meso- or exosystem. This may have been because the focus of this study was on the individual caregiver's experiences. It is however possible that factors such as the TBI survivors' relationship with other family members or their doctors (which represent examples of the mesosystem) and the TBI survivor's employment status (which represents an example of the exosystem) could influence the experiences of caregivers of TBI survivors. This was however outside the scope of this study and could be explored in future studies.

The following sections will include a discussion of the microsystem and the macrosystem irrespectively, focussing on the themes which emerged within this study on each of these two levels. This will be done by discussing the microsystem and the themes related to the challenges that primary caregivers face, followed by the themes associated with the resources that help primary caregivers on this level. The same will be done for the discussion on the macrosystem.

## **Microsystem**

As mentioned earlier, the microsystem consists of an individual's direct surroundings and interactions with others (Bronfenbrenner, 1979). The interviews with participants naturally started with participants' description of the events that led to their family member's TBI and finding out about the accident. Participants recalled experiencing that specific time in their lives as traumatic. The trauma associated with this initial part of the caregiving role emerged as the first main theme with regards to caregivers' challenging experiences.

The reactions of family members to the event that caused the TBI in their loved one could be compared to the reaction processes that occur in individuals who experience significant trauma (Man, 2002). Even though post-traumatic symptoms were not clinically evaluated in this study, signs and symptoms of trauma were perceived and reported by participants. It has been suggested that more than half of family members of TBI survivors' tend to experience clinically significant post-traumatic stress symptoms shortly after their family member's accident (Pielmaier, Walder, Rebetez & Maercker, 2011). Most of the participants of this study considered this experience of trauma to be a major challenge and emphasised the need for support of family members during the initial stages of the recovery of TBI survivors.

A TBI also always occurs unexpectedly and suddenly (Coco, Tossaveinen, Jääskeläinen & Turunen, 2011) and therefore when participants heard the news about their family members' accidents, they experienced feelings of shock and devastation. The news about their family members' accidents was given to participants telephonically through family, friends or health care professionals. Most of the accidents that caused participants' family member's TBIs were as a result of a motor vehicle accident and the remaining participants' family members' accidents were caused by falls. These two causes of TBIs are

considered to be two of the most common causes for sustaining a TBI (Adekoya, et al., 2002).

The hospitalisation period of the TBI survivor is a very stressful experience for their family members (Lefebvre & Levert, 2012). Interaction with health care providers has also been identified as a challenge by the participants, especially during the initial hospital admission of their family member who sustained a TBI. A number of participants experienced health care professionals as lacking interest, support and empathy during their family members' initial hospital stay. It was evident from the findings of this study that the caregivers have a need for support from health care professionals, whether in the form of providing information about what to expect or in the form of support to deal with their experiences of shock and trauma.

According to Coco et al. (2011) it is common for family members of TBI survivors to long for information from health care professionals, however Jumisko et al. (2007) found that health care professionals often pay insufficient attention to caregivers' needs. According to Man (2002), family caregivers become empowered when they gain more knowledge about their family members' conditions. This could then help caregivers to gain a sense of control after experiencing such a traumatic event.

To my knowledge no prior studies have investigated and reported the early experiences of caregivers and the challenge of hearing the news about their family member who sustained a TBI and seeing their family member in the hospital. It is therefore possible that this might be a unique experience for South African caregivers. The paucity of research relating to these initial experiences might also be due to the perception that the caregiver only takes on the caregiving role at a later stage when the family member is discharged from the hospital. These findings therefore highlight the challenging experiences that these caregivers

experience from the outset and emphasise the need for support for these individuals much earlier.

After the participants' family members were discharged from the hospital, they could not take care of themselves due to the severity of their brain injury. Consequently, the participants of this study had to take on the responsibility of the primary caregiver. According to Arango-Lasprilla et al. (2010), when family members lose their independence to look after themselves and need fulltime care, the caregiving responsibility is generally assumed by family members. The participants, who took on the role of primary caregiver, reported that the variety of symptoms presented by the family member who sustained a TBI was very challenging.

The physiological, psychological and neurobehavioural deficits reported are common consequences in individuals who sustained a TBI (Braine, 2011; Gan et al., 2010; Kreutzer et al., 2009; Lefebvre et al., 2008; Livingston et al., 2010; McAllister, 2008; Trevena & Cameron, 2011 2010). Caregivers have reported that the extent of the neurobehavioural consequences of a TBI, make their lives especially difficult (Livingston et al., 2010) and can impact the psychological well-being of family members of TBI survivors (Wood, Lioffi & Wood, 2005). It was also evident in this study that the severity of the consequences of the TBI had an influence on how challenging the caregivers found the caregiving role.

Participants experienced personality changes as particularly challenging to deal with. This was consistent with previous studies' findings that personality changes were particularly challenging consequences to deal with for caregivers of individuals who sustained a TBI (Gan et al., 2010; Man, 2002; McAllister, 2008; Trevena & Cameron, 2011). Personality changes such as anger outbursts, inappropriate and unpredictable behaviour were reported in this study and elsewhere (Braine, 2011).

These personality changes seemed to affect participants' relationship with the TBI survivor as a number of participants reported going through a grieving process as a result of these personality changes. This is noteworthy, because in addition to primary caregivers' experiences of trauma, they also reported feeling a sense of loss and grief as a challenge within the caregiving role. This finding also supports prior research where caregivers felt they almost had to get to know their family member again (Jumisko et al., 2007) and they felt a sense of loss of their relationship with their family member (Braine, 2011). These experiences highlight the importance for family members to have resources available that will support them in their mourning process (Lefebvre & Levert, 2012).

Memory problems were another major challenging consequence that participants found difficult to deal with. Specific memory problems that were reported by participants include forgetfulness and retrograde amnesia which are common in patients who sustained a TBI (Braine, 2011; Zillmer et al., 2008).

An individual suffering from a brain injury may be unable to communicate as a result of a change in brain functioning after the injury (Grieve, 2002). Problems with communication, specifically speech problems, were another major challenge that was reported in this study. Changes in TBI survivors that affect language were also reported by Faul et al. (2010) as a great challenge. These problems with speech affected participants emotionally due to the lack of adequate communication with their family member and the severity of the speech problems. The participants reported that some of their family members who sustained a TBI could not speak, they spoke with great difficulty, or they spoke in a child-like voice after waking up from a coma. Several of the participants also had to experience the challenge of teaching their family member to speak again and to communicate in a different way.

Another major consequence that participants found challenging included their family members' lack of independence and need for constant supervision. The consequences of a TBI also seemed to affect the role the caregiver needs to play in their family member's life and therefore also affected the responsibilities of the caregiver and emerged as the third main theme.

It was evident, not only in this study, that caregivers with family members who had more severe TBIs and consequences, seemed to carry a larger burden (Livingston et al., 2010) and had to take more responsibility for them. The severity and nature of such consequences affected the need for the caregivers' assistance on a daily basis. Responsibilities of participants included helping their family member with basic daily tasks (Kreutzer et al., 2009) and in this study included assistance with feeding, bathing and dressing their family member, helping their family member go to the toilet and changing their family member's diapers. The severity of the TBI of a family member could therefore also give an indication of the potential responsibilities associated with the caregiver's role and therefore also the stress load that the caregiver may experience.

Participants also experienced the responsibility to supervise their family members as a challenge due to their family members' need for twenty-four-hour supervision. When family caregivers are always on stand-by for their loved ones (Jumisko et al., 2007), it can lead to many caregivers sacrificing other aspects of their lives.

Sacrifices that participants reported that were associated with a lack of time for themselves included sacrificing doing the things that they had been doing before assuming the role of primary caregiver. It included sacrificing their careers and hobbies. Several studies have reported that caregivers spent less time doing things for themselves, especially as the recovery time of their relative increased (Jumisko et al., 2007; Lefebvre et al., 2008; Marsh et al., 2002). Caregiving can become a full-time job and it was evident in this study because a

number of participants were unemployed as a result of the challenging caregiving role, their responsibilities and the time needed to fulfil this role. These caregivers had to re-evaluate their professional careers after the TBI survivor came home from hospital. It is common for caregivers to take leave and in many cases to be forced to choose between following a career and providing care for a family member who sustained a TBI (Lefebvre et al., 2008). In addition to a lack of time for themselves, the decision between assuming the caregiver role full-time and keeping their job also have major financial implications which can place even more burden on the caregiver.

With this in mind, it was not surprising that the financial burden associated with the caregiving role also emerged as another important main theme. Due to the severity of family members' brain injury and the specialised medical care and rehabilitation needed, the financial expenses and medical bills can become problematic for caregivers. Several participants reported that the caregiving role placed strain on their financial situation. Studies on caregivers in the context of brain injury are consistent with this finding that caregivers experience financial pressure in the caregiving role (Jumisko et al., 2007; Marsh et al., 2002; Rotondi et al., 2007). A need for financial assistance has been reported by caregivers of TBI survivors previously and in this study (Lefebvre & Levert, 2012).

The participants in this study also reported that the TBI survivors' income were not sufficient to cover all their medical expenses. Loss of income and employment in individuals with a chronic condition is common (Rotondi et al., 2007) and can affect their caregivers negatively. In addition to this challenge, very few TBI survivors in this study had access to a private medical aid scheme, which made the medical expenses more financially burdensome for the caregivers. Caregivers often needed to use their own finances to help share the financial burden of their relatives, but as mentioned previously, the caregivers often had to

give up their jobs to provide full-time care to their family member and this intensified the financial challenges.

Medical expenses and the impact of the financial burden of TBI survivors on family caregivers involve paying for treatment, the loss of employment of family caregivers due to the caregiving role, a reduction in hours worked due to lack of time available and/or re-entering employment in a lower-paying job (Rotondi et al., 2007).

In this study, the TBI survivor's only income consisted mostly of social grants for disability. If an individual, living in South Africa, is unable to work for more than six months due to a mental or physical disability, that individual is eligible to apply for this grant (South African Government Services, 2013). The maximum amount that the individual with the disability will receive per month is R1 270 (South African Government Services, 2013). Even though this grant serves as a resource for TBI survivors and their caregivers, this does not seem to be enough to cover all the daily living expenses of the TBI survivor. It was evident that participants still suffer financially due to the financial burden of TBI survivors' rehabilitation and loss of any other income.

Expenses related to transportation were an additional financial challenge reported by the participants. The need for transportation to visit and/or to take their family member to the hospital intensified caregivers' financial burden. Many of the participants do not own a car, and needed to rely on public transport and other individuals to help them with transport to and from the hospital. This challenge became particularly evident when the interviews were arranged with the participants, because most participants struggled with transportation. To overcome this hurdle, interviews were scheduled during the time that participants had to take their family members to the rehabilitation centre, or when they went there to visit them. Some interviews were also conducted at participants' homes to make it easier for them to participate in this study.

It is therefore clear that financial burden is a significant challenge for caregivers. Even though some of the TBI survivors receive social grants for disability, it did not necessarily substitute the loss of income of the TBI survivors or their caregivers.

Caregivers play a significant role and take responsibility for the care of their family members who sustained a TBI. It was however evident from the interviews that these individuals do not always get the support they need. A lack of support therefore emerged as another main theme and a lack of support groups for caregivers of individuals who sustained a TBI was emphasised in particular.

Only a few participants reported that they knew about a support group for caregivers and their family members who sustained a TBI. However, this support group was reportedly still in its infancy and only started a couple of months ago. This new support group was established in order to provide support that was not currently available to caregivers, emphasising the need for support groups and support in general for primary caregivers of TBI survivors. Intervention programmes that include support groups could be beneficial for caregivers in the Western Cape where there are not many available resources.

It is also worth mentioning that I did not find any easily accessible existing support groups in the Western Cape area, other than the one that the participants mentioned. Many contacts that I found were either retired individuals who did not lead a support group anymore, or the telephone lines were disconnected. The contact information was therefore not up to date and also lacked any type of referral system. There is clearly a need for support groups amongst the caregivers, but there seems to be a paucity of relevant information about such groups. This is worrying due to the emerging trend of health information being available on the Internet (Cole & Gary, 2012), yet it was difficult to find any support groups in the Western Cape area.

The Internet could potentially be an important tool for relevant information on the caregiving role and resources available in South Africa and the Western Cape area specifically. There are several websites with information on support networks associated with caregiving and brain injury in the United States, for example the Family Caregiver Alliance (2012) and the Brain Injury Association of America (2014). These websites offer information and relevant research to the public and those affected by caregiving and brain injury irrespectively. The relevance of online support networks in the context of South Africa should, however, be researched in future studies, because many caregivers come from a low socio-economic background and therefore might not have access to computers and Internet connections or because of a lack of exposure, they might not have the necessary computer skills.

Unawareness emerged as the next theme. Not knowing what to expect in a family member's recovery was evident as a challenging experience for participants. This uncertainty experienced by caregivers has also been reported in a previous study as a very common feeling in caregivers (Jumisko et al., 2007). A lack of knowledge was reported as problematic by the participants and made their caregiving role more difficult resulting in caregivers feeling like they were thrown into the deep end. A study by Lefebvre et al. (2008) reported that information on available resources and what to expect in the long term, were basically non-existing for these caregivers. Rotondi et al. (2007) also reported that caregivers do not get sufficient information during the recovery process.

In this study participants also found a lack of referrals at the hospital as a challenge. A need for a directory to inform individuals on accessible services targeted at TBI survivors and their family members has also been reported in a previous study to remedy this lack of knowledge (Rotondi et al., 2007). Another more recent study also reported that it was important for family members and caregivers to receive information from health care

professionals specifically (Coco et al., 2011). Receiving information from health care professionals can be an important resource due to the direct interaction that health care professionals have with TBI survivors and their families. It is thus clear that the family members of TBI survivors need to be informed about care and available services (Lefebvre & Levert, 2012).

In addition to the participants' own lack of knowledge, they also reported that a lack of understanding by others contributed to let them feel lonely, isolated and misunderstood. A previous study reported that when others do not understand the TBI survivors' sequelae, caregivers find it difficult to maintain social relationships (Lefebvre et al., 2008). Isolation can also occur in family caregivers and their TBI family members as a result from outsiders' lack of understanding of TBIs and the implications associated with it (Gan et al., 2010; Phelan et al., 2011). Others' lack of understanding emphasises the need for information and guidance for caregivers and their families and should be noted by health care professionals working with TBI survivors and their families.

Emotional challenges also emerged as another main theme. In addition to experiencing trauma and a grieving process for their family member with the TBI, as mentioned earlier, some participants also reported grieving for other individuals that passed away in the same accident that caused their family members' TBI. This was experienced as an emotional challenge for caregivers and also contributed to their challenging experiences with their roles as caregivers.

Anger was another emotion that was not only experienced by the participants of this study (Braine, 2011; Coco et al., 2011). These feelings of anger were mostly experienced in reaction to what happened to their family member and having to deal with the severe changes in their family members. The burden of the responsibilities of the caregivers could also

contribute to feelings of distress, burnout, exhaustion (Lefebvre et al., 2008), chronic fatigue (Gan et al., 2010) and feelings of being overwhelmed (Gan et al., 2010).

Caregivers are often thrown into the deep end and struggle to cope with their new role. Several of the participants of this study reported that they made use of ineffective coping strategies such as smoking, drinking and using medication to help them to cope with their emotions. These coping strategies emphasised how important effective and healthy coping strategies, psycho-education and support services are for these caregivers. Smeets et al. (2012) suggested that the functioning of caregivers could improve if mastery and coping skills are targeted in interventions for both caregivers and TBI survivors.

It is evident from the discussion up to now that the participants of this study experience numerous challenges at the micro-level. However, a number of resources also emerged that seem to help the participants to cope with the caregiving role.

Although participants experienced the consequences of a TBI as challenging, many participants reported that the change and progress of their family members' symptoms gave them hope.

Sources of hope for participants include improvements with speech, emotional maturity, mobility, anger outbursts and wearing of diapers. This progress also affected their level of independence. For example, when family members did not need to wear diapers any longer, family members became more independent by not needing help with diaper changes. Therefore caregivers' burden load and responsibilities grew lighter with the progress of their family members.

This progress that has been reported by participants varied from several months after the accident up to a decade after the accident. This is an interesting finding because many participants reported that health care professionals advised them that there would not be significant progress after 2 years of rehabilitation. This was however, not the case for most of

these participants' and progress continued up to a decade after sustaining a TBI. According to Novack and Bushnik (2013), improvements in TBI survivors do slow down substantially after 2 years of rehabilitation, but may still occur.

A crucial resource that contributed to most of the family members' progress included the services that health care professionals offered to brain injury survivors. These services included physiotherapy, speech therapy and occupational therapy. Participants were grateful for these services and reported that their family members showed significant progress due to these services that were provided. This finding emphasised the importance of long-term rehabilitation for TBI survivors (Ketzeback, 2012) and the positive effect that their progress could have on their family members.

Social support emerged as another important resource in this study. Similar findings have been reported by previous studies which demonstrate that social support is a valuable resource for caregivers (Gan et al., 2010; Jumisko et al., 2007). The literature seems to suggest that social support could potentially decrease the burden and stress associated with the caregiving role (Davis et al., 2009; Hanks et al., 2007). Support from family was reported by participants as particularly helpful in the caregiving role. Specific family members that aided participants in their role included participants' siblings, children and grandchildren. Support from friends and other community members were also reported as an important resource. Participants also valued the meals that community members would bring to them in the initial recovery stages because it helped lessen the burden of needing to cook meals for their family in that difficult time of their lives.

As mentioned earlier, others' lack of understanding can be a significant challenge for these caregivers. Therefore participants reported that connecting with other caregivers, whether it was through mutual acquaintances or at the hospital, it was found to be a helpful resource for them in the caregiving role. Participants reported that speaking to others in the

same situation was something that they felt helped them cope better. Connecting with other caregivers through support groups have not only been reported as a valuable resource by other studies, but also emerged as an important resource in this study (Davis et al., 2009; Gan et al., 2010; Hanks et al., 2007; Jumisko et al., 2007).

Social support in the form of family, friends and community members and connecting with other caregivers are particularly important in the Western Cape of South Africa, due to the limited existing resources for caregivers in this region.

Specific coping strategies were also reported as resources for caregivers. It was reported that focussing on taking care of themselves was an important resource for the participants. According to the Family Caregiver Alliance (2012), only when we first help ourselves, we can effectively help others and it is one of the most essential things a caregiver can do in the caregiving role. Participants also reported that taking a break from the caregiving role helped them cope better. Whether it is going away for a few days, or asking a family or friend to care for the TBI survivor, it served as a type of respite care for participants.

Attitude also seemed to be an important resource that helped caregivers in their role. Staying positive, being grateful, exercising patience and celebrating small victories in the rehabilitation process was found to help alleviate some of the caregiver burden. Positive ways of coping, such as the latter, have been reported to be associated with less anxiety, depression and better quality of life in family members of TBI survivors (Norup, Siert & Mortensen, 2013).

Faith also played a significant role in most of the participants' lives and gave them hope for the future. Many participants used prayer as valuable sources of strength and hope in the caregiving role to cope with challenging experiences. Religious practices, such as prayer, reportedly has significant effects on psychological well-being and over-all functioning of the body and can act as a buffer in stressful situations (Joshi, Kumari & Jain, 2008).

It is evident by the discussion above that there are numerous challenges and resources that caregivers reported in this study to occur within their microsystem and direct interactions with others. The next section will include the discussion on the themes considered as part of the macrolevel.

### **Macrosystem**

The macrosystem is the broadest level of development, which includes laws, values, culture and policy making (Bronfenbrenner, 1979). As mentioned earlier, most of the caregivers reported experiencing trauma while their family member who sustained a TBI was in hospital. In this study, at the macrolevel, practical and logistical difficulties emerged as particularly challenging. During the TBI survivors' hospitalisation, a lack in open hospital beds for the TBI survivor was for example reported as a challenge by the participants. The Western Cape Department of Health (2003) has previously recognised and acknowledged that this is often a problem. Problems like these therefore seem to be a factor within the South African public health care system that contributes to the challenges that caregivers of TBI survivors face.

Another challenge on the macro level included medical aid insurance (for those who had access to it) which did not cover all their family members' therapeutic services. As medical aids' goals are to serve as a resource for those who have it, it is quite problematic for caregivers when it does not cover all medical expenses. Caregivers consequently needed to

battle with their medical aids to pay for specific medical expenses and this contributed to their financial burden in the caregiving role. It could be that problems with the policies of these medical aid insurances are to blame or that TBIs and the long-term rehabilitation services are just too expensive for medical aids to cover all of the associated medical costs. Unfortunately, the continued high cost of medical services for individuals with chronic conditions (Yen et al., 2010) like TBI, will therefore fall on the family caregivers, even if they pay for a medical aid.

When considering the resources at macrolevel, a specific and vital financial resource for caregivers and their family members that was reported in this study includes the Road Accident Fund (RAF). In South Africa, the RAF is:

a juristic person established by an Act of Parliament, namely, the Road Accident Fund Act, 1996 (Act No. 56 of 1996), as amended ("RAF Act") ... the RAF is responsible for providing compulsory social insurance cover to all users of South African roads; to rehabilitate and compensate persons injured as a result of the negligent driving of motor vehicles in a timely and caring manner; and to actively promote the safe use of all South African roads (Road Accident Fund, 2012, p.6).

This financial resource was therefore only reported by caregivers' whose family members sustained a TBI as a result of a motor vehicle accident. Damages could be claimed by family members from this third party when the negligence was not caused by the family member that sustained the TBI. The RAF is considered as part of the macrosystem due to the legal and governmental level of this resource.

The RAF helped several primary caregivers alleviate some of the financial burden when they claimed from this fund. According to participants the fund paid for all the TBI survivors' medical bills and potential long-term rehabilitation services that were deemed necessary as a result of the accident. This was a very significant resource for caregivers in

this study, considering the significant financial burden that these caregivers often have to face. The RAF helped lessen the burden financially and caregivers therefore did not have to sacrifice their own finances for the TBI survivor.

It is evident from this discussion that primary caregivers of TBI survivors in the Western Cape experience several challenges and resources associated with the caregiving role within their micro- and macrosystems.

### **Limitations of this study**

One of the limitations of this study is that the sample comprised of a convenience sample of family caregivers that only included female participants. The findings can therefore not be generalised to male caregivers and other caregivers of more heterogeneous samples. Participants in this study ranged between different levels of education and socio-economic status. However, it would be advisable to replicate this study in a more representable group of South African citizens that include male caregivers as well as a more diverse racial population group.

The results of this study can also not be generalised to all South African populations due to this study's focus on primary caregivers in the Western Cape area. The challenges and resources associated with the primary caregivers of this study may differ from other contexts and can therefore not be generalised.

The themes that emerged from the data-analysis could have been verified in different ways. The participants could have been provided with the translated transcripts of the interviews to check whether the translation is a true reflection of their experience. The themes that were identified through thematic analysis could have been verified by the participants through focus groups, where the identified themes could have been discussed. However, due to logistical difficulties and time constraints not one of the above was possible.

## **Recommendations**

As with most exploratory studies, the value of the current study appears to be that it has taken the first step in attempting to understand the experiences of family caregivers of family members' who sustained a TBI and who reside in the Western Cape, South Africa. Given that the current sample was a convenience sample of family caregivers, it is necessary to replicate this study, with a more representative sample. This study served as groundwork for similar studies, but in other contexts. A quantitative study could therefore also be conducted in order to gain insight in a larger and more representative population group.

Another avenue for further research includes the implementation and evaluation of the impact of support groups for primary caregivers of TBI survivors. Findings of this study highlighted that there is a great need for support and information in the form of support groups.

Future studies could also focus on the experiences and perceptions of health care professionals who often work with TBI survivors and their caregivers. Health care professionals' perceptions about the needs of caregivers and referral systems that are in place could be a relevant avenue for future research.

Due to the Internet's potential to serve as an important tool for relevant information on the caregiving role and resources available in South Africa and the Western Cape area specifically, future studies could focus on the relevance of online support networks in the context of South Africa.

## Conclusion

The purpose of this exploratory qualitative study was to investigate the experiences of primary caregivers of TBI survivors in the Western Cape. These experiences included the challenges that caregivers face and the resources that help them cope with the caregiving role. The current study supports the findings within existing literature that consequences of TBIs, lack of support for caregivers and TBI survivors, lack of information and knowledge in caregivers and others, emotional challenges, ineffective coping strategies and financial burden are challenges that primary caregivers face in this role. However, unique challenges that emerged from this study consist of the experiences of trauma that related to hearing the news about their family member's injury. Insufficient support from health care professionals as well as practical and logistical challenges within the South African health care system, were reported as a major challenge. A lack of open hospital beds for the TBI survivor was highlighted as a particular challenge.

Regarding the resources that may help primary caregivers of TBI survivors to cope with the caregiving role, this study's finding that social support serves as a valuable resource is consistent with prior research. In this study it was found that primary caregivers also perceived progress in their family members as a resource and a source of hope. To my knowledge, progress was not specifically reported as a resource in previous studies. However, hope has been reported as a resource for coping in the caregiving role. Support in the form of respite care, effective coping strategies, information and caregivers' attitude also seemed to be important resources as suggested in prior research. A unique resource that was reported in this study is the assistance of the Road Accident Fund. This resource seems to be unique to South Africa and this sample in the Western Cape and serves as a financial resource for TBI survivors and their caregivers who have been victims of motor vehicle accidents.

The findings of this study suggest that interventions in the form of psycho-education on the consequences of TBIs, how to manage these consequences, support networks for caregivers, how to effectively cope in this role and information about financial aid and resources could be beneficial to caregivers of TBI survivors. In addition, a need for support groups from the initial stages of recovery throughout the rehabilitation and caregiving period emerged from the findings of this study. The role of health care professionals with regard to providing guidance, empathy and information to the caregivers was also emphasised. It seems as if the caregivers view the relationship between themselves and the health care professionals who are involved in the treatment of their family member who sustained a TBI as very important. It was however evident from the findings of this study that the caregivers are generally not satisfied with the quality of the interaction between the health care professionals and themselves. Lastly, this study's findings serve as a basis for future research studies on the experiences of family caregivers of TBI survivors in the Western Cape.

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## **Appendix A**

### **Interview Schedule (English Version)**

A semi-structured interview (60-90 minutes)

#### **A) Welcoming**

I'd like to thank you for your willingness to take part in this study. Firstly, I'd like to start with the informed consent and just go over what this study is about. This study is about the experiences of caregivers, such as yourself, that look after family members or spouses who sustained a traumatic brain injury. I'm just going to ask you a couple of questions about your experiences and what it is like for you to be caregiver. If at any point in time you feel that you don't want to continue or answer a specific question it is absolutely fine. Don't feel pressured in any way. As I mentioned on the phone, I will be recording our interview but it will only be for me to listen again for research purposes. You also don't have to worry about your personal details, it will be kept confidential so whatever you say or talk about will not in any way be connected back to you. So if you'd like you can read the informed consent form and then you can sign at the bottom. Are there any questions you'd like to ask at this point?

#### **B) Demographic questions**

- 1) What is your name?
- 2) How old are you?
- 3) What is your home language?
- 4) What is your level of education?
- 5) What is your occupation?
- 6) What is your relationship to the TBI patient?
- 7) What is your marital status?
- 8) Do you have children?

- 9) When did your family member sustain a TBI?
- 10) How long have you been the primary caregiver?
- 11) How many hours a day do you spend on caring for the patient who sustained a TBI?

**C) Open ended questions**

Five main questions will be asked and more information about each will be gathered through probing questions.

- 1) What happened to your family member/spouse that he/she sustained a TBI?

Probing questions:

How did you find out? How did you react when you first heard the news? What did the doctors tell you about the patient? What was challenging for you when you think back at the time of learning about your family member/spouse's injury? What helped you to cope with the news?

- 2) What has your experience been like since your family member's injury?

Probing questions:

What has happened since the patient sustained the injury? Tell me about your relationship with your family member in comparison to before the accident/injury? What changed in your life since then? How has your social life been impacted? Has there been a change in your professional life? How did it change? How has your day to day life changed since the injury? Describe a typical day for you as a caregiver? How many hours do you spend taking care of your family member? How do you make sense of what happened? How do you feel about what happened? How do others react to what happened? How do others treat you and your family member after the injury was sustained?

- 3) What do you find the most difficult to cope with? What do you struggle with the most?

Probing questions:

Tell me about the things that made your experience as a caregiver more difficult? Tell me about the communication between you and the patient? In the same way I will probe about possible challenges like:

- Unpredictability of behaviour
- Household tasks
- Burnout/time for self
- Loneliness
- Insight of the patient
- Personal care
- Personality changes
- The physical and mental health of the caregiver
- How the patient deals with change

4) Are there any factors that you feel help you cope better with your caregiving role?

Probing questions:

- Tell me about your support systems (friends, family). What do you do when you have a bad day? Who do you turn to for help? What are your hobbies? What do you do to take your mind off the caregiving role? Tell me about the involvement of the community? I will ask similar probing questions about potential resources like:
  - Support groups
  - The role of spirituality and/or religion
  - Psychiatric and/or psychological services
  - Treatment/medication
  - Availability of formal services
  - The use of a diary to record thoughts and feelings

- Sense of humour

D) Conclusion

- 1) Is there anything else that you want to share about your experience?

Probing question:

Has there been anything that I didn't ask that you want to share?

I want to thank you again for taking part in this study.

## Appendix B

### Onderhoudskedule (Afrikaanse weergawe)

'n Semi-gestruktureerde onderhoud (60-90 minute)

#### **A) Verwelkoming**

Ek wil u bedank vir u bereidwilligheid om deel te neem aan hierdie studie. Eerstens wil ek begin deur na die ingeligte toestemmingsvorm te kyk. Hierdie studie gaan oor die ervaring van versorgers, soos u self, wat na gesinslede of huweliksmaats kyk wat 'n traumatiese breinbesering opgedoen het. Ek gaan net vir u 'n paar vrae vra oor u ervarings en hoe dit vir u spesifiek is om 'n versorger te wees. Indien u op enige punt voel dat u nie wil voortgaan met die onderhoud of nie enige spesifieke vrae wil beantwoord nie, is dit heeltemal in orde. U hoef nie onder enige druk te voel nie. Soos telefonies bespreek, sal ek die onderhoud opneem. Ek neem dit net op vir navorsingsdoeleindes en om na die onderhoud weer daarna te luister. U hoef ook nie bekommerd te wees oor u persoonlike inligting nie, want dit word konfidensieel gehou. So wat ook al u sê sal op geen manier aan u verbind kan word nie. So as u wil, kan u deur die ingeligte toestemmingsvorm lees en dan aan die onderkant van die bladsy teken. Is daar enige vrae wat u op hierdie stadium wil vra?

#### **B) Demografiese vrae**

- 1) Wat is u naam?
- 2) Hoe oud is u?
- 3) Wat is u huistaal?
- 4) Wat is u vlak van onderwys?
- 5) Wat is u beroep?
- 6) Wat is u verhouding met die TBB-patient?

- 7) Wat is u huwelikstatus?
- 8) Het u enige kinders?
- 9) Wanneer het u familielid of huweliksmaat 'n TBB opgedoen?
- 10) Vir hoe lank is u al die primêre versorger?
- 11) Ongeveer hoeveel ure per dag bestee u aan die versorging van die patient wat die TBB opgedoen het?

### **C) Oop-einde vrae**

Vier hoofvrae gaan gevra word en meer inligting kan ingesamel word deur opvolgvrae .

- 1) Wat het met u familielid/huweliksmaat gebeur dat hy/sy 'n TBB opgedoen het?

Opvolgvrae:

Hoe het u uitgevind? Hoe het u reagerer toe u die eerste keer die nuus gehoor het? Wat het die dokters vir u vertel oor die pasiënt? Wat was moeilik vir u as u nou terugdink aan die tyd toe u uitgevind het van u gesinslid of huweliksmaat se besering? Wat het u gehelp om die nuus te hanteer?

- 2) Vertel my meer oor u ervaring vandat u gesinslid/huweliksmaat se besering opgedoen is?

Opvolgvrae:

Wat gebeur vandat die patient die besering opgedoen het? Hoe is u verhouding met u gesinslid in vergelyking met voor die besering? Wat het in u lewe verander daarna? Hoe het dit u sosiale lewe beïnvloed? Was daar enige verandering in u professionele lewe? Hoe het dit verander? Hoe het jou dag tot dag lewe verander van toe af? Beskryf 'n tipiese dag vir u as versorger. Hoeveel ure bestee u daaraan om na u gesinslid te kyk? Hoe maak u sin van wat gebeur het? Hoe reageer ander op wat gebeur het? Hoe behandel ander u en u gesinslid nadat die besering opgedoen is?

3) Waarmee sukkel u die meeste as 'n versorger?

Opvolgvrae:

Vertel my oor die dinge wat u ervaring as 'n versorger vir u moeiliker gemaak het?

Vertel my oor die kommunikasie tussen u en die pasiënt? Op dieselfde manier sal ek opvolgvrae vra oor moontlike struikelblokke soos:

- Onvoorspelbaarheid van gedrag
- Huiswerk/-take
- Uitbranding/ tyd vir uself
- Eensaamheid
- Insig van die pasiënt
- Persoonlike voorsiening
- Persoonlikheidsverandering
- Die fisieke en sielkundige gesondheid van die versorger
- Hoe die pasiënt verandering hanteer

4) Is daar enige faktore wat u help om 'n beter ervaring te hê?

Opvolgvrae:

Vertel my oor die ondersteuningstrukture (familie, vriende?) Wat doen u as u 'n slegte dag ervaar? Na wie toe draai u vir hulp? Wat is u stokperdjies? Wat doen u om u gedagtes van die versorgingsrol af te neem? Vertel my oor die gemeenskap se betrokkenheid? Ek sal soortgelyke vrae vra oor hulpbronne soos:

- Ondersteuningsgroepe
- Die rol van spiritualiteit en/of geloof
- Psigiatryse en/of sielkundige dienste
- Behandeling/medikasie
- Toegang tot formele dienste

- Die gebruik van 'n joernaal om rekord te hou van gevoelens en gedagtes
- Sin vir humour

#### **D) Afsluiting**

1) Is daar enige iets anders wat u met my wil deel oor u ervaring?

Opvraag:

Is daar enigiets wat ek nie gevra het nie wat u dalk wil deel?

Ek wil u net weereens bedank dat u aan hierdie studie deelgeneem het.

## Appendix C

### **PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM**

(English Version)

**TITLE OF THE RESEARCH PROJECT:**

Traumatic brain injury caregivers' experiences: An exploratory study in the Western Cape

**REFERENCE NUMBER: S12/06/155**

**PRINCIPAL INVESTIGATOR: Mandi Broodryk**

**ADDRESS: Stellenbosch University, Psychology Department**

**CONTACT NUMBER:**

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff or doctor any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the Health Research Ethics Committee at Stellenbosch University and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

*The study will be conducted where it suits you, the participant, best. At this point in time we would have already discussed the location and time of your choice.*

*This study aims to explore what the experiences are of a caregiver in the context of traumatic brain injury patients. After learning more about these experiences, the information can be used to design future interventions to alleviate the burden associated with the caregiving role.*

*The participant volunteers to participate in a once-off interview that can last between 60 and 90 minutes. A tape recorder will be also be used. The interview will be divided into 3 sections: A) The welcoming of the participant and signing of informed consent form; B) asking of demographic information; C) questions about caregiving experience and D) ending of interview.*

Why have you been invited to participate?

*You have been invited to participate in this study, because you are the primary caregiver of a family member OR spouse that has sustained a traumatic brain injury.*

What will your responsibilities be?

*Your responsibilities for participating in this study involves that you take part in a once-off interview lasting from 60 – 90 minutes to talk about your experiences as the primary caregiver of an individual family member/spouse who sustained a TBI.*

Will you benefit from taking part in this research?

You will not directly be benefited by taking part in this study. However, future caregivers might reap the benefits of this study. This means that interventions or programs which could help caregivers with the burden of this role could be designed from the information that is acquired through these interviews.

Are there any risks involved in your taking part in this research?

This study does not hold any foreseeable risks. It merely asks questions about the caregiver's experience. I do not anticipate that the participants in the proposed research will experience emotional distress and/or discomfort during the interview, to the extent where referral for counselling will be needed. However, if this is the case, the participants will be referred to Tygerberg Hospital's Psychiatric Unit.

If you do not agree to take part, what alternatives do you have?

*This study does not include any form of treatment.*

Who will have access to your medical records?

*The information collected will be treated as confidential. Participants' identities will also be protected and kept anonymous even when this research is published in academic journals or as a thesis. Only I, the primary researcher, and my supervisor will have access to your information.*

What will happen in the unlikely event of some form of injury occurring as a direct result of your taking part in this research study?

N/A

Will you be paid to take part in this study and are there any costs involved?

*Participants will not be paid to take part in the study.*

Is there anything else that you should know or do?

*You can contact the Health Research Ethics Committee at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by your study doctor.*

*You will receive a copy of this information and consent form for your own records.*

Declaration by participant

By signing below, I ..... agree to take part in a research study entitled *TBI caregivers' experiences: An exploratory study in the Western Cape*.

I declare that:

I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.

I have had a chance to ask questions and all my questions have been adequately answered.

I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.

I may choose to leave the study at any time and will not be penalised or prejudiced in any way.

I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) ..... on (*date*) ..... 2013.

.....  
Signature of participant      Signature of witness

Declaration by investigator

I (*name*) ..... declare that:

I explained the information in this document to .....

I encouraged him/her to ask questions and took adequate time to answer them.

I am satisfied that he/she adequately understands all aspects of the research, as discussed above.

I did not use an interpreter. (*If an interpreter is used then the interpreter must sign the declaration below.*)

Signed at (*place*) ..... on (*date*) ..... 2013.

.....  
Signature of investigator      Signature of witness

## Appendix D

### **DEELNEMERINLIGTINGSBLAD EN -TOESTEMMINGSVORM**

(Afrikaanse Weergawe)

TITEL VAN DIE NAVORSINGSPROJEK:

Die ervaring van versorgers van traumatiese breinbeserings pasiënte: 'n Verkennende Studie in die Wes-Kaap

**VERWYSINGSNOMMER: S12/06/155**

**HOOFNAVORSER: Mandi Broodryk**

**ADRES: Stellenbosch Universiteit, Sielkunde Departement**

**KONTAKNOMMER:**

U word genooi om deel te neem aan 'n navorsingsprojek. Lees asseblief hierdie inligtingsblad op u tyd deur aangesien die detail van die navorsingsprojek daarin verduidelik word. Indien daar enige deel van die navorsingsprojek is wat u nie ten volle verstaan nie, is u welkom om die navorsingspersoneel of dokter daaroor uit te vra. Dit is baie belangrik dat u ten volle moet verstaan wat die navorsingsprojek behels en hoe u daarby betrokke kan wees. U deelname is ook **volkome vrywillig** en dit staan u vry om deelname te weier. U sal op geen wyse hoegenaamd negatief beïnvloed word indien u sou weier om deel te neem nie. U mag ook te eniger tyd aan die navorsingsprojek onttrek, selfs al het u ingestem om deel te neem.

Hierdie navorsingsprojek is deur die Gesondheidsnavorsingsetiëkkomitee (GNEK) van die Universiteit Stellenbosch goedgekeur en sal uitgevoer word volgens die etiese riglyne en beginsels van die Internasionale Verklaring van Helsinki en die Etiese Riglyne vir Navorsing van die Mediese Navorsingsraad (MNR).

Wat behels hierdie navorsingsprojek?

*Die studie word gedoen waar dit vir u, die deelnemer, die beste pas. Teen hierdie tyd sou ons die tyd en ligging van die onderhoud al bespreek en ooreengekom het volgens u keuse.*

*Die studie poog om die ervaring van 'n versorger in die konteks van traumatiese breinbeserings pasiënte te verken. Deur meer van hierdie ervaringe te leer kan hierdie inligting gebruik word om toekomstige intervensies te ontwerp om sodoende die las wat geassosieer word met die versorgingsrol, te verlig.*

*Die deelnemers gaan deelneem aan 'n enkele onderhoud wat ongeveer 60 – 90 minute gaan duur. 'n Bandopnemer gaan ook gebruik word. Die onderhoud gaan in 3 seksies opgedeel word naamlik: A) Die verwelkoming van die deelnemer en teken van die ingeligte toestemmingsvorm; B) die vra van demografiese inligting; C) vrae oor die versorgingservaring en D) die beëindiging van die onderhoud.*

Waarom is u genooi om deel te neem?

*U is uitgenooi om deel te neem aan hierdie studie omdat u die primêre versorger is van 'n gesinslid OF huweliksmaat wat 'n traumatiese breinbesering opgedoen het.*

Wat sal u verantwoordelikhede wees?

*U verantwoordelikhede vir deelname aan hierdie studie behels dat u deelneem aan 'n enkele onderhoud wat tussen 60 en 90 minute sal duur. In hierdie onderhoud sal u praat oor u ervaring as 'n primêre versorger van 'n individu wat 'n traumatiese breinbesering opgedoen het.*

Sal u voordeel trek deur deel te neem aan hierdie navorsingsprojek?

*U sal nie direk voordeel trek deur deel te neem aan hierdie studie nie, alhoewel toekomstige versorgers voordeel mag trek. Dit beteken dat intervensies of programme ontwerp kan word deur gebruik te maak van die inligting wat verkry is deur hierdie onderhoude, Dit kan hulle dan help om die las in hierdie versorgingsrolle te verminder.*

Is daar enige risiko's verbonde aan u deelname aan hierdie navorsingsprojek?

*Hierdie studie hou nie enige voorsienbare risiko's in nie. Dit vra basies net vrae oor die versorger se ervaring. Ek, die navorser, voorsien nie dat deelnemers in die voorgestelde navorsing enige emosionele ongemak gedurende die onderhoud sal ervaar tot so mate dat verwysing vir berading benodig sal word nie. Maar, indien dit die geval is, sal die deelnemer verwys word na Tygerberg Hospitaal se Psigiatriese Eenheid.*

Wie sal toegang hê tot u mediese rekords?

*Die inligting wat ingesamel word, sal as konfidensieel behandel word. Deelnemers se identiteit sal ook beskerm word en anoniem gehou word, al word die navorsing in akademiese joernale of as tesis gepubliseer. Ek, die primêre navorser, en my studieleier is die enigste persone wat toegang het tot hierdie inligting.*

Wat sal gebeur in die onwaarskynlike geval van 'n besering wat mag voorkom as gevolg van u deelname aan hierdie navorsingsprojek?

*N.V.T*

Sal u betaal word vir deelname aan die navorsingsprojek en is daar enige koste verbonde aan deelname?

*U word nie betaal vir u deelname aan hierdie studie nie. Deelneme aan hierdie navorsingsprojek sal u ook niks kos nie.*

Is daar enigiets anders wat u moet weet of doen?

*U kan die Gesondheidsnavorsingsetiekadministrasie kontak by 021-938 9207 indien u enige bekommernis of klagte het wat nie bevredigend deur u studiedokter hanteer is nie.*

*U sal 'n afskrif van hierdie inligtings- en toestemmingsvorm ontvang vir u eie rekords.*

Verklaring deur deelnemer

Met die ondertekening van hierdie dokument onderneem ek,  
....., om deel te neem aan 'n navorsingsprojek  
getiteld *Die ervaring van versorgers van traumatiese breinbeserings pasiënte: 'n Verkennende Studie in die Wes-Kaap.*

Ek verklaar dat:

Ek hierdie inligtings- en toestemmingsvorm gelees het of aan my laat voorlees het en dat dit in 'n taal geskryf is waarin ek vaardig en waarmee ek gemaklik is.

Ek geleentheid gehad het om vrae te stel en dat al my vrae bevredigend beantwoord is.

Ek verstaan dat deelname aan hierdie navorsingsprojek **vrywillig** is en dat daar geen druk op my geplaas is om deel te neem nie.

Ek te eniger tyd aan die navorsingsprojek mag onttrek en dat ek nie op enige wyse daardeur benadeel sal word nie.

Ek gevra mag word om van die navorsingsprojek te onttrek voordat dit afgehandel is indien die studiedokter of navorser van oordeel is dat dit in my beste belang is, of indien ek nie die ooreengekome navorsingsplan volg nie.

Geteken te (*plek*) ..... op (*datum*) ..... 2013.

.....  
Handtekening van deelnemer

.....  
Handtekening van getuie

Verklaring deur navorsers

Ek (*naam*) ..... verklaar dat:

Ek die inligting in hierdie dokument verduidelik het aan

.....

Ek hom/haar aangemoedig het om vrae te vra en voldoende tyd gebruik het om dit te beantwoord.

Ek tevrede is dat hy/sy al die aspekte van die navorsingsprojek soos hierbo bespreek, voldoende verstaan.

Ek nie 'n tolk gebruik het nie. (*Indien 'n tolk gebruik is, moet die tolk die onderstaande verklaring teken.*)

Geteken te (*plek*) ..... op (*datum*) ..... 2013.

.....  
Handtekening van navorsers

.....  
Handtekening van getuie