CAREGIVING FOR ADULTS WHO SUFFERED SEVERE TRAUMATIC BRAIN INJURY (STBI): TOWARDS A PSYCHOLOGICAL EXPLANATORY MODEL

by

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DECLARATION

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Caregiving for adults who suffered severe traumatic brain injury (sTBI): Towards a psychological explanatory model.

I declare that the above thesis is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

I further declare that I submitted the thesis to originality checking software and that it falls within the accepted requirements for originality.

I further declare that I have not previously submitted this work, or part of it, for examination at Unisa for another qualification or at any other higher education institution.

1 February 2023

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SUMMARY

Traumatic brain injury (TBI) is presented in literature as one of the major public health and socioeconomic problems that often results in disability and death. Literature further shows that families of individuals who suffered TBI are often faced with the burden of caring for the individual member, with people with severe traumatic brain injury (sTBI) having limited functional independence and requiring care and support from significant others. Having noted the need for care by individuals who suffered sTBI, the aim of the current study was to explore caregiving in a family context for adults who suffered severe traumatic brain injury with a view to develop a psychological explanatory model. A phenomenological research design was used, with Interpretative Phenomenological Analysis (IPA) being the method utilised. Purposive and snowball sampling methods were used to select 14 individuals who were providing care to adult family members who sustained severe traumatic brain injury. Semi-structures interviews were conducted in Sepedi, Tshivenda and Xitsonga, and later translated into English. Meanings were derived from data collected using IPA.

The following superordinate themes were identified: caregiver lived experiences; attributions and meaning making; facilitators and barriers; essential attributes for caregiving; coping strategies; and, motivation for caring. The overall findings indicate that family members who care for adults who suffered severe traumatic brain injury experience barriers and endure emotional difficulties such as shock, denial, anger, frustration, and loss of hope. Based on the findings of the study, I developed a psychological explanatory model on caregiving for adults who suffered sTBI. The Model identified three types of variables, namely, the antecedent variable (which is sTBI), two key variables (that is, caregiver and caregiving), and consequent variables (for example, meanings attached, facilitators and barriers). The interaction of the three variables impact on the beneficiary who is the care recipient. The implications of the current study in terms of theory, clinical practice, research and policy are highlighted.

KEY TERMS:

Caregiving; Caregiver; Care recipient; Traumatic brain injury; Severe traumatic brain injury; Caregiver lived experiences; Meaning making; Essential attributes; Barriers; Facilitators; Motivating factors; Coping strategies; Psychological explanatory model

TSHIVENDA SUMMARY

Ṱhoho ya Ṱhoḓisiso:

Vhulondoti ha Vhathu vho Tshenzhelaho Dambudzo ḽa Khuvhalo ya Vhuluvhi: Ndivhanyoni na Mveledzo ya Nḓila ya Ṱhaluso ya u ṱhogomela.

Dambudzo ḽa khuvhalo ya vhuluvhi ḽi bvukululwa kha maṅwalwa sa ḽiṅwe ḽa thaidzo khulwane dza zwa mutakalo na matshilisano, hune ḽa anzela na u vhanga vhuholefhali na lufu. Maṅwalwa a dovha hafhu a sumbedza uri miṱa ine ya vha na vhathu vho tshenzhelaho khuvhalo ya vhuluvhi yo livhana na muhwalo wa u ṱhogomela vhenevho vhathu vhane kanzhi vha sa tou vha na vhukoni ha u ḓiitela zwithu nga vhoṱhe. Nga murahu ha u limuwa uri hu na ṱhoḓea ya u londotwa ha vhathu vho huvhalaho vhuluvhi, ndivho ya ino ṱhoḓisiso yo vha i ya u tandula vhulondoti miṱani ine ya vha na vhathu vho tshenzhelaho khuvhalo ya vhuluvhi hu u ṱoḓa u bveledza nḓila ine ya nga ṱalutshedza zwa u thogomela. Ngona ya ṱhoḓisiso i saukanyaho tshenzhemo ya vhathu yo shumiswa, khathihi na ngona i sengulusaho tshenzhemo ya vhathu hu u itela u ṋea ṱhaluso ya tshenzhemo yeneyo ho katelwa na kuvhonele kwa muṱoḓisisi. Ṱhumbulo yo anganywaho khathihi na ṱhumbulo ine khayo vhadzheneleli vha themendela vhaṅwe vhaḓivhi uri vha shele mulenzhe kha ṱhoḓisiso, zwo shumiswa musi hu tshi nangwa vhadzheneleli vha fumi iṋa (14) vhe vha tshi khou londota vhathu vho ṱanganaho na khuvhalo ya vhuluvhi miṱani yavho. Mbudzisavhathu dzo farwa na vhadzheneleli nga Sepedi, Tshivenḓa na Xitsonga, nga vhuya dza pindulelwa kha Luisimane. Ṱhalutshedzo dza mawanwa dzo tutuwa kha mafhungo o kuvhanganywaho hu tshi khou shumiswa tsenguluso na ṱhaluso ya tshenzhemo ya vhathu.

Mihumbulo mihulwane i tevhelaho yo tutuwa: tshenzhemo ya vhalondoti ya ḓuvha nga ḓuvha; mveledzo ya ṱhalutshedzo; zwileludzi na zwithivheli; zwiṱaluli zwa ndeme zwa vhulondoti; nḓila dza u tambala; na, ṱhuṱhuwedzo ya u londota. Mawanwa nga u angaredza a sumbedza uri miraḓo ya muṱa ine ya ṱhogomela vhathu vho ṱanganaho na dambudzo ḽa khuvhalo ya vhuluvhi vha ṱangana na vhukonḓi vhu katelaho zwipfi zwa dzhenuwo, khanedza, tsinyuwo, mbiti na u shaya fulufhelo. Ho livhanywa na mawanwa, ho bveledzwa nḓila ya ṱhaluso ya zwa muhumbulo. Nḓila yeneyo yo ṱalusa tshakha tharu dza zwiteṅwa, dzine dza vha, tshiteṅwa tsha murango wa tshenzhemo (tshine tsha vha khuvhalo ya vhuluvhi), zwiteṅwa zwa ndeme vhukuma (zwine zwa vha, mulondoti na u londota), na zwiṅwe zwiteṅwa zwo tutuwaho khazwo (sa tsumbo, ṱhalutshedzo dzo bveledzwaho, zwileludzi na zwithivheli). Ho wanala uri hu na vhuḽedzani vhukati ha izwi zwiteṅwa zwiraru zwine zwa vha na mutsindo kha muṱanganedzi wa ṱhogomelo ane a vha mulondotiwa. Mbuelo dza ino ṱhoḓisiso dzi dodombedzwa dzo livhanywa na thyiori, nḓowenḓowe dza vhulondoti ha mutakalo, ṱhoḓisiso na milayotibe.

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Thank you all!!!

DEDICATION

I dedicate this thesis to my late mother, Muofhe Nyamunzhedzi Mudau-Muelelwa, who passed away when I was busy making the last corrections to this thesis in response to comments from external asessors.

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CHAPTER 1: INTRODUCTION

This chapter introduces the current study by providing the background to the study and highlighting the magnitude of issues related to traumatic brain injury (TBI). Focus is directed to the prevalence of TBI and its levels of severity with more emphasis on severe levels of TBI. This is followed by an outline of the research problem. The research aims and objectives are then presented, followed by the rationale for the study which gives the contextual challenges that gave rise to the study. Lastly, definitions of key terms used in the study are provided and an outline of the organisation of this thesis follows.

1.1 Background

Traumatic brain injury (TBI) remains one of the major public health and socioeconomic problems throughout the world, often resulting in disability and death (Davis & Ings, 2015; Sherer et al., 2015). In a study that used open-source epidemiological data on road traffic injuries (RTIs) to quantify the case burden of TBI across World Health Organization (WHO) regions and World Bank (WB) income groups, Dewan et al. (2018) estimated that 939 out of every 100 000 people will suffer TBI each year. In absolute numbers, this translates to an estimated 69 million people worldwide who will suffer TBI each year. In another study that sought to estimate global incidents of TBI, Li et al. (2016) found that the average age at the time of TBI ranged from 27 to 59.67 years, with men at a higher risk when compared to women. Furthermore, the overall ratio of the TBI cases (based on the Glasgow Coma Scale [GCS]) were estimated to be 55 (mild): 27.7 (moderate): 17.3 (severe). Regarding regional prevalence of TBI, Dewan et al. (2018) used the aggregated data to rank different countries in the world. The results showed that New Zealand followed by the United States of America were relatively high when compared to Switzerland and Belgium which were ranked to be considerably low.

Apart from the global epidemiological estimates, there are several other studies that have sought to estimate the incidents and prevalence of TBI in different regions of the world. For instance, in a systematic review and meta-analyses of articles describing the epidemiology of TBI in 16 European countries, an overall incidence rate of 262 per

100 000 for admitted TBI was reported (Peeters et al., 2015). Though there was a great variation in terms of case definition and case ascertainment between studies, this particular epidemiological study found that falls and road traffic accidents (RTA) accounted for the higher number of the TBI cases in the selected European countries. In an earlier study, Puvanachandra and Hyder (2009) also reported that falls and RTA were the leading causes of TBI in Asian countries. A similar trend was later reported in studies by Li et al. (2016) and Agrawal et al. (2016) who found falls and RTAs to be the leading causes of TBI. Agrawal et al. (2016) found that there were more cases of severe TBI in India (53% of hospital admitted cases; GCS ≤ 8) when compared to those found to be mild (18%) or minor (29%).

Whilst there have been a number of epidemiological estimates for TBI in different regions of the world (for example, Northern America, Europe and Asia), very little appear to have been done to estimate the continental incidents of this debilitating condition in Africa. According to Wekesa et al. (2013), one of the reasons to explain this paucity of literature on TBI estimates is the scarcity of CT scans in many developing regions such as part of Africa. In a modelling study that used data derived from Kenya, Wong et al. (2016) estimated TBI count in Africa to be six to fourteen million cases by the year 2015, with more males than females affected. In a study that aimed to collect data on head trauma from Kamuzu Central Hospital, a tertiary care center in the capital of Malawi, Eaton et al. (2017) found that the majority of the patients (33%) had severe TBI with a GCS score of ≤8. Eaton and her colleagues further found that RTAs constituted the leading cause of TBI.

In South Africa, trauma has been suggested as one of the leading causes of mortality and disability, with RTAs accounting for the majority of these incidents (Parkinson et al., 2014). In a January 2012 to December 2014 audit of TBI at Pietermaritzburg Metropolitan Trauma Service in Kwazulu Natal, Jerome et al. (2017) found that there were more males with TBI when compared to females. The study further found that the majority of cases were mild (76.9%), with moderate and severe cases reported to be 9.9% and 10% respectively. Like other previous studies, RTAs were found to be one of the leading causes of TBI. In an earlier audit conducted at Groote Schuur Hospital (GSH) in Cape Town, it was found that 10 046 trauma patients (approximately 24%) admitted in 2009 were classified as head-injury patients, with 654 having a moderate to severe TBI (Webster et al., 2015). According to Naidoo (2013), the major risk factors for TBI in South Africa are extremes of age, male gender, and low socioeconomic status.

Apart from the above studies suggesting a high TBI prevalence, there is ample evidence showing that TBI has a significant impact on the individual, family, and the broader society (Chembeni & Nkomo, 2017; Juengst et al., 2015; Ponsford, 2013). The World Health Organization estimated that TBI would be one of the major causes of death and disability by the year 2020 (Hyder et al., 2007). Still in the same breath, Dewan et al. (2018) reported that sixty-nine million individuals are estimated to suffer TBI from all causes each year, with the Southeast Asian and Western Pacific regions experiencing the greatest overall burden of disease. According to Haarbauer-Krupa et al. (2021), TBI poses a large burden as its prevalence is high, has risk for long-term effects of the injury, lead to loss of the work force, put pressure on the healthcare systems, and affect the manner in which families function. TBI usually manifests as a complex injury leading to higher rates of residual disabilities after one-year of hospitalisation (Corrigan et al., 2010). Some studies have shown that the impact of TBI includes cognitive and physical deficits, psycho-social, emotional, and behavioural deficits (Chembeni & Nkomo, 2017; Noggle & Pierson, 2010). Review research on Quality of Life (QoL) in TBI patients has shown that this condition has a significant, long-term impact on all QoL domains with a more profound impact on psychosocial domains (Jaracz & Kozubski, 2008). The review also suggested that traumatic brain injury has a more profound effect on the psychosocial domains than on the physical domain, thus suggesting a cumulative impact of TBI. According to Haarbauer-Krupa et al. (2021), TBI impacts negatively on levels of subsequent employment and educational opportunities.

Literature has also shown that families of individuals who suffered TBI are often faced with the burden of caring for the individual member (Boyle & Haines, 2002; Johnson et al., 2004; Mbakile-Mahlanza et al., 2017). For example, Johnson et al. (2004) noted that families are likely to be at significant risk for psycho-social adjustment difficulties even years after the medical risks have passed. The same authors also noted that it is often difficult for the family to talk about the changes that TBI has brought to family functioning. As will be pointed out in the next section, it is caregivers who are often faced with the daily challenges and stress of having to care for family members with TBI.

1.2 Research problem

Literature shows that caregivers of individuals who suffered TBI are primarily faced with the burden of caring for the individual member (Boyle & Haines, 2002; Johnson et al., 2004; Mbakile-Mahlanza et al., 2017), including the psychosocial challenges associated with the caregiving experience (Baker et al., 2017; Rawlins-Alderman, 2014). In their interaction with the health care system after a relative's traumatic brain injury, caregivers commonly report a number of problems such as receiving limited information from the hospital regarding their relatives' injuries and management methods (Baker et al., 2017; Mbakile-Mahlanza et al., 2017), frustrating interactions with health care professionals (Broodryk & Pretorius, 2015), being informed about the serious consequences of the injury, and having the relative with TBI transferred to non-specialised rehabilitation facilities (Manskow et al., 2018). After discharge from hospital, people with severe traumatic brain injury have limited functional independence when compared to their premorbid level. This requires that they receive care and support from significant others as they start a new life with a severe disability.

Evidence from several studies indicate that most caregivers tend to experience elevated levels of anxiety and depression (Chembeni & Nkomo, 2017; Kratz et al., 2017), social isolation (Mbakile-Mahlanza et al., 2017), and poor support from the community (Kilonzo, 2004). In an earlier study, Boyle and Haines (2002) found that there was an indication that conditions like depression might be elevated in caregivers when faced with the task of taking care of a person with TBI. In this study by Boyle and Haines (2002), caregivers displayed decreased ability to express their feelings, as well as experience decreased time and energy for social and recreational activities. There is an indication that TBI presents sudden disruption in life continuity and dynamics, which profoundly impact on the ability of the affected family to adjust. For example, Johnson et al. (2004) noted in their study that families are likely to be at significant risk for psycho-social adjustment difficulties even years after the medical risks have passed. The same sentiment was expressed by Boyle and Haines (2002) who noted that decreased time and energy for social and recreational activities caused by caring for a family member who suffered a severe traumatic brain injury could result in family isolation which could last for many years.

Literature shows that caregivers tend to perceive caregiving as a responsibility that has cultural meaning. For example, in a study conducted by Pharr et al. (2014), it was found that some cultural groups consider caregiving to be a cultural mandate. These authors also found that different cultural groups have different values and norms that shape their unique caregiving experiences (Pharr et al., 2014). Mbakile-Mahlanza et al. (2017) found that the injured individuals often tended to attribute their injuries to supernatural causes. Mbakile-Mahlanza et al. (2017) also found that cultural factors such as devotion to one's family, faith and belief in God moderated the burden and distress on the part of caregivers. Caregivers were also found to hold beliefs that influence their decision to assume the role of being caregivers. For example, a review of studies that investigated caregiving for individuals with dementia found that cultural beliefs impinge on key elements of the caregiving process, including caregivers' appraisal of stress, coping strategies, and informal and formal support (Sun et al., 2012).

Whilst there is ample evidence from international literature to show that families and caregivers of people with severe traumatic brain injury (sTBI) experience high levels of psychosocial stressors that require new methods of coping, there appears to be paucity of studies on how caregivers in the South African context experience and cope with sTBI in their families. Given the heavy burden of care that is imposed on caregivers when looking after relatives suffering from sTBI, the current study seeks to explore caregiving within a family context for adults who suffered sTBI with a view to develop a psychological explanatory model.

1.3 Purpose of the study

1.3.1 Aim of the study

The aim of the study was to explore caregiving in a family context for adults who suffered sTBI with a view to develop a psychological explanatory model.

1.3.2 Objectives of the study

- To investigate the experiences of caregiving by a primary caregiver who is caring for an adult member of the family who suffered sTBI;
- To determine the meanings that primary caregivers attach to sTBI;
- To investigate perceived facilitators and barriers in caring for adults who suffered sTBI;
- To examine coping strategies used by primary caregivers caring for adult family members who suffered sTBI; and
- To develop a psychological explanatory model on caregiving for adults who suffered sTBI, within a family context.

1.3.3 Research questions

The study addresses the following specific research questions:

- What are the experiences of primary caregivers who are caring for adult family members who have suffered sTBI?
- What are the meanings that primary caregivers attach to sTBI?
- What do caregivers perceive as facilitators and barriers in caring for adults who have suffered sTBI?
- What are the coping strategies that primary caregivers use in caring for adult family members who suffered sTBI?
- What is the contextually relevant psychological model that can be developed to explain caregiving for adults who suffered sTBI?

1.4 Rationale for the study

The study is motivated by two main considerations. Firstly, in the process of working with individuals who suffered TBI, I have observed that family members who find themselves being faced with the responsibility to care for their loved ones appear to endure the responsibility with some difficulties. This observation is also noted in literature (Chembeni & Nkomo, 2017; Kratz et al., 2017). The study is therefore motivated by the need to provide insights on caregiving for adults who suffered sTBI.

Secondly, I sought to develop a psychological explanatory model of caregiving for adults who suffered sTBI based on the insights on caregiving for adults who suffered sTBI. The explanatory model will assist in providing guidelines that can improve the provision of care for adults who suffered sTBI. This is in line with the suggestion by Sherer et al. (2015) who pointed out that knowledge about an individual patient's profile of functioning may assist when developing his/her treatment programme.

1.5 Operational definition of terms

For the purpose of the current study, the listed terms will be defined as indicated below:

- **Traumatic brain injury (**TBI)**:** Lezak et al. (2012) define traumatic brain injury as an injury to the brain resulting from an externally applied mechanical force that affects the brain and leads to loss of consciousness or coma. According to Menon et al. (2010), this involves an alteration in brain function, or other evidence of brain pathology. In the context of the current study, TBI is understood to mean an injury to the brain from external force that result in alteration of brain function.
- **Severe traumatic brain injury (sTBI):** Hoofien et al. (2001) define sTBI as a traumatic brain injury that is characterised by loss of consciousness or coma for more than 24 hours and relates to post-traumatic onset of cerebral neurological dysfunction which has failed to recover and has resulted in permanent disabling impairment of cerebral neurological function. For the purpose of the current study, sTBI will carry the same meaning as per the definition by Hoofien et al. (2001).
- **Caregiving:** Caregiving is defined as the provision of care for the physical and emotional needs of a family member or a friend at home ("Benzie Senior Resources," n.d.). In the context of the current study, the definition is adapted to refer to the responsibility to look after an adult who suffered severe traumatic brain injury.
- **Adult:** A person who is fully grown and developed (Hawker, 2006).
- **Explanatory model:** This is defined as a useful description of why and how a thing works or an explanation of why a phenomenon is the way it is. In line with Kleinman et al. (1978) seminal paper, an explanatory model has been used to

present knowledge of the beliefs that caregivers hold about their experiences of providing care, pointing out facilitators and barriers in the provision of care.

1.6 Organisation of the thesis

The thesis consists of the following chapters: The current chapter (Chapter 1) is an introductory chapter that orientates readers to the study. It also provides background to the study, the research problem, the purpose of the study including the objectives, rationale of the study, operational definitions of key terms and the organisation of the thesis.

Chapter 2 provides information on relevant literature review. The focus is on TBI with special reference to severe TBI, severity classification and outcome prediction, TBI sequalae, re-integration, caregiving and cultural interpretations following TBI.

Chapter 3 focuses on theories that have sought to explain caregiving, stress, and coping. In the first part of the chapter, focus is on caregiving theories. The second part of the chapter looks at stress related theories. The third part focuses on coping theories that explain how people cope when faced with stress and other life challenges. In the fourth part, the chapter looks at theories that integrate aspects of stress and coping. The last part of the chapter focuses on the Contextual Model of Family Stress and Coping which is the theory that the current study uses in understanding the experiences of caregivers of adults with sTBI.

Chapter 4 presents the research methodology for the current study. The chapter begins by providing an overview of the quantitative and qualitative research paradigms, followed by a presentation of phenomenology. Information relating to population and sampling procedures, data collection and data analysis is also presented. A presentation about the development of an explanatory model of caregiving for adults with sTBI is done, followed by the trustworthiness of the research process, ethical considerations and what I consider my positionality.

Chapter 5 outlines the results of the study. The results are presented in the form of thematic analysis from the interviews with caregivers as guided by the study objectives indicated in chapter 1.

Chapter 6 critically discusses the results and the implications in relation to the literature reviewed. The proposed explanatory model of caregiving for adults with sTBI is also presented.

In the final chapter (chapter 7) conclusion is drawn, limitations presented, and an outline for proposals for future research is provided.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

This chapter presents the conceptualisation of TBI with special reference to severe TBI. Literature on the severity classification and outcome prediction of TBI is also reviewed and presented. The severity classification and sequelae are presented to provide information regarding the level of functioning of the person who sustained TBI. The focus of the review also extends to cover TBI sequelae, integration, social caregiving, social support, cultural element, care for caregivers, and the role played by multiple caregivers.

2.2 Traumatic brain injury

In the introductory chapter, definitions of TBI were provided. For the purpose of the current study, I have opted to adopt the definition by Lezak et al. (2012) who describe TBI as an injury to the brain resulting from an externally applied mechanical force that affects the brain and leads to loss of consciousness or coma. Lezak et al. (2012) further indicate that traumatic brain injury has different severity levels that include mild, moderate and severe TBI. Mild traumatic brain injury (mTBI) is described as an acute brain injury resulting from mechanical energy to the head from external physical forces, and is characterised by confusion or disorientation, loss of consciousness for 30 minutes or less (Carroll et al., 2004). Carroll et al. (2004) further indicates that mTBI is also characterised by post-traumatic amnesia that is less than 24 hours, and the manifestations of mTBI must not be due to drugs, alcohol, medications, caused by other injuries or treatment for other injuries. In other words, the brain injured person experiences confusion and disorientation for at least 30 minutes and is unable to remember what happened from the time of the accident, with the inability to remember ending within a period of 24 hours.

Moderate traumatic brain injury (moderate TBI) happens when a person receives a trauma to the head, and such trauma results in more than 30 minutes of unconsciousness, but less than 24 hours, and is characterised by post-traumatic onset of cerebral neurological dysfunction which has failed to recover and has resulted in permanent significant impairment of cerebral neurological function (King & Tyerman, 2008). For a moderate TBI, it means that the impairment is likely to result in some loss of the individual's educational capacity or employment capacity, or a reduced quality of life associated with partial loss of life roles or amenities. Severe TBI, which is the focus of the current study, relates to post-traumatic onset of cerebral neurological dysfunction which has failed to recover, and has resulted in permanent disabling impairment of cerebral neurological function (Hoofien et al., 2001). This means that the impairment has resulted in a quantifiable loss of the individual's educational capacity or employment capacity. This also means that the person may experience a total loss of one or more meaningful life roles or amenities, or a loss of independence in managing own affairs or activities of daily living. From a psychological point of view, severe TBI causes malfunction of the mental states and personality. According to Mazaux et al. (2001), severe TBI has a disruptive impact on a person's life plans and the individual who suffered severe TBI is mostly unaware of the changes in cognitive function and behaviour, making it difficult for such a person to properly care for the self. The different levels of severity play significant roles when it comes to predicting outcome following TBI. The next section focuses on factors that assist in making outcome predictions.

2.3 Traumatic brain injury severity classifications and outcome prediction

Literature shows that the outcome following TBI depends on the severity of the injury (Noggle & Pierson, 2010; Ryan et al., 2015). For example, Noggle and Pierson (2010) noted that the resultant of other deficits following TBI is related to how vulnerable the different regions of the brain are to injury. These authors further suggest that the area where the injury happens in the brain and the gravity as well as environmental factors, play a significant role in the consequences thereof and how the person ultimately recovers. Lezak et al. (2012) indicate that the site and size of the lesion determine many characteristics of the changes in behaviour that the injured person displays. The authors also indicate that even though there could be localisation of a lesion and functioning, the regions of the brain work together as interconnected and distributed neural networks. This implies that lost function due to a localised injury may be carried out by another region of the brain. Consequently, localisation may not necessarily mean difference in functioning, but may be reflective of the level of severity of the injury.

There are indications that physical and cognitive problems caused by brain damage are often made worse by anxiety, depression, irritability or frustration (King & Tyerman, 2008). It therefore means that the symptoms that the injured person experiences may be exacerbated by psychological conditions like anxiety and depression, leading to increased distress and reduced coping. Research also shows that psychosocial problems tend to grow rather than diminish over time, both for the individual and for their relatives (Lippert-Gruner et al., 2006). In their handbook of neuropsychological rehabilitation, Ben-Yishay and Driller (2011) noted that neurologic, cognitive and personality factors always interact and influence one another. The authors further indicated that the functional failure that the individual displays is mainly because a neurologic impairment leads to the failure that is in turn influenced by cognitive deficits that are associated with the brain injury. These cognitive deficits are also influenced by the person's unique personality characteristics (Ben-Yishay & Driller, 2011).

A study by Ryan et al. (2015) found that profiles of recovery over a lengthy period were mainly as a function of the severity of the injury. The same study by Ryan et al. (2015) also found that children who suffered severe TBI showed evidence for late-emerging social problems. The information presented from studies indicate that the severity of the injury plays a significant role when it comes to the outcome, and that psychological problems tend to grow. The implication is that outcome depends on several factors that include severity of the injury and secondary aspects like psychological sequalae that in turn put pressure on the injured, thereby making it difficult for full recovery. The next section focuses on the psychological sequelae following TBI.

2.4 Traumatic brain injury sequelae

People who suffered TBI experience significant physical and psychological problems. For example, McDonald and Genova (2021) provided a review of the emotional and psychosocial consequences of moderate to severe traumatic brain injury (TBI), with an indication that many of the disorders affecting an individual's socioemotional functioning arise from damage to the physical structures of the brain. Other studies do show that there are many physical and psychological (cognitive, emotional and behavioural) TBI sequelae, with changes and deteriorations that continue after onset (Chembeni & Nkomo, 2017; Corrigan & Hammond, 2013; Noggle & Pierson, 2010;

Sherer et al., 2015). Lezak et al. (2012) and Chembeni and Nkomo (2017) noted that the impairments that occur following TBI may result in loss of basic self-care ability for the injured, calling for the need to have carers. There is furthermore an indication that life satisfaction is affected following TBI (Juengst et al., 2015; Stalnacke, 2007). This section specifically focusses on the psychological sequelae, including loss of basic self-care ability and associated life satisfaction changes following TBI.

2.4.1 Psychological sequelae following TBI

2.4.1.1 Cognitive problems: Traumatic brain injury is associated with cognitive problems. According to Lezak et al. (2012), individuals who suffer severe TBI display a full range of severe dysfunctions in their cognitive abilities. Lezak et al. (2012) have pointed out that functional difficulties in cognitive skills include executive dysfunction, attentional and concentration problems, learning and memory deficits, information processing difficulties, language and constructional deficits, visuospatial and visuo-perceptual difficulties, and disturbance in basic motor functions. Executive functioning disorders are often experienced following TBI. For example, King and Tyerman (2008) noted that executive functioning, characterised by reasoning, planning, problem solving, self-awareness and self-monitoring problems are common following TBI. Thus, executive dysfunction disorders involve capacities for self-determination, self-direction, self-control, and regulation which depend on the individual’s sound awareness of the self and surroundings. Judgment and motivation are also some of the executive skills that get to be affected following TBI (Wells et al., 2009). According to Lezak et al. (2012), executive dysfunction is “the most crippling and often the most intractable disorder associated with severe TBI” (p. 214). The conclusion of a study conducted by Tsai et al. (2021) shows that the overall prevalence of executive dysfunction is notable in individuals who suffered severe TBI. In a study that investigated the severity, insight, and psychosocial influences of apathy in executive, emotional, and initiation dimensions on apathy with individuals having moderate to severe traumatic brain injury, executive apathy was regarded to be lower when compared to controls (Quang et al., 2022). Ponsford (2013) pointed out that planning and problem-solving abilities are also impaired following TBI. There is an indication that thinking in a concrete manner, inability to initiate things, dissociation between thought and action, and inflexibility get to be problematic for the TBI survivor (Ponsford, 2013).

In a study that compared adolescents who suffered TBI ten years post-injury with typically developing adolescents, Beauchamp et al. (2011) found that participants who had severe injuries displayed poorer performance when expected to set goals and on processing speed tasks. Beauchamp et al. (2011) then concluded that childhood TBI has a potential to affect complex executive skills in a negative way and necessitate support even in adulthood. The implication is that an individual who displays executive dysfunction following TBI is unable to initiate activities and is therefore in need for continuous care and supervision.

In addition, attention and concentration problems are reported to be common for TBI survivors. For example, a study by Chembeni and Nkomo (2017) found that survivors of TBI presented with problems that included attention and concentration difficulties. The findings by Chembeni and Nkomo (2017) were based on a study that focused on the challenges that individuals who survived traumatic brain injury experience together with their families. In the study by Chembeni and Nkomo (2017), in-depth interviews were conducted with participants who survived TBI, and their immediate family members who were caretakers. In the study by Beauchamp et al. (2011), attention and concentration problems were also found to be common for TBI survivors. The study had explored selective changes in executive functioning ten years after severe childhood traumatic brain injury. In a meta-analytic review of research examining attention following severe TBI, Mathias and Wheaton (2007) found that participants who suffered severe traumatic brain injury presented with significant difficulties in specific measures of attention span, focused or selective attention, sustained attention, and supervisory attentional control. King and Tyerman (2008) on the other hand also noted that attention and concentration were amongst the most common cognitive difficulties after TBI.

In a book chapter on TBI mechanism and sequelae, Ponsford (2013) noted that following severe TBI, attentional difficulties get to be characterised by reduced speed of information processing. Beauchamp et al. (2011) found that individuals who sustained TBI still presented with information processing difficulties 10 years post injury. Processing speed was found to be slower in TBI survivors when compared to controls in a study by Madigan et al. (2000). Mathias and Wheaton (2007) on the other hand, found that severe TBI affected performance in greater ways on measures of information-processing speed, attention span, focused and selective attention, sustained attention, and supervisory attentional control. These authors concluded that speed of information processing is significantly impaired following severe TBI. King and Tyerman (2008) indicated that after TBI, individuals experience difficulties with speed of information processing. Lippert-Gruner et al. (2006) noted that problems with information-processing speed are some of the most common neurobehavioural deficits that get to be experienced. In their study, Lippert-Gruner et. al (2006) had administered The Neurobehavioural Rating Scale (NRS) to patients who had suffered severe TBI, and the aim of the study was to determine neurobehavioural deficits after severe TBI.

Memory and learning abilities are also reported to be problematic following TBI. In their study, Chembeni and Nkomo (2017) found that learning and memory problems following TBI get to be experienced. In the study by Chembeni and Nkomo (2017), participants shared their difficulties pertaining to the ability to recall information. The extract below indicates how memory problems were experienced:

> “My memory was also bad, you would tell me something and I would forget now in few minutes’ time and somebody would come to my house and say ..., but when he walks through the door, I had forgot what he was saying, and my sister’s children would always try to help me remember things.” (Chembeni & Nkomo, 2017, p. 485)

Ponsford (2013) noted that there is usually a marked contrast between the capacity to remember events and skills learned prior to the injury. The ability to learn and retain new material since the time of the injury also gets to be impaired. This implies that individuals who sustain TBI are unlikely to adequately acquire new material or remember what they learned pre-morbid. In a longitudinal study that focused on adult patients with severe traumatic brain injury, Ruet et al. (2018) found that eight years after the injury, memory problems constituted 71%, with slowness being 68%, and concentration difficulties found to be at 67%. The initial sample for this study was 504 participants. Eight years at follow-up, 257 were still alive when they got discharged from acute care, 261 of the initial 504 were deceased, 128 patients were lost to follow-up, 22 refused to participate, and 86 were finally available to participate in the study. The percentages reported above are based on the assessment of the 86 participants.

Literature furthermore show that language and communication abilities get to be impaired following TBI. For example, Chembeni and Nkomo (2017) found that participants in their study reported difficulties reading, often confusing words and sounds, and not knowing what to say or which words to use. King and Tyerman (2008) on the other hand noted that after TBI, deficits in language skills are evident, characterised by difficulties in comprehension, verbal fluency and word finding. The authors reported receptive or expressive dysphasia and acquired dyslexia. Ponsford (2013) noted that following TBI, aphasia can occur, and the individual may experience excessive talking with poor turn-talking skills. Ponsford (2013) further pointed out that the aphasic individual may repeat the self or have difficulty keeping to the point and processing auditory information. In a study by Lippert-Gruner et al. (2006), participants were found to display expressive and articulation deficits.

In addition, visuospatial, visuo-perceptual and constructional abilities are reported to be negatively affected following TBI. For example, King and Tyerman (2008) noted that other specific impairments that are displayed following TBI include problems with visuo-perceptual, visuospatial and construction abilities. According to Lezak et al. (2012), individuals who suffered severe TBI show reduced visuo-perceptual, visuo-spatial and construction abilities. These authors noted that these visuo-abilities may be negatively impacted because of reduced information processing speed that severely injured individuals experience. There is an indication that basic motor functions such as manual speed, dexterity and increased reaction time on simple tasks get to be impaired (Lezak et al., 2012).

2.4.1.2 Emotional and behavioural problems: Emotional and behavioural problems tend to be common among TBI survivors. Among others, the emotional and behaviour problems experienced may include difficulties in accepting one’s life after severe TBI, and loss of sense of self (Chembeni & Nkomo, 2017; Mazaux et al., 2001). Other difficulties include impulsivity, irritability or temper outbursts, and anger (Gouick & Gentleman, 2004; Ponsford, 2013). In their study that focused on the challenges that individuals who sustained traumatic brain injury experience together with their families, Chembeni and Nkomo (2017) found that TBI survivors found it the hardest to accept that their lives will never be the same following the TBI. Participants in that study also reportedly struggled to understand why the injury happened to them. Furthermore, the participants, were found to be asking themselves why they were in a situation that they realise that they do not deserve to be in. The difficulties to accept, and the inability to understand their situation resulted in feelings that characterise sadness, anger and self-blame, with some participants indicating feelings of wanting to give up on life. Chembeni and Nkomo (2017) noted participants' sense of loss of the self. For example, the authors highlighted that participants tended to use metaphors that helped in trying to reduce the feeling of having lost the self by explaining the changes in their ways of functioning using words that dissociated themselves from such functional changes or challenges.

Ponsford (2008) reported on impulsivity and irritability or temper outbursts. She indicated that low tolerance of frustration was one of the most reported problems following TBI. The anger that is displayed, at times accompanied by physical aggression, may not correspond to the situation being experienced. Gouick and Gentleman (2004) noted the apathy, mania, agitation, irritability, and anger to be some of the problems following TBI. The conclusion reached by Gouick and Gentleman (2004) was based on a review of articles that focused on the resulting emotional and behavioural outcome following traumatic brain injury. Anger outbursts were also reported to be displayed often following TBI and resulting in strong negative impact on social outcomes (Rochat et al., 2019). In a study by Lippert-Gruner et al. (2006), agitation, blunted affect, emotional withdrawal, hostility, suspiciousness, fatigue, liability of mood and tension were found to deteriorate during the post-traumatic follow-up. These authors concluded that instead of reducing, emotional problems seemed to worsen with time.

2.4.1.3 Depression, anxiety and posttraumatic stress following TBI: Apart from the emotional and behavioural problems observed following TBI, literature shows that clinical conditions like depression, anxiety and posttraumatic stress disorder are likely to be experienced following TBI. Ruet et al. (2018) found that TBI survivors recorded symptoms that were associated with depression and anxiety on the Hospital Anxiety and Depression scale eight years after TBI. According to Gouick and Gentleman (2004), depression is one of the mental health problems that is often experienced after TBI and affect the way in which rehabilitation gets to be carried out. Depression also affects psychosocial adjustment, and survivors' return to work (Gouick & Gentleman, 2004). These authors further indicated that at least half of all people who suffered TBI get depressed at some point during the first year after the injury. The review shows that depression following TBI have some organic basis given the injury and tends to have adverse effects on psychosocial functioning (Gouick & Gentleman, 2004). Jorge and Arciniegas (2014) on the other hand noted that mood disorders are the common psychiatric complications that survivors of TBI experience. These authors noted that in a considerable number of cases, the disorders become chronic and resistant to treatment.

Symptoms of posttraumatic stress disorder (PTSD) are often experienced following TBI. In a study that focused on investigating factors that tend to predict PTSD following severe TBI, Bryant et al. (2000) found that there was evidence to support that patients do present with PTSD following severe traumatic brain injury. In the review that Gouick and Gentleman (2004) conducted, it was noted that PTSD symptoms were rated high, and avoidance was mainly used as a coping strategy. In their review, Gouick and Gentleman (2004) found that anxiety was often experienced following TBI. According to Gouick and Gentleman (2004), TBI survivors and their families experience elevated levels of anxiety because of the sudden and frightening events surrounding TBI and the changes in the survivor's functioning and physical appearance.

2.4.1.4 Psychosocial problems: Studies have suggested that people tend to experience several psychosocial problems after traumatic brain injury. The study by Chembeni and Nkomo (2017), found that participants tended to isolate themselves. These authors attributed the isolation to the perception by the injured that they were not understood. The authors also went on to interpret the isolation to be a result of being isolated by friends, families, or communities who perceive the injured as different. Factors that include lack of social skills, lack of interest or inability to initiate social behaviours, and personality changes were identified to be contributing towards the social isolation that survivors of traumatic brain injury displayed (Chembeni and

Nkomo, 2017). According to Ponsford (2013), individuals who sustained TBI are likely to display difficulties in controlling behaviour, and this can lead to the prevention of appropriate responses, thereby resulting in socially inappropriate behaviours. Ponsford (2013) furthermore noted self-centredness that can lead to being insensitive to feelings and emotional needs of others. The problem of inappropriate social behaviour and being insensitive to others was also reported by Chembeni and Nkomo (2017) who found that the injured individuals end up with limited contacts with friends, if any.

In a review by Jaracz and Kozubski (2008) focusing on QoL in TBI patients, the authors found that even though the review showed that TBI has a significant, long-term impact on all QoL domains, they noted that TBI tended to have more negative impact on psychosocial domains when compared to physical domains. Based on this observation, the authors concluded that psychosocial problems tend to grow rather than diminish over time. Lezak et al. (2012) noted that “the most far-reaching effects of TBI involve personal and social competences” (p. 182). Arnould et al. (2016) noted social awareness challenges that are related to negative consequences in the way patients function.

2.4.2 Personality changes and life satisfaction

Severe TBI appears to cause problems that impact negatively on the enjoyment of life and life satisfaction. These problems may include changes in personality (Chembeni & Nkomo, 2017; Jorge & Arciniegas, 2014); disruption of life plans and projects (Juengst et al., 2015; Mazaux et al., 2001); dissatisfaction with leisure activities, and difficulties in vocational adjustment and sexual life, among others (Mazaux et al., 2001). Guided by the findings of a study that focused on satisfaction of life and late psycho-social outcome after severe brain injury, Mazaux et al. (2001) concluded that sTBI causes abrupt mental malfunctioning. These authors further found that, on average, nine years after the injury, most patients were satisfied with their ability to be in control of their lives, the way in which their finances were and their family life. There was however an indication that the patients experienced changes in their personalities (Mazaux et al., 2001).

In their study, Jorge and Arciniegas (2014) noted that TBI survivors experience frequent psychiatric complications that become chronic and resistant to treatment, implying that TBI survivors must live with the changes in their characters. The sentiment of dissatisfaction about life due to personality changes was echoed by Chembeni and Nkomo (2017) who remarked on the possibility that lack of social contact can impact negatively on self-esteem, which in turn give rise to personality difficulties and consequently affect life satisfaction. There is also an indication that life plans and roles that existed pre-morbidly get to be disrupted. For example, in a study that focused on trajectories of life satisfaction after TBI, Juengst et al. (2015) found that loss of life roles after a moderate to severe TBI made survivors of TBI to be vulnerable to low or declining life satisfaction. In that study, Juengst et al. (2015) administered the Satisfaction with Life Scale with data collected prospectively at one, two-, and five-year post-injury. Mazaux et al. (2001) also indicated that following severe TBI, life plans get to be disrupted, and life satisfaction is deeply changed. Stalnacke (2007) on the other hand noted that psychosocial difficulties, with low levels of life satisfaction in particular, were experienced by a considerable proportion of people who sustained mTBI. The study by Stalnacke (2007) was a population-based follow-up, three years after the injury. It was found that, together with other problems, life satisfaction difficulties were still being reported after three years. Jorge and Arciniegas (2014) noted that other complications that include mental difficulties impact negatively on the quality-of-life post injury. According to Mazaux et al. (2001), TBI survivors also get to be dissatisfied with leisure and vocational adjustment. The inability or reduced ability to perform work responsibilities furthermore contribute to dissatisfaction with life. In a study that focused on cognitive ability and sexual functions in patients who suffered traumatic brain injury, War et al. (2014) found that problems with sexual functioning was experienced by a higher percentage of patients and that impacted negatively on their satisfaction with life. In a study that examined the effects of age cohort on post-injury life satisfaction in elderly persons with TBI, Niemeier et al. (2021) found that the young-old sub-group demonstrated the poorest life satisfaction outcomes, while the oldest sub-group experienced greatest life satisfaction. The authors noted that participation in the study decreased with age. One of the reasons for the variations in satisfaction was attributed to generation-based lived experience, implying that the older participants had experience and in the process developed greater resilience.

2.5 Social support

Literature shows that social support plays a role in mitigating psychological distress (Gouick & Gentleman, 2004; Sabella & Suchan, 2019). For example, in a study that focused on the contribution of social support and other forms of support to family caregivers after TBI, Sabella and Suchan (2019) found that social support made a difference in life satisfaction of family caregivers. The findings of the study by Sabella and Suchan (2019) were based on results obtained through measures that assess elements of support and financial hardship to life satisfaction of family caregivers. In another study conducted by White et al. (2007), the support and attitudes of family members ranked among the facilitators that were reported. In other words, the support shown by family tended to facilitate effective functioning on the part of the injured member of the family. In a study that examined whether social support is predictive of depression in persons who sustained TBI, Leach et al. (1994) found that the use of effective problem-solving and behavioural coping strategies by the family in response to TBI was closely related to reduction in the levels of depression for the person who sustained TBI. In that study, interviews were conducted with individuals who had sustained TBI to assess the manner in which the family was functioning, their perceptions with regards to social support, and to determine depressive symptoms that were experienced. The findings indicated that the support from family contributed positively towards the wellbeing of TBI survivors.

2.6 Family reintegration and functioning following TBI

Following TBI, survivors must be reintegrated back into their families. Several studies (Rashid et al., 2014; Rawlins-Alderman, 2014; Stevensa et al., 2013) suggest that family functioning tends to be impacted in several ways following severe TBI. For instance, in a review that focused on the impact of paediatric TBI on the functioning of family, Rashid et al. (2014) found that moderate to severe TBI had a continuous negative impact in the functioning of the family. In this study, the authors reviewed articles that focused on the impact that moderate or severe TBI in children have on family functioning. Though there were differences between study groups in terms of family functioning, families that had children with severe TBI were found to be more dysfunctional when compared to families of children who had moderate TBI or orthopaedic injuries. Parents of young adults with brain injury were found to cope better than spouses. Parents were coping better as there were less disruptions in their role towards their children post-injury. With spouses, there were reports of loss of financial and parenting support from the brain-injured partner. Furthermore, losses in being sexually intimate and empathic communication, concerns about children in the family, and reduced social support were reported as potential problems for integration in families. Parents, on the other hand, expressed concerns about the long-term future of the injured adult child and having to negotiate issues relating to independence as the person recovers (Gouick & Gentleman, 2004).

In three of the studies that Gouick and Gentleman (2004) reviewed, the burden that was associated with injury continued post-injury and was found to be experienced more in families that had a child who sustained a severe TBI as compared to those families whose child had a moderate TBI. Gouick and Genteman (2004) also found that lack of interpersonal resources and social support had a significant contribution towards problems in family functioning, elevated stress levels and burden. The authors also found that different parental roles impacted differently to the manner in which families adapted to the injury. For example, in this review, Gouick and Gentleman (2004) found that in one of the studies reviewed, fathers, as compared to mothers pointed that there was more dysfunction in the family because of the child’s injury. In two other studies in the review, social support and the levels of stress experienced were found to affect the way in which mothers adapted while on the other hand, the way fathers adapted were not dependent on these factors.

In a study that was conducted to obtain the views of adult siblings following traumatic brain injury, Degeneffe et al. (2013) found that there were disruptions in the manner in which family functioned. In this study, Degeneffe et al. (2013) noted the findings by Sach (1991 as cited in Degeneffe et al., 2013) who indicated that TBI can influence the sense of cohesion in a family (for example, those members of the family who are not injured may feel neglected), identity (for example, losing the sense of purpose within the family), relationship to the outside world (for example, the needs of the member of the family who has been injured may be more prominent and flood the social needs of other family members), and organizational structure and communication (for example, it may disorganises the ranks and roles within the family structure). In an earlier study, Degeneffe (2001) found that members of family who provide long-term care for members of their families who sustained traumatic brain injury experience extensive challenges. Such challenges included the kind of care that is required, stress and burden experienced, and the way families coped with the demands of providing care. Based on the above findings, Degeneffe (2001) concluded that roles within a family end up being changed given the care expected. For example, parenting responsibilities get to be extended in some instances.

Rawlins-Alderman (2014) found that caregivers often experience the responsibility of providing care as robbing them of their personal time and causing changes in family dynamics. Family functioning gets to be affected following TBI. The findings by Rawlins-Alderman are consistent with the results of an earlier study that was conducted by Schonberger et al. (2010) who found that individual family members as well as the whole family need support to deal with distress associated with TBI. Schonberger et al. (2010) noted that changes in behaviour that the injured individual experience can cause anxiety for the relatives and as a result impact negatively in the way that the family functions. Schonberger et al. (2010) also noted that there was a relationship between the changes in mood for the injured individuals and depressive symptoms that the relatives experience. The methodology in the study by Schonberger et al. (2010) involved having to administer measures that assessed the functioning of a family, changes that the injured patient experiences, and factors that were associated with anxiety and depression.

Degeneffe et al. (2013) reported on emotional liabilities that family members of TBI survivors experience. Degeneffe et al. (2013) attributed these emotional difficulties mostly to the impairment that the TBI survivor suffers, and what other family members must do to support their TBI survivor family member. The challenges associated with family reintegration and functioning as highlighted above, suggest that caregivers of TBI survivors experience functional difficulties that necessitate the need for care.

2.7 Community re-integration following TBI

After TBI survivors have been integrated into their families, they also need to participate in community activities and get back to work environments (Pugh et al., 2018). The TBI survivor individual must be part of a community as a whole and is expected to go back to work where possible. A literature review by Gouick and Gentleman (2004) indicated that families experience the transition from hospital care to community reintegration as being difficult. The review further suggested that family burden, distress, depression and anxiety may be greatest in the first year after discharge from hospital with some areas of family functioning improving with time.

Pugh et al. (2018) found that individuals who sustained TBI experience more difficulties when it comes to being integrated back into the community. In this study, Pugh et al. (2018) examined the association between the severity of traumatic brain injury, social functioning, family functioning, and community reintegration outcomes. The study also focused on the association between TBI severity and the return-to-work status of the post-9/11 veterans who were in the care of Department of Veterans Affairs (VA). These authors found that veterans whose TBI was not classified or had moderate or severe TBI experienced more difficulties with reintegration into the community and were unlikely to be employed as compared to those who did not have TBI. The veterans whose TBI severity was not classified also reported considerable difficulties with family functioning. Arnould et al. (2016) noted neuro-behavioural and social awareness challenges that they related to negative consequences on social reintegration following TBI.

A scoping review conducted by McColl (2007) noted that reintegration is experienced as challenging for the TBI survivors. The review noted that there were programmes that survivors of brain injuries go through to assist them to be integrated in their communities. Of the five programmes that the author found following the review, traditional rehabilitation was used to help promote independent living for the survivors of TBI. When it comes to occupational sphere, McColl (2007) found that supported employment programme was commonly used to encourage fruitful occupation. Other programmes that were found to be effective included programmes that focused on adapting to one’s environment, development of support and transitional living (McColl, 2007). The review noted that there was a need to have programmes that are specifically tailored for individuals, approaches that involve practical exposure for survivors of TBI, support that is survivor specific, intervention that is offered early and focusing on having survivors participate on activities. Environmental adaptation programs were also found to be useful as they focused on providing signals; they also reduced distractions and increased structure in the nonhuman environment as a way of trying to achieve better outcomes for community integration outcomes. These programmes were offered individually to ascertain that environmental factors and special needs that survivors had were taken into consideration. The rehabilitation programmes presented in this review had a focus on more structured interventions as professionals were involved.

In a study conducted by Rubenson et al. (2007), participants expressed their frustrations regarding work activities. They reported challenges like not being able to follow up the things they initiated pre-morbid, loss of social contacts and not being able to do much regarding work content and end up feeling that since they worked so little, it was hard to feel participation in the workplace. Participants in that study had returned to work but had remaining cognitive disabilities. In a study where face-to-face interviews were conducted with adult patients with severe traumatic brain injury eight years after TBI, Ruet et al. (2018) found that the cognitive deficits and somatic problems that were experienced because of severe traumatic brain injury still caused difficulties with social integration and survivors’ participation long after TBI. In their study on mood disorders after TBI, Jorges and Arciniegas (2014) found that TBI survivors experienced consequences that had deleterious impact on community reintegration.

2.8 Caregiving following TBI

Literature shows that families of individuals who suffered TBI are faced with the burden of caring for the individual member (Boyle & Haines, 2002; Johnson et al., 2004; Mbakile-Mahlanza et al., 2017). There is an indication that TBI presents sudden disruption in life continuity and dynamics, which profoundly impacts on the ability of the family to adjust. For example, Johnson et al. (2004) noted in their study that families are likely to be at significant risk for psycho-social adjustment difficulties years after the medical risks have passed. The same authors also noted that it is difficult for the family to talk about the changes that TBI brings to family functioning. Review research on QoL in TBI patients shows that TBI has a significant, long-term impact on all QoL domains (Jaracz & Kozubski, 2008). The review also show that psychosocial domains tend to be profoundly affected following traumatic brain injury as compared to physical domain, thus suggesting a cumulative impact of TBI. To explore further on caregiving phenomenon, a presentation of factors that include caregiver health, caregiving burden and mental health, and barriers and facilitators in caregiving are presented.

2.8.1 Caregiver health

Studies show that caregiving role may affect the health of a caregiver. For example, Hawkley et al. (2020) found that a decrease in well-being was associated with becoming a caregiver. In the study, Hawkley et al. (2020) compared mental and social well-being status of married partners who became caregivers to their spouses versus those who were not caregivers or provided care to someone who was not their spouse. In a study conducted by Arango-Lasprilla et al. (2011), caregivers of individuals who sustained traumatic brain injury reported having poor quality of life that was because of health problems in various domains that include mental and general health. The results of the study were based on a health-related quality of life self-report measure that consisted of eight component areas, namely: physical functioning, role-physical functioning, bodily pain, general health, vitality, social functioning, mental health, and role-emotional functioning. The self-report was administered to ninety family caregivers of individuals with traumatic brain injury and eighty-three healthy controls. The results showed that caregivers scored low on role-emotional, vitality, mental health, social functioning, bodily pain, and general health when compared to a healthy control group. The findings suggest that caregivers experience health problems in the process of providing care for the injured family member.

2.8.2 Caregiving burden and mental health

Caregiving has been identified to be a stressful experience (Baker et al., 2017; Brickell et al., 2019; De Mamani et al., 2018; Hawkley et al., 2020; Rawlins-Alderman, 2014). For example, a study conducted by Brickell et al. (2020) found that caregivers experienced increased stress and indicated that they were worried, anxious, feeling sick from stress, feeling angry and crying frequently. In a study that focused on challenges of caregiving during COVID-19, Russell et al. (2020) found higher rates of reported caregiver burden. A study conducted by De Mamani et al. (2018) with a focus on caregiver perception of objective and subjective burden and depression, found that greater burden was associated with poor mental health.

In a review that focused on identifying factors that have negative and positive outcomes for caregivers of the traumatic brain injury and spinal cord injury cohorts, Baker et al. (2017) found that good family functioning, coping skills and social support were reported to reduce the burden for caregivers and promoted positive outcomes. The authors further suggested that the burden was often due to executive functioning deficits which manifest in behaviours of concern displayed by care recipients. As reported under the section that focused on cognitive problems, executive functioning gets to be impaired following TBI and result in the injured person lacking in for example, self-awareness, motivation and judgment abilities. The relationship between burden of care and poor functioning on the part of the care recipient was also noted by Hawkley et al. (2020) who found that as physical and mental functioning of the care recipient decline, social activities get to be difficult for both the care recipient and the caregiver, and this tend to affect mental wellbeing.

In a study that focused on Burden and Mental Health Among Caregivers of Veterans with Traumatic Brain Injury, Griffin et al. (2017) found that the intensity of care that was required by care recipients and the neurobehavioural problems that they had were associated with more burden which in turn was associated with poor mental health for caregivers. The study by Griffin et al. (2017) used cross-sectional data and structural equation modelling to examine among other things the relationship between caregiver stress (i.e., *veterans' neurobehavioral problems and intensity of care required*), and caregiver well-being (i.e., *caregiver burden and mental health*). The sentiment of burden and mental health was also echoed by De Mamani et al. (2018) who found that better mental health was associated with levels of burden which were lower, and greater mindfulness that caregivers displayed. In a study conducted by Hawkley et al. (2020), the results showed that stress and caregiver burden that was reported by wives and husbands who became spousal caregivers was significantly greater.

2.8.2.1. Caregiving and depression: Mental health condition like depression is presented in literature as commonly experienced by caregivers (Band-Winterstein et al., 2019; Pendergrass et al., 2017; Shaffer et al., 2017). Literature shows that caregivers are likely to experience depression. For example, Shaffer et al. (2017)

noted that individuals who provide long-term caregiving for patients with recurrent or prolonged illnesses present with elevated depressive symptoms. In a study that focused on determining if ultra-orthodox Jewish caregivers experienced depressive symptoms as they provide care to ultra-orthodox frail older adults, Band-Winterstein et al. (2019) found that caregivers experienced mild to moderate levels of depression with the levels of depression being correlated to care provision. Band-Winterstein et al. (2019) further noted that being a spouse to the care recipient was found to be one of the predictors of elevated levels of depression. The sentiment of increase in depressive symptoms was noted by Pendergrass et al. (2017) who found that the caregivers of stroke survivors reported more depressive symptoms which were associated with greater impairment and more frequent problem behaviours exhibited by the care recipient. The relationship between poor functioning on the part of the care recipient and distress experienced by caregivers was also noted by Baker et al. (2017) who reported that the burden of care gets to be affected by impairment on the part of the care recipient.

2.8.2.2. Caregiving and anxiety: Literature shows that caregivers of individuals who sustained TBI experience anxiety that is related to the role of being a caregiver. A study conducted by Vilchinsky et al. (2014) showed that attachment related anxiety moderated caregiving burden and depressive symptoms for females caring for their spouse. In the study with caregivers of children with physical disabilities, Ma and Mak (2016) found that lower functional status in children was associated with more worries related to caregiving and caused psychological distress for the parents who were providing care. Increased levels of anxiety were reported by husbands who became spousal caregivers in the study conducted by Hawkley et al. (2020). The relationship between low functioning status of a care recipient and more distress for caregivers has been reported by Carlozzi et al. (2020) who found that caregivers of low-functioning persons with TBI consistently had higher base rates for severe symptoms and impairment as compared to those who were providing care to a high-functioning individual with TBI.

2.8.3 Barriers and facilitators in caregiving

Studies have found that there are factors that caregivers consider as barriers and facilitators in the process of providing care (Newcomb et al., 2018; Rawlins-Aldernam, 2014; White et al., 2007). Factors that caregivers identified as primary barriers to undertaking and maintaining the caregiving role include lack of collaboration with the health care team, the intensity of the caregiving role, the negative impact on the caregiver and, lack of community support for the caregiving role (White et al., 2007). A study by Raggi et al. (2015) found that disability following neurologic conditions is not only for the patients but also for their caregivers, and the difficulties in addressing barriers in the environment. Following their study, White et al. (2007) concluded that the needs of the family caregiver must be addressed independent of the needs of the person with the acquired disability for effective functioning. In the study by Newcomb et al. (2018), caregivers indicated that the lack of a unified system of coordination after the patient goes home put distress on them as they end up assuming the role of being a care coordinator.

Whilst there are barriers that exist, there are also several facilitators that tend to play a positive role in caregiving. These, among others include availability of coordination of care, progress of the patient towards normalcy, mastery of the caregiving role, supportive social environment, and accessible community resources (White et al., 2007). Newcomb et al. (2018) noted that support from friends, family members, church groups, or neighbours who can take care of specific tasks or carry out important roles are considered to be facilitators or enablers for the provision of care. Factors like organized system of support and information were also identified as facilitators of care by participants in the study conducted by Newcomb et al. (2018).

2.9 Caregiving and culture

Literature shows that cultural practices and belief systems do play a role when it comes to assuming a caregiving role. For example, in an interpretative phenomenological qualitative study that focused on how cultural values and norms influence the caregiver experiences, Pharr et al. (2014) found that there was a culturally perceived mandate to provide care in the African, Asian, and Hispanic American cultures. In this study, Pharr et al. (2014) conducted focus group interviews with participants from the African American, Asian American, Hispanic American, and European American cultural groups to explore cultural influences on caregiving. Despite the culturally perceived mandate to provide care, Pharr et al. (2014) found commonalities among the cultural/ethnic groups of caregivers in their experiences of the difficulties of caregiving. The study furthermore found that there were some significant differences in the cultural values and norms that shaped the caregiving experience:

> … cultural values and norms influence the following: perception of the caregiving role in terms of the role being an expected or unexpected part of the life course; the cultural embeddedness of caregiving also impacted whether or not caregiving was viewed as a choice or an expected duty; taxonomy of caregiving or a prescription for who was supposed to provide care; and lastly the values that familism and filial piety mandated and sustained caregiving responsibilities and strongly prevented caregivers from saying no to caregiving (Pharr et al., 2014, p.7).

The findings by Pharr et al., (2014) suggest that it is important to understand cultural nuances that may play a role in caregiver stress and coping processes. In some instances, the injured individuals may believe that some spiritual forces are involved in their injuries. For instance, in a study that focused on the experience of caregiving for individuals with TBI in Botswana, Mbakile-Mahlanza et al. (2017) found that the injured individuals tended to attribute their injuries to supernatural causes. Mbakile-Mahlanza et al. (2017) found that cultural factors such as devotion to one's family, faith and belief in God moderated the burden and distress on the part of caregivers. Caregivers were also found to hold beliefs that influence their decision to assume the role of being caregivers. For example, a review of studies that investigated caregiving for individuals with dementia found that cultural beliefs have an impact on key elements of the caregiving process, including caregivers' appraisal of stress, coping strategies, and informal and formal support (Sun et al., 2012).

In a study conducted in some rural African communities, Mokhosi and Grieve (2004) found that caregiving for individuals who suffered traumatic brain injury was influenced by social practices and local cultural beliefs. The injured individuals believed that the accidents as well as the injuries that happened, were the results of witchcraft, ancestral anger, God's will or *go thwasa*. The attribution of an accident to witchcraft was also noted by Phalane (2017) in her unpublished master's dissertation. In her study, Phalane (2017) found that participants believed that witchcraft was one of the main causes for them being involved in accidents. Reasons advanced by the participants for such accidents were revenge and jealousy. Phalane (2017) further indicated that other participants believed that the accidents were a form of punishment from ancestors who were angry with the injured for not performing rituals. God’s Will was also advanced as one of the reasons why an accident happened in Phalane’s (2017) study. The implication that Phalane (2017) remarked on was that some cultural groups believe that there will be fewer accidents in instances where the living perform rituals and observe God and ancestral orders.

Literature shows that cultural values play a role in decisions regarding caregiving and sustaining it. The findings of a study conducted by Santos et al. (2013) noted that cultural values such as familism and religiosity can influence the reasons to become a caregiver within the Latin American communities. Santos et al. (2013) observed that positive religious coping helps in finding a meaning for caregiving tasks. Other cultural elements that Santos et al. (2013) identified among the Latin American communities that encourage caregiving include tradition and spirituality which are considered social norms. Other motivations described by caregivers in the study by Santos et al. (2013) are based on religious beliefs that emphasise that they should bear what God lays on them. Thus, caregivers believed that by providing care, they were fulfilling God’s expectation and because of providing care, they will be rewarded. Santos et al. (2013) also found that having faith served as a source of support that helped caregivers to face difficulties and suffering, and offering them strength to overcome them. There was however an observation that Santos et al. (2013) made that indicates that even though the Latino caregivers considered caregiving as being meaningful, their religiosity and sense of gratitude towards the care recipient impacted negatively in their own mental health when they were compared with European American caregivers. A study on depression for caregivers of ultra-orthodox frail older adults on the other hand, found that religious and cultural practises served as mitigating factors for emotional distress (Band-Winterstein et al., 2019).

2.10 Care for caregivers

The discussion on caregiving experiences do indicate the possible health problems that caregivers experience. Literature shows that there is a need for caregivers to receive care and support (Broodryk & Pretorious, 2015; Kajiwara et al., 2018; Piccenna et al., 2017). In a longitudinal study conducted with in-home family caregivers, Kajiwara et al. (2018) found that caregivers require support to help decrease their personal strain, reduce caregiving burden as well as support to improve positive appraisal. Piccenna et al. (2017) on the other hand recommended interventions that include possibilities of having more than one caregiver, offering comprehensive training programmes, multi-faceted and individualised which include training and education, comprehensive counselling sessions, telephone calls and home visits to help caregivers.

In a qualitative analysis of spouse and parent perspectives on quality-of-life study, Kratz et al. (2017) identified factors that caregivers articulated as possibilities for the care that they need. Such factors that Kratz et al. (2017) identified included the need for help and support with regards to information pertaining to the kind of care relevant and prognostic possibilities for the care recipients, need for treating health practitioners at rehabilitation facilities to show empathy and to share information with them, and expressed the desire for prolonged and ongoing contact with rehabilitation professionals even after their family members were discharged. The caregivers in the Kratz et al. (2017) study also expressed the desire to be assisted with daily activities and the monitoring of the person with TBI so that they can have moments to attend to other things or take some personal time. Those caregivers who had assistants who were paid or received some help from family noted the relief that they experienced from even minimal assistance and the reduction of the overwhelming daily responsibilities that the relief offered. In the study by Baker et al. (2017) that focused on caregiver outcomes, the authors concluded that caregivers should receive intervention. In this study, Baker et al. (2017) conducted a systematic review of studies that focused on interventions for caregivers. The findings of a South African study conducted by Broodryk and Pretorious (2015) indicate that there is a need for caregivers to receive support, information and psychoeducation from healthcare professionals from the very beginning stages of recovery from a TBI. Ma and Mak (2016) on the other hand indicated that to promote the well-being of individuals with disability and their caregivers, planned interventions should include the care recipients, caregivers and members of the family who play important roles in the process of rehabilitation.

Research findings presented above indicate that caregiving for people who suffered traumatic brain injury is characterised by mental and social problems for both the care recipient and the caregiver. The responsibility to care is associated with considerable emotional problems, health problems and social problems for the caregiver. In a systematic scoping review of literature on traumatic brain injury and spinal cord injury, Baker et al. (2017) noted that the burden of care is over-represented in the literature. Given the identified burden of care, the results from this systematic review suggested that in clinical practice, carers themselves, and not the care recipient, should be targeted for intervention. De Mamani et al. (2018) recommended that interventions should be targeted to caregivers to help improve their psychological well-being. The recommendation by De Mamani et al. (2018) was made following the findings of their study with caregivers of individuals with dementia that indicated that some correlation existed between mindfulness and mental health of caregivers.

2.11 Multiple caregivers

As it is noted that there is a need for caregivers to receive care, literature shows that the availability of more than one caregiver can provide support to help mitigate against the burden that impacts negatively on the wellbeing of caregivers. One of the recommendations that Piccenna et al. (2017) made that is intended to mitigate poor health for caregivers was that of having more than one caregiver. In the study, a review of evidence-based recommendations between the years 2000 and 2015 pertaining to transfers and manual handling in people with TBI was conducted. The role of a secondary caregiver was found to be significant in a study conducted by Newcomb et al. (2018). Newcomb et al. (2018) found that caregivers turned to long-time friends, family members, church groups and neighbours to play a role of a secondary caregiver. Magana and Smith (2006) found that mothers who were caring for their children with autism spectrum disorder articulated that having the whole family together was important as it made provision for extra help, and it provided them with peace of mind.

2.12 Concluding remarks

The literature reviewed indicate that severe TBI is associated with psychological problems that include cognitive, emotional, psychosocial and behavioural problems. The cognitive and emotional problems experienced make it difficult for the TBI survivor to provide adequate care for the self and to show functional interpersonal relations with other people. The inadequacy therefore impacts negatively on the wellbeing of TBI survivor and that of the caregivers, and family functioning. Life satisfaction is also affected negatively following TBI. Literature furthermore show that social support enhances functioning on the part of the TBI survivor. There is an indication that re-integration to the family, community and the workplace get to be problematic given the cognitive, emotional and social problems faced by the TBI survivor. As presented above, cultural beliefs play a significant role in understanding the injury and caregiving. From the literature presented, it can be concluded that both the person with severe TBI and the caregiver experience psychological problems and this impact negatively on their functioning. There is an indication that caregivers need to receive interventions that focus on providing care for them. In the next chapter, some of the psychological theories that explain caregiving, stress and coping are presented. The theoretical framework for the current study is also presented together with the theoretical support for explanatory model.

CHAPTER 3: THEORETICAL BACKGROUND

3.1 Introduction

The previous chapter focused on literature regarding traumatic brain injury and its sequelae on the injured, impact on the family and the process of reintegration for the injured. The literature reviewed gave an indication of difficulties that are experienced by the injured, the caregiver and the family. Thus, the presence of an individual with sTBI in the family presents a stressful experience for the injured individual, the caregiver, and the family. The current chapter focuses on theories that have sought to explain caregiving, stress, and coping. In the first part of the chapter, focus is on theories that have been advanced to explain caregivers' psychological, behavioural and other forms of reaction associated with their caregiving role. The second part of the chapter looks at stress theories and how they explain the ways in which individuals deal with this challenge in the face of adversity. The third part focuses on theories that aim to explain how people cope when faced with stress and other life challenges. In the fourth part, stress and coping theories are presented, incorporating family functioning. The last part of the chapter focuses on the Contextual Model of Family Stress and Coping. This is the theory that I adopted as a lens to understand the experiences of caregivers of adult family members with sTBI.

3.2 Caregiving theories

Caregivers are mostly family members who do not have any training with regards to caring for a person with ill health, and do not require any compensation for provision of care which is often for a variety of conditions. According to Bevans and Sternberg (2012), family caregiving is different from professional caregiving by physicians and nurses who usually focus on specific conditions and are remunerated for their services. In this context, the experience of family caregiving is commonly perceived as a chronic stressor, with the caregivers reported to often experience negative psychological, behavioural, and physiological effects on their daily lives and health (Bevans & Stenberg, 2012). Lee et al. (2019) have noted that taking on a caregiver role may increase the stress for family caregivers. This calls for a full understanding of the experiences of caregivers, including the need to provide effective interventions to support them as they transition into the caregiving function (Lee et al., 2019). It is evident from the literature that caregivers experience stress and have to cope with it. Thus, the experience of taking care of a family member who is ill is stressful.

3.2.1 The Roy Adaptation Model

3.2.1.1 *Basic tenets of Roy's Adaptation Model (RAM):* One of the prominent caregiving theories was developed and popularised by Callista Roy. She argued that human beings are holistic in their nature and that they constantly interact with their environment (Roy, 2009). She further pointed out that as human beings interact with and respond to their environment, they adapt using a system that is both innate and acquired. This model is based on philosophic, scientific, and cultural assumptions derived from systems theory, adaptation-level theory, and cultural challenges of the 21st century (Roy, 2009). The philosophical assumptions underpinning RAM are humanism, veritivity, and cosmic unity (Hanna & Roy, 2001). According to Humanism assumption, the behaviour that individuals display is purposeful, the individuals possess intrinsic holism, they acknowledge the need to engage in relationships, to share in creative power, and they strive to maintain integrity. Veritivity is a principle of human nature that complements humanism and affirms that there is purpose in the existence of human beings. It assumes the activity and creativity for the common good, the purposefulness of human existence, the unity of purpose of humankind, and the value and meaning of life. Cosmic unity posits that reality is based on the integral relationship and common patterns that exist between people and the earth. Thus, reality is based in the manner in which individuals relate to the environment. The scientific assumptions of the model are based on the phenomena of living systems having complex processes of interaction and acting to maintain the purposefulness of existence in a universe. The cultural assumptions on the other hand, are an integration of cross-cultural experiences, cultural needs, and the necessity to eliminate culture-bound analysis of key concepts.

The major concepts of the RAM include the individual as an adaptive system; the environment; health; and the goal of nursing (Roy & Zhan, 2005). As an adaptive system, an individual is viewed as a whole that has different parts that function as a unity for a purpose. The environment is understood to comprise the conditions, circumstances, and influences that surround and affect the development and behaviour of human beings. Roy's model posits that adaptive responses that individuals demonstrate, support health which is "a state and process of being and becoming integrated and whole" (Roy & Zhan, 2005, p. 270). According to RAM, the goal of nursing is to enhance life processes to promote adaptation. Adaptation is therefore promoted in each of the four modes leading to integrated level of functioning. These modes are interdependence, physiological, role-function, and self-concept (Jennings, 2017). Interdependence is associated with the need for integrity, and a feeling of security in relationships. Giving and receiving of love, respect and value enhance integrity and feelings of security. The physiological mode is associated with physiologic integrity that is reflected through all physiologic activities of the human body. With role function mode, the need is social integrity which is manifested in how a person relates to others in society. The self-concept mode relates to the individual's integrity in the psychic and spiritual realms. This mode is also associated with the person's set of beliefs and feelings about how own behaviour is shaped. What is implied in Roy's Adaptation Model is that individual adaptive functioning is a result of the integration of the whole.

3.2.1.2 Applying The Roy's Adaptation Model in restoring adaptive functioning: Roy's Adaptation Model advocates for caring that is aimed at restoring functioning with a focus on the interdependence, physiological, role functioning and self-concepts modes. Jennings (2017) sought to demonstrate the applicability of RAM as a theoretical approach by conducting a case study on the provision of care to an individual with anorexia nervosa. Using RAM as a theoretical framework, a summary of Jennings' (2017) case study is presented to illustrate how RAM can be used to restore adaptive functioning. In the case, interdependence was depicted in a person with anorexia and struggled with trust for other people, struggled to establish and maintaining friendships or intimate relationships, and experienced social withdrawal and isolation. The physiologic mode was found to regulate and preserve a homeostatic balance in the human body. This bodily balance helps to avert potential medical and cognitive problems. The anorexic individual (participant) struggled with being autonomous and being in control, and also struggled with own identity within the society. Furthermore, the anorexic individual struggled with overvaluation of shape and weight, which impacted negatively on self-esteem, self-worth and self-confidence.

During acute treatment, three nursing goals were identified. Firstly, it was to identify the patient’s adaptation levels and coping capacities. The second goal was to identify behaviours and stimuli that can result in the restoration of weight. Thirdly, the goal was to provide interventions that will change defence mechanisms and promote adaptation in at least one of the four adaptive modes.

The nurses focused on facilitating change in all areas of functioning and did not primarily focus on the behaviours that interfered with weight restoration with the patient with anorexia nervosa. With the assessment of specific mechanisms in each adaptive mode that were done in various intervals, nurses were able to guide interventions that altered patient’s responses and patterns to promote weight restoration, and health. Even though there were challenges experienced within the residential environment, nurses provided opportunities and collaborated with the patient to develop goals to experience autonomy and a sense of control (Role Function Mode). Nurses assessed and monitored patient's body weight, caloric intake, and physical activity on a regular basis. Interventions were developed at the same time to discuss difficulties experienced in regulating emotions and to producing alternative strategies to manage negative emotions (Physiologic Mode). During the first week of treatment, a nurse would monitor the patient’s electrolytes (i.e., potassium, calcium, phosphate, magnesium) to assess for possible refeeding syndrome and need to slow down the rate of feeding or replenish essential electrolytes (Physiologic Model). Throughout the treatment, nurses monitored urine specific gravity to evaluate hydration status and potential water loading (Physiologic Model). Nurses assessed and discussed how shape and weight overvaluation impacted the patient's self-concept and treatment, and collaborated with the patient to establish goals to challenge her self-concept (Self-Concept Mode). Nurses promoted social support to help the patient develop relationships that re-established affectional adequacy and sufficient support in her friendships as an adult (Interdependence Mode). In essence, nursing interventions rooted in the RAM theoretical framework altered the patient's defense mechanisms, and promoted adaptation including weight restoration, and overall health. This case example from Jennings’ (2017) study illustrates how RAM can be utilised in providing health care to restore adaptive functioning. Whilst RAM primarily focuses on how a patient interacts with and adapts to the environment, it does not extend to address how a caregiver of such an individual should deal with the challenges of providing care.

3.2.2 Theory of Caregiver Stress

The Theory of Caregiver Stress was derived from Roy's Adaptation Model to use as basis in understanding the relationships among caregivers and the stress faced when caring for a chronically ill relative. Tsai (2003) identified four assumptions that underlie the Theory of Caregiver Stress. The assumptions are: (i) the caregivers can respond to environmental change; (ii) the caregivers' perceptions will determine how they will respond to the environmental stimuli; (iii) the caregivers' adaptation is a function of their environmental stimuli and adaptation level; and lastly, (iv) the caregivers' effectors are results of chronic caregiving with examples that include marital satisfaction and self-esteem. This theory as outlined by Tsai (2003), has a structure within which the above-mentioned assumptions occur. The structure is comprised of inputs, control processes and outputs. The input section is made up of an objective burden which serves to stimulate the caregivers' situation, meaning the responsibilities that are associated with the provision of care and support to someone who has a chronic condition. Since the responsibilities take time from the caregiver schedule, they may hinder other areas of the caregiver's life such as finances and relationships with others, referred to as contextual stimuli. Known as contextual stimuli, these aspects of the life of the caregiver also include social supports, social roles and life events that may be stressful. The Theory of Caregiver Stress defines stressful life events as those life conditions that may result in distress for the individual. Tsai (2003) further posited that caregivers with unresolved stressful events in their lives tend to experience higher levels of stress when compared to those caregivers who do not. This theory views social support as one of the contextual stimuli that influences how the individual will interpret the care, love, and respect that they receive within their network. The theory of caregiver stress proposes that if a caregiver perceives the quality of social support as high, they are likely to feel supported and equipped to cope with the stress in a way that will enhance their well-being. We also saw in the literature presented in the previous chapter that social support mitigates against psychiatric conditions like depression (Gouick & Gentleman, 2004; Sabella & Suchan, 2019). Social role is the last contextual stimuli in the Theory of Caregiver Stress and is defined as the role that caregiver plays in relation to others. For instance, such a role could be that of being a parent, sister, or supervisor.

The Theory of Caregiver Stress suggests that caregivers who have more roles are likely to have better physical and mental resources to manage stress. In other words, those with multiple social roles can express their feelings and ventilate. Tsai (2003) further suggested that variables such as the race, age, gender, and relationship that the caregiver has with the care recipient serve as residual stimuli. Factors such as cultural beliefs and values influence the caregivers' cognitive appraisal of the stress that they might face. As a residual stimulus, race refers to a group of individuals that have common ancestry through blood or heredity. It is also a cultural element that shapes personal beliefs and values. This implies that people from diverse cultures perceive and handle stress differently. As another residual stimulus, age has the potential to change how individuals perceives the world around them. For example, younger caregivers are likely to experience more stress than older caregivers who developed better coping skills with time.

Regarding gender, the theory of caregiving suggests that women will experience higher levels of stress than men. The reason for this is that women are more likely to take on the responsibility of caregiving. Lastly, the relationship that the caregiver has with the care recipient can have an impact on the caregiver's level of stress. Tsai (2003) defines the relationship in terms of the individuals' association through blood, marriage, adoption or by other means.

The control process of the Theory of Caregiving Stress is governed by a dynamic relationship between the input or environmental stimuli and the output sections or adaptation responses based on the perception of the stress and depression that the caregiver may have. Output portion of the Theory of Caregiver Stress is made up of the caregiver's responses to stress. There are four categories of responses, and these include the physical function, self-esteem/mastery, role enjoyment, and satisfaction in a marriage (Tsai, 2003). Examples of the physical functions are activity, rest, nutrition, and neurological functioning. The optimal physical function of an individual results in an effective and adaptive response to stress. Self-esteem/mastery refers to the perception that the caregiver has of themselves and how they relate to others. Low self-esteem reflects difficulties in managing stress whilst self-esteem suggests that one manages the stress better (Tsai, 2003). The related concept of mastery is defined as the ability of the caregiver to be in control. Thus, responding to stress in an ineffective manner indicates low mastery. Role enjoyment, which is the third category is described as the "…caregiver's expressive behaviour in their major social role" (Tsai, 2003, p. 142). A higher level of role enjoyment is associated with adequate adaptive responses. If adaptive responses are inadequate, then the caregiver demonstrates low role enjoyment. Regarding the last category of the adaptive modes, namely marital satisfaction, Tsai (2003) posited that low levels in this regard are likely to result in a maladaptive response to stress. The Theory of Caregiver Stress therefore proposes that a caregiver who perceives high stress will experience ineffective responses in the four adaptive modes. On the other hand, caregivers who perceive their stress levels as low are likely to show effective responses in the four adaptive modes indicated. The problem with the Theory of Caregiver Stress is that it presupposes the existence of social support and relationships which might not necessarily be in existence.

3.3 Stress related theories

This section focuses on theories that explain stress and how individuals cope with stress. According to Krohne (2001), theories that focus on the specific relationship between external demands (stressors) and bodily processes (stress) can be grouped in two different categories: approaches to systemic stress based on physiology and psychobiology, and approaches to psychological stress developed within the field of cognitive psychology.

3.3.1 Selye's Systemic Stress Theory

The theory was developed by Hans Selye, an endocrinologist who is credited for pioneering the concept of stress in the fields of science and mass media through his research with animals. Seyle posited that a variety of stimulus events (for example, heat, cold and toxic agents) applied intensely and long enough, are capable of producing common effects, meaning not specific to either stimulus event. Besides these nonspecific changes in the body, each stimulus produces its specific effect. For example, heat produces vasodilatation, whilst cold results in vasoconstriction.

According to Selye, these non-specifically caused changes constitute the stereotypical, that is, specific, response pattern of systemic stress (Krohne, 2001).

From a systemic perspective, stress is defined as a state manifested by a syndrome which consists of all the non-specifically induced changes in a biologic system. This stereotypical response pattern, called the General Adaptation Syndrome (GAS), proceeds in three stages (Krohne, 2001): (a) The alarm reaction comprises an initial shock phase and a subsequent counter-shock phase. The shock phase exhibits autonomic excitability, an increased adrenaline discharge, and gastro-intestinal ulcerations. The counter-shock phase marks the initial operation of defensive processes and is characterized by increased adrenocortical activity. (b) If noxious stimulation continues, the organism enters the stage of resistance. In this stage, the symptoms of the alarm reaction disappear, which indicates the organism's adaptation to the stressor. However, while resistance to the noxious stimulation increases, resistance to other kinds of stressors decreases at the same time. (c) If the aversive stimulation persists, resistance gives way to the stage of exhaustion. When the organism's capability of adapting to the stressor is exhausted, the symptoms of the initial stage (a) reappear, but resistance is no longer possible. Irreversible tissue damages appear, and, if the stimulation persists, the organism dies (Krohne, 2001).

Although Seyle’s work influenced a whole generation of stress researchers, it has weaknesses that include: (a) The conception of stress as a reaction to a multitude of different events and becoming a synonym for diverse terms such as anxiety, threat, conflict, or emotional arousal. This weakness makes this concept of stress to be in danger of losing its scientific value; (b) With regards to the theory's core assumption of a nonspecific causation of the GAS, other theorists like Mason pointed out that the stressors that Seyle considered to be effective tended to have a common emotional meaning. Such stressors were described as novel, unusual, and not familiar to the animal. (c) Unlike the physiological stress investigated by Selye, the stress experienced by humans is almost always the result of a cognitive mediation. Selye, however, fails to specify those mechanisms that may explain the cognitive transformation of objective noxious events into the subjective experience of being distressed. In addition, Selye does not consider coping mechanisms as important mediators of the stress–outcome relationship (Krohne, 2001). Having highlighted the limitations, it is important to point out that Selye’s formulation of adaptation and disease provided an important conceptual matrix for subsequent discussions of the mechanisms and manifestations of stress reactions. Selye's journey from the physiology of shock and adaptation to the biochemistry of stress and the psychology of happiness exemplifies the complex history of modern stress research (Jackson, 2014). Selye's initiative also helps in viewing stress as a unifying concept to understand the relationship between organic life and the environment (Viner, 1999).

3.3.2 Lazarus' Stress Theory

The psychological stress theories put emphasis on the presence of cognitive processes in producing a response. According to Krohne (2001), key concepts in psychological stress theory include: appraisal (that is, how an individual evaluates the importance of what is happening for their well-being), and coping (that is, how an individual thinks and behave in relation to specific demands). Lazarus' Stress Theory has been revised several times since its inception. In the latest version, stress is perceived in transactional terms (that is, as some kind of relationship the individuals and their environment have) (Krohne, 2001). In other words, psychological stress can be understood as a relationship with the environment that the person appraises as important, and in which the demands tax or exceed available coping resources (Lazarus & Folkman 1986). This definition points to two processes as central mediators within the person–environment transaction, namely cognitive appraisal and coping. The concept of appraisal is key in understanding transactions that are associated with stress. It is necessary to explain why different people will react differently in environments that are objectively equal given the differences in quality, intensity, and duration of the resultant emotion. The implication is that a specific pattern of appraisals will generate, maintain, and eventually alter the resulting state which is influenced by personal and situational factors. On the personal side, factors such as motivational dispositions, values, goals, and generalised expectancies are considered as crucial. How predictable, controllable, and imminent a potential stressor is, will influence the relevant situational parameters.

In his monograph on emotion and adaptation, Lazarus (1993) developed a comprehensive emotion theory. The stress theory which distinguishes between two types of appraisals (namely primary and secondary appraisal), is embedded in this overarching emotion theory. In primary appraisal, the focus is on factors that affect the wellbeing of the individual. Lazarus (1993) identified three components of primary appraisal which are goal relevance, goal congruence and ego involvement. Goal relevance relates to an individuals' evaluation of the significance of the situation to one's wellbeing. Goal congruence relates to how an individual evaluates the consistency of a situation to one's goals. For instance, a situation that is evaluated as consistent with one's goals is likely to elicit positive emotions. Ego involvement entails some degree of personal commitment that is reflected in the individual's self- esteem, moral values, ego-ideal, or ego-identity. Secondary appraisal on the other hand, is about coping options and the individual's coping potential. In this regard, Lazarus (1993) identified problem-focused and emotion-focused coping strategies that an individual can use to deal with stressors in their lives.

3.3.3. Resource Theories of Stress

Unlike the classical stress theories that tend to focus primarily on factors that lead to stress, the Resource Theories of Stress on the other hand are concerned with the resources that preserve the individual's well-being when faced with stressful situations. One of the key proponents of the Resource Theories of Stress is Stevan Hobfoll who proposed what is known as the Conservation of Resources (COR) Theory (Hobfoll,1989). Primarily, the theory suggests that humans are motivated to maintain the current resources they have whilst seeking to attain new resources (Hobfoll, 1989). He further identified three instances that could lead to psychological stress. These are a) the threat of losing resources that one already has; b) the actual loss of existing resources; and c) inability to replenish resources that have been spent.

Together with other colleagues, Hobfoll later expanded on the COR Theory by outlining several principles associated with the conservation of resources (Hobfoll et al., 1996). The first principle suggests that loss of resources is the primary source of stress. For instance, loss of a loved one can be a source of stress. The second principle suggests that resources act to preserve and protect other resources. For example, self-esteem is a crucial resource that may be beneficial for other resources. Hobfoll and Leiberman (1987), for example, observed that women who were high in self-esteem made beneficial use of social support when confronted with stress, whereas those who lacked self-esteem interpreted social support as an indication of personal inadequacy and, consequently, misused support. The third principle suggests that individuals have an increasingly depleted resource pool to combat further stress following stressful circumstances. This depletion impairs individuals' capability of coping with further stress, thus resulting in a loss spiral.

3.4 Coping theories

Coping theories are categorised into two independent parameters. These parameters are the focus-oriented theories (trait and state), and approach-oriented theories (micro-analytic versus macro-analytic approaches (Krohne 1996). The focus-oriented state and trait theories identify if individuals have internal resources and mental capacities to cope with the demands of the stressful encounter that they are confronted with. The approach-oriented micro and macro analytic coping theories focus on higher level of abstraction, concentrating on more fundamental constructs. For example, ascertaining how concrete the coping mechanisms are (Carver et al., 1989). The use of defence mechanisms when faced with stressful situation is an example of a macro-analytic approach (Krohne, 2001).

Macro-analytic trait-oriented coping theories include repression–sensitisation, monitoring and blunting, and model of coping modes (MCM). The repression-sensitisation theory elaborates on coping in the form of different poles, with repression in one end, and sensitization on the other. According to this theory, people who utilise repression to cope, tend to dismiss the existence of a stressor to help cope. On the other hand, people who lean towards sensitisation tend to think excessively, tend to worry and get to react in an impulsive manner when faced with stressful situations (Krohne, 1996). The monitoring and blunting theories explain that individuals use their cognitive skills in reducing the impact of stressful stimuli that they are confronted with. Individuals tend to use avoidant cognitive strategies when faced with stressful stimuli. Such avoidant cognitive strategies that include blunting mechanisms like denial, restructuring, and distraction may be helpful to overlook temporary stressors. With regards to monitoring strategies, initiatives like information processing and emotional management get to be employed to help manage ongoing negative stress and anxieties that individuals experience. The mode of coping theory has its base from the monitoring-blunting model and is to some extend connected to the repression-sensitisation theory. This theory elaborates on the concept of cognitive avoidance and suggests that individuals have a natural inclination to avoid stressful situations and perceive such situations as ambiguous. The theory assumes that most stressful situations are characterised by the presence of aversive stimulation and a high degree of ambiguity (Krohne, 2001). These two coping processes are representatives of personality as they reflect individual differences in the susceptibility to emotional arousal or uncertainty. Individuals who are especially susceptible to states of stress-induced emotional arousal automatically utilise cognitive avoidance to help protect the self from an increase in arousal (arousal-motivated coping behaviour). On the other hand, individuals who get to be affected by the uncertainty experienced in most stressful situations make use of vigilant coping. The employment of vigilant strategies helps to minimise the probability that unexpected aversive events (uncertainty-motivated coping behaviour) occur (Krohne, 2001). The weakness of the coping theories reviewed above is that they tend to put more emphasis on the use of defense mechanisms which are maladaptive ways of dealing with stress.

3.5 Stress and coping theories

The Stress and Coping Theory espoused by Lazarus and Folkman views psychological stress as being characterised by a relationship between an individual and the environment that is appraised as being potentially dangerous to the individual’s well-being (Lazarus & Folkman, 1984). In this person-environment relationship, there are two critical mediating processes, namely cognitive appraisal and coping. The cognitive appraisal process involves the evaluation that determines why and to what extent a particular interaction that happens between the person and the environment is stressful. Coping on the other hand is the process that helps the individual to manage the demands of the person-environment relationship and the emotions generated from this relationship.

The cognitive appraisal can be seen as a process of categorising an encounter and its significance to one’s well-being. Lazarus and Folkman (1984) identified three forms of appraisal that make up this process. The first one is primary appraisal which serves as judgement of the encounter by an individual as being irrelevant, benign-positive, or stressful. This form of appraisal can take one of three forms, namely: harm/loss (that is, the damage that has already been sustained); threat (that is, the harm or loss that is being anticipated); or challenge (these involve events that hold potential for mastery or gain). Secondary appraisal is some form of judgement concerning what might be done. This form of appraisal serves as an evaluation of the benefits and consequences of a particular coping strategy, given the person's goals and constraints. Finally, the reappraisal is a successive valuation that is based on new information obtained from the environment and/or person during the interaction. The reappraisal differs from the primary appraisal only in that it follows an earlier cognitive evaluation. Primary appraisals therefore evaluate perceived control of the situation and the resources that an individual has at his or her disposal. Secondary appraisals on the other hand guide the use of specific coping strategies. Reappraisal and the manner in which the individual adjusts is therefore determined by the effectiveness of the coping strategies. Coping is defined as "constantly changing cognitive and behavioural efforts to manage specific external and internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984, p.141).

Coping is closely related to the concept of cognitive appraisal which is the individual's subjective interpretation of the stimuli in the outside world. Lazarus and Folkman's (1984) work influenced most approaches in the research field of coping. The two authors define coping as the cognitive and behavioural efforts made to master, tolerate, or reduce external and internal demands and conflicts among them. This definition contains the following implications: (a) Coping actions are not classified according to their effects (for example, as reality-distorting), but according to certain characteristics of the coping process. (b) This process encompasses behavioural as well as cognitive reactions in the individual. (c) In most cases, coping consists of different single acts, and is organised sequentially, forming a coping episode. In this sense, coping is often characterised by the simultaneous occurrence of different action sequences and, hence, an interconnection of coping episodes. (d) Coping actions can be distinguished by their focus on different elements of a stressful encounter. They can attempt to change the person–environment realities behind negative emotions or stress (problem-focused coping). They can also relate to internal elements and try to reduce a negative emotional state or change the appraisal of the demanding situation (emotion-focused coping) (Lazarus & Folkman, 1984).

Sun et al. (2012) referred to the coping and appraisal theory in their review where they noted that cultural values and levels of acculturation play a role in coping with the caregiving experience. In this study, Sun et al. (2012) found that cultural beliefs may influence how Chinese American caregivers perceive their caregiving situations and affect their emotional well-being. The authors reviewed 25 studies of Chinese American dementia caregiving and found that perceptions and cultural beliefs played a role in motivating caregivers to take the role of being caregivers. They noted in the reviews that in Chinese culture, a certain degree of cognitive decline and return to a child-like state is embraced and considered to be a natural part of aging. The authors also found that filial piety, a prominent Confucian principle in Chinese and other Asian cultures, which emphasises honour and devotion to one's parents was found to be a family centered cultural construct that implied that adult children have a responsibility to sacrifice individual physical, financial, and social interests for the benefit of their parents or family. Some of the conclusions in the studies reviewed by Sun et al. (2012) indicate that the link of stronger identification with traditional values and lower caregiver burden is due to a clear expectation and sense of acceptance of the role of being a caregiver and their duty to an elder who is sick. Thus, caregivers appear to hold to traditional values and cultural practices as ways of helping them to cope with the burden of caregiving.

The premise of appraisal theory is that people are constantly evaluating relationships with the environment with respect to their implications for personal well-being. This implies that a person negotiates between two complementary frames of reference: first, wanting to view what is happening as realistically as possible and second, wanting to put the best possible light on events to be optimistically cheerful and confident, and not to lose hope (Lazarus, 2001). Appraisal can therefore be seen as a compromise between life as it is and what one wishes it to be, and effective coping depends on both. The Stress, Coping and Appraisal Theory gives an indication of the transactions that happen when individuals are exposed to situations that call for attention, and how their interpretations of the situations inform the reaction or behaviour displayed. We see from the review by Sun et al. (2012) how traditional and cultural beliefs play a role in getting people to develop coping strategies to a rather challenging situation. Hence, Lazarus also refers to a situation when the demands exceed the personal and social resources the individual is able to mobilise as the transactional model of stress and coping (Krohne, 2001). One limitation about the stress and coping theories is that they tend to assume that an individual is always conscious of all the factors that cause them to experience stress.

3.6 The ABC-X Model of Family Stress and Coping

The ABC-X Model of Family Stress and Coping was developed by Reuben Hill (Rosino, 2016). This model is a framework for analysing the factors that determine the relationship between stressful events and crises that families face. The development of this model was inspired by the pioneering work that Reuben Hill undertook during the period between 1949 and 1958 in the context of the potentially disruptive effects of World War II and the Great Depression on family structures. According to Rosino (2016), Hill conducted his studies to try to understand and explain the differences in families' abilities to remain resilient, functional, and intact when faced with stress brought about by social and economic changes. Noting that families react differently to stressful events, Hill proposed that available resources and proper definition of a situation can help mitigate the negative impact that stressors may have on family well-being and functioning. The framework and approach of the ABC-X Model of Family Stress and Coping was inspired by social systems theory and insights from family sociological research.

According to Rosino (2016), the development of the ABC-X model was influenced by the emergence of concepts such as family resilience, which suggests that families may come out better after successfully facing hardships, increased study of the role of religion in family life, and the social contexts of war and economic disaster. The ABC-X model takes a family as a system that must maintain equilibrium to function and provide adequate material and emotional resources to its members. The stressor event creates a disturbance of family equilibrium such that the family system must somehow re-establishes equilibrium in order to avoid dysfunction. In re-establishing the state of equilibrium, the ABC-X model presents the following four main components in understanding how the disequilibrium arose and what can influence the attaining of equilibrium state (Lazarus, 1993): A, crisis-precipitating event and stressor – referring to a situation for which the family has had little or no prior preparation and must therefore be viewed as problematic; B, the resources or strengths – factors in family organisation that, by their presence, kept the family from crisis or, by their absence, urged a family into crisis. In other words, resources determined the adequacy (crisis-proofness) or inadequacy (crisis-proneness) of the family; C, the perception of or the meaning given to the stress - the tendency to define the stressor events and the accompanying hardships of the stressor as crisis-producing/-provoking versus the challenges that made the family more crisis prone. In this model, the interaction of the crisis-precipitating event, the family's resources, and the family's definition of the event may lead to crisis, and X (the stress outcome). According to the ABC-X model, A (the crisis-precipitating event/stressor) interacting with B (the family's crisis-meeting resources) interacting with C (the definition the family makes of the event) produces X (the crisis). The ABC-X model contends that hardships are attributes of the stress or event and that whether a family defined a stressor positively or negatively is affected by whether the stressor leads to hardships in the family.

The ABC-X model defines the B factor/family resources as the adequacy (crisis-proofness) or inadequacy (crisis-proneness) of family organization. The C factor in the formula is the definition, meaning, or interpretation of the A factor/stressor. According to the ABC-X, a family may become crisis-prone based on its definition of a stressor events and the accompanying hardships that are brought about by a stressor. The implication here is that a family that is in a state of crisis will have role patterns that are changing and expectations that are shifting. This may result in negative impact on affectional and emotion-satisfying performances.

Whilst the ABC-X formula is considered the basis of most family stress models (Boss, 2002), there are some studies that have pointed to the weaknesses of this model. For instance, a study by Rosino (2016) has suggested that the ABCX model lacks consideration for social context. Rosino (2016) further pointed out that the ABCX model does not deal with the processes that occur when a family faces a crisis, it focuses only on a family's ability to mitigate a stressor rather than a crisis.

3.7 Theoretical framework for the current study: The Contextual Model of Family Stress and Coping

The current study adopted Boss' Contextual Model of Family Stress and Coping as a lens to understand caregiving for family members with sTBI. The Contextual Model of

Family Stress and Coping is a theory that considers contextual issues when trying to understand the functioning of families (Boss, 2002). This model is an adaptation of the ABC-X Model of Family Stress and Coping. In accordance with the Contextual Model (Boss, 2002), a closer look at the A, B, and C factors indicate that there is reason to be concerned about outcomes for families. According to the contextual model, the family experiences a significant stressor (the A factor) against the backdrop of various other stressors. Boss (2002) contended that resources (the B factor) and meaning (the C factor) moderate the relationship between stressors and eventual outcomes. The family’s minimal internal and external resources, combined with the complicated or possibly negative meaning assigned to changes in the family (stressor), suggest that the stressor has the potential to precipitate a crisis in the family.

By expanding on the ABC-X formula, Boss hoped to make the model more useful to a broader range of professionals such as teachers, therapists, doctors, nurses, researchers, and policy makers who work with stressed families from different backgrounds in terms of beliefs, ethnicity, and age. The model focuses on understanding meanings and perceptions aiming at multicultural contexts and applications. I opted to use this model for the current study given the facts that it allows for interaction with people of diverse groups and that it considers different contexts. According to Boss (2002), the Contextual Model of Family Stress and Coping is best explained in terms of internal and external contexts which were added to the ABC-X formula in order to consider the unique experiences of individuals from diverse backgrounds.

3.7.1 External contexts

This comprises of elements that the family cannot control, and these elements influence how families react to stressors. These include the cultural, historical, economic, developmental, and hereditary context (Boss, 2002). Cultural context includes rules of the society and the subculture to which the family belongs. Historical context includes events that are going on at the time of the stressor and events experienced by ancestors. An example in this case is that of intergenerational trauma that has been transmitted from generation to generation. Economic context includes financial situation both in the community, and in the larger society. Examples in this case include recession, and economic depression. Developmental context refers to stages in the life cycle of both the family and each individual family member. Hereditary context on the other hand refers to the genetics which influence our health, stamina, and energy. What Boss is suggesting here is that all these external factors do affect how the individual perceives the stress that he/she is facing.

3.7.2 Internal contexts

This comprises elements that the family can change and control including the structural, psychological, and philosophical context. The focus of the Contextual Model of Family Stress and Coping is primarily on internal context because this changes more easily than the external context (Boss et al., 2017) The family's internal context may change over time. For example, family members may have different internal context from each other. There may also be changes in structural context, which is the form and function of boundaries, role assignments, and rules about who is in or out of the boundaries of the family. Boss (2002) refers to the situation of unclear rules about who is in or out of the family as boundary ambiguity. In other words, boundary ambiguity refers to the situation where there is no clarity regarding members of the family. Apart from changes in the structural context, there may also be changes in psychological context. The psychological context refers to the family's perception of the stressor, including both cognitive and affective (feeling) processes. Philosophical context, which is the third element of the internal context, refers to the family's values and beliefs. Boss (2002) suggests that the philosophical context may also change within the context of the family.

The use of the Contextual Model of family stress was demonstrated in a study conducted by Sullivan (2015). In that study, Sullivan applied the Contextual Model of Family Stress to gather information during the assessment of a family. In utilizing this model, Sullivan highlighted several salient features of the family’s presentation that may be relevant targets for intervention. He also used the Contextual Model of Family Stress in a case study to illustrate how this Model can be used to understand the experiences of military families and to develop appropriate treatment plans for family therapy. Based on case information that was gathered during a family assessment, Sullivan used the model to organize and understand the issues faced by the family and guide treatment. What is remarkable here is that Sullivan (2015) incorporated Boss' suggestion that families are strongly influenced by their culture, genetics, place in the developmental life cycle, and their familial structure, values, and beliefs. He further suggested that the contextual model explicitly addresses the effect of culture, which is particularly relevant for the diverse client base that practitioners serve.

The Contextual Model of Family Stress was also used in the study by DeGraff et al. (2016). These authors explored how key military contextual factors explain when and how the relationships between perceptions of military culture support, parental life satisfaction, and youth well-being vary. In this study, DeGraff et al. (2016) uncovered the important dimension of understanding contextual effects, namely the role that contexts play (for example, the timing of deployment) in explaining how, and when, other relationships exist. The authors concluded that from a theorising perspective, it was "important to examine third factors, that is, the conditions under which individual development and family processes occur" (DeGraff et al., 2016, p. 3030).

3.7.3 Strengths and limitations of the Contextual Model of Family Stress

The Contextual Model of Family Stress has been found to be a useful theoretical tool to explain family stress and coping. For instance, Sullivan (2015) has pointed out that the Model focuses clinical attention on two specific factors, resources and assignment of meaning, which have been empirically linked to outcomes among military families. This model also encompasses the effect of the family's race and culture on the stressors its members experience, the resources they can mobilise, and the meaning they assign to events. In other words, the cultural sensitivity of the model allows it to be applied to diverse populations.

Having noted the usefulness of this model, there are some limitations to the contextual model. As with any theoretical framework, there could be temptations to becoming too wedded to a particular viewpoint. For example, looking at all families through one theoretical approach and possibly ignoring other elements of their presentation that do not fit into that particular orientation may cause researchers to miss crucial factors of an individual family's experience (Sullivan, 2015).

Based on the above considerations, I am of the view that the Contextual Model of Family Stress is a useful theoretical lens to understand severe TBI in a rural context. This Model allows for consideration of both the external and internal contexts that influence families that have individuals with sTBI. Factors that pose as the ‘A’ factor which the family must put meaning to and utilise both the external and internal contexts to develop effective coping mechanisms given the change in the family. The acknowledgement of the role played by cultural practices also make the Contextual Model of Family Stress more relevant for the current study.

3.8 Concluding remarks

Severe traumatic brain injury has been presented in the literature as having negative impact on the lives of the injured individual, the caregiver, and the family. The negative impact experienced get to be stressful and calls for functional adaptive measures. This chapter presented theories that form basis for understanding stress and what informs how individuals and families react and cope with stressful situations. For example, the Stress and Coping theory gives an indication that stress is viewed as a relationship between the person and the environment that is appraised as potentially endangering to one’s well-being. It implies that the appraisal of the person-environment is what determines the coping process. The ABC-X Model of Family Stress and Coping on the other hand shows that the definition that the family gives to the event, or the stressor is what determine the manner of coping. The ABC-X model is also considered the basis for most family stress theories. The last part of the chapter focused on the Contextual Model of Family Stress and Coping, which is an adaptation of the ABC-X model. The Contextual Model of Family Stress and Coping focuses on meaning and perception aiming at multicultural application and considers the unique experiences of individuals from diverse backgrounds. The justification for adopting this Model as the theoretical lens of the current study was given. The strengths and weaknesses of the Model were also presented. The next chapter provides a discussion of the methodology used for the current study.

CHAPTER 4: RESEARCH DESIGN

4.1 Introduction

In this chapter, I discuss the method that was used for the current study. I start by presenting an overview of the two paradigms that are commonly used in research, including their philosophical assumptions. The justification for choosing the qualitative research paradigm is also given. In the second part of the chapter, I give a historical overview of phenomenology, paying particular attention to the works of Edmund Husserl (1859 – 1938) and Martin Heidegger (1889 – 1976). The third part focuses on hermeneutic phenomenology, and more especially on Interpretive Phenomenological Analysis (IPA) which is the method of inquiry that I have chosen for the current study. The fourth part of the chapter looks at the study population and sampling, addressing issues such as the sampling method, sample size, and inclusion and exclusion criteria that were considered when selecting research participants. The fifth part outlines the procedures that I followed in collecting the data. In the sixth part, I present an outline of the method that I have used to analyse the data. Specifically, I focus on Interpretative Phenomenological Analysis (IPA) as the method that I have used, including a justification for such a choice. In the seventh part of the chapter, I describe and outline the steps that I have followed in developing the psychological explanatory model on caregiving for adults who suffered sTBI. Measures pertaining to the steps taken to ensure trustworthiness in the research process that was followed in the current study are presented in the eighth part of the chapter, whilst ethical issues that guided me in conducting the study are covered in the ninth part. Lastly, I engage in a reflexive journey in the section that I have chosen to entitle “My positionality”.

4.2 Overview of quantitative and qualitative research paradigms

The two terms, quantitative and qualitative are popularly used to describe two different worldviews and research paradigms or traditions. The quantitative paradigm is linked to the positivist tradition (Cohen & Crabtree, 2006; Fossey et al., 2002). On the other hand, the qualitative paradigm is associated with the interpretivist tradition (Mackenzie & Knipe, 2006). The positivist and interpretivist traditions represent different ways relating to how researchers conceive reality, and how they subsequently go about studying it. The implication here is that the choice of a paradigm determines the type of research design and methods of data collection and analysis that the researcher ultimately adopt in order to carry out the research (Creswell & Poth, 2018). In other words, a research paradigm provides a broader framework that guides the conceptualisation of reality and associated ways of arriving at it.

4.2.1 Positivism and the quantitative research paradigm

Positivism can be traced to early French thinkers and philosophers such as Henri de Saint-Simon and Auguste Comte (Agassi, 2019). Central to positivism is the notion that all authentic knowledge is an objective reality that can only be arrived at through empirical or scientific methods that are commonly used in the natural sciences. In other words, the role of a researcher is to gather and systematise data from the objective reality that exists out there. According to Robinson (2014), positivism assumes that there is some ultimate scientific truth that is premised on the natural law. What Robinson (2014) suggests is that the focus of research that is steeped in the positivist tradition is to arrive at some generalisation and the development of universal statements or the validation of some existing natural laws.

The same line of thinking that dominated the natural sciences was extended into the social sciences by Emile Durkheim (1858 – 1917). This French thinker and sociologist maintained that social scientists needed to maintain the same kind of objectivity and empirical distance when studying human thought and conduct (Hudson & Ozanne, 1988). Ontologically, positivists posit that a single objective social reality exists out there independently of what individuals perceive and think of that reality (Hudson & Ozanne, 1988). At the axiological level, positivists seek to explain and predict human behaviour in accordance with existing universal laws. Epistemologically, positivist researchers' ultimate aim is to generalise their findings to "… an infinitely large number of phenomena, people, settings and times" (Hudson & Ozanne, 1988, p. 513). According to Smith et al. (1995), when quantitative researchers undertake an empirical investigation, a problem is made up of several variables that can be measured in a predetermined and systemic way, with the view to analyse the data mostly with some statistical procedures. Primarily, the goal of positivists in the collection and analysis of data is to arrive at some form of prediction or to determine a cause. Whilst positivism has been praised for its focus on its vigorous process of experimentation and hypothesis testing, it has been criticised for its inflexible belief that everything can be measured or calculated (Pham, 2018).

4.2.2 Interpretivism and qualitative research

Interpretivism is a philosophy that rejects the positivist and objectivist view that reality, including the social meaning, exists independently of human consciousness. For the interpretivists, reality is socially constructed, and can thus be understood and explained from the viewpoints of those involved. Also called anti-positivism or naturalistic inquiry, interpretivism can be traced to the work of Giambattista Vico, an 18th century Italian philosopher who argued that there is a difference "… between the natural and social world and more importantly, that social organization and social experiences form our perceptions of reality and truth" (Ryan, 2018, p. 8). Ontologically, interpretivists disagree with the positivists' view that there is universal reality and one ultimate truth. Instead, the interpretivists take a relativist position which posits that there is no single reality (Ryan, 2018). In their view, reality is socially created through instruments such as theories and categories to help human beings to make sense of their world. What is implied here is that reality does not exist outside the socially created environments and systems.

Axiologically, interpretivists aim to understand behaviour. At the epistemological level, the interpretivists hold the assumption that new knowledge can be generated through idiographic and time-bound processes that are also context dependent (Creswell & Poth, 2018). The table below provides more information on the philosophical assumptions of qualitative research.

Table 4.1

Philosophical assumptions of qualitative research

Assumption	Questions	Characteristics	Implications for practice
Ontological	What is the nature of reality?	Reality of multiple as seen through many views.	The researcher reports different perspectives as themes develop in the findings
Epistemological	What counts as knowledge? How are knowledge claims justified? What is the relationship between the researcher and that being researched?	Subjective evidence is obtained from participants, the researcher attempts to lessen the distance between herself or himself and that being researched.	The researcher relies on quotes as evidence from the participants as well as well as collaborates, spends time in the field with participants, and becomes and "insider".
Axiological	What is the role of values?	The researcher acknowledges that research is value-laden and that biases are present in relation to their role in the study context.	The researcher openly discusses values that shape the narrative and includes his or her own interpretation in conjunction with those of participants.
Methodological	What is the process of research? What is the language of research?	The researcher uses inductive logic, studies the topic within its context, and uses an emerging design.	The researcher works with particulars (details) before generalizations, describes in detail the context of the study, and continually revises questions from experiences in the field.

Adapted from: Creswell, J.W., Poth, C.N. (2018). Qualitative inquiry and research design: Choosing among five approaches. Sage.

In the social sciences, interpretivism is commonly associated with three schools of thought, namely *phenomenology*, *ethnomethodology,* and *symbolic interactionism* (Creswell, 2014). The above three schools of thought that form the basis for qualitative methodologies, put emphasis on the importance of human interaction when conducting research. In other words, a researcher cannot hope to understand social phenomena without considering the social context in which it occurs. Based on the distinction between the two paradigms as outlined above, the current study locates itself within interpretivist tradition and the qualitative research approach.

4.2.3 Rationale for the choice of a qualitative approach

Qualitative method of inquiry was born out of a growing dissatisfaction with the limitations of quantitative methods of research (Creswell, 2014). Qualitative researchers generally take an idiographic stance which means that they focus on individuality and uniqueness of phenomena (Creswell & Poth, 2018). The research designs and methods of data collection that qualitative researchers adopt are guided by philosophical assumptions of qualitative inquiry. One such assumption is that a researcher needs to take into account the many realities of the participants themselves to arrive at a better understanding of complex phenomenon (Smith & Osborn, 2007). For qualitative researchers, people construct their own realities and personal worlds. In other words, they disagree with the quantitative researchers who are of the view that there is some objective reality out there in the world (Smith & Osborn, 2007). Qualitative researchers rely on natural environments or settings to discover the meanings that participants construct. Qualitative research seeks to arrive at emerging themes and patterns that are embedded in participants' narratives and life-worlds (Choy, 2014).

Since I have decided to align myself with the interpretivist tradition, I have opted to adopt a qualitative approach in my study. As I went about interviewing the caregivers of family members who have suffered severe traumatic brain injuries, I came to appreciate that theirs were complex experiences that required me to be in their shoes. By taking this stance, I was able to understand the participants' lived experiences within their contexts. This enabled me to uncover the themes that emerged from the narratives that the participants shared with me. It is for these reasons that I found the qualitative approach to be relevant for my study.

4.3 Historical overview of phenomenology

The history of phenomenology as a philosophical movement is traced back to the work of a German philosopher by the name of Edmund Husserl (Laverty, 2003). Opposed to the dominant positivist wave during his time, Husserl argued that a higher level of reality can be arrived at by studying human consciousness (Kjosavik et al., 2019). For Husserl, scientific inquiry should begin with the phenomena of consciousness as these were the only ‘givens’ that were available for scientific scrutiny. Phenomenology should thus study that which ‘gives itself’ or phenomena of consciousness which, if explored, will lead the researcher “turning to experience as lived through” (van Manen, 2017, p. 811) or to going “to the things themselves” (Christensen et at, 2017, p.117). Husserl was also critical of psychology and other social sciences in their attempt to apply methods of the natural sciences to human issues (Choy, 2014; Laverty, 2003). Husserl’s notion of the centrality phenomenon of consciousness was challenged by Martin Heidegger who focused on what he referred to as “‘Dasein’, which is translated as ‘the mode of being human’ or ‘the situated meaning in the world’” (Laverty, 2003, p. 27).

According to Sloan and Bowe (2014), descriptive and interpretive phenomenology then evolved from the works of Edmund Husserl (descriptive phenomenology) and Martin Heidegger (interpretive/hermeneutic phenomenology). Also known as transcendental phenomenology (Kaffle, 2011), the main assumption underlying descriptive phenomenology is that it is possible to suspend our personal opinion and arrive at a single, essential description of the things themselves. The emphasis of transcendental phenomenologists is that it is possible for an observer to detach from the phenomena and adopt a global stance in relation to the essence of the discovery (Laverty, 2003). Descriptive phenomenologists commonly use concepts such as intentionality, bracketing and epoche.

As already indicated, interpretive phenomenology, also known as hermeneutic phenomenology (Langdridge, 2007; Laverty, 2003) and existential phenomenology (Spinelli, 2005), is considered to be linked to the writings of Martin Heidegger.

Hermeneutic phenomenology rejects the idea that we can suspend our personal opinions. Instead, those in the hermeneutic phenomenological tradition argue that we need to focus on the subjective experience of individuals and groups. What is important for hermeneutic phenomenology is to understand "the meaning of experience by searching for themes [and] engaging with the data interpretively" (Sloan & Bowe, 2014, p.1299).

One of the psychologists whose work was influenced by Husserl is Amedeo Giorgi, an American psychologist who even went as far as proposing steps that needed to be followed by phenomenologists doing psychological research (Giorgi, 1985; 1986). In the section below, I provide an outline of hermeneutic phenomenology as a research method of choice for the current study.

4.4 Hermeneutic phenomenology and the current study

In the current study, I chose to use Interpretative Phenomenological Analysis (IPA) as my research approach. According to Pietkiewicz and Smith (2014), IPA is a unique research method that brings together ideas from phenomenology and hermeneutics resulting in a form of inquiry that is both descriptive and interpretative. It is descriptive because it seeks to let things speak for themselves, thus allowing the researcher to understand and describe them as they appear. On the other hand, IPA is interpretive as it recognises that "there is no such thing as an un-interpreted phenomenon" (Pietkiewicz & Smith, 2014, p. 363). When used in psychological research, the idiographic focus of IPA enables the researcher to gain insights into how a given person, in each context, makes sense of a given phenomenon (Creswell & Poth, 2018).

According to Smith et al. (2009), IPA has a two-stage interpretation process, or what Giddens (1987) refers to as double hermeneutic. This means that the research environment provides a platform for participants to make sense of their own world and experiences, whilst the researcher uses the same platform to make sense of the participants by trying to make sense of their world. Utilising the two-stage interpretation process, I created a platform through which caregivers of family members who suffered severe traumatic brain injury made meaning or sense of their lived experiences. I analysed the resulting accounts in order to attach psychological meanings thereto.

4.5 Population and sampling

4.5.1 Population

The population for the current study was individuals who were caring for an adult family member who suffered severe traumatic brain injury. Since caregiving was identified as the phenomenon to be investigated, family members who were caring for the injured family member were identified as potential participants.

4.5.2 Sampling

Purposive sampling was selected for the current study as it allows selection of participants with some defining characteristic (Creswell & Poth, 2018). This sampling method allows for some degree of homogeneity as the researcher concentrates on people with characteristics that are a focus of the study (Creswell & Poth, 2018; Pietkiewicz & Smith, 2014). It is for this reason that caregivers were selected given their lived experiences of caring for loved ones who have suffered traumatic brain injury. As Alase (2017) succinctly puts it:

> The selection of these participants should reflect and represent the homogeneity that exists among the participants' sample pool. The essence of conducting an IPA research study with homogenous participants is to get a better gauge and a 'better understanding' of the overall perceptions among the participants' 'lived experiences' (p.13).

In addition to purposive sampling, I also relied on snowball sampling to reach more participants. According to Creswell (2014), in snowball sampling the researcher asks the participants to identify other potential participants who share similar characteristics. This means that the researcher may ask the first participant to assist in suggesting the names of other participants that share the same elements that are being investigated. Similarly, I initially approached a few caregivers of the clients that have consulted in my clinical practice for neuropsychological assessment. The caregivers that I approached provided me details of other potential participants that they knew. Through this unfolding enrolment process, some participants led me to a local occupational therapist whose practice is popularly known for rehabilitation of patients who have suffered traumatic brain injuries. I obtained additional participants through this platform.

Though a sample of 20 participants was initially envisaged for the study, I continued with the interviews till a point of data saturation. According to Fusch and Ness (2015), a saturation in qualitative research refers to a point at which no new information is yielded from additional data gathering. In the case of the current study, a saturation point was reached when I interviewed the fourteenth participant. I consider the number of participants for the current study to be adequate if one considers Pietkiewicz and Smith’s (2014) assertion that in IPA research one should concentrate more on the depth rather than the breadth of the study.

4.5.3 Inclusion and exclusion criteria

To ensure that the correct sample is selected for a study, it is important to decide on the inclusion and exclusion criteria. In the current study, the following inclusion criteria guided the selection of research participants:

- An adult who has been playing the role of a caregiver to a family member who suffered severe traumatic brain injury. The person so identified should have been a caregiver for not less than two years.

- Those caregivers who were identified and were willing to participate.

- Being able to speak at least one of the following languages: Sepedi, Xitsonga, Tshivenda, or English. The reason for this inclusion criterion is because these are the languages that I can speak.

The criteria that I used to exclude potential participants were as follows:

- Individuals who fulfilled the inclusion criteria but were not willing to take part.

- Individuals who fulfilled the inclusion criteria but had mental health problems which may impair their ability to communicate coherently and engage meaningfully in an interview.

- Individuals who fulfilled the inclusion criteria, but who did not speak Sepedi, Xitsonga, Tshivenda, or English.

4.6. Data collection

Guided by the principles of phenomenology as already elucidated in this chapter, I consciously focused my attention on the phenomenon under investigation with each participant that I interviewed. Husserl talks about the need for a researcher to achieve pure and absolute transcendental ego by not allowing their presuppositions about the phenomenon being investigated (Moustakas, 1994). What is implied here is that a researcher is expected to suspend her/his preconceived ideas regarding the phenomenon under investigation to allow the participants to narrate their lived experiences. Before engaging in the actual data collection, consent was sought over the telephone. Potential participants were called and an information sheet that is on the participant's home language was read and discussed with each one of them (see Appendix 1a – English version; Appendix 1b: Northern Sotho version; Appendix 1c: Tshivenda version; Appendix 1d: Xitsonga version). On the day of data collection, I spent the first few minutes of the telephonic interview explaining to each participant the purpose of the study, including ethical aspects associated with the study as per the information sheet discussed with them during the consent phase.

For the current study, I utilised semi-structured interview as a data collection instrument (see Appendix 2a – English version; Appendix 2b: Northern Sotho version; Appendix 2c: Tshivenda version; Appendix 2d: Xitsonga version). Semi-structured interviews are in-depth interviews where the respondents must answer pre-set open-ended questions (Creswell & Poth, 2018). This form of interviews allows the researcher the opportunity to clarify ambiguous statements, permit exploration of topics and to elicit experiential account of the lived experiences (Turner, 2010). In line with Turner's (2010) explanation, semi-structured interviews allowed for the exploration of primary caregivers' experiences of caring for an adult family member who suffered sTBI. In other words, semi-structured interviews allowed me the opportunity to explore a specific topic, using an interview guide (Fossey et al., 2002). According to Mack et al., (2005), semi-structured interviews are optimal when collecting data about personal histories and experiences that may be sensitive for the participants. This is because participants are allowed the opportunity to talk freely about their experiences (Harvey-Jordan & Long, 2001). The interviews were recorded on an audio tape with the permission of the participants.

4.7 Data analysis

In line with my choice of hermeneutic phenomenology as a research method for the current study, I opted to use Interpretive Phenomenological Analysis (IPA) to derive meanings from the collected data. Researchers using IPA are encouraged to be deeply immersed in the data that has been yielded through the interview process. In other words, by reaching deep into the lifeworld of the participants, the researcher can understand their experiences and the meanings that they attach to these experiences. It is these experiences and meanings that the researcher needs to translate into psychological concepts and theories. As Pietkiewicz and Smith (2014) eloquently put it:

> It is recommended that the researchers totally immerse themselves in the data or in other words, try step into the participants’ shoes as far as possible. IPA aims at giving evidence of the participants’ making sense of phenomena under investigation, and at the same time document the researcher’s sense making. The researcher is thus moving between the *emic* and *etic* perspectives. The latter is achieved by looking at the data through psychological lens and interpreting it with the application of psychological concepts and theories which the researcher finds helpful to illuminate the understanding of research problems. (p. 366)

In this movement between the emic and etic perspectives, I was guided by the following four steps that Pietkiewicz and Smith (2014) have elucidated:

4.7.1 Multiple reading and making notes

This first stage in data analysis requires the researcher to read the transcripts and listen to the audio recordings a few times. This gives the researcher the opportunity to make notes based on the transcripts and audio recordings. Apart from providing new insights, Pietkiewicz and Smith (2014) point out that this repetitive process will help immerse the researcher in the data. The researcher is expected to focus on content and context whilst also attending to some initial interpretive comments. The process may also provide an opportunity to reflect about the interview experience and other issues of importance. For example, getting an understanding about how the researcher relates to the interview process and its impact. In accordance with these guidelines by the two authors, I immersed myself in the data by reading the transcripts and listening to the audio tapes several times. I reflected on the content of narratives that I had in front of me, often linking these to the context in which they unfolded. In my reflections, I often felt like I was re-living the moments when the caregivers shared with me their difficult experiences of caring for their loved ones who are no longer able to care for themselves in ways that they used to before sustaining the traumatic brain injury. In the results chapter I demonstrated, through some illustrative extracts from the original transcripts, how I made some notes based on multiple readings and the replays of the audio tapes (see Table 5.2 in Chapter 5).

4.7.2 Transforming notes into emergent themes

The second step that Pietkiewicz and Smith (2014) identified, requires the researcher to rely more on the notes that s/he has made than on the transcripts. The notes were transformed into emerging themes that were expressed with a “slightly higher level of abstraction” (Pietkiewicz & Smith, 2014, p. 367) that reflected some form of psychological interpretation. To ensure that this step was followed, I worked through the notes and transformed them into a number of themes that I conveyed in psychological language. Using the same extracts that I used in the first step; I illustrated how I transformed the notes into emergent themes when I discussed the results in Chapter 6.

4.7.3 Seeking relationships and clustering themes

The third step in the data analysis process is a crucial step that "involves looking for connections between emerging themes, grouping them together according to conceptual similarities and providing each cluster with a descriptive label" (Pietkiewicz & Smith, 2014, p. 367). The clustering results in superordinate themes that the researcher can report on. What this means is that the researcher needs to cluster several themes to yield superordinate themes. Table 5.3 (in Chapter 5) gives an indication of the superordinate themes and their associated themes.

4.7.4 Writing up an IPA study

What follows on the third step in the data analysis process (refer to Table 5.3 in Chapter 5) is a comprehensive presentation of the superordinate themes and their corresponding themes. I have punctuated these superordinate themes and corresponding themes with relevant short extracts to amplify their meanings. According to Pietkiewicz and Smith (2012), using short extracts of participants' narratives give the reader an opportunity to assess the appropriateness of the interpretations that the researcher has made. The extracts from participants' narratives are the voices in the results that help to give the IPA interpretations the unique emic perspective.

4.8 Steps followed in the development of a psychological explanatory model

According to Kühne (2005), a model is a description or analogy that is used to visualise something that cannot be directly discerned. In the current study, I developed a psychological explanatory model to capture caregiving to an adult with sTBI within a family context. This model was informed by the meanings derived from the primary caregivers as they continued to relate to the experiences of providing care to adult family members who suffered sTBI. The procedures for good theory-building as proposed by Wacker (1998) in the process of developing and articulating a psychological explanatory model were closely adhered to.

4.8.1 Definitions of variable

Following Wacker’s (1998) guideline, the initial step involves defining who and what is included or excluded in the definition(s) of the variable(s). In the current study, the definition of variables refers to primary caregivers and caregiving for adult family members who have suffered sTBI.

4.8.2 Limiting the domain

Limiting domain involves observing and limiting the conditions regarding when an antecedent event occurs, when, and where the subsequent events are expected to occur (Wacker,1998). Once I had established the precise definitions of variables, I established the domain so as to limit when and where the explanatory model applies. In the current study, I observed the antecedent events (sTBI) that led to caregiving experience as well as the subsequent events that were related to this experience in the context of the family of the primary caregiver.

4.8.3 Relationship (model) building

Ideally, the development of a model commences after clarifying the definitions and specifying the domain (Wacker, 1998). This step is important as it helps in determining logical connections among variables. Thus, specific connections among variables should be explicitly stated. Similarly, the task in theory-building was aimed at establishing how caregivers experience their roles, including the related coping strategies and challenges associated with the experience.

4.8.4 Theory predictions and empirical support

Following on the above three steps in theory-building, I have attempted to make predictions for future developments to ensure that any future theory or psychological explanation of the experiences of caregivers of family members who have suffered severe sTBI is logical and sound.

Table 4.2

A general procedure for theory-building and the empirical support for theory

	Purpose of this step	Common question	'Good' theory virtues emphasized
Definitions of variables	Defines who and what are included and what is specifically excluded in the definition.	Who? What?	Uniqueness, conserva-Tion
Limiting the domain	Observes and limits the conditions by when antecedent event and where the. subsequent events are expected to occur.	When? Where?	Generalizability
Relationship (model) Building	Logically assembles the reasoning for each relationship for internal consistency	Why? How?	Parsimony, fecundity, internal consistency, Abstractness
Theory predictions and empirical support	Gives specific predictions. Important for setting conditions where a theory predicts. Tests model by criteria to give empirical verification for the theory. The riskiness of the test is an important consideration.	Could the event occur? Should the event occur? Would the event occur?	Empirical tests Refutability

Adapted from: Wacker, J.G. (1998). A definition of theory: research guidelines for different theory-building research methods in operations management. *Journal of Operations Management, 16*, 368.

4.9 Trustworthiness of the research process

In the positivist tradition, the quality of research is usually judged based on its ability to satisfy the criteria of reliability, validity, replicability, and generalisability (Shenton, 2004). In the interpretivist tradition on the other hand, the robustness and quality of research is judged on the basis of its trustworthiness in terms of the four quality criteria of dependability, credibility, confirmability, and transferability (Shenton, 2004). According to Lincoln and Guba (1985), qualitative research demonstrates trustworthiness when experiences of participants are accurately represented. Similarly, I was guided by the following criteria for trustworthiness in conducting the current study:

4.9.1 Credibility

Considered the equivalent of internal validity in quantitative research, credibility refers to the degree to which the findings of the study reflect the meanings and experiences of the participants. According to De Vos (2002), the criterion of credibility involves establishing that the results of a study are believable and plausible from the participant's perspective. Shenton (2003) is of the view that the adoption of research methods that are well established in qualitative research is one way to inspire confidence that the researcher has adequately recorded the phenomenon under investigation. To ensure credibility in the current study, I sought to understand and describe the experiences of primary caregivers of persons with sTBI from their own perspectives. In this regard, I constantly reflected on the participants' responses during the stages of data collection and when analysing and interpreting the data. Furthermore, I relied on well-established qualitative research methods to conduct the study. In particular, I adopted phenomenology as both a philosophical paradigm and method to guide me in conducting the study.

4.9.2 Transferability

This quality criterion (equivalent to external validity in quantitative research) refers to the extent to which the findings can be transferred to other settings or contexts (Francis, 2011). Shenton (2004) suggests that the following are some of the critical issues that should be considered at the outset to ensure transferability of the qualitative study findings: a) the number of participants who were involved in the study; b) the data collection methods that were used; c) the number and length of the data collection sessions; and d) an indication of the period that the researcher took to collect the data. Transferability in the current study was ensured by providing a thorough description of the context, meanings and assumptions underlying the study. In addition, I also considered the above critical issues that Shenton (2004) refers to, to enhance the transferability of my results.

4.9.3 Dependability

Dependability criterion is equivalent to reliability in quantitative research. Quantitative researchers are of the view that if a study was to be replicated using the same methods with same participants, similar results should be arrived at (Creswell, & Poth, 2018). For qualitative researchers, dependability refers to selecting, justifying, and applying theoretically accepted research methods to produce dependable results (De Vos, 2002). According to Shenton (2004), dependability can be enhanced by reporting the processes within the study in more detail to enable a future researcher to repeat the work even though they might not arrive at the same results. Similarly, I followed Shenton's (2004) guidelines by reporting in great detail the processes within the current study. In this regard, I ensured that I collected data using a standard interview guide for all the participants. Furthermore, data were analysed by following the steps of IPA as elucidated by Pietkiewicz and Smith (2014).

4.9.4 Confirmability

Known as objectivity in quantitative research, this quality criterion refers to the extent to which results can be verified for correctness by other researchers (Francis, 2011). One way to improve correctness of the results is to base the findings on the participants' own narratives. To improve confirmability in the current study, I ensured that I documented the procedures that I followed, checking, and rechecking the data throughout the study. Furthermore, I used the participants' own narratives to amplify the emerging themes and subthemes that I reported on in the results section.

4.10 Ethical considerations

The protection of human participants in research is critical. It is therefore important for any researcher who works with human participants to observe all applicable ethical principles and guidelines. In line with this requirement, I was guided by the ethical principles and guidelines applicable in research. I also ensured that my conduct during the research process was in line with the ethical code of conduct for psychologists and other health professionals. The following ethical practices were observed:

4.10.1 Permission to conduct the study

Before the commencement of face-to-face data collection, I applied for and obtained ethical clearance from UNISA's ethics committee in December 2019. Following COVID-19 outbreak and subsequent national lockdown restrictions, data collection method was changed from face-to-face interviews to telephone interviews in line with the communication issued to all researchers from UNISA's office of the Vice Principal: Research, Postgraduate studies, Innovation and Commercialisation.

4.10.2 Informed consent

Informed consent in research means that all potential participants need to understand what is requested of them before they can participate (Creswell & Poth, 2018). In other words, any participant will need to be given a clear explanation about the nature of the research, including the potential negative consequences of their participation. Similarly, in the current study I explained to each participant in full detail what the study was about. In this regard, an information sheet that was in the preferred language of each participant was read and explained before a participant could consent telephonically. The explanation assisted each participant to make an informed decision prior to partaking in the study. Informed consents were received after some time of the explanations. Thus, one to two telephone calls were made to potential participants before informed consent was received as they needed to reflect on the request to participate.

4.10.3 Voluntary participation

According to Neuman (2013), participation in research should be a voluntary activity that does not involve any form of coercion or undue pressure. The researcher should allow the participant to make the choice on whether to participate. In the current study, I spent sufficient time at the beginning of each interview session to explain to participants that participation was voluntary and that they were free to withdraw from the study at any time should they want to do so.

4.10.4 Privacy, confidentiality, and anonymity

Good ethical practice requires the researcher to observe and honour the interrelated ethical requirements of privacy, confidentiality, and anonymity. Privacy means that a participant has a right not to reveal information to a researcher that s/he does not want to disclose. To honour this ethical requirement, I explained at the beginning of each interview that a participant is not expected to reveal any personal information that they would not like to share during the study. Confidentiality means that all identifiable information that the researcher has access to during the research process will not be disclosed to third parties without the permission of the participant. In the case of anonymity, the researcher avoids collecting personally identifying information such as names, addresses, photographs, and any other information that identifies participants. In the current study I used pseudo-names to ensure the anonymity of the participants.

4.10.5 Respect and dignity

In accordance with the Constitution of the Republic of South Africa and the need to honour the personal integrity and dignity of others, the research study undertook to respect each participant regardless of their gender, age, and other personal circumstances. I was mindful throughout the research process that I needed to protect the personal integrity of my research participants. I was particularly mindful of this ethical requirement given the vulnerability of the caregivers of persons who have suffered severe traumatic brain injuries. I therefore had to empathically relate to each participant to ensure that they feel understood and respected.

4.10.6 Benefits, risks, and harm

At the commencement of each interview, I informed each participant that taking part in the study would not carry any immediate and direct benefits for them and their families. However, the participants were informed that the study was going to lead to the development of a psychological explanatory model on caregiving within a family context for adults who had suffered sTBI. Such an explanatory model could, in turn, benefit those who suffered sTBI, including their families and caregivers.

Apart from raising the issue of benefits, good ethical practice requires a researcher to be mindful of the psychological welfare of the participants who might show some adverse emotional reactions as a result of their participation in a study (Neuman, 2013). Such potential harm to a participant could be physical, psychological, or social. Similarly, I ensured that the emotional welfare of the participants was taken care of by making them aware of the psychological support that is available at local primary health clinics and hospitals in the event any one of them experienced some adverse reactions. My professional training and experience as a clinical psychologist also helped me to respond sensitively and empathically to the participants' experiences during the interviews.

4.11 My positionality

It is important to acknowledge that our own world views, values and beliefs will influence the stance that we adopt when we conduct social science research. In other words, the position that we adopt or the lens through which we investigate the social phenomenon of our interest is shaped by our sociocultural, political, historical, geographical and many other forces around us. These forces determine our positionality and influence how we conduct research, including the results that we arrive at (Bourke, 2014; Davis, 2020). In this section, I declare my positionality and submit that my world view, values, religious faith, gender, professional training, social class, and other influences have shaped the way I have related to the topic that I have chosen to research on. I detail here below some of those specific factors and realities that influenced me to conduct this study.

Firstly, I believe that my training and practice as a clinical psychologist both in the public sector and in private practice, orientated me to be more sensitive and empathic when working with people who have psychological problems. Having been in clinical practice for more than twelve years, I have interacted with a wide range of clinical populations in different contexts. I believe this background set the tone for the interest that I have developed over the years in the field of neuropsychology in general and traumatic brain injury.

Secondly, my particular interest in the field of traumatic brain injury started to grow when I moved into private practice as a clinical psychologist. In this environment, I interacted with patients who had suffered traumatic brain injury and were going through rehabilitation. I also started to receive many referrals from law firms whose clients required neuropsychological assessment following motor vehicle accidents. Whilst doing these specialised assessments, I often wondered what happens to these clients after they leave my consulting rooms with the assessment report. The observation I made was that little was known about the care and rehabilitation services that they would be exposed to. In my interactions with some of the family members who have taken on the role of being caregivers, I got the impression that there were considerable challenges that these significant others faced. The responsibility of caring for someone who was independent but has suddenly become unable to care for himself/herself, appeared to be daunting for the caregivers. This gradually increased my curiosity, resulting in my desire to conduct research on the experiences of family members who care for their loved ones who have suffered severe traumatic brain injury.

Third, as I conceptualised the study taking a decision to adopt an interpretivist stance, I realised and appreciated that there was no way I would become an objective and neutral investigator that positivism expects of a ‘good’ scientist. I started to appreciate that I was going to leave my footprints wherever I was going to be collecting data. I needed to accept and embrace the fact that I was going to go into the field, not only as a researcher, but also as someone who has many roles in society such as being a clinical psychologist, sister, daughter and Christian. These different roles influenced how I interacted with the participants whose circumstances I wanted to understand and describe. The process of data collection brought a lot of sad feelings as I continuously reflected on the challenges and difficulties faced by family members who cared for loved ones whose lives have been drastically changed following the traumatic brain injury. I found myself having to empathise a lot with the caregivers given the emotional ‘burden’ that they carry as they continue to lead their lives and to care for their loved ones.

Last, but not least, I acknowledge that there are several external factors that impacted on the process of collecting data for the current study. Just a month before I could start with my data collection, the country went into a lockdown as a result of the COVID-19 pandemic. My plans to do fieldwork were disrupted as movements and face-to-face contacts were curtailed. This meant that I needed to make some changes to my data collection methods and plans. Instead of conducting face-to-face interviews, I resorted to telephone interviews in line with communication from the institution’s research office. The process of collecting data over the telephone brought its own limitations that I had to grapple with. For instance, doing telephonic interviews meant that it was not going to be possible to observe participants regarding their non-verbal communication when interacting with them. Similarly, it was not possible to reflect on such nonverbal cues that would have been important when researching human experiences such as caregiving. Consent to participate in the study was also sought and obtained over the telephone. Even though audio recording of such consent was done, it was not possible to obtain written confirmation. This was also partly because a considerable number of the participants are not able to read and write. Furthermore, most of them come from the rural areas and did not have access to technologies that could allow them to attach electronic signatures and email informed consent forms.

4.12 Concluding remarks

In this chapter, the philosophical basis for adopting phenomenology as a research method was outlined. The approach and design of the study, including data collection and analysis methods were presented. I have concluded the chapter by highlighting the ethical issues that guided me in conducting this study. In the following chapter, I present the results of the current study.

CHAPTER 5: RESULTS

5.1 Introduction

In the preceding chapter, the research design of the study was presented. In the current chapter, the results of the study are presented in three sections. In the first section (5.2), I present the demographic details of the fourteen participants who shared their lived experiences of caregiving with me. The themes and superordinate themes that emerged from the data, including the illustrative notes and tables are outlined in the second section of the chapter (5.3). The last section (5.4) is a write up on the superordinate themes and themes in line with IPA steps suggested by Pietkiewicz and Smith’s (2012). I have punctuated the presentation with extract from participants’ own narratives for the emic perspective to also find expression in the results. What I have presented in this chapter is also extended to Chapter 6 where I outline the psychological explanatory model on caregiving for adults who suffered sTBI. This model is informed by the meanings derived from the primary caregivers’ lived experiences of providing care to adult family members who suffered sTBI.

5.2 Demographic profile of participants

Table 5.1 below shows the demographic profile of the participants.

Table 5.1

Demographic profile of research participants

Participant	Age of research participant	Age of care recipient	Pre-morbid occupation of care recipient	Pre-morbid occupation of caregiver	Relationship
A	69	38	Domestic worker	Unemployed	Mother
B	70	27	Security guard	Unemployed	Mother
C	40	32	Labourer	Seasonal worker	Elder sister
D	67	40	Seasonal worker	Unemployed	Mother
E	48	55	School principal	Stay-at-home spouse	Spouse
F	68	68	School principal	Retired nurse	Spouse
G	58	34	Casual jobs	Unemployed	Mother
H	35	32	Labourer	Unemployed	Elder sister
I	51	56	School principal	Stay-at-home spouse	Spouse
J	37	40	Artisan	Stay-at-home spouse	Spouse
K	55	62	Businessperson / tenderpreneur	Bank teller	Spouse
L	62	34	Student	Unemployed	Mother
M	51	31	Admin officer	General worker	Mother
N	49	30	General worker	Domestic worker	Mother

Participant A

The participant is a 69-year-old woman who has previously worked as a domestic worker and is now retired. The care recipient is her 38-year-old daughter, a mother of two teenagers. At the time when she got involved as a pedestrian in a vehicle accident, she was a domestic worker. She suffered a severe traumatic brain injury during the accident. At the time of the interview, it had been 2 and half years since the accident happened. The care recipient is now confined to a wheelchair. She is staying with her mother and one of her children. The care recipient is continuing with physiotherapy consultations at a public hospital. I had done a neuropsychological assessment for a third-party claim with the care recipient six months before data collection.

Participant B

The participant is a 70-year-old woman. She reportedly never had any formal job. The care recipient is her 27-year-old son who suffered a severe traumatic brain injury following a pedestrian vehicle accident. The care recipient worked as a security guard pre-morbidly and stayed with his mother. He does not have a family of his own. At the time of the accident, he was reportedly waiting at a bus stop to catch a bus to work. Following the injury, a psychiatrist diagnosed the care recipient with psychotic disorder due to head injury. He was on psychiatric treatment at the time when I interviewed the caregiver. At the time of the interview, it had been 5 years since the accident. He was unable to continue with his pre-morbid occupation. I had conducted a neuropsychological assessment with the care recipient for a third-party claim some 2 years before I collected the data.

Participant C

Participant C is a 40-year-old woman who is caring for her 32-year-old brother. She reportedly works as a seasonal worker. The care recipient worked as a labourer for a construction company. Other members of the family include the mother, a younger sister and the last-born younger brother. The younger sister was also recruited to participate in the study. She is Participant H in this study. In addition to a severe cognitive impairment, the care recipient also has weakness of the dominant hand. At the time of the interview, he was continuing with a physiotherapist at a public hospital.

I had conducted a neuropsychological assessment with the care recipient for a third-party claim three years before data collection.

Participant D

The participant is a 67-year-old woman. She reportedly never had any formal job. The care recipient is her 40-year-old daughter who suffered a severe traumatic brain injury following a motor vehicle accident. The care recipient worked as a seasonal worker, offering cleaning service. At the time of the accident, she was travelling home from work. Following the injury, the care recipient has not been able to return to work given the cognitive and physical impairments that she now has. She was referred to consult a psychiatrist given a severely depressed mood. At the time of the interview, it had been 8 years since the accident happened. I had conducted a neuropsychological assessment with the care recipient for a third-party claim ten months before the interview for the study.

Participant E

The participant is a 48-year-old woman who had been a stay-at-home spouse. The care recipient is her 55-year-old husband who suffered a severe traumatic brain injury following a motor vehicle accident. The care recipient was reportedly a school principal and breadwinner for his family. His wife was a stay-at-home spouse at the time of the accident. Following the injury, the care recipient was diagnosed with aphasia and other cognitive deficits. At the time of the interview, it had been 2 years since the accident happened and the care recipient had not gone back to work given the aphasia and other cognitive deficits. I had conducted a neuropsychological assessment with him to help him in his application for permanent incapacity from the employer as he was unable to continue with his job as a school principal. The interview for the study took place 18 months after the neuropsychological assessment.

Participant F

The participant is a 68-year-old woman. She is a retired assistant nurse who worked at a psychiatric ward in hospital. The care recipient is her 68-year-old husband who suffered a severe traumatic brain injury following a motor vehicle accident. The care recipient worked as a school principal pre-morbid. The injury was severe and resulted in severe cognitive impairment. As a result, he was not able to go back to work following the accident. At the time of the interview, it had been 17 years since the accident happened. There was no structured intervention or rehabilitation that was being offered at the time of the interview. I had conducted a neuropsychological assessment with the care recipient for a third-party claim in 2013. The interview took place seven years after I conducted the neuropsychological assessment.

Participant G

The participant is a 58-year-old woman. She reportedly never had any formal job. The care recipient is her 34-year-old son who suffered a severe traumatic brain injury following a pedestrian vehicle accident. The younger brother of the care recipient was reportedly also involved in a separate accident, and he too required some care. Prior to the accident, the care recipient performed casual jobs that included being a queue marshal at a taxi rank and working at a car wash outlet. At the time of the interview, it had been 5 years since the accident happened and the care recipient was unable to continue with his pre-morbid occupational responsibilities given the cognitive impairment and difficulties with basic self-care skills. The care recipient was receiving treatment for epilepsy at the time of the interview. I had conducted a neuropsychological assessment with the care recipient for a third-party claim one year before the interview for the study.

Participant H

The participant is a younger sister to Participant C. She is 35 years old and does not have any job. The care recipient is her 32-year-old younger brother who suffered a severe traumatic brain injury following a motor vehicle accident. The care recipient worked as a labourer for a construction company. Other members of the family include the mother and the last-born younger brother. In addition to severe cognitive impairment, the care recipient also had weakness of the dominant hand. At the time of the interview, the care recipient was receiving physiotherapy services from a local public hospital. I had conducted a neuropsychological assessment with the care recipient for a third-party claim three years before data collection.

Participant I

The participant is a 51-year-old woman who was a stay-at-home spouse before the accident. The care recipient is her 56-year-old husband who suffered a severe traumatic brain injury following a motor vehicle accident. The care recipient was reportedly a school principal when the accident happened. Following the injury, the care recipient was put on permanent incapacity by the employer as reports authored by health practitioners indicated that he was unable to perform his premorbid duties. The caregiver had stopped taking the care recipient for rehabilitation when she received health practitioners' reports that indicated that her husband's functioning will not improve. At the time of the interview, it had been two years since the accident happened. I received the details of the caregiver from a fellow care giver who I had met her at the rehabilitation center.

Participant J

The participant is a 37-year-old woman. The care recipient is her 40-year-old husband who suffered a severe traumatic brain injury following a motor vehicle accident. The care recipient was reportedly an artisan when the accident happened. At the time of the interview, it had been 3 years since the accident happened. The care recipient was going through a rehabilitation programme with an occupational therapist. I met the caregiver at the consulting rooms of the occupational therapist.

Participant K

The participant is a 55-year-old woman who worked as a bank teller. The care recipient is her 62-year-old husband who suffered a severe traumatic brain injury following a motor vehicle accident. The care recipient was reportedly a businessperson when the accident happened. Following the injury, the care recipient was unable to continue running the business due to cognitive and physical impairments. At the time of the interview, it had been 13 years since the accident happened. I had conducted a neuropsychological assessment with the care recipient for a third-party claim before this study was started. Seven years has lapsed between the time I saw the care recipient for assessment and when I conducted the interview for the study with his caregiver.

Participant L

The participant is a 62-year-old woman who reportedly never had any formal job. The care recipient is her 34-year-old daughter who suffered a severe traumatic brain injury following a gunshot incident. The care recipient was a student at an institution of higher learning when the incident occurred. At the time of injury, she was 20 years old. Following the injury, the care recipient has not been able to return to study given cognitive and physical impairments. At the time of the interview, it had been 14 years since the injury happened. The care recipient was going through a rehabilitation program with a physiotherapist and an occupational therapist. I got the details of the caregiver through a fellow caregiver who was taking her spouse to rehabilitation with an occupational therapist.

Participant M

The participant is a 51-year-old woman. She reportedly worked as a general worker prior to taking on the role of being a caregiver. The care recipient is her 31-year-old daughter who suffered a severe traumatic brain injury following a motor vehicle accident. The care recipient was reportedly working as an administration officer for a government department when the accident occurred. Following the injury, the care recipient was diagnosed by a psychiatrist with a psychotic disorder due to head injury. At the time of the interview for the study, the care recipient was on psychiatric treatment. At the time of the interview, it had been 4 years since the accident happened and the care recipient was continuing with psychiatric treatment. She was unable to continue with her pre-morbid occupation. I had conducted a neuropsychological assessment with the care recipient for a third-party claim before data collection a year before the study interview.

Participant N

The participant is a 49-year-old woman who reportedly worked as a domestic worker prior to becoming a caregiver. She stopped working to provide care for her 30-year-old son who suffered a severe traumatic brain injury following a motor vehicle accident. The care recipient worked as a general worker pre-morbid. Following the injury, the care recipient was diagnosed with weakness of the right side and cognitive deficits. At the time of the interview, it had been 3 years since the accident happened and the care recipient was going through rehabilitation with a physiotherapist. He was unable to continue with his pre-morbid occupational activities. I had conducted a neuropsychological assessment with the care recipient for a third-party claim 10 months before the interview.

5.3 Explanatory comments and emerging themes

As I have pointed out in the previous chapter, I followed the four steps that Pietkowitz and Smith (2014) recommended for Interpretive Phenomenological Analysis. By way of illustrating what I did in the first two steps of data analysis, I am presenting here below an illustrative example (Table 5.2), showing: a) how I made notes against the transcripts (i.e., Step 1: Multiple reading and making notes); and b) how those notes were transformed into emergent themes (i.e., what I did in Step 2). I followed this process for all fourteen transcripts.

Table 5.2

Illustrative extracts. Explanatory comments and emerging themes.

Original transcripts	**Explanatory comment**	**Emerging themes**
Researcher: Please share with me your experience of how you have been caring for [your husband]?		
Participant E: Yes, it was difficult. It is difficult because a person who will have been healthy and normal suddenly changes after the car accident. So, it does not become easy to deal with this sudden change in the person's behaviour.	Changes in behaviour on the part of the care recipient.	Fluctuations in behaviour
Suddenly you start to realise that on other days, the person that was always ok, appears to be mentally disturbed. The person is no longer able to explain things the way he used to. He is no longer the way he used to be. A lot of things in his life change.	Indication of mental disturbance on the part of care recipient. Changes in care recipient's life.	Mental impairment
Researcher: Mmhm.		
Participant E: He is no longer able to verbalise and to interact easily with others the way he used to.	Care recipient speech problems.	Cognitive impairment
Some other days you realise that he has changed, and this affect the way we relate in the house. He gets angry.	Changes in behaviour of the care recipient – mood.	Fluctuations in behaviour.
However, as a wife, I have to sit down and be calm. I have to think about what I need to help calm the situation. I need to remain calm and talk to him so that he can also calm down. It will not help if I too get angry when he gets angry. You need to be very patient with him in order to help him calm down. This will not happen if you too are	The need for patience on the part of the caregiver.	Patience

angry when he is angry. You should avoid shouting at him because that is not going to help. By remaining calm you help in getting him to calm down. If that happens you will see that it becomes easy to relate to him.	Calmness and an element of modelling the required behaviour.	Calmness Reciprocity
Researcher: Based on your experience, what advise can you give to other people who are in a similar situation to yours? **Participant E:** Firstly, the caregiver must sit down, relax and ask herself who she is. She needs to accept the situation she finds herself in. You got involved in a relationship with your husband before the injury. So, you need to accept that these things can happen. By getting married to him, you have made a commitment and have sworn before God that you will be with him up to the end. You need to continue to show that you love him. In this situation that he is now, he really needs to be loved. You also need to be positive when you are with him as this will encourage him to be hopeful. The positive attitude must be there all the time.	The need to accept the situation. Need to accept. Using marriage commitment to continue being there for the spouse. The need to continue to show love like pre-morbid. The need to show love.	Acceptance Acceptance Commitment Love
Researcher: I see **Participant E:** Yes, for me what is important when relating to people like him is love. You need to show that love all the time. You should not hide that from him. You should not neglect him. You need to spend time with him as much as it is possible. Remember, he did not choose to be in this position. He just found himself this way.	Continuing to show love. The need to be available and not to neglect the care recipient.	Love Caring

After going through the above steps, I then interrogated the emergent themes to look for relationships that could be established. This process yielded what Pietkowitz and Smith (2014) refer to as superordinate themes. The following superordinate themes were identified: caregiver lived experiences; attributions and meaning making;

facilitators and barriers; essential attributes for caregiving; coping strategies; and motivation for caring. I am presenting these in Table 5.3 below.

Table 5.3

Clustered themes

Superordinate themes	**Themes**
Caregiver lived experiences	• Life before the injury • The act of care giving • Health seeking pathways and experiences • Emotions elicited during caregiving • Social life for caregivers
Attributions and meaning making	• Biological or physical explanation of the injury • Believing in God and caring as a destiny • Cultural explanations in giving strength
Facilitators and Barriers	Facilitators • Medical treatment • Financial support • Prior experience • Support from others Barriers • Physical, cognitive and mental handicaps or impairments • Financial constraints
Essential attributes for caregiving	• Caring and nurturance • Patience and tolerance – acceptance • Perseverance and resilience – courage • Sacrifice, commitment and hope • Love and compassion • Calmness and humility
Coping strategies	• Social coping - support from others • Appraisal-focused coping • Problem-focused coping • Emotional focused coping
Motivation for caring	• Obligation and sense of duty • Reciprocity • Love • Confidence resulting from the experience of caring

In the section below, I present the superordinate themes and their corresponding themes, together with short extracts from the participants' interviews to demonstrate the appropriateness of the interpretations that I have made.

5.4 Superordinate themes

5.4.1 Caregiver lived experiences

In this superordinate theme, what became evident is that the participants shared information associated with their lived experiences of caregiving. In other words, they narrated what it means for them to live with and care for a family member who has suffered severe TBI. The following themes are linked to this superordinate theme:
a) caregivers' understanding of life before the injury; b) the act of care giving; c) help seeking pathways and experiences; d) the emotions elicited during caregiving; and e) the social life of the caregivers.

5.4.1.1 Caregivers understanding of life before the injury: Participants gave an indication that the kind of life that the care recipient lived pre-morbid seems to determine how they adjust to their post-morbid condition that is characterised by limited capacity to care for themselves. There is an indication that care recipients were functioning optimally, both occupationally and socially before the sTBI. The injuries they sustained have significantly disrupted and impaired their social and occupational functioning. For example, some caregivers indicated that the care recipients were experiencing difficulties in accepting the functional changes that have imposed limitations on their ability to care for themselves. The following extracts illustrate this point succinctly:

> *"Before he got injured, he was a school principal. He was okay. He coped well with his work. He related well to people. Many people loved him, and he was popular because of the kind of work that he was doing. Unfortunately, now things have changed as he is no longer able to do the kind of things that he*

> *used to do before he became sick. I try to comfort him as I see that he struggles."* **(Participant I)**

> *"I would say maybe the fact that he used to work a lot. Even now, I tell him to slow down a bit as he tends to work very hard. He would work hard every day every month and every year. I do advise him to take it easy and to relax as I do see that it puts pressure on him when he is unable to do what he used to do."* **(Participant E)**

> *"That is why he is really stressed because his kind of work meant that he had to work with a lot of people. Now all that has changed as he has to spend a lot of time seated and doing nothing. This is indeed hard for him. He can no longer read; he can no longer drive. All these changes are too heavy for him to accept."* **(Participant I)**

> *"He was a hard worker, a tenderpreneur, having cars and being able to look after himself. Now, all those things are gone, and he is no longer able to work. He is finding it difficult. I must help him understand."* **(Participant K)**

The above extracts suggest that caregivers find themselves in situations where they help care recipients to manage the negative impact of the injuries that they sustained. They need to support and encourage care recipients to adjust to their new conditions that are characterised by significant limitations in terms of social and occupational functioning. Based on the above extracts, it is evident that the disruption in the life of the care recipient results in significant stress that requires adjustment by both the care recipient and caregiver.

5.4.1.2 The act of care giving: Participants explained in detail the act of caregiving, providing information about the actual processes involved. The following narratives by some participants illustrate this**:**

> *"What is important is to make sure that you give him all the care and support that he needs. Every time, you need to be there for him so that you can attend to him when he needs you…. I make sure that I am always ready for him. That is very important because you cannot ignore his needs. Sometimes, you may be caught off guard, but you need to be ready all the time to be able to attend to his needs. Yes, it is a big job. Even today, he was not happy in the morning. I observed that when we woke up. I had to try and calm him down and ensure that he is able to have his food. So, when I sometimes see this, I will get some bread and ask him to come and eat. After that you will see that he gets to be contained and relaxed. When I see that he does not have an appetite for bread, I prepare and give him porridge to eat. When I see that his clothes are dirty, I will make sure that I give him clean clothes to wear. In my case, it is very difficult because I have to care for him and the young brother who is also not ok. I sleep close to him all the time. I have to make sure that his needs are met."* ***(Participant G)***

> *"Try to encourage him to be positive and hopeful all the time. You need to be with him often. Do not treat him like a child."* ***(Participant E)***

Nurturance and preparedness to care and support help the care recipient to be calm and cooperative. The following extracts allude to nurturance and being prepared to care and support the care recipient:

> "*You need to understand that each one of us is different. I prepare water for him to take a bath. After that, I make sure that he is properly dressed, and he gets food to eat. If you make sure you care for him that way, you will see that he does not give you problems. He becomes calm and you can attend to his needs without many problems. ... You need to prepare him food and clean clothes. You need to wake up in the morning and prepare for him. When he wakes up, you will need to give him some soft porridge. You will then need to prepare warm water for him to take a bath. After that you should give him some*

> *clean clothes. You also need to make sure that your home is always clean. When he says he feels a bit hot, you need to guide him to go and sit in a shade. This is indeed a big job that you need to be prepared to do all the time.”* ***(Participant G)***

> *“For example, when he was discharged from hospital, he could no longer do the things that he used to do. We would bath and dress him. We would wash his clothes, make up his bed and clean his room because it would be very dirty.”* ***(Participant C)***

> *“We took a decision to look after him and to attend to his needs. We bought some diapers for him to wear as he could not look after himself. We had to get him bathed and dressed as he was not able to do that himself. We had to be tolerant and patient with him. We had to do all these things because we really love [him]. [He] is my younger brother. So, I have to look after him. I will never stop loving him and caring for him. We also had to offer him toilet training as he was unable to care for himself in this area of his life.”* ***(Participant H)***

> *“After bathing, I give him clean clothes to wear. Thereafter I give him food and he eats.”* ***(Participant I)***

Caregivers talk about the fluctuations of emotions that they get to be confronted with, and the need on their side to understand and manage these fluctuations. The following extracts point to the fluctuations experienced.

> *“Because he got troubled mentally, it has not been easy to engage in a meaningful conversation with him. It is not easy for someone like that to understand you. Sometimes he gets stubborn when we talk to him. At times he will swear at you and tell you to leave him alone. Sometimes he will just*

> *say whatever comes to his mind without reflecting on it first. You understand what I mean …. For example, when you tell him to sit down or when you give him some support so that he can walk, he may swear at you or say something irrelevant. You understand what I mean?"* **(Participant C)**

> *"You will need to be aware that he is going to get angry from time to time because of his changed condition. So, you need to understand that in order to avoid quarrelling with him and worsening the situation. Some other days you realise that he has changed, and this affect the way we relate in the house. He gets angry. However, as a wife, I have to sit down and be calm. I have to think about what I need to do to help calm the situation. I need to remain calm and talk to him so that he can also calm down. It will not help if I too get angry when he gets angry. You need to be very patient with him in order to help him calm down. This will not happen if you too are angry when he is angry. You should avoid shouting at him because that is not going to help. By remaining calm you help in getting him to calm down. If that happens you will see that it becomes easy to relate to him."* **(Participant E)**

> *Yes, it is a big job. Even today, he was not happy in the morning. I observed that when we woke up. I had to try and calm him down and ensure that he is able to have his food. So, when I sometimes see this, I will get some bread and ask him to come and eat. After that you will see that he gets to be contained and relaxed." (***Participant G)**

Caregivers acknowledge symptoms that are associated with loss of abilities after the injury. For example, symptoms recognised include speech problems, forgetting, mobility problems, weakness, and loss of functioning of some parts of the body. It shows that basic self-care skills and mental abilities are disrupted, and caregivers must assist with these skills. The following extracts show problems related to speech and memory:

I have also realised that one of the challenges is communication. Sometimes you may find that he has the pressure of speech, and he wants to talk the whole day. Initially, I was very worried about this. Sometimes you would see that he opens his mouth because he wants to say something. Suddenly you will realise that he is not able to verbalise what he wanted to say. Usually, I allow him to interact with his childhood friends because he feels more relaxed when he is with them. I allow him to spend time with them and to talk to them as they do understand him. I encourage that he interacts with his friends because if he does not, I get afraid that he may begin to feel angry."
(Participant E)

"He is now very forgetful. He forgets even the names of his children, and this frustrates him a lot." ***(Participant I)***

"*He gets lost. He does not remember streets and places anymore. The other day I was called and told that he did not know where he was and how to get back home. You see, a stranger just called."* ***(Participant N)***

"I do still realise that he is still forgetful. I can send him to the shops to buy a few items. However, I see that if I send him to buy many things, he tends to forget and may not remember all the things he was requested to buy. So, I make sure that I do not ask him to buy many things when he goes to the shops. For instance, he would come back from the shops and when you ask him where is the other thing that he was supposed to buy. He will say he has forgotten. So, I make sure that I am patient with him, and I do not ask him to buy many things. I try to encourage him to be positive and hopeful all the time. You need to be with him often. Do not treat him like a child." ***(Participant E)***

In addition to speech and memory problems, mobility, loss of function and weakness of body parts put pressure on the act of caregiving. The extracts below point to these physical difficulties.

> *"Though he can feed himself, the sad thing is that he cannot bath himself because his left arm is not working."* ***(Participant C)***
>
> *"His right side of the body is not functional. He also has a lot of tremors in his right hand. He cannot bath himself; he cannot tie shoelaces and his belt. I must help tie his belt. Just imagine, I am talking about somebody who already has a child. Me as his mother doing these things for him, it is difficult."* ***(Participant N)***
>
> *"He has indeed changed a lot. I have now decided to buy him a treadmill to allow him to exercise regularly. It is not easy. It is very difficult. The other thing is that he is not able to write as his right hand is not working."* ***(Participant I)***

For the caregivers, the act of caregiving involves having to acknowledge the disabilities and limitations in functioning that care recipients present with. They must develop skills to manage the physical disabilities, cognitive impairments, and behavioural difficulties that are characterised by changes in mood.

5.4.1.3 Help seeking pathways and experiences: When an injury has happened, the process of seeking for health becomes important. The narratives below give an indication of what is involved in the process of seeking help for the health of the injured.

> *"At the beginning, it was very difficult as she struggled to wake up. I would try to get her to wake up, but it was not easy for her. I took her to a few places to seek help because I was worried about this. I took her to the private doctors, the clinic and the hospital. These days she is much better. She is no longer like she used to be."* ***(Participant A)***

> *"Yes, after the injury he went to the hospital. Upon arrival at the hospital, he lost consciousness. When he woke up, he could not recognise me."* ***(Participant B)***

> *"We have already tried the physiotherapist. It is as if his arm becomes painful."* ***(Participant C)***

> *"Well, the RAF does not get directly involved. When she is sick, as a family we are the ones to take her for consultations. I have to go with her to different doctors. I also go with her to the hospital. The RAF does not get involved."* ***(Participant D)***

It is evident that rehabilitation programs also get to be tried in the process of seeking for help as shown in the following extracts:

> *"After we realised that he had a problem, we went around seeking for help. Remember, if you experience a problem, you will go all over the place trying to get help. Similarly, I went all over trying to get help for my husband. We ended up taking him to a rehabilitation centre in Pretoria. That just shows how far you will go when you are indeed in need of help. After some time, we brought him back home as he is a family man. In our culture, you cannot just have a family member staying in a rehabilitation centre for a long time when he has a family. He has to be at home so that we can care for him. I was coming twice a week to bring him to an OT. I also used to come to see a physiotherapist also twice a week. It was too much but I needed to do that so that he could get better."* ***(Participant I)***

> *"Yes. It was indeed very helpful. At first, I did not see the value of seeing a psychologist. That was immediately after the accident. However, after some time I started to see that it is indeed helpful to receive the services of a psychologist."* **(Participant J)**

> *"Yes, she is better now. Much better. She can walk without assistance even though she is slow. She also forgets a lot. She is still continuing with rehabilitation program at the occupational therapist."* **(Participant L)**

The narratives show that caregivers get to be involved in getting help for the care recipient. There is an indication that caregivers go through a process of adjusting to the disability. During the acute phase, there are many challenges on the part of the care recipient. On the part of the research participants, we see frustrations, difficulties in managing the disability, and feelings of inadequacy in managing the condition. During the chronic phase, there is more acceptance and increased levels of adaptive skills to care for the care recipient. Over a period, there is some apparent improvement as care recipient continue to receive the services of health care practitioners. Caregivers also continue to provide support. There is perceived benefit of seeking help and recognising that the condition has improved over a period of time.

5.4.1.4 Emotions elicited during caregiving: Caregivers express difficulties in managing the condition of the care recipient. The narratives below give an indication of the difficulties experienced, including somatic complaints. The narratives show that caregivers experience difficulties and lack of skills at the beginning of the process, to manage the condition of care recipients. The lack of skills to manage and not knowing what to do seem to bring lack of confidence and feeling overwhelmed on the part of caregivers. The support that caregivers receive from other people assist to calm the care recipient and to control the condition. The expectation to perform other household chores in addition to be a caregiver create more distress for caregivers, though.

“Yes, there are many challenges that I face. It is difficult. My head is always aching because of these challenges that I face.” **(Participant G)**

“It is hard. Very hard. Particularly if one has to care for someone who is older. It is true, it is hard. All is not well; it is very hard.” **(Participant M)**

“For me the experience has been very painful. It is very painful when I think about how he used to be before his life changed. He would be very lively and he was a very responsible husband at home. He used to care a lot about his family. Now things have changed a lot. He is always sitting as he is unable to do the things he used to do before. I do console myself by saying that I am not the first one to experience a problem like this.” **(Participant I)**

“As I had explained earlier, it is not easy at all to take care of my little brother. Yoo, it is not simple. It is not simple to care for someone who is no longer able to care for himself when compared to how he used to be in the past. He is no longer like before. For example, when you tell him to sit down or when you give him some support so that he can walk, he may swear at you or say something irrelevant. You understand what I mean? It has been difficult.” **(Participant C)**

“Before he started taking treatment, it was difficult to manage him. As I said, he did not seem to understand that it is important for him to take a bath. This was frustrating. Yes, it was very difficult at first as I just did not know what to do. I felt overwhelmed when I realised that he was not mentally well. I would request other people to help me as I could not manage him alone. Sometimes I would ask the neighbours to come and help me to restrain him. The problem is that they were not always available to help. So, it was very difficult. Through the help of others, I managed to get him controlled to the point that I took him for treatment.” **(Participant B)**

> *"I am aware, and I accept that it is difficult to be a caregiver. This is more as I have to do other jobs in the house apart from caring for her. This makes it very difficult."* (**Participant D)**

There is also an indication that other members of the family are unable to assist in the caregiving role. The reason advanced for not sharing the caretaking of the injured individual indicates that they were emotionally affected by the care recipient's disability. The above sentiment is shared by Participant C in the extract below:

> *"He is younger than me. I am the first born, and the second born is female. The forth born was so hurt and could not cope with his elder brother's condition. [The care recipient] is the third born in the family. In other words, He is cared for by my younger sister and me. My mother was also too hurt to see him in that condition. So, she would always cry when she saw him in that state."* ***(Participant C)***

Participant E echoes an element that indicates the build-up of emotional distress to a point where the caregiver is unable to contain the self. The following extracts indicate emotional distress:

> *"Once in a while, you will also lose your temper because you are also human. This happens when he does something that is not acceptable. For instance, when we were planning to come and consult with you, he would sometimes be restless and would ask how far we are. You would see that he is not at ease…. At times when we go to consult the medical experts, he will start telling them that I have not treated him well. I need to understand that he is doing this because of the injuries. So, I should not be angry with him."* ***(Participant E)***

There is an indication of shock, denial and loss of hope included in caregivers' experiences. The research participants experienced the injuries as something that brought changes to how things used to be. For example, the extracts from Participants J and E capture the sentiment of sudden change and the emotions elicited by this. It took Participant K a few years to accept the reality of her husband's injuries. For Participant I, lack of improvement in the functioning of her husband brought loss of hope for her. The following extracts echo these emotional experiences:

> **Shock**
>
> "*It was completely unexpected. So, something like this requires that you are very patient and tolerant." (***Participant J)**
>
> "*You know; it is not easy to get used to a situation like this. Here you have lived with someone all these years, relating very well as a couple. All of a sudden something like this happens. The accident comes and disrupts the way you used to live. Your husband changes and becomes different from how you used to know him. You start to tell yourself that this is not the person that I used to know. You start to realise that he has changed significantly because of the injury. This is not the way he was before."* ***(Participant E)***
>
> ***"****It was very hard for me at first. My husband was in a very critical state. He was confined to a wheelchair. He could not do anything. So, it was difficult for me to see him in such a state as I was not used to that. It was indeed very difficult to get used to what I saw."* ***(Participant I)***
>
> **Denial**
>
> *"I think it took me 4 to 5 years to come to terms with my husband's injuries. It was really hard to see him that way…."* ***(Participant K)***

Loss of hope

> "*I was discouraged when the health professionals wrote reports which showed that his condition was very serious. They were showing that his functional ability was compromised. I was very worried about this, and I did not know what to do about that. I then decided to stop taking him to rehabilitation because of this.*" ***(Participant I)***

Caregivers acknowledge the challenges of providing care. There is acknowledgement of the difficulties and frustrations associated with the new role as a caregiver. The behaviours of care recipients that include restlessness, anger, and impulsivity impact negatively on the caregivers. Emotional elements that include shock, denial, anger and frustration, and loss of hope are experienced by the caregivers. There is an indication of a need to consistently remain calm, be understanding, supportive and to avoid negative emotions such as anger.

Difficulties in having to cope with the disability continue to be a daily challenge. Some of the caregivers reminisce about the premorbid state of their relationship with the care recipient as a couple and realise and accepts that the relationship has changed because of the injury. For example, intimacy is no longer possible. Even though there is an indication of difficulty in accepting the condition initially, there is acceptance of the condition and learning to live with it. The support that a caregiver receives from other people seem to encourage and strengthen them. There is also an indication that lack of support and rejection impact negatively on the caregiving role.

5.4.1.5 Social life for caregivers: Caregivers must make changes to their lives to accommodate the role of caregiving. Personal relationships and social interactions are no longer pursued as previously so that the caregiver can focus on providing care for the injured family member.

> *“Yes, people do not want to help you when you are having challenges such as the one we had. Because of that, we decided that it is only us as siblings who will be able to help him. That is why we had to do what we did. I decided to stop many things that I used to do. I paused my relationship with my partner because I felt that I needed to give my little brother the love and attention he needed. I had to do all that because he is my younger brother. I love him.”* ***(Participant H)***

> *“Everyone goes to school and I remain at home with him. I have learnt to live with that because that is the reality. I have learnt to accept that I cannot do some of the things that I used to do. I must now spend a lot of time with him. So, this means that I cannot leave him this way. I can no longer attend any functions. As women we have gatherings; I can no longer attend them. You see how God will judge me if I abandon him when he is in a state like this? It means I have had to sacrifice a lot of things. I no longer do what other women are doing. For instance, when they go to weddings and other functions, I can no longer join them. I have to be mindful that I have someone at home who is not well. I have to accept that, and remain at home to care for him.”* ***(Participant I)***

Changes in their social lives give an indication of the determination on the part of the caregivers. They stop doing things that they used to do so that they can focus their attention on the provision of care. Personal relationship and social interactions are mostly abandoned.

The narratives presented and the subthemes do indicate that the research participants experience the role of being a caregiver as being associated with emotional difficulties that include being frustrated, being angry, being shocked, being in denial, and losing hope. There is also an indication that the support that caregivers receive from other people provide strength and encouragement for them. Feelings of rejection following the injury and lack of sufficient support also get to be experienced. Even though the experience to provide care is portrayed as being difficult and limiting own social life, caregivers appear to be determined to fulfil the responsibilities associated with the caregiving role.

5.4.2 Attributions and meaning making

The traumatic brain injury and the subsequent disruption in the care recipient's life appear to be a life changing experience that prompts a caregiver to search for meaning and to try to understand what it is or what has happened. Attributions and meaning making emerged as one of the key themes in this study. The following themes are associated with this superordinate theme: biological or physical explanation of the accident and injury; believing in God and caring as a destiny; and cultural explanations in giving strength.

5.4.2.1 Biological or physical explanation of the injury: Caregivers provide their understanding of the injury as having involved the physical structure of the brain and therefore having mental consequences for the injured person. There is a need for information to be provided to the caregivers to help them understand what has happened. The following extracts illustrate the caregivers' explanations about the injury affecting the physical structure of the brain and how it functions:

> *"Yes, he sustained a very serious injury to the brain.*" ***(Participant B)***
>
> *"An accident is a very serious thing because once it happens, it can also affect that person's mental functioning. It can affect the person so seriously that she may end up being mentally disturbed. The person may change so significantly that she may no longer be able to do things that she used to do because she gets to be mentally disturbed."* **(Participant D)**
>
> *"Now tell me. At that time when we came to see you, what is it that you found through your assessment?"* ***(Participant C)***

*5.4.2.2 Believing in God and caring as a destiny**:*** The research participants show their belief in God. They believe that God knows about the injury, and He is the one who will help with the recovery process. They also believe that they were meant to be fulfilling the responsibilities of the caregiving role. The following extracts demonstrate the belief in God.

> ***"****I believe that God will help him to get better. That is what I strongly believe in. On the other hand, if we lose him, that will be God's will."* **(Participant E)**

> *"Yes, I do pray a lot, more especially in the morning when it is still cold, I pray during the day, during mealtimes. I pray at night. Yes, I pray more often asking God to give me strength and courage to cope with the challenges I am facing. There is no witch who has brought all this to me. I just need to pray…. I need to always talk to God to give me the power and courage. That is very important for me. Unfortunately, some people do not give themselves time to pray and to talk to God about their problems. As for me, I make sure I kneel and pray all the time. I do not agree that what has happened is because of evil deeds by others. I do believe that all is the will of God." (She recites Psalm 23 in Sepedi).* ***(Participant G)***

> ***"***The LORD is my shepherd;
> I have everything I need.
> He lets me rest in fields of green grass
> and leads me to quiet pools of fresh water.
> He gives me new strength.
> He guides me in the right paths,
> as he has promised.
> Even if I go through the deepest darkness,
> I will not be afraid, LORD,
> for you are with me.
> Your shepherd's rod and staff protect me…."

> *"We thank God for having helped us to have the strength, courage and love to care for him. It is only through God that we were able to do all this. Our understanding is that God knows. Through Him, we were able to continue to love him and to care for him. We were able to be patient and to persevere despite the many challenges we had. This is because of the power of God. We are really grateful for this, and we pray every day to thank God for this."* **Participant H)**

> *"For us we are very thankful to God because he is still alive, and he is with us. Many others have lost their lives when they were in a condition like this. He is lucky because he can wake up and see his children. God has made it possible."* ***(Participant I)***

> **"***I mean we needed to go on with life. The accident happened but life does not end there. The fact that we survived the accident, it means God has a purpose with our lives."*

Believing and trusting in God seem to be strongly upheld by the research participants as they try to understand what has happened and to go on with their lives and the responsibilities of caregiving. They also reject a view that there could be evil forces or intentions by others that may have caused the injury. The following extracts allude to believing in God and rejecting the presence of evil deeds.

> *"The advice that I can give is that if people know God and trust him, their problems will not be difficult to deal with. I base my trust in God because that is what has made me who I am today. From worldly beliefs, I do not know what to say. I always base my things in God so that he can be the one who see whatever I come across. But since he also believes in God, he has accepted*

> *that time has passed. I indicated to him that we should go before God as he is the one who knows. He knows our plans and we do not know.”* ***(Participant K)***

> *“As far as I am concerned, I do not think there was any external force that led to him getting involved in the accident. No. I do not think there are external forces involved. I do not think there are witches or ancestors involved in this.”* ***(Participant B)***

> ***“****Other people would say that he got to be this way because some of his colleagues at work were not happy with his successes. So, they may have caused him to be the way he is now. However, on my side, I am not going to follow that line of thinking and belief. I have chosen to follow the path that I am following now. I am going to continue getting him to be assisted through medical treatment like I am doing now.”* ***(Participant E)***

The research participants also seem to believe that what is happening is what is meant to have happened. They perceive their roles as having been destined. The following extracts capture this belief. The Psalm that participant G recited also gives a picture that whatever is happening, is what God predetermined.

> “*God knows everything. I strongly believed that he would get better because I believe strongly in the power of God. God knew that we would have to be doing this.”* ***(Participant H)***

> *“Just to rest my mind as working in the bank is hectic. I decided to leave the things of this world and look upon God. To wait on what God wants me to do. This, I believe is what has been there from the start.”* ***(Participant K)***

5.4.2.3 Cultural explanations in giving strength: Participant G shared a cultural practice that is meant to discourage showing being distressed in the face of adversity.

> *"Yes, I have really been through a lot of challenges. I do persevere all the time. You should not cry when you are confronted with a situation like this. You need to be strong. If you give up and start crying, that will affect the patient badly. You see in our culture, if your child is injured or sick and you cry, that child's condition is going to get worse. So, you must not cry. You must always appear to be strong even though it is difficult.***" (Participant G)***

The research participants perceive the care recipient's condition as a result of an injury, not any supernatural forces. There are no evil intentions that are suspected to have been caused by other people. There is recognition that the injury has significantly affected the care recipients' mental functioning, causing changes to premorbid occupational and social functioning. Participants use their belief in God and spirituality to explain and accept the injury and functioning of the care recipients. They appear to get courage and strength from spirituality and attribute life to the power of God. Spirituality also seems to assist with acceptance of new realities and being able to persevere. Cultural belief also provides resilience and strength when a caregiver is faced with difficulties. Research participants consult western healing systems for the improvement of the health of the care recipients.

5.4.3 Facilitators and barriers

Information that participants shared indicates that there are some factors that help them in providing care, and those that make it difficult for care to be provided. Factors that are identified as facilitators for caregiving include medical treatment, financial support, previous experience related to caring, and support from others. Factors that are perceived as hindrances are physical, cognitive, and mental problems on the part of the care recipient, and financial constraints.

5.4.3.1 Facilitators: There were four facilitators that made it easier for caregivers to manage their situations. These include the provision of medical treatment, financial support, prior experience, and support from others.

Medical treatment: Caregivers acknowledge the value of medical treatment received from hospitals in helping to calm the care recipient. There is an indication that following the injury, most care recipients' levels of mental functioning got to be impaired and as a result needed medication to help manage them. It was a source of worry for the caregivers not to be able to manage care recipients. The extracts presented below indicates that medical treatment assist in getting care recipients to be in a manageable state.

> *"Yes, at the clinic, they assured me that they will help me. The treatment has been very helpful. After he got the treatment, he became subdued. I could then sit down with him in a way that I could not do before that. He needs to be constantly on the medication because if he skips taking the medication for a while, he gets impatient". When I see his behaviour changing, I will usually ask if he has taken his medication. When I see that he is becoming a bit aggressive, I usually request other people to help me so that we can get him to take the medication…." However, after they gave him some treatment, he started to get better. He started to listen and take the medicine. Now I can see that he takes his medication regularly; I just supervise without having to remind him all the time."* ***(Participant B)***

> *"I have chosen to follow the path that I am following now. I am going to continue getting him to be assisted through medical treatment like I am doing now."* ***(Participant E)***

Financial assistance: Caregivers appear to acknowledge the role that financial assistance plays in the process of providing care. The information that they provided indicates that when there is financial support, the burden of caring is lessened. For example, disability grants that care recipients receive from the state reportedly provide relief for caregivers. It is also hoped that anticipated compensation from the Road Accident Fund for some of the care recipients can relief caregivers as it may help in accessing health care for their family members who suffered sTBI.

> *"It was much better when she was still receiving the temporary disability grant as I was able to get some financial support to buy some food. Though I get some social grant myself, this is too little to sustain us if we do not get the extra amount that she used to get."* ***(Participant M)***

> *"You know, he used to support us financially as a family. Following the accident, he was unable to continue working and the income stopped. He was put on a temporary disability grant which has been stopped. The time that the disability grant was availed, it was better. Now it is difficult without any source of financial support."* ***(Participant N)***

> *"I was told that some money will come from RAF to compensate her for the injury. I am hopeful that the money will help relieve us of the burden as we may be able to take her to consult so that her health problems may be treated."* ***(Participant D)***

Prior experience: From the interviews, it became apparent that caring experience that the research participants had or gain in the process assist in getting them to cope better with the role of being a caregiver. For example, experience of having worked in a health facility help one of the caregivers to cope better with the role. Other participants indicated that the experience that they gained in the role help them to cope better. The sentiment of the value of experience is echoed in the extracts below:

> *"I was working in a psychiatric ward as an assistant nurse. That is why I said earlier that I have worked with many people who are like him. It is because of my background in psychiatric nursing that I am able to understand his condition*

> *much better. Yes, indeed my experience of having worked with people like this in a psychiatric setting has really helped me a great deal. Through that, I am in a better position to deal with his situation than someone who may not have worked in a psychiatric environment.”* ***(Participant F)***

> *“People would sometimes come to ask us how we care for him. They asked that because they saw that we were really trying our best to care for him. I am now confident that I can do this job. It was not easy, but I have learnt a lot.”* ***(Participant H)***

Support from others: Caregivers value the support that they get from other people. The support that is offered to directly help in the care of the care recipient and emotional support makes a difference in the process of providing care.

> *“When I see his behaviour changing, I will usually ask if he has taken his medication. When I see that he is becoming a bit aggressive, I usually request other people to help me so that we can get him to take the medication. ... I also requested our lawyer to assist. He came and advised my son to take the medication regularly so that he does not become mentally disturbed. Yes, he listened to the lawyer.”* ***(Participant B)***

> *“Well, I am lucky because my husband’s sister is very supportive. She is always there to give us support. This definitely makes a big difference. I do not know how it will have been if his sister was not this supportive. She is always there for us.”* ***(Participant I)***

> *“When everyone goes to work, I remain looking after him. My sister relieves me when she comes back from work.”* ***(Participant H)***

Caregivers note that medical treatment assists in helping to manage the care recipients. They also note that financial support lessens the burden and hope that anticipated financial support will help to lessen the burden of taking care. Support by other people is also appreciated as it helps with direct care and in providing emotional strength for caregivers. Background experience in caring environments and experience learned in the role as caregiver is perceived as helpful in terms of providing care and support for the care recipient.

5.4.3.2 Barriers: Participants identified two categories of barriers that tend to hinder their ability to provide care and support to the care recipients. These are: a) physical, cognitive, and mental handicaps or impairments, and b) financial constraints.

Physical, cognitive, and mental handicaps or impairment: The research participants find that physical handicaps that the care recipient has, impose challenges to the provision of care as they must assist with basic self-care.

> *"She was unable to wake up, I would bath her. She was not in a position to do anything for herself. I needed to help her all the time. Yes, it was difficult, dressing her. All these basic care functions, having to do all this, it was difficult for me. With this kind of a severe injury, the person goes back and become a child. She was no longer able to do things that she was able to do before the injury happened. For example, she needed to be bathed. In fact, basic self-care needed to be provided. I struggled a bit at the beginning."* ***(Participant L)***

> *"Though he can feed himself, the sad thing is that he cannot bath himself because his left arm is not working. So, this makes it difficult for us as we need to continue to bath him."* ***(Participant C)***

> *"He is still experiencing some problems in his waist area. Because of that he is not able to bath himself. We must help him to bath. We also had to offer him*

> *toilet training as he was no longer able to care for himself. It has not been easy, but we are continuing.”* ***(Participant H)***

> *“His right side of the body is not functional. He also has a lot of tremors in his right hand. He cannot bath himself; he cannot tie shoelaces and his belt. I must help tie his belt. Just imagine, I am talking about somebody who already has a child. Me as his mother doing these things for him, it is difficult.”* ***(Participant N)***

In addition to difficulties imposed by physical handicaps, the cognitive deficits and mental difficulties that care recipients present with impose difficulties to the provision of care.

> *“Yes, it is difficult. It is difficult because a person who will have been healthy and normal suddenly changes after the car accident. So, it does not become easy to deal with this sudden change in the person’s behaviour. Suddenly you start to realise that on other days, the person that was always ok, appears to be mentally disturbed. The person is no longer able to explain things the way he used to. He is no longer the way he used to be. A lot of things in his life change. He does not understand what is happening. He does not understand that he was injured and that his life has changed. He gets to be angry from time to time because of his changed condition. So, you need to understand these changes in mood and behaviour in order to avoid quarrelling with him and worsening the situation…. I do realise that he is still forgetful. I can send him to the shops to buy a few items. I see that if I send him to buy many things, he tends to forget and may not remember all the things he was requested to buy. So, I make sure that I do not ask him to buy many things when he goes to the shops. .... For instance, he would come back from the shops and when you ask him where is the other thing that he was supposed to buy. He will say he has forgotten. So, I make sure that I am patient with him, and I do not ask him to buy many things.”* ***(Participant E)***

"He is stressed because the right side of his body is not functioning that well. He uses some crutches to walk. This seems to also give him a lot of stress because it is not something that he is used to. The other thing is that he is not able to write as his right hand is not working. His mind is coming back gradually. He is able to talk even though it is still a bit hard for him. He can no longer read; he can no longer drive. All these changes are too heavy for him to accept. This is definitely not how he used to be. A lot of things have changed, and it looks like he finds it very difficult to accept. .... He is now very forgetful. He is no longer having that kind of enthusiasm that he used to have. Even when you tell him about the people that he used to relate to, he does not show that enthusiasm about them any longer. He has indeed changed a lot. I have now decided to buy him a treadmill to allow him to exercise regularly. It is not easy. It is very difficult." ***(Participant I)***

"Hmm, heh! – since he was injured, sometimes he does experience some difficulties and it is still hard on his side. He still experiences some problems with his mind, and sometimes with mobility, problems here and there." ***(Participant K)***

"She forgets a lot…. Because the mind regressed, it makes it difficult as she is unable to remember things and to do anything." ***(Participant L)***

"You see, she used to work for the public service before the accident. She can no longer work now after the accident due to the mental problem. It is difficult to manage her at times." ***(Participant M)***

"He gets lost. He does not remember streets and places anymore. The other day I was called and told that he did not know where he was and how to get

> *back home. You see, a stranger just called. So, it puts pressure on me.”* ***(Participant N)***

Financial constraints: Financial constraints put distress on caregivers. This distress adds to the burden of caretaking and emotional difficulties that caregivers struggle with given the role they play.

> *“Yes, she used to get a disability grant. Now that has been stopped. This is negatively affecting her, and it is very difficult to make ends meet.”* ***(Participant M)***

> *“We have been struggling because there is no money to take her to the doctors. We cannot afford the money for transport and the money to pay for consultations with the doctors.”* ***(Participant D)***

The narratives presented give indications that there are facilitators and barriers in the provision of care for a person who suffers from sTBI. For example, access to medical treatment, financial support, experience with caring, and support from others are experiences regarded as being supportive in terms of caregiving. Background experience as a psychiatric ward assistant, for example, is perceived as helpful in terms of providing care and support. On the other hand, physical, cognitive, and mental impairments on the part of the care recipients present difficulties for caregivers. The physical disabilities make it difficult for caregivers to provide care; they must put in more physical effort. The basic self-care skills of a person with a brain injury are compromised, and caregivers must ensure that adequate care is provided. This is a source of worry for caregivers. The cognitive and mental challenges following severe brain injury also put strain on caregivers. For example, difficulties in communication and writing skills of the individuals suffering from sTBI are observed. There are thus far-reaching changes in the care recipients’ functioning when compared to their premorbid level of functioning. Caregivers must bear with the mood fluctuations, anger and other behavioural problems that care recipients display. Care recipients also display a lack of insight and poor judgement which contribute to putting strain on caregivers. The inability to perform at premorbid levels of functioning is perceived to be stressful for a care recipient. Financial hardship because of the termination of disability grants for care recipients put distress on caregiving and caregivers.

5.4.4 Essential attributes for caregiving

Participants tended to agree that there are key attributes that one should possess to be an effective caregiver. The themes associated with this superordinate theme are caring and nurturance; patience, tolerance, and acceptance; perseverance, resilience, and courage; sacrifice, commitment, and hope; love and compassion; and calmness and humility.

5.4.4.1 Caring and nurturance: Most of the research participants seemed to appreciate the acts of caring and nurturance as especially important attributes for taking care of their loved ones who have sustained serious traumatic brain injury. Some of their utterances are noted below.

> *"Well, it is all about caring and looking well after him. I make sure that he is always wearing clean clothes. I wash his clothes. I make him food regularly. I am always giving him the care and support. Also, what is important is to have patience and tolerance. You need to take it easy and not to be impatient with him. I do not quarrel with him. I make sure I avoid that all the time. When his is out there, I will pick a phone and call him and say please come home. I need to make sure I always know where he is."* **(Participant G)**

> *"Yes, we had to do everything for him as he was unable to care for himself. He could not do anything by himself. He was completely dependent on us as family. So, we had no choice but to care for him. Every day, we had to train him to walk after he was discharged from hospital. We did that until he was able to*

> *walk by himself. He ended up walking because of our continuous efforts to get him to walk. He was not going to be able to do that if we had not persisted in training him to walk.”* **(Participant H)**

> *“Most importantly, you need to care for her.”* **(Participant M)**

> *“I realise that my job is really to make sure that he is able to function to some extent. I have to provide whatever care to help him. I need care for his physical needs and also be there to support him in any way.”* **(Participant N)**

5.4.4.2 Patience, tolerance, and acceptance: Caregivers provide information that emphasise practising patience and being tolerant as important aspects in the provisioning of care. The extracts below allude to these attributes.

> *“It is not easy to care for someone who is not well. It is a matter of being patient and tolerant. It is not easy to work with someone who is not well if you are not patient or tolerant. You must have love, patience, tolerance and compassion. That is why I must accompany him everywhere he goes. For example, when he goes to see medical practitioners, like the time when he had to go to see medical doctors in Johannesburg when he was still wearing diapers. It was me who accompanied him there. The same happened when he had to consult local medical doctors here in Polokwane. I am the one who accompanied him.”* **(Participant C)**

> *“You need to be patient all the time when you relate to him. It is very important to understand that his condition has changed and be patient and tolerant given the changes.”* **(Participant E)**

“You need to be patient when you relate to him. I always ensure that he is at ease and that he does not become impatient. Yes, you really have to be very patient when you are caring for someone who is in this position. You need to take your time and make sure you are not in a hurry because that will make things worse. To cope with all these challenges, you need to be very patient. You need to show understanding and to be caring. I make sure that I am patient all the time. I do not get discouraged. I also make sure that I do not show sad emotions. I always try to appear strong and to show that I am in control. He spent three weeks not able to talk after the accident. So, it was very serious. He only started talking after three weeks. Yes, he really had a serious accident. So, I need to understand his condition. To cope with all these challenges, you need to be very patient. You need to show understanding and to be caring. I make sure that I am patient all the time. I do not get discouraged. I also make sure that I do not show sad emotions. I always try to appear strong and to show that I am in control. My advice to anyone who is in this position is to be very patient and tolerant.” ***(Participant G)***

“We had to be tolerant and patient with him. Yes, you really have to have that patience and be prepared to care for someone who is like this. Someone who will have changed in many ways compared to how you know him before the accident. Yes, even now, he is very short tempered. However, we are very patient with him. We do not allow his short temper to interfere with our commitment to love and care for him. We always remain calm and patient when we relate to him. We do know and understand that he is the way he is now because of the injuries that he has sustained during the accident. It is through the accident that his behaviour has now changed. But you really need to be very patient in order to get to this point. Unfortunately, some people lose patience and start neglecting the patients. That is not good at all. Someone will say, this is too much, I cannot handle all this.” ***(Participant H)***

> *“Yes. The other thing is that you need to have tolerance, perseverance, and patience. These are necessary qualities that will get you to cope much better when you are confronted with a situation like this one. When you really show that you cared for him, that you love him, he will also get better much quicker. My advice is that you need to have patience and tolerance. You need to persevere and to continue caring for him. You should not lose hope when you care for someone like that. What helps me a lot is patience and being cool headed.”* **(Participant J)**

> *“You need to be patient with the person who has sustained the injury. You need to sit with her and make her aware that this is not the end of the world and that things will get better. Most importantly, you need to care for her.”* **(Participant M)**

In addition to patience and tolerance, an element of acceptance is also echoed by some caregivers.

> *“Yes. I have learnt to accept his condition and to live with it. I have learnt to be patient and to accept his condition the way it is. I did not have any choice as that is the way he is. If I do not accept the way he is, there is no way I will deal with his condition. I have learnt to accommodate his condition and now I understand his needs and also how I need to meet his needs. One needs to be patient and to understand the nature and extent of the person’s injury. You need to fully understand his needs so that you can give him the support and care he needs. This takes time but you need to try hard to understand what the person needs. It is only when you have reached a point where you understand the person that you will be able to care for him and to attend to his different needs.”* **(Participant F)**

> *“If I did not accept what has happened, I do not think I would have had the courage and strength to look after them. They would not be alive now. So, I had to accept everything that has happened to me. I asked God and said please help me. I have now accepted the situation. I will also be able to accept if God takes anyone of them away. That will be His will.”* ***(Participant G)***

5.4.4.3 Perseverance, resilience, and courage: Caregivers indicate that there is a need to persevere and be resilient when one is faced with the task of caring for someone who was independent and suddenly is dependent on others even for basic self-care skills. The following extracts support these attributes.

> *“You need to persevere and to be resilient when you find yourself in a situation like mine. You must have patience and tolerance. What else can you do? You must be available to assist your child who cannot help herself.”* ***(Participant D)***

> *“If you keep on crying and feeling overwhelmed, who do you think will help you. You need to have some strength to cope. You can only have that strength through prayer. Remember each one of us have their own problems. You need to persevere and accept the situation as it is. You will need to tell yourself that what has happened has happened and that you cannot reverse that. I have really been through a lot of challenges. I do persevere all the time. You should not cry when you are confronted with a situation like this. You need to be strong…. You must always appear to be strong even though it is difficult.”* ***(Participant G)***

> *It required perseverance. It was difficult. Having to care for an adult who used to be able to care for herself, and all of a sudden, she is no longer able to do so. It was not easy; it was very difficult. This is somebody who was independent, she then had to be dependent for even basic care.”* ***(Participant L)***

> *"Yes, it is hard, but I keep trying."* ***(Participant M)***

> *"You need to persevere and to continue caring for him. You should not lose hope when you care for someone like that…. The other thing is that you need to have tolerance, perseverance and patience. These are necessary qualities that will get you to cope much better when you are confronted with a situation like this one…. You need to persevere and to continue caring for him."* ***(Participant J)***

In addition to perseverance and resilience, the need for courage is indicated.

> *"You should not cry. You should always show some courage."* ***(Participant G)***

5.4.4.4 Sacrifice, commitment, and hope: The interviews show that there are sacrifices that caregivers make to ensure that adequate care is provided. There is also an indication of commitment on the part of caregivers.

> *"I console myself by saying that time will come in the future when I will be able to enjoy some of these things. That can only happen when my husband has recovered. I have to now focus all my attention to make him get better."* ***(Participant I)***

> *"You should not lose hope when you care for someone like that."* ***(Participant J)***

> *"You will go through. They say: a dark cloud has a silver lining."* ***(Participant K)***

5.4.4.5 Love and compassion: Love and compassion are referred to as some of those essential attributes that are necessary for a caregiver to be able to provide proper care. The extracts below attest to the notion that love, and compassion is important in caregiving.

> *"Love is very critical for one to care for someone like that. I do all this because of the love I have for him and respect for him as well. Is it called 'kwelo bohloko' in Sepedi?" (Compassion?). You cannot care for someone if you do not have compassion."* ***(Participant C)***

> *"He needs a lot of love and respect. You need to show him the respect that you used to show before. For me what is important when relating to people like him is love. You need to show that love all the time. You should not hide that from him. You should not neglect him. You need to spend time with him as much as it is possible. Remember, he did not choose to be in this position. He just found himself this way."* ***(Participant E)***

> *"We had to do all these things because we really love him. He is my younger brother. So, I have to look after him. I will never stop loving him and caring for him. Even now, he is very short tempered. However, we are very patient with him. We do not allow his short temper to interfere with our commitment to love and care for him."* ***(Participant H)***

> *"I really wanted to give him all the love so that he could get better. Showing him love was very important for me."* ***(Participant J)***

5.4.4.6 Calmness and humility: Caregivers indicate that their ability to be calm and humble assists in the process of providing care for individuals with sTBI. The extracts below show that caregivers rely on these attributes to manage the behaviour that care recipients display.

> *"Some other days you realise that he has changed, and this affect the way we relate in the house. He gets angry. However, as a wife, I have to sit down and be calm. I have to think about what I need to do to help calm the situation. I need to remain calm and talk to him so that he can also calm down. It will not help if I too get angry when he gets angry. You need to be very patient with him in order to help him calm down. This will not happen if you too are angry when he is angry. You should avoid shouting at him because that is not going to help. By remaining calm you help in getting him to calm down. If that happens you will see that it becomes easy to relate to him. As his wife, I tell myself that I need to remain calm and humble myself to help him to cope and to get better. I should not be impatient with him. I need to learn to humble myself and to care for him. By doing that, by supporting him, I am able to encourage him to also try so that we end up having to have a reasonable relationship."* ***(Participant E)***

> *"We always remain calm and patient when we relate to him. We do know and understand that he is the way he is now because of the injuries that he has sustained during the accident. It is through the accident that his behaviour has now changed."* ***(Participant H)***

> *"What helps me a lot is patience and being cool headed. I do not allow anger to get in my way. I try by all means to control that and to stay calm even when I find myself in a situation that may get one to lose temper. I try by all means to control my temper. I also continue telling myself that my husband did not choose to be the way he is. He just found himself in that position."* ***(Participant J)***

The narratives presented above indicate that there is a need to be patient, tolerant and caring when it comes to the provision of care. Love and compassion are furthermore considered to be important in the process of providing care. The research participants also give an indication that caregiving is a fulltime commitment as they must always be available for the care recipient. The real act of providing care and nurturance characterise caregiving. With the marked behavioural changes on the part of the care recipient and the demand for care, perseverance and resilience assist in sticking to the role. There are serious emotional changes that affect the relationship between the care recipient and the caregiver. Calmness, humility, and effective communication skills help in terms of managing the relationship with the care recipient.

Caregivers believe that in the process of providing care, they model adaptive behaviour that care recipients can imitate. This in turn helps to improve the relationship that has been considerably disrupted by the injury. The need to do self-introspection to appreciate own strengths and weaknesses was alluded to by one of the caregivers. It is believed that the self-introspection can assist in taking the responsibility of the new role as a caregiver. There is a need to accept the new reality and to continue to be resilient, be calm and to provide love, care and support to the individual who suffered a traumatic brain injury.

Most of the caregivers draw strength from their spirituality and refer to the need to be strong and courageous. Even when there are fluctuations in the mood of the care recipient, patience, calmness, and tolerance are required to manage these mood changes. We also see that caregivers sacrifice some of their personal and social practises so that they can solely dedicate their time and focus to the task of caring. The caregivers indicate that staying calm can be an effective management attribute for negative emotions such as anger and short temper. Acceptance and showing understanding of the reality and permanence of disability also assist in coping with the hardships associated with caregiving.

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5.4.5 Coping strategies

The caregivers have indicated clearly the difficulties that are associated with the role of providing care. They have also indicated the attributes that are essential for one to be effective in fulfilling the role of a caregiver. They employ different strategies to cope with the demands of the caregiving role. From their narratives, the following coping strategies are identified: social coping, appraisal-focused coping, problem-focused coping, and emotion-focused coping. Relevant extracts are presented under each of these coping strategies.

5.4.5.1 Social coping: The extracts below give an indication that the support that caregivers receive from other people assist them to cope with the process of providing care. Social interaction is also advanced as a practise that assist them to cope with the challenging role they must fulfil.

> *"Yes, it was very difficult at first as I just did not know what to do. I felt overwhelmed when I realised that he was not mentally well. I would request other people to help me as I could not manage him alone. Sometimes I would ask the neighbours to come and help me to restrain him. The problem is that they were not always available to help. So, it was very difficult. Through the help of others, I managed to get him controlled to the point that I took him for treatment.*
>
> *At the clinic, they assured me that they will help me in the future if he does not get better. The nurses explained and they said that he will get better one day …. When I see that he is becoming a bit aggressive, I usually request my neighbours to help me so that we can get him to take the medication. When they come, they help me to restrain him, and it becomes easy to get him to take the medication. I also requested our lawyer to assist. The lawyer also came forward and advised him to take the medication regularly so that he does not become mentally disturbed. Definitely, the support of other people has been helpful because alone I would not have made good progress in caring for him. I would also want to thank you for reaching out to us. It does show that other people think about us."* ***(Participant B)***

“Well, my younger sister and I are both involved in caring for him. We had to continue to care for him because he is not married, and he does not have a child. So, we had to take care of him. There is no one else to care for him. Well, we have come to accept that we must care for him. What really helped us is that we ended up accepting his condition. We told ourselves that our brother is not well and that we need to care for him. So, as siblings, we had to accept him the way he was after the injury. So, we came to terms with his condition as our younger brother.” ***(Participant C)***

“You also need to go out with him from time to time so that he can meet other people and talk to them. When he is given more opportunities to meet positive people, he will start to get better.” ***(Participant E)***

“When everyone goes to work, I remain looking for him. My siblings relieve me when they come back from work.” ***(Participant H)***

“I strongly believe that he will get better with time. Many people have given me support and they console me. I am hopeful that he will get better. Well, I am lucky because my husband’s sister is very supportive. She is always there to give us support. This definitely makes a big difference. I do not know how it will have been if his sister was not this supportive. She is always there for us. She gives him support. She gives all of us support. You really feel comforted and relaxed when you are with her. She is always there to support us through the many challenges that we are facing. She gives us good counselling to help us face the challenges. This gives me a lot of strength to make me feel like I can go on to face the challenges. Now, I feel that I no longer have the kind of challenges that I used to have before. He is much better now, and I can cope much better. I no longer feel the kind of pressure that I used to feel.” ***(Participant I)***

> *“The first year was difficult as he could not do anything. He was unable to even bath himself. I had to request some young man to help him with basic self-care activities.”* ***(Participant K)***

5.4.5.2 Appraisal-focused coping: The extracts below indicate that the understanding and acceptance of the care recipient’s condition help caregivers to cope better. Caregivers also draw strength from within.

> *“Well, we have come to accept that we have to care for him. What really helped us is that we ended up accepting his condition. We told ourselves that our brother is not well and that we need to care for him. So, as siblings, we had to accept him the way he was after the injury. So, we came to terms with his condition as our younger brother. Generally, we are coping with his condition. We have never really had a challenge up to this point.”* ***(Participant C)***

> *“Firstly, the caregiver must sit down, relax, and ask herself who she is. She needs to accept the situation she finds herself in. You got involved in a relationship with your husband before the injury. So, you need to accept that these things can happen. By getting married to him, you have made a commitment and have sworn before God that you will be with him up to the end. You need to continue to show that you love him. In this situation that he is now, he really needs to be loved. You also need to be positive when you are with him as this will encourage him to be hopeful. The positive attitude must be there all the time.”* ***(Participant E)***

> *“Over the years, I have learnt to understand him. He does not have a problem. I do understand the way he is, and I am able to attend to his needs as I have learnt about his conditions over a long period. It is through my many years of experience that I have learnt to cope with his condition. I fully understand his condition now and this makes it easy for me to cope when compared to the time*

just after the accident. Yes, that is why I am able to understand his condition much better. I am also in a better position to cope with his condition because of my background in nursing. This has certainly helped me a lot. The support and care I am able to give to him is because I do understand people who are in a position like this." ***(Participant F)***

"Yes, even when he gets angry, we have accommodated that because we know he is short tempered. We have learnt to live with that." ***(Participant H.***

"I also continue telling myself that [he] did not choose to be the way he is. He just found himself in that position. He does not choose to behave the way he is doing. He is that way because of the accident that has occurred. It is because he has suffered some injuries to his brain that he is like that. You need to understand his situation as such." ***(Participant J)***

"Yes, an accident can happen to anyone at any time. You will not be warned about the day it will happen. It just happens. So, you need to accept that." ***(Participant M)***

"As a person you need to lift yourself as people can drag you into a pit. So, you cannot just say I am in a pit. On your own you need to lift yourself. It is life, you choose to keep on complaining, and the more you complain, depression will hit, and you will be crying alone, and other diseases may also creep in, but if you take things in a positive way, you will survive." ***(Participant K)***

"There is a saying that states as follows: Everything has its own time (a direct translation of what she said). Life should go on, whatever is happening. If you see him now, you may not tell that something happened that resulted in him being in coma for 7 days, no you may not believe it. That is why I say to you if you stay in a situation and focus on negativity, even stroke can happen. On

> *your own you need to choose; in life it is either you think positively, or you dwell on negative things.”* **(Participant K)**

5.4.5.3 Problem-focused coping: Caregivers develop ways that focus on what they would have identified as problems. For example, working out a plan to target specific problem or deficits. The targeted interventions, activities that caregivers engage in, and treatment plans assist in coping with the role. For example, medical treatment assists as it reduces uncontrollable behaviour on the part of the care recipient. Participants also learn ways of fulfilling the responsibilities associated with the role. The extracts below support problem-focused coping.

> *“Yes, the treatment has been very helpful. After he got the treatment, he became subdued. I could then sit down with him in a way that I could not do before that. I was able to talk to him about his condition and the need to take medication. He needs to be constantly on the medication because if he skips taking the medication for a while, he gets impatient. He gets to be uncontrollable without the medication.”* **(Participant B)**

> *“I do fully understand you, my child. I do understand what your request is. There is no way you will not end up developing skills to care for someone who has sustained head injuries during a car accident when you are in a position like I am in. You have no choice but to try hard and to learn to deal with the situation that confronts you. You cannot run away. You have to find means and ways to cope with the situation that you are confronted with. You need to support the person who has sustained the injuries and cannot look after himself. You need to teach him to develop some skills to help him cope with his new condition…. Over the years, I have learnt to understand [him]. He does not have a problem. I do understand the way he is, and I am able to attend to his needs as I have learnt about his conditions over a long period. Yes, I have now learnt over many years to live with someone who has sustained serious head injuries. As a result, I now know how to deal with*

> *someone who is in this position. This comes over a long period of time. You need to know that if a person is like this, you need to behave in this particular way. It all comes with time. I have also managed to understand his condition and to cope a bit better because I have worked with many people like him before…. Do you see that, my child? You really need to give yourself time to learn about what the person needs in order to be of assistance to him. You are not going to succeed if you do not have the patience and desire to help him."* ***(Participant F)***

The responsibilities that are in involved in the real act of caregiving give an indication of the coping strategy that is focusing on the difficulties that need attention, thus a problem-focused approach. The following utterances by caregivers indicate the activities undertaken in the provision of care to cope with the demands.

> *"So, you need to care for him and look after him so that his friends may want to be with him. If you do not do that, no one will want to be with him as he will be dirty. You really need to look after someone who is like this. You need to prepare him food and clean clothes. You need to wake up in the morning and prepare for him. When he wakes up, you will need to give him some soft porridge. You will then need to prepare warm water for him to take a bath. After that you should give him some clean clothes. You also need to make sure that your home is always clean. When he says he feels a bit hot, you need to guide him to go and sit in a shade. This is indeed a big job that you need to be prepared to do all the time. Many people are too afraid and are unable to cope with this. For some people it is really bad. With me, I have really developed some strength and courage. I am so courageous that I can confront what many people are afraid of. When everyone else is afraid, that is the situation I am prepared to confront. I will go there and say to myself, I want to see what will happen."* ***(Participant G)***

> *"Yes, the first year was difficult as he could not do anything. He was unable to even bath himself. I had to request some young man to help him with basic self-care activities. Also, communication is very important as it is able to get to a person's mind. To talk to him, sharing whatever information that can be helpful."* ***(Participant K)***

> *"You also need to go out with him from time to time so that he can meet other people and talk to them. When he is given more opportunities to meet positive people, he will start to get better…. Usually, I allow him to interact with his childhood friends because he feels more relaxed when he is with them. I allow him to spend time with them and to talk to them as they do understand him."* ***(Participant E)***

The decision to stop other personal engagements and to control personal emotions and dedicate time to care for the injured family member gives an indication of the caregivers' assigning time to focus on the problem at hand.

> *"Yes, people do not want to help you when you are having challenges such as the one we had. Because of that, we decided that it is only us as siblings who will be able to help him. That is why we had to do what we did. I decided to stop many things that I used to do. I paused my relationship with my partner because I felt I needed to give [him] the love and attention he needed. I had to do all that because he is my younger brother. I love him."* **(Participant H.**

5.4.5.4 Emotion-focused coping: The caregivers develop ways to help them emotionally. For example, most of the caregivers rely on spiritual support for their emotional stability. Also, trying to stay calm help the caregivers to cope emotionally. The extracts below allude to emotion-focused coping.

“What helps me a lot is my belief in God. What else can I do? There is nothing else I can do other than to continue to believe that God will help me.” ***(Participant D)***

“Sometimes when I realise that he is still angry, I prefer to keep quiet so that I avoid being confrontational with him.

However, on my side, I am not going to follow that line of thinking and belief…. I believe that God will help him to get better. That is what I strongly believe in.” ***(Participant E)***

“…. You therefore need to give all this to God and say to Him, please help me to cope with all this. When you do that, you will see that things get better. When I feel I am going to be overwhelmed or emotional, I try to calm down. I then would ask God to give me courage and strength. I would at that point kneel down and pray. I pray and also pour snuff on the ground to communicate with the ancestors.” ***(Participant G)***

“We take our troubles to God all the time. We always thank God for giving us the courage and strength. You see if you believe in God, you will see that a lot of things are possible.” ***(Participant H)***

“Even in cases where someone is unable to walk, it is possible for him to walk if you believe in the power of God. You see at first [my brother] could not walk when he was discharged. He later started using a wheelchair. I prayed to God, and I said he will ultimately walk. You see, now he can walk. God knows everything. I strongly believed that [he] will get better because I believed strongly in the power of God.” ***(Participant H)***

> *"You see somebody who was used to driving himself and it is no longer possible, for him to pull himself to get back is difficult. When you are busy changing the diapers, with God's word, it helps. The main thing is the word of God. If one believes in God, coping is better. It means that when one is in trouble, and trust in God, you will go through. It means the Word is what can strengthen the person to be able to stand up and face life. You see in this world, if you put your trust in people, people can just stop supporting you and disappear. But if you trust in God, it is helpful if you rely on him. You will be left alone if you put your trust in people and depression can start and you just do not know what to do. So, the advice that I can give to people is we should trust in God in all situations."* ***(Participant K)***

5.4.6 Motivation for caring

The information that the research participants presented gives a picture of hardships that are experience when providing care to the individuals with a brain injury. Still with the hardships, the caregivers continue to provide the care. The narratives suggest that there are factors that keep them motivated to provide the necessary care. The themes associated with this superordinate theme are as follows: caring as an obligation and a sense of duty; caring as an act of reciprocity; caring as labour of love; and the confidence resulting from the experience of caring. Below are the themes and the associated extracts:

5.4.6.1 Caring as an obligation and sense of duty: The research participants gave the impression that the fact that they are parents, siblings, and spouses to the injured, they are obliged to provide care. They feel that it is their responsibilities to care for the injured family member. For the spouses, there is also an element of the commitment that they made when getting married to the person who later suffered the injury. The extracts below allude to the sense of obligation and fulfilling responsibilities.

> *"She is my child. I have no choice but to be strong for her. I have to endure the hardship as I do not have any other choice. She is my child. Yes, I have to*

> *continue to care for her. What else can I do? I have no choice but to look after her.... Precisely, it becomes our responsibility as a family to care for her and to ensure that she gets all the help she needs."* **(Participant D)**

> *"It was indeed not easy, but I had to provide because she is my child. It was just not going to be easy to just not care for her. That connection as my child is what made it an obligation for me as a mother to care for her. Who will I give her to or assign the responsibility to? There is no one who can care for her. I had to take the role. As a mother, I could not just leave her to suffer as she was no longer able to do things for herself. I had to, you see, do everything for her."* **(Participant L)**

> *"You know, he used to help care for the family. Now that he is no longer able to function, I have to really take care of him. He is my first-born-child. I need to take the responsibility and care for him. It just has to be like that. I have to. There is not any other person who can do it."* **(Participant N)**

> *"Yes, we had to do everything for him as he was unable to care for himself. He could not do anything by himself. He was completely dependent on us as family. So, we had no choice but to care for him."* **(Participant H)**

For the spouses, the obligation they had to care was coupled with the commitment related to their marriage vows. Information shared by Participants I and J share this sentiment.

> *"Yes, that is because I am at home. I am not working. Even now, I spend a lot of time with him.... I have to now spend a lot of time with him. So, this means that I cannot leave him this way. You see how God will judge me if I abandon him when he is in a state like this? I will never leave him, alone. I will*

> *always be there for him. He is my husband. I have to make sure that I do my best to care for him. If I do not do that, who will?"* **(Participant I)**

> *"Before the accident, we had relationship problems. It was not nice in the relationship. This was the kind of thing that could have made it difficult to care for him. When the accident happened, I had to forget about the difference that we had in the relationship. I had to care for him because he is my husband. I also did not want to let my family of origin down as they were always there for me when the relationship with my husband was not good."* **(Participant J)**

5.4.6.2 Caring as an act of reciprocity: The role of being a caregiver and continuing to care seem to draw some motivation from the interaction between the caregiver and the care recipient, and the observations of improvement in the functioning of the injured person.

> *"For me as a wife, I tell myself that I need to remain calm and humble myself to help him to cope and to get better.... By doing that, by supporting him, I am able to encourage him to also try so that we end up having to have a reasonable relationship. Yes, he realises that you are with him and that you understand his situation when you talk to him nicely and you are calm. You need to treat him well in the way you used to before he got involved in an accident. You need to continue to support him and to care for him.... You need to be with him and support him all the way so that he feels you are with him."* **(Participant E)**

> *".... If you make sure you care for him that way, you will see that he does not give you problems. He becomes calm and you can attend to his needs without many problems."* **(Participant G)**

> *"Every day, we had to train him to walk after he was discharged from hospital. We did that until he was able to walk by himself. He ended up walking because*

> *of our continuous efforts to get him to walk. He was not going to be able to do that if we had not persisted in training him to walk. We got encouraged when we saw that he was beginning to walk because we were training him. This made us to continue doing what we were doing because we saw that he was improving.... What is good is that [he] was cooperative. He listened to us, and he heeded our instructions. We offered him the support and care he needed. He accepted that and we were also very ready and prepared to help him. At the end we saw that he started to get better.”* ***(Participant H)***

> *“Now things are much better than before. I say that because he can now eat when I give him food. He can get into the bath when I tell him to do so. It encourages me to go on helping him this way when I see that he is improving. Yes, you need to give your best to care for someone who is in a position like this. If you do that diligently and consistently, his condition will get much better.”* ***(Participant I)***

> *“When you really show that you cared for him, that you love him, he will also get better much quicker.”* ***(Participant J)***

> *“Currently she is getting better. That is the reason I can delegate some tasks to her. It gives me strength to continue when I see that she is improving.”* ***(Participant M)***

> *“We are supposed to bath him. But these days he does not want to be bathed by women. He tells us he would like to be bathed by a man. We would then try to convince him until he agrees, and we will then bath him.”* ***(Participant C)***

5.4.6.3 Caring as a labour of love: This was referred to by the research participants as one of the essential attributes to help with caregiving. The caregivers also point to the love that they have for the injured family member as an element that motivates them to continue with the provision of care.

".... He is our brother. We love him dearly. So, it was therefore easy for us to give him the care and love as he is our brother." ***(Participant H)***

"Yes, my husband and I are one. I love him. Things have to continue to be that way. I always tell myself that everything has its own time. As things stand now, I have to accept that I have to stay at home to care for my husband. He needs me now." ***(Participant I)***

5.4.6.4 Confidence resulting from the experience of caring: As caregivers continue with the role of providing care, they learn the ropes of the trade and begin to be confident in their abilities. The confidence and experience gained motivate caregivers to continue caring. Participants B, G and H echo an element of confidence and experience that they gained as reflected in the extracts below.

> *"I think I now have the understanding and experience to help others who are in a similar position. It is just that you have to wait for such people to come to you for help. You cannot just go out there and say you can help someone who does not come forward."* ***(Participant B)***

> *"With me, I have really developed some strength and courage. I am so courageous that I can confront what many people are afraid of. When everyone else is afraid, that is the situation I am prepared to confront. I will go there and say to myself I want to see what will happen."* ***(Participant G)***

> *“People would sometimes come to us to ask what it is that we do care for [him]. They asked that because they saw that we were really trying our best to care for him.”* ***(Participant H)***

5. 5 Concluding remarks

In this chapter, I started by giving a presentation of the demographic profile of the research participants. What followed that was a step-by-step process to present the results based on the phenomenological analysis of the lived experiences of the research participants. The six superordinate themes, including the corresponding themes, were presented with supporting extracts taken from the participants’ narratives. The results presented above form the basis for the development of a psychological explanatory model on caregiving that is presented in the next chapter.

CHAPTER 6: DISCUSSION

6.1 Introduction

In the previous chapter, I presented the results of the study, highlighting the seven superordinate themes and their associated themes. The superordinate themes are caregiver lived experiences; attributions and meaning making; facilitators and barriers; essential attributes for caregiving; coping strategies; and motivation for caring. The content of this chapter has two sections. In the first section, I discuss the superordinate themes in relation to the exiting body of literature. I explain and evaluate these superordinate themes and their associated themes, demonstrating how they relate to the literature reviewed in Chapter 2 and the research aim and objectives as outlined in Chapter 1. In the second section, I present the psychological explanatory model that I have developed which focuses on caregiving within a family context for adults who suffered sTBI.

6.2 Discussion of superordinate themes

This section discusses the superordinate themes in relation to existing literature.

6.2.1 Caregiver lived experiences

Based on the findings of the current study, the following can be described as the lived experiences of caregivers: their understanding of life before and after the injury sustained by the care recipient; the act of caregiving; help seeking pathways and experiences; the emotions elicited during caregiving; and the social life of the caregivers.

6.2.1.1 Caregivers' understanding of life before and after the injury: According to the caregivers, the severe traumatic brain injuries sustained have significantly disrupted the care recipient's premorbid personal, social and occupational functioning. The description provided in the previous chapter regarding care recipients give an indication that some of them were high functioning individuals who were entrusted with management responsibilities at school levels. Following the injuries, these high functioning individuals are no longer able to function at their pre-morbid levels. They have cognitive impairments that make it difficult for them to lead their lives independently. Some of the limitations imposed by the brain injury included the following: speech problems; forgetfulness; mobility problems; and weakness or loss of functioning of some parts of the body. These findings lend support to existing literature by Lezak et al. (2012) and Ponsford (2013) who reported that cognitive impairments are common in individuals with severe TBI experience. Such cognitive impairments include diminished planning and problem-solving abilities, increase in concrete thinking, lack of initiative, dissociation between thought and action, and inflexibility which make it difficult for the injured individuals to exercise independent care for themselves. I have extensively reviewed the works by Lezak et al. (2012) and Ponsford (2013) in Chapter 2.

Caregivers in the current study gave an indication that care recipients' pre-morbid level of functioning seems to determine how they adjust to their post-morbid conditions. Limited capacity to care for oneself seems to impact negatively on how care recipients function and accept their disabilities. The caregivers indicated that the care recipients were experiencing a wide range of feelings such as sadness, depression and anger as they found it difficult to accept the functional changes that have imposed limitations on their ability to care for themselves. This finding is consistent with the results of some previous studies that have found that TBI survivors struggled to accept that their lives will never be the same following the injury (Chembeni & Nkomo, 2017; Rochat et al., 2019). For instance, in a study that focused on challenges experienced by survivors of traumatic brain injury and their families, Chembeni and Nkomo (2017) noted that TBI survivors found it difficult to accept their post-morbid condition. This tended to result in feelings of sadness, anger, and self-blame, with some survivors even expressing a wish to give up on life. A study by Rochat et al. (2019) found that people who were living with a disability following TBI were also prone to anger outbursts. In an earlier study, Psarra and Kleftaras (2013) found that there was a significantly high level of depression among individuals with physical disabilities as they feel that their lives have been disrupted. The findings by Psarra and Kleftaras (2013) were based on a study in which they administered three questionnaires to assess depressive symptomatology, meaning in life and adaptation to disability among individuals with physical disabilities. The study by Psarra and Kleftaras (2013) found that that there was a strong relationship that existed between meaning in life (i.e., goals and mission in life, a clear sense of personal identity, the freedom to make choices responsibly and viewing death as a natural aspect of life) and depression. In other words, those care recipients who tended to feel that life had meaning despite their disability, were found to be less prone to manifestation of depressive symptoms.

6.2.1.2 The act of caregiving: The caregivers explained in detail the act of caregiving, providing information about the actual processes involved. Generally, caregivers indicated that the care recipients' basic self-care skills and mental abilities are significantly disrupted, resulting in a need for constant support. For the caregivers, the act of caregiving involves having to acknowledge the disabilities and limitations in functioning that care recipients present with. The functional limitations such as physical disabilities, cognitive impairments, and behavioural difficulties that are characterised by changes in mood on the part of care recipients, required caregivers to perform several critical tasks to support the care recipients. These included having to provide basic care like bathing them, assisting with toileting, dressing them, transfer, and positioning, preparing meals, helping with feeding and mobility.

The tasks associated with caregiving for persons whose disabilities are associated with an injury have been reported in previous studies. For example, in a qualitative concept analysis study conducted by Hermanns and Mastel-Smith (2012), caregivers identified tasks that include having to assist with bathing, dressing, toileting, ambulation, preparing meals, managing disease (seizures), and doing laundry. In their study, Hermanns and Mastel-Smith (2012) used a hybrid qualitative model of concept development to analyse caregiving. In another qualitative study that explored the phenomenon of caregiving for people with dementia in a rural context in South Africa, Gurayah (2015) reported that caregivers felt that it was their responsibility to perform activities like cleaning up when care recipients wet or soiled themselves. Gurayah (2015) further found that some caregivers had to try to make sense of the care recipients' speech that did not make sense. According to Saloojeei and Bezuidenhout (2020), there is a need for caregivers to have practical skills such as good communication and ability to position and feed the care recipients. Saloojeei and Bezuidenhout ‘s (2020) observations were made following a review that focused on community-based peer supporter training programmes for people with disability. The review by Saloojeei and Bezuidenhout (2020) described the development and implementation of peer-supporter training programmes for caregivers of children with cerebral palsy (CP) at 18 sites nationally, and adults with spinal cord injuries (SCIs). These peer-supporter training programmes assisted caregivers to understand CP and helped them learn how to care for their children in helpful ways. The training programme also helped caregivers to learn to transform a sense of hopelessness, isolation and guilt into pride, acceptance, and increased self-confidence. The programmes also helped individuals with newly acquired SCIs to be included and integrated in their families and in community settings.

6.2.1.3 Help seeking pathways and experiences: The current study shows that sTBI triggers some help seeking behaviour on the part of the family of the care recipient. Such behaviour may include taking their injured family member to health practitioners and health facilities.   In some instances, such help might be sought from alternative institutions such as local clinics and rehabilitation centres. What the findings suggest is that help seeking behaviour tends to be influenced by what the caregiver perceives as the most optimum option.
A review of studies that focused on health-seeking behaviour in Indonesia found that people’s help seeking behaviour was determined by a range of internal and external factors (Widayanti et al., 2020). The internal factors included individual characteristics, perceptions and beliefs about the disease/injury and its treatments. On the other hand, external factors included the influence of significant others and perceptions about the health care system. The findings of the current study and that of Widayanti et al. (2020) that support health seeking behaviour that is influenced by the perceptions that the individuals have, are in line with Kroeger’s model of health-seeking behaviour. The Kroeger model posits that decisions that people make regarding choices of health providers are influenced by three major factors. Such factors include characteristics of the person, characteristics of disorders and the perceptions of the people seeking health, and characteristics of the health services system (Kroeger, 1983). Other studies have utilised Kroeger’s model in understanding health seeking behaviour. For instance, Shaikh and Hatcher (2005) reviewed the relationship of factors affecting health seeking behaviour and the use of health services in the developing world including Pakistan, encompassing public as well private sectors.

6.2.1.4 Emotions elicited during caregiving: The results of the current study indicate that caregivers experience a wide range of emotions that include shock, denial, anger, frustration, and loss of hope. These findings are consistent with findings of some previous studies (Arango-Lasprilla et al., 2011; Hawkley et al., 2020). For example, Broodryk and Pretorius (2015) found that the injury of a relative was received with shock. In their study, Broodryk and Pretorius (2015) explored the challenges that family caregivers experience during the initial stages of recovery when a relative has sustained a TBI. The sample comprised of participants who were caring for a relative that has sustained a TBI. In a study that aimed to explore the course of caregiver strain, illness denial, and their reciprocal relation in cardiac rehabilitation setting, Ferrario and Panzeri (2020) found that illness worsened where there was an indication of denial. Ferrario and Panzeri (2020) administered specific questionnaires at admission and discharge to 44 left ventricular assist devices (LVADs) patients and their caregivers. The questionnaires that were completed when the patients were discharged showed that there was a positive improvement in the emotional measures used, but showed a worsening in the illness on the denial measure.

Anger and frustration were some of the emotions that were found among those providing care. Some previous studies also reported on these two emotions as being experienced by caregivers. For example, in a study that sought to determine the extent of anger that caregivers of patients diagnosed with schizophrenia have and their level of burden, Bademli et al. (2017) found that caregivers experience anger in the process of caregiving. In another study conducted by MacNeil et al. (2010), anger was found to be experienced in this study that examined the ability of anger to mediate and moderate the relations of depression, resentment, and anxiety with potential harmful behaviour (PBH).

Loss of hope is another emotion that caregivers in the current study experienced. One of the caregivers indicated loss of hope and feeling discouraged when health professionals indicated that the condition of the care recipient was unlikely to improve. Loss of hope was reported by Duggleby et al. (2013) in an earlier study that sought to explore the hope experience of family caregivers of persons living with dementia. The three authors found that participants lost hope and experience feelings of despair when they perceived that they were unable to connect with their family member in the long-term care (LTC) facility in Edmonton, Alberta. The findings by Duggleby et al. (2013) were based on the open-ended face to face interviews that they had with family caregivers of persons with dementia who resided at LTC.

The experiences of shock, denial, anger, and frustration bring in an element of loss and grief–the loss of ability and the person that was. The emotional encounters that caregivers experience can be associated with some of the stages in Kübler-Ross' stages of grief and loss (Kübler-Ross, 1981). Kübler-Ross' stages of grief involve having to go through the process of a loss of a loved one where the bereaved person is likely to experience denial, anger, bargaining, depression, and acceptance. The emotions experienced do not necessarily come in the order noted, nor are all steps experienced by all patients, but a person may have some experiences that indicate the stages (Lim, 2013). A recent study by Park (2021) found that long-term caregivers were more likely to experience heightened levels of psychological distress when compared to non-caregivers. In this particular study, Park (2021) investigated differences in the mental and physical health of the U.S. population during the early stages of the COVID-19 pandemic among three groups, namely: non-caregivers, short-term caregivers (1 year or less), and long-term caregivers (greater than 1 year). The study concluded by indicating that caregivers performed worse than non-caregivers in terms of mental health and fatigue (Park, 2021). Other studies have also found that anxiety and depression are common forms of psychological distress that is experienced by caregivers (Band-Winterstein et al., 2019; Hawkley et al., 2020; Ma & Mak, 2016; Pendergrass et al., 2017). For example, Carlozzi et al. (2020) found that caregivers of low-functioning persons with TBI consistently had higher base rates for severe psychological symptoms and impairment. In another study, Shaffer et al. (2020) found that individuals who provide long-term caregiving for patients with recurrent or prolonged illnesses present with elevated depressive symptoms.

Psychological distress and somatic complaints were reported in an earlier study conducted by Arango-Lasprilla et al. (2011). The results of this study showed significantly lower scores for traumatic brain injury caregivers compared with healthy controls on role-emotional, vitality, mental health, social functioning, bodily pain, and general health. A qualitative study conducted by Huis in het Veld et al. (2016) in the Netherlands found that caregivers reported feeling stressed when faced with the responsibility of caregiving. The study was conducted using four online focus groups with 32 family caregivers of people living with dementia. The authors recommended support for caregivers given the stressful nature of the role.

6.2.1.5 The social life of caregivers: The results of the current study show that caregivers make changes to their lives to accommodate the role of caregiving. For instance, some caregivers reported that they could no longer go out to socialise with their friends because they were now expected to provide constant care and support to the injured family member. The decision to stop doing things that they used to do to and to adjust their social lives to accommodate their new roles, suggests that most caregivers are determined to focus on their new roles. Previous studies have also found that caregivers often give up on their social lives when they take the new role of caregiving. In a study conducted by Liu et al. (2021), caregivers reported lower satisfaction with social activities and greater decline in their social network size after taking on the role of caregiving. In this study, Liu et al. (2021) aimed to compare incident family caregivers and matched controls on change in social network variables and satisfaction with social activities. Liu et al. (2021) found that caregivers who were caring for their own spouses experienced higher strain, whilst also reporting lower satisfaction with social activities.

In some instances, the curtailment of social life in order to care for loved ones tended to result in caregivers prioritising the needs of care recipients over their own. This is reflected in the findings of an integrative review of 26 studies conducted by Gibbons et al. (2014). This review that sought to synthesise the qualitative literature regarding the transition into the caregiving role as a liminal experience, found that caregivers experienced the role as an event that resulted in the need to respond with a commitment to care for their loved one, followed by a period of transition when life as they previously experienced it, including social roles and relationships, had changed, and was surrounded by uncertainty and suffering. Though the authors acknowledged the possibility that some relevant studies may have been omitted in the review, it did however show that a caregiving experience is consuming for caregivers and their life expectations often change dramatically. The results of this integrative review by Gibbons et al. (2014) also shows that in a number of the studies, there was a sense of commitment to the care recipient that was not questioned, and caregivers prioritised the needs of the care recipients over their own and were committed to the provision of care regardless of whether the caregiver felt a close or loving relationship to the care recipient. The liminal caregivers in the study by Gibbons et al. (2014) reported loss of social connection, a reduced participation in life and neglect of themselves as they focused on the transition. In a fairly recent study by Geard et al. (2020) focusing on exploring how family members of persons with acquired brain injury (ABI) and spinal cord injury (SCI) in the chronic phase make sense of and adjust to living with an altered life situation, participants highlighted the need to be flexible in order to find the best possible solutions to challenges in everyday life as they care for their injured family member. The findings by both Gibbons et al. (2014) and Geard et al. (2020) suggest that the caregiving role calls for changes in the lives of caregivers if the role is to be fulfilled adequately.

6.2.2 Severe traumatic brain injury and meaning making

Though many caregivers tended to explain the injuries sustained by their loved ones in terms of biological and physical factors, they were prompted to try to find meaning and to make sense of what has happened. In this regard, meaning making included caregivers affirming their belief in God and perceiving their act of caring as some form of destiny. Some cultural explanations were also advanced to try and explain the injury.

6.2.2.1 Believing in God and caring as a destiny: The findings of the current study show that many of the research participants believe that God knows about the injury, and that He is the one who will help with the recovery process. In other words, caregivers were found to use spirituality as a way to explain and accept the injury and functioning of the care recipients. They appeared to get courage and strength from spirituality and to attribute life to the power of God. Spirituality also seemed to assist with acceptance of new reality and being able to persevere. The belief and trust in God seemed to assist the caregivers to make meaning of their circumstances. Reliance on spirituality in caregiving has been reported in literature (Durr & Greeff, 2020; Vigna et al., 2020). In a study that aimed to identify and describe characteristics and resources that helped families to adjust and adapt after their children had been diagnosed with a severe or a profound intellectual disability, participants mentioned that spiritual resources helped their families to adapt (Durr & Greeff, 2020). In this study by Durr and Greeff (2020), participants indicated that having faith in God, prayer and spiritual support helped them to adjust and to provide care to their children. The sample in the study consisted of two-parent families with a child with severe or profound intellectual disability. The researchers conducted semi-structured interviews with both parents to determine the characteristics, strengths and resources that help their families to adapt after the diagnosis of the child's intellectual disability.

The role of spirituality and faith in God was also reported in a study by Vigna et al. (2020) who investigated the relationship between spirituality and the emotional burden of family members of patients receiving exclusive palliative care. The authors hypothesised that, in patients under exclusive palliative care, there would be an inverse relationship between the spiritual well-being and the burden of caregivers. Family members with higher spirituality reported feeling less burdened to take care of their loved ones under exclusive palliative care, with faith being considered the strongest predictor of protection against burden of care (Vigna et al., 2020). The authors concluded their study by indicating that psycho-socio-spiritual interaction can improve the coping ability of family caregivers of patients under exclusive palliative care, suggesting that the interaction addresses a critical gap in the provision of holistic palliative care services. Based on their findings, Vigna et al. (2020) recommended that the spiritual needs of caregivers should be identified in order to provide support for their spiritual well-being to reduce their sufferings.

Believing in God and explaining one's condition of ill health or injury as a reflection of God's will has been reported in other previous studies (Phalane, 2017; Santos et al., 2013). For example, a recent study by Nkoana et al. (2022) found that cancer patients reported that having faith in God helped them to make sense of their medical condition. The study by Nkoana et al. (2022) explored the role of religion in meaning making among men who were diagnosed with prostate cancer and were receiving treatment at a local hospital in Limpopo Province, South Africa. The study further found that the men attributed their condition to the will of God. The belief in God helped the participants to understand their condition and to cope better (Nkoana et al., 2022).

6.2.2.2 Caring as destiny: Caregivers also seem to believe that what is happening is what was meant to have happened. In other words, the injury and subsequent disability on the part of their loved ones is perceived as some kind of destiny that the caregiver could not avoid. Participants in Durr and Greeff's (2020) study indicated that establishing themselves in God will get their lives to be right and good, believing that God has a plan for their lives and their families. The participants also went on to use their religious beliefs to reframe their situations into something more positive (Durr & Greeff, 2020).

6.2.2.3 Caregiving and cultural explanations: The results of the current study show that cultural practices and belief systems do play a role when it comes to assuming a caregiving role. There is also an indication that cultural belief provides resilience and strength when a caregiver is faced with difficulties. The results of the current study lend support to some previous studies that have found that belief systems and cultural practices of caregivers influence the way they relate to their caregiving role. For example, in a qualitative study by Pharr et al. (2014) discussed in detail in chapter 2, it was found that there is a culturally perceived mandate to provide care in the African, Asian, and Hispanic American cultures.

Other studies do show that the decision to take a role of being a caregiver is influenced by cultural practises (Mbakile-Mahlanza et al., 2017; Mokhosi & Grieve, 2004). Cultural factors such as devotion to one's family, and other cultural beliefs that caregivers hold were found to have influenced their decision to assume the role of being caregivers in the study conducted by Mbakile-Mahlanza et al. (2017). A study conducted by Mokhosi and Grieve (2004) found that a decision to take the role of a caregiver was influenced by local cultural beliefs. Gurayah (2015) on the other hand found that a correlation existed between closer kinship that was indicated to be part of African culture and the burden that caregivers experienced. Gurayah (2015) remarked that there was a sense of duty and kinship in African culture. In another study focusing on the role of culture on caregiving, Ho et al. (2003) found that caregivers accepted their caregiving role as a cultural obligation. Ho et al. (2003) conducted in-depth interviews with Chinese-Canadian female caregivers to determine their feelings and experiences of providing care for relatives with Alzheimer’s disease. The caregivers were asked about their feelings of providing care for relatives with Alzheimer's disease. The study found that caregivers were concerned about the influence of western culture on traditional values and in particular, intergenerational issues regarding caregiving provided and added burden. In the review that focused on motivations for being an informal carer, Greenwood and Smith (2019) also found that cultural factors play a role in caregiving. A similar finding was made by Santos et al. (2013) who found that culture play a role in motivating family members to take caregiving roles. The two studies by Greenwood and Smith (2019) and Santos et al. (2013) suggest that cultural values and beliefs encourage individuals to take the responsibility of providing care to their injured family members. One of the research participants in the current study used cultural belief to be resilient. She indicated that culturally, one is not supposed to cry following an injury as this can cause further deterioration in the functioning of the care recipient.

Caregivers in the current study rejected a view that there could be evil forces or intentions by others that may have caused the injury. Literature reviewed show that in some instances, the injured individuals may believe that some evil forces are involved in their injuries (Mbakile-Mahlanza et al., 2017). It was interesting that in the current study, caregivers did not believe in any evil forces in understanding the injuries. This could be due to the demographics and how the participants were recruited. They were assisting their injured family members to access western healthcare and some of them were involved in the process to claim compensation for the injured. Those who believed in evil intentions may not have bothered to seek western health treatment or get involved in claiming for the injuries. The results highlight that culture plays a significant role as far as it inspires caregivers to look after their loved ones. This finding supports what Pharr et al. (2014) found in their study which indicated that culture mandates caregivers to look after their loved ones. The caregivers in the current study do not necessarily explain the causes of the injury in terms of evil spirits and witchcraft. This is contrary to previous studies such as those by Mokhosi and Grieve, (2004) and Mbakile-Mahlanza et al. (2017) which suggested that the meanings that caregivers had regarding the injury were influenced by the belief that evil spirits and witchcraft played a role in the injury happening.

6.2.3 Facilitators and barriers

The findings of the current study indicate that there are facilitators and barriers that influence the act of caregiving. Financial support, and previous experience related to caring and support from others were found to be some of the facilitators whilst physical, cognitive, and mental problems on the part of the care recipient, and financial constraints were perceived as some of the barriers that hinder effective caregiving.

6.2.3.1 Facilitators: The current study found that there are four facilitators that make it easy for caregivers to manage their situations. These include access to healthcare facilities, financial support, prior experience, and support from others. In the case of medical treatment, it was found that many caregivers tended to acknowledge and appreciate the support that they were receiving from health care facilities. The support from health care facilities was sought because most care recipients' levels of mental functioning was significantly impaired to warrant such an intervention. Previous studies have also found that care recipients tended to benefit from treatment they receive from healthcare facilities following TBI and other debilitating conditions that lead to some form of disability. Previous studies (Lewis et al., 2019; Whitlatch et al., 2001) show that having access to healthcare facilities to receive treatment is perceived as an enabler for the provision of care by caregivers. For instance, a study by Lewis et al. (2019) noted that reliable hospital access may address the structural barriers that inhibit kangaroo mother care (KMC), reduce burdensome costs, and improve the health of those involved. The finding that indicates the role played by accessibility of healthcare facilities was echoed by Whitlatch et al. (2001) who found that being a resident at a nursing home assisted with adjustment on the part of caregivers.

Caregivers also acknowledge the role that financial assistance play in the process of providing care. The information that they provided indicates that when there is financial support, the burden of caring is lessened. For example, disability grants that care recipients receive from the South African Social Security Agency (SASSA) reportedly provide relief for caregivers. Caregivers remain hopeful that anticipated compensation from statutory bodies like the Road Accident Fund provides relief as this helps them to access health care and other basic services for care recipients. Previous studies have found that financial assistance serve as a facilitator in the process of caregiving. For instance, in the study by Pretorius and Steadman (2017), many caregivers indicated that they relied on the Care Dependency Grant from SASSA in order to survive. They often described the grant as their only source of income. The findings of the current study and those of Pretorius and Steadman (2017) imply that there is a dire need to provide financial support to assist caregivers in their roles.

From the interviews in the current study, it became apparent that prior caring experience was beneficial for some of the participants who had to care for loved ones who have suffered sTBI. For example, the experience of having worked in a health facility helped one of the caregivers to cope better with the role of caring for an injured family member. Other research participants expressed the same sentiment in that the experience that they gained in their previous caregiving roles assisted them in their new role of taking care of a family member who suffered sTBI. They also indicated that the experience that they gained in the role boosted their confidence and continued to help them in providing care to their loved ones. This is consistent with the results of a study by Duggleby et al. (2016) who found that confidence in the role and the ability to deal with difficult situations was positively related to improvement in the mental health of caregivers as a result of assisting in the provision of care. The study by Duggleby et al. (2016) focused on the relationships among the changes in health-related quality of life of family caregivers from baseline to six months. Even though the study by Duggleby et al. (2016) does not provide information regarding ways to support caregivers of older persons with multiple chronic conditions living at home, the findings do however point to the fact that there is a positive relationship between the general self-efficacy (the confidence in their ability to deal with difficult situations) of caregivers and their mental health.

The caregivers in the current study valued the support that they received from other people such as other family members and neighbours. Such external support from others was found to make a difference in the process of providing care. For example, some of the caregivers received support from their neighbours to help manage the care recipients. One participant was helped by her younger sister who also participated in the current study. The two sisters highlighted the importance of the support they give each other in helping their injured sibling. Previous studies also show that support that caregivers receive do play a positive role when it comes to caregiving. For example, Newcomb et al. (2018) noted that support from friends, family members, church groups, or neighbours who take care of specific tasks or carry out some important roles served as facilitators in supporting care recipients. A similar finding was made by Pretorius and Steadman (2017) in their study with caregivers of children with CP. Other studies have also found that support from community members played a significant role in assisting the caregiver (Durr & Greeff, 2020; Pretorius & Steadman, 2017). The above studies, including the results of the current study suggest that social support plays a significant role in mitigating against psychological distress for caregivers. Studies by Kratz et al. (2017) and Sabella and Suchan (2019) have found that social support plays a mitigating role against daily responsibilities that are at times experienced as overwhelming. Baker et al. (2017) on the other hand, found that social support coupled with other factors like good family functioning and coping skills were reported to reduce the burden that caregivers experienced, and promoted positive outcomes in the provision of care.

6.2.3.2 Barriers: As previously stated in the results chapter, caregivers identified physical handicaps, cognitive and mental difficulties, and financial constraints as some of the barriers that hinder effective caregiving. Orthopaedic injuries and physical impairments resulting from sTBI were identified as impediments in the provision of care as caregivers must help with basic self-care. The research participants found themselves having to perform tasks like turning and positioning the injured, and helping with feeding, toileting and mobility. The caregivers experienced the performance of these tasks as a barrier in the provision of care. There is ample evidence in previous studies showing that physical impairments hinder the performance of caregiving tasks (Durr & Greeff, 2020; Newcomb et al., 2018; Rawlins-Aldernam, 2014; White et al., 2007). For instance, a study by Hawkley et al. (2020) noted that physical functioning of the care recipient often declines which affects even the mental wellbeing of care recipients and caregivers. The study by Hawkley et al. (2020) compared mental and social well-being in marital partners who became a spousal caregiver versus those who remained non-caregivers or became caregivers for someone other than a spouse.

In addition to difficulties imposed by physical handicaps, the cognitive deficits that care recipients present with, impose difficulties in care provision. Research participants referred to neurocognitive disorders that include memory problems and language difficulties that care recipients display. For instance, a study by Raggi et al. (2015) found that disability following neurologic conditions is not only a hindrance to patients, but also for their caregivers. In the study, the International Classification of Functioning, Disability and Health (ICF) was used to describe the most relevant aspects of disability in patients with neurological conditions (Raggi et al. (2015). A similar finding was made by Griffin et al. (2017) in a study that sought to examine the relationship between caregiver stress (i.e., veterans' neurobehavioral problems and intensity of care required), and caregiver well-being (i.e., caregiver burden and mental health). The study also examined how intrapersonal, family, or social, and financial resources mediate and moderate the relationship between caregiver stress and well-being. In this study, the authors conducted a survey with 564 caregivers caring for veterans who served after September 11, 2001, survived TBI/polytrauma during service, and received inpatient rehabilitation care in a Veterans Affairs Polytrauma Rehabilitation Center. Structural equation modelling was used to examine the relationship between caregiver stress and caregiver well-being. The study by Griffin et al. (2017) found that the intensity of care required by care recipients and the neurobehavioural problems increased the burden of care for caregivers. In a study that compared mental and social well-being in marital partners who became a spousal caregiver, Hawkley et al. (2020) noted that as cognition declines, social activity becomes more difficult for both the patient and the spousal caregiver.

The current study found that mental difficulties that care recipients present with impose difficulties to the provision of care. Research participants were worried that some care recipients displayed behavioural problems and mental difficulties that made it difficult for them as caregivers to provide care. For example, two care recipients were on psychiatric treatment following their injuries. The caregivers reported that the behavioural problems and mental difficulties posed some challenges in the provision of care. For instance, it was difficult for caregivers to administer medication to care recipients who were mentally disturbed following their injuries. Behavioural problems such as anger and aggression were also reported by caregivers. Previous studies have found that mental problems on the part of care recipients impact negatively on caregiving. For instance, in the study that sought to determine if the disease of the care recipient affects the emotional state of the non-professional caregiver, Otero et al. (2019) found that caring for a care recipient with autism was related to having a probable mental health case and could be linked to the higher levels of challenging behaviour and aggressiveness of autistic care recipients. In a recent cross-regional study conducted in Hong Kong and New Zealand, care recipient behaviour problems were identified as one of the factors that contributes towards caregiver burnout (Chan et al., 2021). In their study, Chan et al. (2021) explored the prevalence and contributing factors of burnout of caregivers of community-dwelling older people with dementia in Hong Kong, China, and New Zealand.

The results of the current study show that financial constraints serve as a barrier to caregiving as this leads to caregivers feeling emotionally distressed. Some of the specific limitations imposed by financial constraints include inability to access health care and difficulties in providing for care recipients’ basic needs. Financial constraints as a barrier have also been reported in previous studies. In a study focusing on the effects of perceived financial costs on caregiving burden experienced by family caregivers, Lai (2012) found that caregiving imposed a significant financial burden on caregivers. A similar finding was made in a study that Bouldin et al. (2018) conducted with a view to assess whether financial or health-related barriers were more common among rural caregivers in ten states in the United States of America. The study further explored whether rural caregivers experienced more caregiving-related difficulties than their urban peers. The authors found that caregivers in the rural context had more financial barriers that impacted negatively on their ability to provide care. Pretorius and Steadman (2017) found that caregivers of children with CP identified financial difficulties as a barrier in the provision of care. The study by Pretorius and Steadman (2017) aimed to explore barriers and facilitators that caregivers of children with CP encounter through their daily caring roles in rural communities of the Western Cape in South Africa. A similar finding was reported by Mafune et al. (2017) who found that financial burden made it difficult for caregivers to take their care recipients for their medical check-ups. The study by Mafune et al. (2017) sought to explore and describe the challenges faced by caregivers of children on anti-retroviral treatment (ART) at Mutale Municipality, Vhembe District, Limpopo Province. What the above studies and the findings of the current study suggest is that in the process of providing care, caregivers are confronted with financial challenges that impact negatively on the provision of adequate care.

6.2.4 Essential attributes for caregiving

The results of the current study suggest that there are certain key attributes that a caregiver should have to provide effective caregiving. These attributes are caring and nurturance; patience, tolerance and acceptance; perseverance, resilience and courage; sacrifice, commitment and hope; love and compassion; and calmness and humility.

6.2.4.1 Caring and nurturance: Caregivers showed that attributes like nurturance and preparedness to care help them in the provision of care. Caregivers felt that such attributes assisted in making the care recipients calm and cooperative. This finding is consistent with the results of previous studies that have shown that higher caregiver nurturance is associated with larger declines in avoidance on the part of the care recipient (Chopik et al., 2014). The study by Chopik et al. (2014) examined the influence of caregiver nurturance on the development of attachment orientation from adolescence to emerging adulthood. Chopik et al. (2014) concluded by indicating that caregivers' nurturance has enduring influence on the development of attachment orientation during emerging adulthood. In another study that sought to describe the attributes of meaningful encounters in the Swedish healthcare system based on patients' and caregivers' written narratives, Snellman et al. (2012) found that there are similarities and differences in patients' and caregivers' opinions about the attributes of a meaningful encounter. The authors noted that nurturance was offered through communication with words and communication through body language. In the study, nurturance through words helped patients to be relaxed and being empowered. As some patients lacked the will to talk, communicating by showing a friendly face or with gentle hand and eye contact created a feeling of nurturance. It was also found that knowing about the attributes associated with meaningful encounters makes it possible for caregivers to individualise care and makes it easier to help and support patients in what they need support for (Snellman et al., 2012).

6.2.4.2 Patience, tolerance, and acceptance: The results of the current study suggest that patience, tolerance, and acceptance are some of the important attributes that a caregiver should have in order to provide adequate care. Patience as an important caregiver attribute has also been identified in previous studies. For instance, Adams and Dahdah (2016) found that patience was needed when fulfilling the caregiving role for adult TBI survivors. The study by Adams and Dahdha (2016) explored the needs and deficits of adult TBI survivors and primary caregivers. The study identified coping and adaptive strategies that care recipients and caregivers initiated for themselves, including coping and adaptive strategies that participants adopted after their discharge from inpatient and rehabilitation treatment. In a study that explored the relationship of caregiving burden and distress tolerance with self-health care among mentally ill women, Ram (2017) found that caregiving burden was inversely associated with ability to tolerate distress. Thus, caregiving burden was found to be less in situations where distress was tolerated appropriately. A study by Cheng et al. (2016) focusing on family caregivers of relatives with Alzheimer's disease also found that caregivers learned to become more tolerant and patient.

In addition to patience and tolerance, acceptance is perceived by some caregivers as one of the important attributes in caregiving. For example, one of the caregivers put it in this way:

> "*Yes. I have learnt to accept his condition and to live with it. I have learnt to be patient and to accept his condition the way it is. I did not have any choice as that is the way he is. If I do not accept the way he is, there is no way I will deal with his condition."*

The significance of acceptance as a caregiver attribute has also been indicated in previous studies (Cheng et al., 2016; Gurayah, 2015). One such study was conducted by Duggleby et al. (2013) to investigate the hope experience of family caregivers of persons with dementia living in a long-term care (LTC) facility. The study found that caregivers indicated the importance of accepting their own situation as well as the care recipients' situation so that they could move forward and connect to the care recipients in different ways. Duggleby et al. (2013) further reported that caregivers needed to accept that the cognitive abilities of their family member or friend would not improve. Such acceptance tended to help caregivers to reframe their hope in the way they related to the care recipient.

6.2.4.3 Resilience, perseverance, and courage: The results of the current study suggest that resilience, perseverance, and courage are essential caregiver attributes in caring for persons who have suffered sTBI. There is ample literature to show that resilience is one of the key factors in caregiving. For instance, in a study that investigated biopsychosocial resilience in an older adult caregiver, Ewen et al. (2015) found that resilience was characterised by buffering significant stress through cognitive reframing and acceptance of interpersonal limits. A systemic review conducted by Teahan et al. (2018) shows that resilience is a multifaceted response to the caregiving role and is influenced by a multitude of interrelated factors. It was on the basis of the multifaceted nature that Teahan et al. (2018) proposed a model of resilience for family carers of people with dementia, which incorporates the context of caring, social, and cultural characteristics, and psychological dimensions of caring. In another review that focused on resilience and associated variables in caregivers of patients with chronic, advanced illness and at the end of life, Palacio et al. (2020) found that resilience was associated with a positive impact on the quality of life and emotional distress. In the review, communication and social support were found to increase resilient coping strategies (Palacio et al., 2020).

In a study that focused on families with children with severe or profound intellectual disability, Durr and Greeff (2020) found that perseverance was one of the attributes that sustained such families. A similar finding regarding the need to persevere was reported by Gurayah (2015) who conducted an exploratory pilot study into the phenomenon of caregiving for people with dementia in a rural context in South Africa. Through perseverance, some of the participants in Gurayah's (2015) study perceived dementia as a normal part of ageing and did not consider it as a mental illness. As a result of this perception, they took the problem behaviours in their stride and continued to provide the care needed. In a study by Snellman et al. (2012), courage was reported as one of the attributes that facilitated meaningful encounters between care recipients and caregivers. Snellman et al. (2012) noted that it was a relief for patients to meet courageous caregivers who were fearless and stayed with them when they were in a chaotic health condition. This implies that care recipients acknowledge that the courage that caregivers display help them to cope with the functional difficulties that they experience. Courage was also described as caregivers' ability to make demands on care recipients.

6.2.4.4 Sacrifice and commitment: The results of the current study show that sacrifice is one of the key attributes that a caregiver is expected to have. Two of the participants in the current study indicated that they had to stop other personal activities so that they can dedicate their time to caring for their loved ones. This suggests that caregivers are often required to sacrifice their own interests for the sake of others. This finding resonates with the results of a study by Van Nistelrooy (2014) who pointed out that the act of caregiving in itself implies some sort of self-sacrifice. In this study, van Nistelrooy (2014) aimed to extend on Ricoer's (van Nistelrooij et al., 2014) argument that giving of the self or even giving one's life may be the ultimate expression of one's belonging, in friendship, devotion or loyalty, thereby supporting the claim that some sort of self-sacrifice is implied in the very act of caring for others. In conclusion, van Nistelrooy (2014) stated that caregiving "… brings to our attention the fact that care situations often are not situations that we freely chose, but situations that are given to us, that we find ourselves in, as a consequence of being related, of being someone's relative, of being in a position to care" (p. 527).

Commitment emerged as one of the caregiver attributes that was associated with sacrifice. Caregivers, especially the three research participants who were providing care to their spouses, indicated that it was important for them to show commitment when providing care to their loved ones who have suffered sTBI. A similar finding was made by Lin et al. (2012) who found that commitment was one of the factors that caregivers indicated as an essential element in caregiving. The findings by Lin et al. (2012) were based on a longitudinal, grounded theory study conducted in three phases with spouses of care recipients. Specifically, the study by Lin et al. (2012) sought to identify, describe, and explore the changes in caregivers' experiences of looking after a relative living with dementia, including the impact of caring on the caregivers' autonomy and health over a period of time. The findings by Lin et al. (2012) are consistent with those by Cheng et al. (2016) who found that caregivers who were caring for relatives with Alzheimer's disease identified with the role and were committed to it. The implication of the current study and those by Lin et al. (2012) and Cheng et al. (2016), is that, sacrifice and commitment are critical caregiver attributes when caring for people who have suffered sTBI or a debilitating health condition such as dementia.

6.2.4.5 Love and compassion: Caregivers in the current study indicated that love and compassion were important attributes that helped them to care for their injured family members. In a review of articles that focused on motivations for being an informal carer, Greenwood and Smith (2019) found that the act of caring was underwritten by love. The review by Greenwood and Smith (2019) focused on factors that motivates individuals to take the role of being an informal carer of people living with dementia. Though limited in its scope as it only focused on literature on motivations, Greenwood and Smith's (2019) study does highlight the significance of love as being both a motivating factor and an attribute in caregiving. Similarly, compassion was identified as an important attribute in a study by Goodrich (2016) that aimed to understand a compassionate relationship between a caregiver and patient. Being kind, taking time to be with the patient and touching them were found to be acts of compassion (Goodrich, 2016). Snellman et al. (2012) also noted that being humane and showing love to patients are important attributes in caregiving. Based on the findings of the current study and studies reviewed above, it does appear that love and compassion are some of the necessary caregiver attributes that facilitate effective caregiving.

6.2.4.6 Calmness and humility: The results of the current study show that there is a need on the part of caregivers to consistently remain calm and being humble. One of the caregivers in the current study indicated that what helps her a lot is being cool headed and not allowing anger to get in her way. She further pointed out that she tries to stay calm even when she finds herself in a situation that may result in loss of temper. The sentiment of calmness was also reported by caregivers as an attribute that is associated with meaningful encounters with care recipients in a study by Snellman et al. (2012).

6.2.5 Coping strategies

As already reported in the results chapter, the findings indicate that there are four types of strategies that caregivers rely on to cope with the task of caring for loved ones who have suffered sTBI. These are identified as: social coping; appraisal-focused coping; problem-focused coping; and emotion-focused coping.

6.2.5.1 Social coping: The results of the current study show that the support that caregivers received from other people assisted them to cope with their care role. For instance, six research participants reported that the support they received from other members of the family, neighbours and members of the community provide them with the strength to continue providing care. In a study that aimed to determine the associations between caregiving burden and the use of coping strategies among caregivers of older patients with a history of stroke, Kazemi et al. (2021) found that caregivers relied on social support to help them cope. The same finding was noted by Rao et al. (2020). In the study by Rao et al. (2020), caregivers were found to often use adaptive coping mechanisms that included seeking social support. The study by Rao et al. (2020) sought to evaluate the coping strategies, including religious coping, used by the caregivers of patients with schizophrenia to deal with caregiving stress. Based on the findings of the current study and the results of the previous studies such as those of Kazemi et al. (2021) and Rao et al. (2020), it can be concluded that social support help caregivers to cope with the responsibilities of the caregiving role.

6.2.5.2 Appraisal-focused coping: Difficulties in having to cope with the disability continue to be a daily challenge. Spousal caregivers reminisce about the premorbid state of their relationships as couples, realising and accepting that the relationships have changed because of the injury. For example, intimacy is no longer possible. Even though there is an indication of difficulty in accepting the condition initially, there is acceptance of the condition and learning to live with it. The process of re-thinking and coming up with a way of coping (appraisal-focused coping) has been presented in literature. For instance, in their study, Rao et al. (2020), found that positive reappraisal was associated with lower level of psychological morbidity among caregivers. The same sentiment was noted by Kazemi et al. (2021) who found that positively interpreting situations (positive reappraisal, wherein thinking about stressful events may be re-framed) was a coping strategy that caregivers used. Some previous studies have also found that appraisal-focused coping was practised by mothers who were caring for their children with chronic illnesses and diseases. For instance, a study by Sodi and Kgopa (2016) that explored coping strategies by South African mother carers of children with chronic illnesses and diseases (CID), found that mothers coped by accepting and loving their children unconditionally.

6.2.5.3 Problem-focused coping: The results of the current study show that caregivers develop ways that focus on what they would have identified as problems and come up with ways of targeting the identified problem. They would for example, come up with treatment plans that assist them to cope with their roles of being caregivers. Literature shows that confrontive coping and planful problem-solving, classified under problem-focused coping help caregivers to cope with the role (Kazemi et al., 2021). The same sentiment was noted by Hawken et al. (2018) in their systemic review of coping and adjustment in caregivers. In the systemic review by Hawken et al. (2018), problem-focussed coping as a method that caregivers used to adjust to the role and responsibilities of caregiving was associated with more positive adjustment and outcomes.

6.2.5.4 Emotion-focused coping: There is an indication that caregivers develop ways to help themselves emotionally. For example, relying on spiritual support for their emotional stability and trying to stay calm helped the caregivers to cope emotionally. The systemic review by Hawken et al. (2018), shows that even though there may be a negative relationship between emotion-focused coping and psychological wellbeing, some qualitative studies noted subjective reports of helpful emotion-focused coping strategies. These qualitative subjective reports indicate the importance of considering individual circumstances. Kazemi et al. (2021) also referred to the use of emotion-focused coping as a way of coping with a caregiving role. In a study that I have already cited above, Sodi and Kgopa (2016) concluded that the way mothers cope emotionally helps them to best manage their children's CID.

6.2.6 Motivation for caring

The findings of the current study suggest that caregivers continue to provide care to their loved ones despite the emotional difficulties and other barriers they face in their caring role. The following factors were identified as motivators that inspire caregivers to continue caring for persons with sTBI: caring as an obligation and a sense of duty; caring as an act of reciprocity; caring as labour of love; and the confidence resulting from the experience of caring.

6.2.6.1 Caring as an obligation and a sense of duty: The different relationships that existed between care recipients and their caregivers seem to determine the care that needs to be provided. Some caregivers were of the view that being a parent, sibling, or spouse of the injured person, for instance, made caregiving to be obligatory. They feel that it is their duty to care for the injured family member. In a study that focused on identifying, describing, and exploring the changes in the caregivers' experiences of looking after a relative living with dementia, including the impact that caring has on the caregivers' autonomy and health over time, Lin et al. (2012) found that participants referred to a sense of duty when looking after a relative living with dementia. The sense of kinship as a motivating factor for caregiving has also been noted in previous studies (Gurayah, 2015; Kim, 2009). In the study that explored the phenomenon of caregiving for people with dementia in a rural context in South Africa, Gurayah (2015) found that participants expressed a strong sense of kinship and duty in caring for their relatives. A similar finding was made by Kim (2009) who, in an earlier study, found that caregiving was a family affair that runs within families, with the children feeling that they must care for the elderly. The implication here is that caregivers feel an obligation to provide care by virtue of being a family member. For example, caregivers indicated that the kind of relationships that they had with the injured person who is a member of the family is what motivate them to continue with that role.

Caring as a sense of duty in a family context does appear to be a strong motivating factor for spouses who played a caregiving role. For example, one caregiver indicated that she had partner relationship problems with her husband before the injury happened. Following the husband's injury, she put aside the problems and took on the role of being a caregiver. She also perceived her actions as a way of showing the value that families attach to their individual members. This finding is consistent with results of previous studies that have found that caregivers who were spouses to care recipients referred to the commitment that they made in marriage as a factor that obliges them to provide care to their husbands. For instance, Tzitzika et al. (2020) found that commitment to marriage is positively associated with relational satisfaction. The study by Tzitzika et al. (2020) investigated possible effects that commitment to relationship, caregiving burden, and pro-relational behavioural tendencies have on relational satisfaction.

In their study with Chinese-Canadian female caregivers, Ho et al. (2003) found that cultural obligation served as a motivating factor for caregivers to care for their relatives with Alzheimer's disease. The motivating role of culture in caregiving was also highlighted by McDonnell and Ryan (2014) in a study that sought to explore the experiences of sons caring for a parent with dementia. They used semi structured interviews to explore the experiences of sons who were providing care to their parents with dementia. They found that parental bond and the strong sense of duty motivated sons to be committed to their caregiving roles.

6.2.6.2 Caring as an act of reciprocity: The caregivers in the current study indicated that the improvements they observed on the part of care recipients motivated them to continue with their roles. In other words, there seems to be some form of reciprocal benefit for both the caregiver and care recipient when the condition of the care recipient improves. Previous studies have also reported on the role that reciprocity play in caregiving (Lin et al., 2012; Quinn et al., 2020). For instance, Quinn et al. (2020) noted that caregiving competence had an association with outcomes for the person with dementia. Thus, “it is possible that caregivers’ level of competence is influencing their caregiving behaviour and in turn influencing the person with dementia” (Quinn et al., 2020, p.1510). The study by Quinn et al. (2020) sought to identify the potential impact of caregivers’ perception of the caregiving experience on how people with mild to moderate dementia self-rate their quality of life, well-being, and satisfaction with life. The study utilised data from 1283 informal caregivers and the 1283 people with dementia. Multivariate modelling was used to investigate the associations between measures related to the caregivers’ perception of the caregiving experience. The findings of the current study and those of the study by Quinn et al. (2020) indicate that improvement in the functioning of the care recipient encourages the caregiver to continue providing care, thereby benefiting the care recipient.

6.2.6.3 Caring as labour of love: In addition to love being considered an essential attribute for caregiving, the results of the current study show that love for the injured family member motivated the participants to take on the caregiving role. For example, one of the participants indicated that the love that they have as siblings made it easy for her and her sister to take the responsibility of providing the care for their brother. The finding on caring as a labour of love is consistent with the results of previous studies (Durr & Greeff, 2020; Snellman et al., 2012). For instance, a study by Durr and Greeff (2020) found that the love that family members shared amongst themselves, and the love for children with severe or profound intellectual disability assisted the families to be resilient in their role of providing care. Durr and Greeff’s (2020) study was focusing on qualities and resources utilised by families with children with severe or profound intellectual disabilities. What the study suggests is that love is one of the important characteristics in family resilience. Based on the results of the current study and the findings by Durr and Greeff (2020) it can be concluded that love play a significant role in caregiving, contributing to improvement in the care recipient's wellbeing and better general family functioning.

6.2.6.4 Caregiving and confidence building: The findings of the current study indicate that the experience that caregivers develop in the process of fulfilling their roles of providing care gave them confidence and serves as a motivating factor for them to continue providing care. Previous studies (Dizazzo-Miller et al., 2020; Lin et al., 2012) also show that the confidence that caregivers gain in the role motivates them to continue providing care. For instance, Lin et al. (2012) found that even though caregivers experienced changes, they learned through experience to manage their situations. In the study that examined how 'The Family Caregiver Training Program' impacts caregiver confidence, Dizazzo-Miller et al. (2020) found that lack of confidence impacts caregiver distress, thereby having a tremendous influence on the overall health of caregivers. To boost confidence for caregivers, the authors suggested implementation of training programmes that include follow-up visits. The findings of the current study together with those of Lin et al. (2012) and Dizazzo-Miller et al. (2020) indicate that the confidence that caregivers gain in the role serve as an important motivating factor as they continue with the provision of care.

6.3 Proposed Psychological Explanatory Model of Caregiving

The previous section discussed the findings of the current study in relation to existing literature. There is an indication that the caregiver of a family member who has suffered sTBI goes through some profound emotional experiences. These emotional experiences result in caregivers having to come up with ways to cope with their new role. Based on the findings from the phenomenological explication in the results chapter and guided by Wacker's (1998) theory, I propose a psychological explanatory model for caregiving. The model considers the different emotional experiences that caregivers go through, the meanings they attach to the role and their ways of providing care. It also factors in the facilitators and barriers in the provision of care, attributes that caregivers consider to be essential in fulfilling their caregiving responsibilities, and the factors that motivate them to continue providing care.

6.3.1 Guidelines for developing the psychological explanatory model

As already pointed out in Chapter 4 (Research Design), I followed Wacker's (1998) guidelines for good theory-building in developing and articulating the psychological explanatory model. In this regard, I was guided by the following four steps of theory building: defining the variables, limiting the domain, relationship (model) building, and theory predictions and empirical support. Below, I demonstrate how I have gone about developing the psychological explanatory model for caregiving in accordance with Wacker's (1998) four steps.

6.3.1.1 Defining the variables: As Wacker (1998) has pointed out, the initial step in theory-building involves defining who and what is included or excluded in the definition of the variables. In my model, I identify the key variables to be caregivers and caregiving. In other words, the phenomenon of caregiving is what the model seeks to define, including the role of caregivers and a proposition of the ways of relating to this experience. Caregiving in the model involves what it means for caregivers to care for adult family members who have suffered sTBI and their experiences because of their caregiving role. The meanings that caregivers attach to caregiving entail their understanding of the circumstances that led to the need for caregiving, including the physical, cognitive, and mental status of the care recipients, cultural explanations and their belief in God. The actual act of providing care, the emotions elicited, and the changes in the caregivers' social lives are critical experiences associated with caregiving as an important variable.

6.3.1.2 Limiting the domain: According to Wacker (1998), the second step entails identifying and articulating the antecedent events that could have led to the key variable and how the key variable is linked to subsequent variables. Accordingly, I propose that severe traumatic brain injury is the antecedent event that has triggered the caregiving experience and called for caregivers to take the role. In other words, it is the injury that got caregivers to take the role of caregiving. Help seeking behaviour on the part of the caregiver and the family, as well as the actual provision of care are some of the actions that follow the antecedent event.

6.3.1.3 Relationship (model) building: As Wacker (1998) pointed out, relationship or model building typically begins after the key variables (caregivers and caregiving) and the domain (severe traumatic brain injury) have been specified. From here, I move on to establish the logical connections between the key variables and consequent variables interlinked to the key variables. In this regard, I relate caregivers and caregiving to a wide range of other consequent variables (that is, meanings attached to the injury, experiences that caregivers have, attributes, facilitators, barriers experienced, coping strategies and motivating factors). Figure 6.1 below is a graphical representation of the psychological explanatory model.

6.3.1.4 Theory predictions and empirical support: In line with Wacker's (1998) suggestion of having to give specific predictions, I posit that the psychological explanatory model that I have proposed here allows for fair predictions regarding the caregiving experience, the antecedents and the consequent reactions and behaviours associated with sTBI. It is therefore up to future research to test the applicability of the psychological explanatory model that is proposed here.

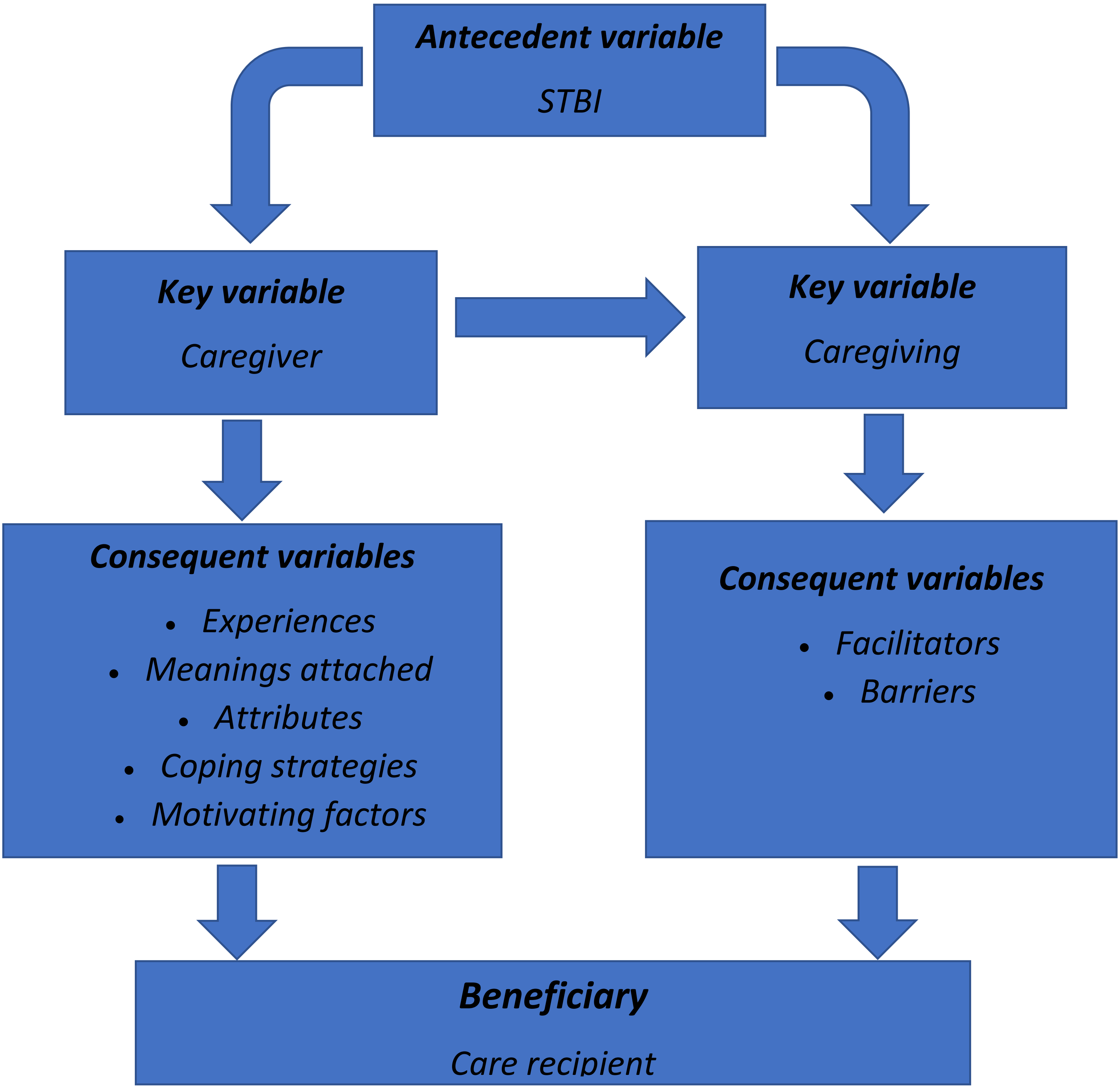
Given the fact that the current study was qualitative in nature, generalisability was not envisaged. It is however important to note that the findings and the model explain the phenomenon and provide guidance in understanding, and ways of coping with the role of being a caregiver. Regarding parsimony, the model is put in simple terms and there are no exorbitant costs implied. There is consistency and logic regarding identified concepts and what is outlined in the model. Future research can build on the current model given the fact that it is replicable.

6.3.2 The proposed model for caregiving

The current study shows that caregiving calls for individuals to be dedicated to the role given the difficulties that they experience. The proposed model (see Figure 6.1 below) indicates that caregiving and caregivers are the main variables that are interlinked with antecedent and consequent variables. The consequent variables include meanings attached to the injury, experiences that caregivers encounter, attributes, facilitators, barriers experienced, coping strategies and motivating factors. All these variables impact on the provision of care to the care recipient.

Figure 6.1

Psychological Explanatory Model of Caregiving



6.3.3 Description of the model

6.3.3.1The antecedent variable (The injury): The need to provide care resulted from a sTBI that an adult member of a family suffered. A fellow member of the family offers to take care of the injured. The model proposes that it is important for the family member who takes the responsibility of being a caregiver to understand the injury. Thus, caregivers should be knowledgeable about the injury and the consequences thereof. This entails having to know about the severity of the injury in terms of functional possibilities, progression of recovery, possible cognitive impairments, physical handicaps and possible behavioural responses associated with the injury. Specific information to be obtained by the caregiver could include for example, information about the possibility of care recipients showing fluctuations in mood and behaviour changes.

6.3.3.2 The key variables: Caregivers and caregiving: The findings of the current study show that caregiving is one of the key variables that is triggered by the antecedent event (that is, the sTBI). Caregivers are drawn to caregiving following the brain injury of an adult family member. Based on the phenomenological accounts of the caregivers, it is evident that there is a need on the part of the caregiver to understand the role and the activities that caregiving entails.

Caregivers made decisions to provide care to their injured family members. As they take the decisions to take caregiving as their roles, there are factors that they experience and interact with that serve as consequent variables. Such factors that serve as consequent variables interlinked to caregiving include having to make sense of the injury. Thus, attaching meanings to what the injury is. Caregivers also experience caregiving with emotional reactions and must find ways to cope with these emotional reactions. It emerged that in the process of caring, there are attributes that are considered essential by the caregivers themselves to fulfil the role. Caregivers also develop strategies that help them to cope with caregiving and they find factors that motivate them as they continue in the role.

6.3.3.3 Caregiver related consequent variables

Meanings attached to the injury and caregiver experiences

Caregivers experience caregiving as a fundamental experience that significantly disrupts their social and occupational functioning. For instance, a few research participants reported having to put aside their personal activities so that they could care for the injured family member. In some instances, relationships were terminated resulting in limited engagement in social activities on the part of the caregiver. The proposed model suggests that caregivers attach different meanings to the injury of their loved ones. These include biological and physical explanations as well as relying on spiritual explanations. For instance, some of the research participants perceived the injury as God's will. For those who tended to explain the injury in spiritual terms (that is, as the will of God), the act of caring was perceived as a form of destiny. Cultural explanations are also advanced in explaining the injury. Cultural beliefs provided support and resilience, in that some caregivers relied on these to help them deal with situations that could bring possible conflicts and sadness. Thus, caregivers reject the view that there could be evil forces or intentions by others that may have caused the injury.

Attributes

The current study shows that caregivers need to have attributes that assist them in the provision of adequate care. The attributes that the proposed model identifies include caring, nurturance, patience, tolerance, acceptance, perseverance, resilience, courage, sacrifice, commitment, love, compassion, calmness, and humility. Even though it may not be possible for a caregiver to possess all these attributes, it is proposed that caregivers should have at least some of these attributes in order to make their task of caring more bearable.

Coping strategies

The proposed explanatory model of caregiving indicates that caregivers develop strategies that help them to cope with the caregiving role. The identified coping strategies include social coping, appraisal-focused coping, problem-focused coping, and emotion-focused coping. For instance, support that caregivers receive from other people helps them to cope with the demands of caregiving. Caregivers also get to a point of accepting the changes that are brought by the family member's injury. When acceptance happen, it helps caregivers to cope with the expectations of the role. Coping strategies also include having to identify specific problems and coming up with solutions. For example, with the acceptance of the care recipient's limited level of functioning, some caregivers developed activities to target specific problems like having a structure to provide specific interventions.

Motivation for caring

There are factors that motivate caregivers to continue providing care. Such factors include caring as an obligation and a sense of duty; caring as an act of reciprocity; caring as labour of love; and the confidence that caregivers develop through the experience of caring. Caregivers feel obliged to continue caring due to the relationships they have with the injured family member. The recovery and progress in the functioning of the injured person also motivates caregivers to continue with care. The existing love for the injured, and experience that caregivers gain in the process of caring motivate them to continue caring.

6.3.3.4 Caregiving related consequent variables: In the process of caregiving, there are factors that are perceived to facilitate caregiving and those that hinder caregiving. A description of these factors is presented below.

Facilitators

The model shows that there are factors that caregivers experience as enablers for caregiving. Such factors include having access to healthcare facilities, financial support, prior experience and support from others.

Barriers

Factors such as care recipients' physical handicaps, cognitive and mental difficulties, as well as financial constraints were identified as some of the barriers that hinder effective caregiving. Thus, the functional difficulties that are caused by the injury make it difficult for caregivers to provide care as care recipients present with physical, cognitive and mental difficulties. Financial constraints also impose challenges as it becomes difficult for caregivers to afford some of the needs for the care recipients. For example, most of the participants mentioned the high costs as a significant factor that hinders access to treatment, care and rehabilitation for their injured family members. High costs were mostly associated with money that was needed to travel to health care facilities.

6.3.4 The psychological explanatory model and caregiving skills

Based on the phenomenological accounts and the proposed psychological explanatory model that I have presented above; it is evident that caregivers need to have some caregiving skills in order to function effectively in their role. Some of the skills identified are presented below.

6.3.4.1 Communication and sharing of information: This involves sharing of information with caregivers. There is a need for caregivers to understand the level of functioning of the care recipient. For example, the caregiver's awareness and appreciation of the capabilities and limitations of the care recipient is critical information. Such empowering information can be provided by the health care practitioners at discharge from care facilities or during check-up visits. There is a need for caregivers to talk to care recipients. This involves general communication and where relevant, having to share information regarding caretaking. This is dependent on the level of comprehension of the care recipient.

6.3.4.2 Understanding the mood and behaviour changes of the care recipient and self as a caregiver: Mood fluctuations have been identified as one of the emotions that care recipients present with. Caregivers also indicated their own emotional instabilities at times. There is a need for caregivers to acknowledge the difficulties and frustrations experienced because of fluctuations in the care recipient's and their own mood.

Caregivers need to understand the self to be able to take the role and be able to execute it properly, and to develop ways to manage their own tempers as caregivers.

6.3.4.3 Positive thinking and optimism: The caregivers indicated that given the exhaustion they experience emotionally and physically, thinking positively gives them strength to continue with the caregiving role without experiencing stress. For example, one participant who was caring for her husband, indicated that she had told herself that her emotional and physical well-being will be restored in the future as her husband was recovering, albeit slowly.

6.3.4.4 Encouraging social interaction: The research findings show that encouraging care recipients to interact socially is helpful. This can be achieved by allowing the care recipients to meet with friends that they had pre-morbid. The research participants did however indicate that arrangements for such social interactions should be tried only when there is an indication that the care recipient stands to benefit. This is because in some instances, care recipients did not show interest in engaging in such social interactions. Some care recipients could not even remember the friends that they had pre-morbid.

6.3.4.5 Developing a schedule for daily chores and activities: This can include having a schedule for skills training for the care recipient. For example, teaching of skills to the care recipients, and engaging in activities such as physical exercise and cognitive stimulating tasks to improve functioning. One of the caregivers indicated that she bought exercising equipment for the care recipient to help with physical skills training. There was also an indication that having a daily activity schedule helps to ease the burden of caring. In other words, engaging a care recipient in this way would at times enable the caregiver to have time to do other things. Caregivers also highlighted the importance of giving fewer instructions as the care recipient may not have the requisite attention and concentration capabilities to deal with detailed instructions.

6.4 Concluding remarks

In this chapter, I discussed the study's findings in relation to the existing literature about caregiving. Specifically, the following superordinate themes were discussed in relation to existing literature: the lived experiences of caregivers; the meanings associated with caregiving; what caregivers perceive as facilitators and barriers; and attributes that are considered to be essential in providing care. The strategies assisting caregivers to cope with their caregiving role and the factors that motivate them to continue in providing care were also discussed in relation to existing literature. Even though the focus of the current study was on caregivers of family members who suffered sTBI, the findings are consistent with results of other studies that investigated other debilitating conditions such as dementia, schizophrenia, other conditions of the nervous system like spinal cord injuries, and other medical conditions related to anti-retroviral and maternal care. This implies that the experiences and ways of coping associated with caregiving are generally similar despite the disability or condition that call for the provision of care.

A model that could assist in caring for adult family members who sustained sTBI was also presented. The proposed Psychological Explanatory Model of Caregiving shows that a sTBI brings the need for care to be provided. Family members of the injured person need to understand the injury and the implications it holds. Furthermore, there are emotional encounters that caregivers and care recipients experience. Attributes and factors that assist the caregivers in the provision of care are indicated. Even though some barriers are experienced, there are various factors that help caregivers to cope with their role and motivate them to continue with caregiving. This chapter discussed in detail the themes in relation to existing literature and proposed a model that can assist caregivers. Summary and conclusion for the study are presented in the next chapter.

CHAPTER 7: SUMMARY AND CONCLUSION

7.1 Introduction

The aim of the current study was to explore the experiences of caregivers caring for an adult family member who sustained severe traumatic brain injury. Central to the study was to gain an understanding of the caregivers' lived experiences as they relate to sTBI. Following the findings, an explanatory model for caregiving was developed. I start the chapter by presenting a summary of the superordinate themes and their corresponding themes. This is followed by a brief summary of the psychological explanatory model. The implications of the study and its limitations are also presented.

7.2 Summary of the superordinate themes and their corresponding themes

The study yielded six superordinate themes and corresponding themes that are related to the experiences of caregiving for an adult family member who suffered sTBI. The superordinate themes are as follows: caregiver lived experiences, attributions and meaning making, facilitators and barriers, essential attributes for caregiving, coping strategies, and motivation for caring.

7.2.1. Caregiver lived experiences

When the caregivers narrated what it means for them to live with and care for a family member who has suffered sTBI, the following corresponding themes emerged: caregivers' understanding of life before the injury; the act of caregiving; help seeking pathways and experiences; the emotions elicited during caregiving; and the social life of the caregivers.

7.2.1.1 Caregivers understanding of life before and after the injury: The results of the current study show that severe traumatic brain injury significantly disrupts the care recipients' premorbid personal, social and occupational functioning. The injury affects care recipients who were high functioning individuals who had management and occupational responsibilities. They present with cognitive impairments that make it difficult for them to lead their lives independently. For example, their speech gets to be affected; they get to be forgetfulness; they experience mobility problems; and may have limb weakness or loss of functioning of some parts of the body. Following the injury, care recipients often experience a wide range of feelings such as sadness, depression, and anger as they find it difficult to accept the functional changes that have imposed limitations on their ability to care for themselves.

7.2.1.2 The act of care giving: Given the functional limitations like physical disabilities, cognitive impairments, and behavioural difficulties that are characterised by changes in mood that care recipients display, the act of caregiving implies providing basic care and constant support. Caregivers must deal with the disabilities and limitations in functioning that care recipients present with. They are expected to perform critical tasks like bathing care recipients, helping with toileting, dressing them, transferring and positioning them, preparing meals, helping with feeding and mobility.

7.2.1.3 Help seeking pathways and experiences: When faced with a family member who has suffered sTBI, caregivers are faced with the responsibility to seek help for their injured family member. The process of seeking help includes taking their injured family members to health practitioners and health facilities such as local clinics and rehabilitation centres. There is an indication that help seeking behaviour tends to be influenced by what the caregiver perceives as the most optimum option.

7.2.1.4 Emotions elicited during caregiving: The experience of caregiving entails emotions such as shock, denial, anger and frustration, and loss of hope. These emotional responses are triggered by having to provide even basic care, and general interaction with care recipients that is often characterised by mood fluctuations. In addition to emotions experienced in the act of caring, caregivers also get to feel hopeless and discouraged at the lack of progress and unlikely improvement on the part of care recipients.

7.2.1.5 The social life of caregivers: The responsibility of caring for a loved one who has suffered sTBI affects the social lives of caregivers to a great extent. For some caregivers, this entails having to abandon their personal preferences to take care of their injured family member. For instance, some caregivers had to significantly limit their personal and social relationships because they had to prioritise the needs of care recipients over their own. The decision to take up the role of being a caregiver is important as caregivers even give up their personal preferences such as intimate relationships and attending social gatherings.

7.2.2 Severe traumatic brain injury and meaning making

In trying to understand the injuries, the caregivers relied on biological and physical explanations. There was however an indication that caregivers also attempted to find meaning and to make sense of what has happened. In the process of trying to find meaning and making sense of events, the following themes emerged: believing in God, caring as destiny, and caregiving and cultural explanations.

7.2.2.1 Believing in God: Some caregivers relied on spirituality to make meaning of the injuries suffered by their loved ones. For instance, they believed that God knows about the injury, and that He will help with the recovery process. They got courage and strength from their spiritual beliefs and attributed life to the power of God. Spirituality also helped caregivers to accept their fate and to persevere in the face of adversity. Believing in and trusting God assisted caregivers to make meaning of the circumstance surrounding the injury and having to take the responsibility of caring.

7.2.2.2 Caring as destiny: The caregivers believe that the role of being a caregiver was meant to happen. The injury and having to take the responsibility of caring is perceived to be a destiny that caregivers could not avoid.

7.2.2.3 Caregiving and cultural explanations: The current study shows that cultural practices and belief systems play a role when it comes to assuming a caregiving role. Cultural beliefs also provide resilience and strength when a caregiver is faced with difficulties. Contrary to what exists in the literature, the findings of the current study do not support the view that there could be evil forces or intentions by others that may have caused the injury. Instead, the findings of the current study suggest that culture plays a significant role as far as it inspires caregivers to look after and care for their loved ones.

7.2.3 Facilitators and barriers

There are factors that caregivers found to facilitate the process of providing care. Such factors include access to health care facilities, financial support, previous experience related to caring, and support from others. On the other hand, physical, cognitive, and mental problems on the part of the care recipient, and financial constraints were perceived as some of the barriers that hinder effective caregiving.

7.2.3.1 Facilitators

Access to health care facilities: The caregivers found having access to healthcare facilities as being a factor that assisted them with the provision of care. They indicated that access to health care facilities assisted in managing the care recipients, especially those that tended to present with mental problems.

Financial assistance: The financial assistance that was received helped caregivers to be able to afford stuff required in the provision of care. It was indicated that state disability grants that care recipients received from SASSA provide the financial assistance required to care. For those whose injuries were caused by road accidents, there was hope that the monetary compensation that care recipients are likely to receive from RAF will provide relief that will enable access to health care and other basic services for care recipients.

Previous experience related to caring: The results of the current study show that caring experiences that some caregivers had prior to taking on the new role, was beneficial. For example, such previous experience includes having worked as a nurse. The experience that caregivers gained in the role assisted them to manage better with time. Caregivers also indicated that the experience gained boosted their confidence and helped them to continue providing care to their loved ones.

Support from others: The caregivers indicated that the support they received from other people helped them in their new role. Such support was received from other members of the family, neighbours, and health care professionals. Family members who assisted with care made it easier for the primary caregiver as there were moments to have some rest. Neighbours on the other hand helped in situations where the caregiver was unable to restrain the care recipient. The caregivers appreciated the support that they received from health care professionals when they took care recipients for consultations.

7.2.3.2 Barriers

The results of the current study show that barriers include physical handicaps, cognitive and mental difficulties, and financial constraints that hinder effective caregiving.

Physical handicaps: The caregivers identified orthopaedic injuries that often resulted in physical impairments as a factor that make it difficult for them to provide efficient care. The difficulty is imposed by the inability on the part of care recipients to perform basic self-care activities. As a result of these handicaps, caregivers are expected to perform tasks like turning and positioning the care recipient, helping with feeding, toileting, and mobility.

Cognitive and mental difficulties: The care recipients involved in the current study presented with neurocognitive disorders that include memory problems and language difficulties. These neurocognitive disorders make it difficult for caregivers to provide care as care recipients would forget some of the basics that they are expected to keep, and with some, it would be difficult to communicate what they wanted to communicate.

In addition to difficulties imposed by neurocognitive disorders, mental challenges that care recipients present with impose difficulties in the provision of care. Some care recipients displayed behavioural problems and mental difficulties that made it difficult for caregivers to provide care. For example, caregivers needed support to help restrain those care recipients who were receiving psychiatric treatment following their injuries.

Financial constraints: The caregivers were worried about lack of money to help them provide for care recipients. For example, without financial support, it was difficult to access health care facilities and to get appropriate medical treatment. The caregivers were often unable to provide the basic needs for care recipients.

7.2.4 Essential attributes for caregiving

The current study identified the following attributes that caregivers considered to be essential in the provision of care: caring and nurturance; patience, tolerance and acceptance; resilience, perseverance, and courage; sacrifice and commitment; love and compassion; and calmness and humility.

7.2.4.1 Caring and nurturance: Being prepared to care was identified as one of the essential attributes that caregivers needed to have to fulfil their responsibility of providing care. The caregivers also indicated that nurturance help them in the provision of care. For example, the caregiver's availability to take care and protect the care recipient was seen to provide positive results in caring. According to the caregivers, these attributes assisted in making the care recipients to be calm and cooperative.

7.2.4.2 Patience, tolerance, and acceptance: The caregivers indicated that being patient on their part and tolerating the behaviours of the care recipients helped them in the provision of care. In addition to being patient and tolerant, caregivers indicated that accepting the condition of the care recipients and their functioning assisted them in their roles of providing care. One caregiver indicated having learned to accept the care recipient's condition and to live with it.

7.2.4.3 Resilience, perseverance, and courage: Resilience was indicated to be one of the attributes that help in the process of providing care. Caregivers indicated that as they tolerate the care recipients' behaviours, they can bounce back and continue with the role. They also indicated that they continue to be persistent even when caregiving is difficult. Furthermore, having courage was indicated as a helpful attribute that helps caregivers.

7.2.4.4 Sacrifice and commitment: Some caregivers had to abandon some of their personal activities to take the role of being a caregiver. Other caregivers relied on the commitments that they made when taking marriage vows to help them in their roles of being caregivers. The caregivers indicated that the ability to sacrifice and to show commitment is important in fulfilling the responsibility of being a caregiver.

7.2.4.5 Love and compassion: Love and being compassionate were advanced as some of the essential attributes in caregiving. The caregivers indicated that the love that they had for their injured family members is what made them to take the role and to continue caring. Observing the sufferings of the injured family member also drew caregivers to taking the role. Thus, the love and compassion that caregivers had for the injured family member made them to take the responsibility and to commit to the role of caregiving.

7.2.4.6 Calmness and humility: The ability to stay calm and to show humility was considered to be crucial in caregiving. The caregivers indicated that with the fluctuations in mood that some care recipients display, calmness and humility help in controlling possible rise in temper.

7.2.5 Coping strategies

Caregivers use coping strategies that include social coping, appraisal-focused coping, problem-focused coping, and emotion-focused coping to help them cope with the responsibilities associated with caregiving.

7.2.5.1 Social coping: Support that the caregivers received from other people assisted them to cope with their caring role. Support received from other members of the family, neighbours and members of the community has been reported to help in giving strength to continue providing care.

7.2.5.2 Appraisal-focused coping: To cope with the caregiving role, the caregivers indicated that they had to accept the changes as a result of the injury and learn to live with such changes. The caregivers do indicate that it was not easy to accept but having to re-think the situation and come up with a way of coping in the form of acceptance, has helped.

7.2.5.3 Problem-focused coping: The caregivers indicated that having to identify specific problems and coming up with targeted interventions has helped them to cope with the responsibilities of being caregivers.

7.2.5.4 Emotion-focused coping: It was noted that the caregivers developed ways to help themselves emotionally. Some of them relied on spiritual support for their emotional stability. Having ways to help with emotionally stability helped caregivers to cope with the role as they were able to stay calm and managed care recipients appropriately.

7.2.6 Motivation for caring

The following were identified as factors that motivate caregivers to continue caring for members of their families who suffered sTBI: caring as an obligation and a sense of duty, caring as an act of reciprocity, caring as labour of love, and the confidence resulting from the experience of caring.

7.2.6.1 Caring as an obligation and a sense of duty: The caregivers pointed to the relationships that they had with the injured member of the family as a motivating factor. For example, the caregivers indicated that the fact that they are parents, siblings or spouses to the injured person make them feel obliged to take the caregiving role. The caregivers thus indicated that they feel that it is their duty to care for the injured family member. In a spousal relationship, taking the responsibility to care for a spouse was found to surpass even the partner relational problems that existed prior the injury. One spouse indicated that she decided to put aside the differences that existed in the relationship to uphold what she believed was her duty as a spouse to care for her husband.

7.2.6.2 Caring as an act of reciprocity: The improvement that the caregivers observed as they provided care to care recipients played a role in motivating them to continue with their roles. This implies that improvement on the part of the care recipient encouraged caregivers to continue with providing efficient care.

7.2.6.3 *Caring as labour of love*: Love has been considered an essential attribute in caregiving. The findings of the current study show that in addition to love being an essential attribute, it also motivates caregivers in their role of providing care. Caregivers indicated that the love that they had for the injured family member motivated them to continue to provide care even when the process is difficult and tiring.

7.2.6.4 Caregiving and confidence building: The experience that the caregivers gained in the process of providing care gave them confidence in the role. As they gained confidence through experience, caregivers got motivated to continue providing the much-needed care.

7.3. Summary of the psychological explanatory model for caregiving

The proposed model of caregiving that was developed based on the findings of the current study identifies caregiving and caregivers as the key variables. The injury sustained, sTBI, is identified as the antecedent event that triggers caregiving and caregivers having to take on the role. The model highlights the need for caregivers to understand the injury (sTBI) and the sequelae thereof. It furthermore shows the interlink between the key variables and consequent variables. For example, caregivers come up with meanings that they attach to the injury sustained by a loved one. The model shows that there are some attributes that are considered essential to the efficient provision of care. There are also coping strategies and motivating factors that help caregivers to provide care effectively. It is furthermore clear that there are some barriers and facilitators in the process of providing care. In addition, the model proposes skills that are required to help caregivers to manage in their roles. Such skills include an understanding of the instructions that need to be given to care recipients.

Furthermore, such skills assist the caregiver to determine how and when such instructions will need to be given.

7.4 Implications of the study

7.4.1 Implications for theory

7.4.1.1 The adopted theoretical framework: Boss' Conceptual Model of Family Stress and Coping: The findings of the current study and the Boss' (2002) explanatory model indicate that caregiving as a phenomenon within a family context requires family members to respond to an injury that befall a member of the family. In line with the theoretical framework that I adopted for the current study, the findings show that an injury to a member of the family is experienced as a significant stressor (the A factor in Boss' Conceptual Model of Family Stress and Coping). Having the injury as the identified stressor, family pull together resources (B factor) and attach meaning (C factor) to the injury. In line with the adopted theoretical framework, the findings show that the caregivers attach different meanings to the injury, and these help them in fulfilling the caregiving role. It is also clear from the findings that other factors like financial and developmental context play a role in caregiving for an injured family member. For example, developmental stages in the life cycle of family members played significant roles in caregiving. This is evident in situations where some family members took the caregiving role because they are elder siblings, or they are a parent. The theoretical framework adopted refers to internal context that includes cognitive and affective (feeling) processes, values, and beliefs. The findings show that the caregivers were motivated and coped with the roles because of the feelings they had. For example, the love towards the injured and receiving emotional support, having to come up with problem-focused interventions, and beliefs that they had make them to be involved in the caretaking role. Boss' Conceptual Model of Family Stress and Coping provided a relevant platform to understand caregiving within a family context.

7.4.1.2 The developed model: The psychological explanatory model of caregiving: The psychological explanatory model that I developed is in line with Wacker's theory development guidelines. Guided by Wacker's (1998) guidelines, I was able to identify and define key variables; namely, the caregivers and caregiving. Furthermore, I identified severe traumatic brain injury as the antecedent event that triggered the caregiving experience and called for caregivers to take on the role. A wide range of consequent variables were identified, including an explanation on how they are logically linked to the key variables. This is where I showed how the consequent variables relate to caregivers and caregiving as the key variables. The proposed model has consistency and logic regarding the variables identified and the way they interlink. Caregiving skills to help caregivers to function effectively in their role are also proposed. I can therefore conclude that Wacker's guidelines were relevant in guiding the development of the explanatory psychological model of caregiving.

In summary, both the Conceptual Model of Family Stress and Coping and the psychological explanatory model have, in my view, demonstrated that it is possible to use existing theories to expand on and develop new knowledge. Specifically, the current study contributes to new knowledge development by providing a psychological explanatory model for caregiving and suggesting a basket of skills to help in managing caregiving as a role.

7.4.2 Implications for clinical practice

The current study and the model developed indicate that there are factors that are important in the provision of care. It is vital that health care practitioners get to recognise caregiving as a role that requires their support. It is thus important for health care practitioners to support caregivers through information sharing regarding the condition of care recipients. Information regarding possible skills that caretakers need and that the model highlighted must also be shared.

7.4.3 Implications for research

The findings of the current study revealed a need for more studies to further explore some aspects of caregiving such as long-term impact of caregiving on the relationship between caregivers and care recipients. Further studies may also expand on the sample, and possibly investigate the impact and value that the identified variables have on caregiving as per the developed model.

7.4.4. Implications for policy

South African National Home-Care Based Guidelines and National Policy Framework and Strategy on Palliative Care 2017 – 2022 (National Department of Health, 2017) provide information regarding the care to be provided and the different groupings and individuals to provide such care. Goals and objectives indicated in this strategic policy document include among others, empowering carers through appropriate targeted education and training, and the need for access to some form of support. The findings of the current study provide more information regarding the experiences of the carers involved in caring and the specific skills that can be useful in the provision of care. The identified experiences and skills can be included in the guidelines and shared with those who provide support to carers and, those involved in training of carers.

7.5 Limitations of the study

The study was conducted with caregivers residing in Limpopo Province of South Africa. This means that the results of the current study cannot be generalized to other cultural groups in South Africa. The research participants belong to Venda, Tsonga and Northern Sotho cultural groups. It is also worth noting that generalization of the findings was not anticipated as the purpose of this qualitative study was to explore caregiving in a family context for adults who suffered sTBI. My study was therefore intended to understand caregiving as a phenomenon, and not to generalize the findings.

Data-collection was conducted using three indigenous languages namely, Tshivenda, Sepedi and Xitsonga that are dominant in Limpopo. The data was transcribed and translated into the English language to make the study results readily accessible to the broader community. It is possible that during translations, the meaning of some words could have been lost or altered. This may have resulted in distortions of the original meaning of some indigenous words.

7.6 Final remarks

The current study aimed to explore the experiences of caregivers providing care to adult family members who sustained severe traumatic brain injury. The findings of the study show that caregiving is a role that requires inner attributes that will help people to take the responsibility that is characterised by cognitive and physical impairments, and emotional instability. The findings further suggest that even though there are considerable barriers, caregivers continue to provide care drawing motivation from support, improvement on the part of the care recipient, the kind of pre-morbid relationships they had with the injured, and their positions in the family.

The psychological explanatory model developed suggests that it is important for caregivers to understand the injury and its sequelae so that they can provide appropriate care. It is also worth noting that cultural beliefs help in inspiring caregivers to continue with the role. This study has contributed to the body of knowledge in that it provides some new insights into the care of adults who have suffered sTBI. It has also resulted in the development of a psychological exploratory model to understand the scope and impact of caregiving for sTBI survivors.

REFERENCES

Adams, D. & Dahdah, M. (2016). Coping and adaptive strategies of traumatic brain injury survivors and primary caregivers. *NeuroRehabilitation,* 39 (2), 223 – 237. https://doi: 10.3233/NRE-161353

Agassi, J. (2019). Auguste Comte and his legacy. *Philosophy of the social sciences*.

https://doi: 10.1177/0048393119851091

Agrawal, D., Ahmed, S., Khan, S., Gupta, D., Sinha, S., & Satyarthee, G. D. (2016). Outcome in 2068 patients of head injury: Experience at a level 1 trauma centre in India. *Asian Journal of Neurosurgery*, 11 (2), 143 – 145.

https://doi:10.4103/1793-5482.145081

Alase, A. (2017). The interpretative phenomenological analysis (IPA): A guide to a good qualitative research approach. *International Journal of Education & Literacy Studies*, 5(2), 9 – 19. https://doi.org/10.7575/aiac.ijels.v.5n.2p.9

Arango-Lasprilla, J. C., Nicholls, E., Cabrera, T. V., Drew, A., Jimenez-Maldonado, M. & Martinez-Cortes, M. L. (2011). Health-related quality of life in caregivers of individuals with traumatic brain injury from Guadalajara, Mexico. *Journal of Rehabilitation Medicine*, 43, 983–986. https://doi: 10.2340/16501977-0883

Arnould, A., Dromer, E., Rochat, L., Van der Linden, M. & Azouvi, P. (2016). Neurobehavioral and self-awareness changes following traumatic brain injury: Towards new multidimensional approaches. *Annals of Physical & Rehabilitation Medicine*, 59 (1), 18–22.

https://doi: 10.1016/j.rehab.2015.09.002

Bademli K, Lök N, Kılıc AK. (2017). Relationship between caregiving burden and anger level in primary caregivers of individuals with chronic mental illness. Archives of Psychiatric Nursing, 31(3), 263-268.
https:// doi: 10.1016/j.apnu.2016.12.001

Baker, A., Barker, S., Sampson, S., & Martin, C. (2017). Caregiver outcomes and interventions: A systematic scoping review of the traumatic brain injury and spinal cord injury literature. *Clinical Rehabilitation*, 31(1), 45 – 60.

https://doi: 10.1177/0269215516639357

Band-Winterstein, T., Edelstein, O.E. & Bachner, G.Y. (2019). Correlates of depression in caregiver of ultra-orthodox frail older adults. *American Journal of Orthopsychiatry*, 89 (6), 654-664. https://doi: 10.1037/ort0000337

Beauchamp, M., Catroppa, C., Morse, S., Rosenfield, J.V. & Anderson, V. (2011). Selective changes in executive functioning ten years after severe childhood traumatic brain injury. *Developmental Neuropsychology*, 36(5), 578–595.

https://doi: 10.1080/87565641.2011.555572

Ben-Yishay, Y. & Driller, L. (2011). *Handbook of holistic neuropsychological rehabilitation: Outpatient rehabilitation of traumatic brain injury*. Oxford University Press. https://doi.org/10.1080/09084282.2012.678161

Benzie Senior Resources. n.d. What is caregiving? Retrieved from https://benzieseniorresources.org/wp-content/uploads/2015/01/What-is-Caregiving.pdf.

Bevans, M.F. & Sternberg, E.M. (2012). Caregiving burden, stress, and health effects among family caregivers of adult cancer patients. J*AMA,* 25, 307(4): 398–403. https://doi: 10.1001/jama.2012.29

Boss (2002). Family stress management: A contextual approach. (2nd ed). SAGE Publications. https://dx.doi.org/10.4135/9781452233895

Boss, P. Bryant, C.M. & Mancini, J.A. (2016). Family stress management: A contextual approach (3rd ed). SAGE Publications, Inc

Bouldin, E.D., Shaull, L. Andresen, E.M., Edwards, V.J. & McGuire, L.C. (2018). Financial and health barriers and caregiving-related difficulties among rural and urban caregivers. *Journal of Rural Health*, 34 (3), 263 – 274. https://doi: 10.1111/jrh.12273

Bourke, B. (2014). Positionality: Reflecting on the research process. *The Qualitative Report*, 19 (33) 1-9. https://doi.org/10.46743/2160-3715/2014.1026

Boyle, G. J., & Haines, S. (2002). Severe traumatic brain injury: Some effects on family caregivers. *Psychological Reports*, 90 (2), 415 – 425.

Brickell, T.A., Cotner, B.A., French, L.M., Carlozzi, N.E., O'Connor, D.R., Nakase-Richardson, R. and Lange, R.T. (2020). Severity of military traumatic brain injury influences caregiver health-related quality of life. *Rehabilitation Psychology*, 65 (4), 377–389. https://doi: 10.1037/rep0000306

Brickell, T. A., French, L. M., Gartner, R. L., Driscoll, A. E., Wright, M. M., Lippa, S. M., & Lange, R. T. (2019). Factors related to perceived burden among caregivers of service members/veterans following TBI. *Rehabilitation Psychology, 64*(3), 307– 319. https://doi.org/10.1037/rep0000272

Broodryk, M. & Pretorius, C. (2015). Initial experiences of family caregivers of survivors of a traumatic brain injury. *African Journal of Disability*, 4 (1), 165 - 171. https://dx.doi.org/10.4102/ajod.v4i1.165

Bryant, R.A., Marosszeky, J.E., Crooks, J., Baguley, I. & Gurka, J. (2000). Coping style and post-traumatic stress disorder following severe traumatic brain injury. *Brain Injury,* 14 (2), 175–80. https://doi: 10.1080/026990500120826

Carlozzi, N. E., Boileau, N. R., Kallen, M. A., Nakase-Richardson, R., Hahn, E. A., Tulsky, D. S., Miner, J. A., Hanks, R. A., Massengale, J. P., Lange, R. T., Brickell, T. A., French, L. M., Ianni, P. A., & Sander, A. M. (2020). Reliability and validity data to support the clinical utility of the Traumatic Brain Injury Caregiver Quality of Life (TBI-CareQOL). *Rehabilitation Psychology, 65*(4), 323–336. https:// doi: 10.1037/rep0000295

Carroll, L.J, Cassidy, J.D., Holm, Kraus, J & Coronado, V.G. (2004). Methodological issues and research recommendations for mild traumatic brain injury: The WHO Collaborating Centre Task Force on Mild Traumatic Brain Injury. *Rehabilitation Medical Supplement*, 36 (43suppl), 113–125.

https://doi: 10.1080/16501960410023877

Carver, C. S., Scheier, M. F. & Weintraub, J. K. (1989). Assessing coping strategies: A theoretically based approach. *Journal of Personality and Social Psychology, 56*(2), 267–283. https://doi.org/10.1037/0022-3514.56.2.267

Chan, C.Y., Cheung, G., Martinez-Ruiz, A., Chau, P.Y.K., Wang, K., Yeoh, E. K., and Wong, E.L.Y. (2021). Caregiving burnout of community-dwelling people with dementia in Hong Kong and New Zealand: a cross-sectional study. *BMC Geriatrics*, 21:261. https://doi.org/10.1186/s12877-021-02153-6

Chembeni, N. & Nkomo, T.S. (2017). Challenges experienced by survivors of traumatic brain injury and their families. *Social Work / Maatskaplike Werk*, 53 (4), 479 – 495. https://dx.doi.org/10.15270/52-2-594

Cheng, S-T. Mak, E.P.M, Lau, R.W.L. Ng, N. S. S. & Lam. L.C.W. (2016). Voices of Alzheimer caregivers on positive aspects of caregiving. *The Gerontologist*, 56 (3), 451–460. https://doi: 10.1093/geront/gnu118

Chopik, W. J., Moors, A. C., & Edelstein, R. S. (2014). Maternal nurturance predicts decreases in attachment avoidance in emerging adulthood. *Journal of Research in Personality, 53,* 47– 3. https://doi.org/10.1016/j.jrp.2014.08.004

Choy, L. (2014). The strengths and weaknesses of research methodology: Comparison and complimentary between qualitative and quantitative approaches. *Journal of Humanities and Social Science*, 19(4), 99-104.

Christensen, M., Welch, A. & Barr, J. (2017). Husserlian descriptive phenomenology: A review of intentionality, reduction and the natural attitude. *Journal of Nursing Education and Practice*, 7 (8),113 – 118.

Cohen, D.J., & Crabtree, B.J. (2006). *Qualitative research guidelines project*. Retrieved from http://www.qualres.org/

Corrigan J. D. & Hammond F. M. (2013). Traumatic brain injury as a chronic health condition. *Archives of Physical Medicine & Rehabilitation*, 94(6), 1199-2001.

https://doi: 10.1016/j.apmr.2013.01.023

Corrigan, J. D., Selassie, A. W., & Orman, J. A. L. (2010). The epidemiology of traumatic brain injury. *The Journal of Head Trauma Rehabilitation, 25*(2), 72–80. https://doi: 10.1097/HTR.0b013e3181ccc8b4

Creswell, J.W. & Poth, C.N. (2018). *Qualitative inquiry and research design: Choosing among five approaches*. Sage.

Creswell, J.W. (2014). *Research design: Qualitative, quantitative and mixed methods approaches*, 4th Ed. Sage.

Davis, T. & Ings, A. (2015). Head injury: triage, assessment, investigation and early management of head injury in children, young people and adults (NICE guideline CG 176), *Archives of Disease in Childhood—Education & Practice Edition*,100 (2), 97–100.

Davis, D. (2020). Presenting research reflexivity in your PhD thesis. Retrieved from http://usir.salford.ac.uk/id/eprint/57467/

DeGraff, A.N., O'Neal, C.W. & Mancini, J.A. (2016). The significance of military contexts and culture for understanding family well-being: Parent life satisfaction and adolescent outcomes. *Journal of Child and Family Studies,* 25, 3022–3033. https://doi.org/10.1007/s10826-016-0471-0

Degeneffe, C. E., Gagne, L. M. & Tucker, M. (2013). Family systems changes following traumatic brain injury: Adult sibling perspectives. *Journal of Applied Rehabilitation Counselling*, 44 (3), 32-41.

https://doi10.1891/0047-2220.44.3.32

Degeneffe, C. E. (2001). Family caregiving and traumatic brain injury. *Health & Social Work*, 26(4), 257-268. https://doi: 10.1093/hsw/26.4.257

De Mamani, A.W., Weintraub, M.J., Maura, J. de Andino, A.M. & Brown, C.A. (2018). The interplay among mindfulness, caregiver burden, and mental health in family members of individuals with dementia. *Professional Psychology: Research and Practice*, 49 (2), 116–123.

https://dx.doi.org/10.1037/pro0000181

De Vos, A. S. (2002). Intervention research. In: A. S. De Vos. (Ed.), *Research at grass roots: For the social sciences and human service professions*. (2nd ed.). (pp.114–126). Van Schaik.

Dewan, M. C., Rattani, A., Gupta, S., Baticulon, R. E., Hung, Y., Punchak , M., Agrawal, A., Adeleye , A. O., Shrime , M. G., Rubiano, A. M., Rosenfeld, J. V. & Park, K. B. (2018). Estimating the global incidence of traumatic brain injury. *Journal of Neurosurgery*, 130 (4), 1080 – 1097.

https://doi.org/10.3171/2017.10

DiZazzo-Miller, R., Pociask, F.D., & Adamo, D.E. (2020). The role of confidence in family caregiving for people with dementia. *Physical & Occupational Therapy in Geriatrics*, 38 (4), 355-369. http://doi: 10.1080/02703181.2020.1762824

Duggleby, W., Schroeder, D. & Nekolaichuk, C. (2013). Hope and connection: The experience of family caregivers of persons with dementia living in a long-term care facility. *BMC Geriatrics,* 13, 112. https://doi.org/10.1186/1471-2318-13-112.

Duggleby, W., Williams, A., Ghosh, S., Moquin, H., Ploeg, J., Markle-Reid, M., & Peacock, S. (2016). Factors influencing changes in health related quality of life of caregivers of persons with multiple chronic conditions. *Health and Quality of Life Outcomes*, *14*, 81 - 90. https://doi.org/10.1186/s12955-016-0486-7

Durr, E. & Greeff, A. (2020). Resilience characteristics of families with children with severe of profound intellectual disability. *Social Work*, 56(2), 221-234. https://dx.doi.org/10.15270/52-2-822

Eaton, J., Hanif, A.B., Grudziak, J., & Charles, A. (2017). Epidemiology, management and functional outcomes of traumatic brain injury in Sub-Saharan Africa. *World Neurosurgery*, 108, 650-655. https://doi: 10.1016/j.wneu.2017.09.084

Ewen, H.D., Chahal, M.G.S., Fenster, E.S. (2015). A portrait of resilience in caregiving. *Research in Gerontological Nursing*, 8 (1), 29 - 38. https://doi:10.3928/19404921-20141111-01

Ferrario, S. R. & Panzeri, A. (2020). Exploring illness denial of LVAD patients in cardiac rehabilitation and their caregivers: A preliminary study. *Artificial Organs*, 44 (6), 655-660. https://doi: 10.1111/aor.13630.

Fossey, E., Harvey, C., McDermott, F., & Davidson, L. (2002). Understanding and evaluating qualitative research. *Australian and New Zealand journal of psychiatry*, *36*(6), 717-732. https://doi: 10.1046/j.1440-1614.2002.01100.x.

Francis, C. D. (2011). *Evaluating research methodology for people need to read research*. Sage.

Fusch, P.I. & Ness, L.R. (2015). Are we there yet? Data saturation in qualitative research. *The qualitative report*, 20 (9), 1408 - 1416.

Geard, A., Kirkevold, M., Lovstad, M. & Schanke, A-K. (2020). How do family members of individuals with spinal cord and acquired brain injuries make sense of their experiences: A qualitative study of meaning making processes. *Health Psychology Open*, 7, 1. https://doi.org/10.1177/2055102920913477

Gibbons, S. W., Ross, A., & Bevans, M. (2014). Liminality as a conceptual frame for understanding the family caregiving rite of passage: an integrative review. *Research in Nursing & Health*, 37(5), 423–436. https://doi.org/10.1002/nur.21622

Giddens, A. (1987). *Social theory and modern sociology.* Polity Press.

Giorgi, A. (1985). Sketch of a psychological phenomenological method. In A Giorgi (Ed.), *Phenomenology and psychological research*. (pp. 8 - 22). Duquesne University Press.

Giorgi, A. (1986). Theoretical justification for the use of descriptions in psychological research. In P.D. Ashworth, A, Giorgi & All de Koning (Eds), *Qualitative research in psychology: Proceedings of the International Association for Qualitative Research in Social Science* (pp. 3 - 22). Duquesne University Press.

Goodrich, J. (2016). What makes a compassionate relationship between caregiver and patient? Findings from the ‘anniversary’ Schwartz Rounds. *Journal of Compassionate Health Care* 3, (8). https://doi.org/10.1186/s40639-016-0026-7oodrich

Gouick, J. & Gentleman, D. (2004). The emotional and behavioural consequences of traumatic brain injury. *Trauma*, 6, 285–292. https://doi.org/10.1191/1460408604ta323oa

Greenwood, N. & Smith, R. (2019). Motivations for being informal cares of people living with dementia: a systematic review of qualitative literature. *BMC Geriatrics*, 19(1), 169. https://doi: 10.1186/s12877-019-1185-0

Griffin, J.M., Lee, M.K., Bangerter, L.R., C.H., Van Houtven, G. Friedemann-Sánchez, S.M., Phelan, Carlson, K.F. & Meis, L.A. (2017). Burden and

Mental Health Among Caregivers of Veterans with Traumatic Brain Injury/Polytrauma. *American Journal of Orthopsychiatry*, 87 (2), 139–148. https://doi: 10.1037/ort0000207

Gurayah, T. (2015). Caregiving for people with dementia in a rural context in South Africa. *South African Family Practice*, 2015; 57(3), 194– 197. https:// doi:10.1080/20786190.2014.976946

Haarbauer-Krupa, J., Pugh, M.J., Prager, E.M., Harmon, N., Wolfe, J. & Yaffe, K. (2021). Epidemiology of chronic effects of traumatic brain injury. *Journal of Neurotrauma,* 38 (23), 3235-3247. https://doi: 10.1089/neu.2021.0062

Hanna, D.R., Roy, C. (2001). Roy adaptation model and perspectives on the family. *Nursing Science Quarterly,* 14(1):10-13. https://doi:10.1177/08943180122108148

Harvey-Jordan, S., & Long, S. (2001). The process and pitfalls of semi-structured interviews. *Community Practitioner*, 74 (6), 219 – 221.

Hawken, T., Turner-Cobb, J., & Barnett, J. (2018). Coping and adjustment in caregivers: A systematic review. *Health Psychology Open*, 5(2). https://doi.org/10.1177/2055102918810659

Hawker, S. (2006). Little oxford English dictionary. In *Oxford dictionaries* (ninth). Oxford University Press.

Hawkley, L., Zheng, B., Hedberg, E. C., Huisingh-Scheetz, M., & Waite, L. (2020). Cognitive limitations in older adults receiving care reduces well-being among spouse caregivers. *Psychology and Aging,* 35(1), 28– 40.

https://doi.org/10.1037/pag0000406

Henry C.S., Hubbard R.L., Struckmeyer K.M., Spencer T.A. (2018). Family resilience and caregiving. In: Bailey W., Harrist A. (eds) *Family caregiving: Emerging issues in family and individual resilience*. Springer, Cham. https://doi.org/10.1007/978-3-319-64783-8_1

Hermanns, M. & Mastel-Smith, B. (2012), Caregiving: A qualitative concept analysis. *Qualitative Report* 17(38), doi:10.46743/2160-3715/2012.1727

Ho, B. Friedland, J., Rappolt, S. & Noh, S. (2003). Caregiving for relatives with Alzheimer's disease: feelings of Chinese-Canadian women. *Journal of Aging Studies*, *17*(3), 301–321. https://doi.org/10.1016/S0890-4065(03)00028-8

Hobfoll, S. E. (1996). Social Support: Will you be there when i need you? In N. Vanzetti, & S. Duck (Eds.), *A lifetime of relationships* (pp. 46-74). Belmont, CA: Thomson Brooks/Cole Publishing Co.

Hobfoll, S.E. (1989). Conservation of resources: A new attempt at conceptualizing stress. *American Psychologist*, 44(3), 513-524.

Hobfoll, S. E., Freedy, J. R., Green, B. L., & Solomon, S. D. (1996). Coping in reaction to extreme stress: The roles of resource loss and resource availability. In M. Zeidner & N. S. Endler (Eds.), *Handbook of coping: Theory, research, applications* (pp. 322–349). John Wiley & Sons

Hobfoll, S. E., & Leiberman, J. R. (1987). Personality and social resources in immediate and continued stress resistance among women. *Journal of Personality and Social Psychology, 52*(1), 18– 26.

https://doi.org/10.1037/0022-3514.52.1.18

Hoofien, D., Gilboa, A., Vakil, E., & Donovick, P.J. (2001). Traumatic brain injury (TBI) 10-20 years later: A comprehensive outcome study of psychiatric symptomatology, cognitive abilities and psychosocial functioning. *Brain Injury*, 15(3), 189-209.

Howitt, D. (2010). *Introduction to qualitative methods in psychology*. Pearson Education Limited.

Hudson, L.A., & Ozanne, J.L. (1988). Alternative ways of seeking knowledge in consumer research. *The Journal of Consumer Research,* 14(4), 508 – 521.

Huis in het Veld, J., Verkaik, R., van Meijel, B., Verkade, P., Werkman, W., C., Hertogh & Francke, A. (2016). Self-management by family caregivers to manage changes in the behavior and mood of their relative with dementia: an online focus group study. B*MC Geriatrics,* 3 (16), 95. https://doi: 10.1186/s12877-016-0268- 4.

Hyder, A.A., Wunderlich, C.A., Puvanachandra, P., Gururaj, G. & Kobusingye, O.C. (2007) The impact of traumatic brain injuries: A Global Perspective. *Neurological Rehabilitation*, 22, 341-353.

Jackson, M. (2014). Evaluating the role of Hans Selye in the modern history of stress. In Cantor, D & Ramsden, E (Eds), *Stress, shock, and adaptation in the twentieth century*. Rochester (NY): University of Rochester Press.

James, S.L., Theadom, A., Ellenbogen, R.G, Bannick, M.S., Montjoy-Venning, W., Lucchesi, L.R., et al. (2019). Global, regional, and national burden of traumatic brain injury and spinal cord injury, 1990–2016: A systematic analysis for the Global Burden of Disease Study. *Lancet Neurology*, 18, 56–87.

Jaracz, K. & Kozubski, W. (2008). Quality of life after traumatic brain injury. *Neurochirurgia Polska*, 42(6), 525-535

Jennings, K.M. (2017). The Roy Adaptation Model: A theoretical framework for nurses providing care to individuals with anorexia nervosa. *Advances in Nursing Science,* 40(4): 370–383. doi: 10.1097/ANS.0000000000000175.

Jerome, E., Laing, G.L., Bruce, J.L., Sartorius, B. Brysiewicz, P. & Clarke, D.L. (2017). An audit of traumatic brain injury (TBI) in a busy developing-world trauma service exposes a significant deficit in resources available to manage severe TBI. *South African Medical Journal*, 107 (7), 621 – 625.

Johnson, B.D., Crane, S.C.M., & Tatekawa, L. (2004). Communication on both sides of the mirror: Helping a family cope with a traumatic brain injury. *The Family Journal: Counselling & Therapy for Couples & Families*, 12(2), 178 - 183.

Jorge, R. E. & Arciniegas, D. B. (2014) Mood disorders after TBI. *Psychiatric Clinics of North America*, 37(1), 13–29.

Juengst, S. B., Adams, L.M., Bogner, J. A., Arenth, P. M., O'Neil-Pirozzi, T. M., Dreer, L., E., Hart, T., Berquist, T.F., Bombardier, C.H., Dijkers, M.P. & Wagner, A.K. (2015). Trajectories of life satisfaction after TBI: Influence of life roles, age, cognitive disability, and depressive symptoms. *Rehabilitation Psychology*, 60(4), 353–364. doi: 10.1037/rep0000056

Kaffle, N.P. (2011). Hermeneutic phenomenological research method simplified. *Bhodi: An Interdisciplinary Journal,* 5, 181-200.

Kajiwara, K., Noto, H., and Yamanaka, M. (2018). Changes in caregiving appraisal among family caregivers of persons with dementia: A longitudinal study over 12 months. *Psychogeriatrics*, 18: 460–467.

Kazemi, A., Azimian, J., Mafi, M., Allen, K-A & Motalebi, S.A. (2021). Caregiver burden and coping strategies in caregivers of older patients with stroke. *BMC Psychology,* 9, 51 (2021). https://doi.org/10.1186/s40359-021-00556-z

Kilonzo, J.M.M. (2004). *Experiences of caregivers regarding their participation in community-based rehabilitation for children aged 0-12 years in Botswana.* Unpublished Masters Dissertation. University of The Western Cape.

Kim, Y. (2009). Korean-American post caregivers on dementia caregiving: A phenomenological inquiry. *Journal of Gerontological Social Work*, 52 (6), 600 – 617. https://doi: 10.1080/01634370903048352

King, N. S. & Tyerman, A. (2008). Introduction to traumatic brain injury. In A. Tyerman, A. & N.S. King. (Eds.). *Psychological approaches to rehabilitation after traumatic brain injury* (pp 1-14). Blackwell: The British Psychological Society.

Kjosavik, F., Beyer, C., & Fricke, C. (2019). *Husserl's phenomenology of intersubjectivity: Historical interpretations and contemporary applications.* Routledge.

Kleinman A., Eisenberg L., Good B. (1978). Culture, illness, and care: Clinical lessons from anthropological and cross-cultural research. *Annals of Internal Medicine*, 88, 251–288.

Kratz, A., Sander, A.M., Brickell, T.A, Lange, R.T. & Carlozzi, N.E. (2017). Traumatic brain injury caregivers: A qualitative analysis of spouse and parent perspectives on quality of life. *Neuropsychological Rehabilitation*, 27 (1), 16 – 37. http://dx.doi.org/10.1080/09602011.2015.1051056#2015

Kroeger A. (1983). Anthropological and socio-medical health care research in developing countries. *Social Science & Medicine,* 17,147–61.

Krohne, H.W. (2001). *Stress and coping theories*. Retrieved from http//userpage.fu-berlin.de>sehuez>folien>Krohne_Stress.

https://doi:10.1016/B0-08-043076-7/03817-1

Krohne, H. W. (1996). Individual differences in coping. In M. Zeidner & N. S. Endler (Eds.), *Handbook of coping: Theory, research, applications* (pp. 381–409). John Wiley & Sons.

Kübler-Ross, E. (1981). *Living with death and dying*. MacMillan Publishing Co., Inc

Kühne, T. (2005). *What is a model?* Darmstadt University of Technology: Darmstadt: Germany. Retrieved from http//drops.dadstuhl.de/opus/volltexte/2005/23

Lai, D.W.L. (2012). Effect of financial costs on caregiving burden of family caregivers of older adults. *Heath Psychology, Family Studies*, 2 (4). https://doi:10.1177/2158244012470467

Langdridge, D. (2007). *Phenomenological psychology: Theory, research and methods*. Pearson.

Laverty, S.M. (2003). Hermeneutic phenomenology and phenomenology: A comparison and historical methodological consideration. *International Journal of Qualitative Methods*, 2 (3), 21-35.

Lazarus, R.S. (2001). Relational meaning and discrete emotions. In Scherer, K.R., Schorr, A., & Johnstone, T. Eds. *Appraisal processes in emotion: Theory, methods, research*. Oxford University Press, ebook.

Lazarus, R. S. (1993). Coping theory and research: Past, present and future. *Psychosomatic Medicine*, 55, 234 – 247.

Lazarus, R. & Folkman, S. (1986). *Stress, appraisal and coping*. New York. Springer.

Leach, L. R., Frank, R.G., Bouman, D. E. & Farmer, J. (1994). Family functioning, social support and depression after traumatic brain injury. *Journal of Brain Injury*, 8 (7), 559-606.

Lee, K., Puga, F., Pickering, C.E.Z., Masoud, S.S. & White, C.L. (2019). Transitioning into the caregiver role following a diagnosis of Alzheimer’s disease or related dementia: A scoping review. *International Journal of Nursing Studies,* 96, 119-131. https://doi: 10.1016/j.ijnurstu.2019.02.007.

Lezak, M. D., Howieson, D. B., Bigler, E. D., & Tranel, D. (2012). *Neuropsychological assessment,* (5th ed). New York. Oxford University Press.

Lewis, T. P., Andrews, K. G., Shenberger, E., Betancourt, T. S., Fink, G., Pereira, S., & McConnell, M. (2019). Caregiving can be costly: A qualitative study of barriers and facilitators to conducting kangaroo mother care in a US tertiary hospital neonatal intensive care unit. *BMC Pregnancy and Childbirth*, 19(1), 227. https://doi.org/10.1186/s12884-019-2363-y

Li M., Zhao Z., Yu, G. and Zhang, J (2016). Epidemiology of traumatic brain injury over the world: A systematic review. *Austin Neurology & Neuroscience,* 1(2), 1007.

Lim, W.M. (2013). Revisiting Kubler-Ross's five stages of grief: Some comments on the iphone 5. *Journal of Social Sciences*, 9 (1), 11-13. https:// doi:10.3844/jsssp

Lin, M-C. Macmillan, M. & Brown, N. (2012). A grounded theory longitudinal study of carers' experiences of caring for people with dementia. *Dementia*, 11 (2), 181-197. https://doi.org/10.1177/1471301211421362

Lincoln, Y. S. and Guba, E. G. (1985). *Naturalistic inquiry.* Sage.

Liu, C., Fabius, C.D., Howard, V.J. Haley, W.E. & Roth, D.L. (2021). Change in social engagement among incident caregivers and controls: Findings from the caregiving transitions study. *Journal of Aging and Health*, 33 (1-2). https://doi:10.1177/0898264320961946

Lippert-Gruner, M., Kuchta, J., Hellmich, M., & Klug, N. (2006). Neurobehavioural deficits after severe traumatic brain injury (TBI). *Brain Injury*, 20 (6), 569-574.

Ma, G.Y.K. and Mak, W.W.S. (2016). Caregiving-specific worry, affiliate stigma, and perceived social support on psychological distress of caregivers of children with physical disability in Hong Kong. *American Journal of Orthopsychiatry*, 86 (4), 436– 446.

Mack, N., Woodsong, C., MacQueen, K. M., Guest, G., & Namey, E. (2005). *Qualitative research methods: A data collector's guide*. *Family Health*

International (Vol. 1). Retrieved from http://www.fhi.org/en/RH/Pubs/booksReports/QRM_datacoll.htm

Mackenzie, N., & Knipe, S. (2006). Research dilemmas: Paradigms, methods and methodology. *Issues in Educational Research*, *16*(2), 193-205.

MacNeil, G., Kosberg, J. I., Durkin, D. W., Dooley, W. K., DeCoster, J., & Williamson, G. M. (2010). Caregiver mental health and potentially harmful caregiving behavior: The central role of caregiver anger. *The Gerontologist, 50*(1), 76–86. https://doi.org/10.1093/geront/gnp099

Madigan, N.K., Deluce, J., Diamond, B.J., Tramontano, G., & Averill, A. (2000). Speed of information processing in traumatic brain injury: Modality-specific factors. *Journal of Head Trauma Rehabilitation*, 15(3), 943-56.

Magana, S. and Smith, M.J. (2006). Psychological distress and well-being of Latina and non-Latina white mothers of youth and adults with an autism spectrum disorder: Cultural attitudes towards coresidence status. *American Journal of Orthopsychiatry*, 76 (3), 346–357.

Mafune, R. V., Lebese, R. T., & Nemathaga, L. H. (2017). Challenges faced by caregivers of children on antiretroviral therapy at Mutale Municipality selected healthcare facilities, Vhembe District, Limpopo Province. *Curationis*, 40(1), e1–e9. https://doi.org/10.4102/curationis.v40i1.1541

Manskow, U.S., Arntzen, C., Damsgard, E., Braine, M., Sigurdardottir, S., Andelic, N., Røe, C. & Anke, A. (2018). Family members' experience with in-hospital health care after severe traumatic brain injury: a national multicentre study. *BMC Health Services Research*, (18), 951.

https://doi.org/10.1186/s12913-018-3773-7

Marsh, N.V., Kersel, D.A., Havil, J.H., & Sleigh, J.W. (1998). Caregiver burden at 1 year following severe traumatic brain injury. *Brain injury*, 12 (12), 1045-1059. https://doi: 10.1080/026990598121954

Mathias J.L., & Wheaton, P. (2007). Changes in attention and information-processing speed following severe traumatic brain injury: A meta-analytic review. *Neuropsychology*, 21(2), 212-223.

Mazaux, J.M., Croze, P., Quintard, B. Rouxel, L., Joseph, P.L, Richer, E. Debelleix, E., & Barat, M. (2001). Satisfaction of life and late psycho-social outcome after severe brain injury: A nine-year follow-up study in Aquitaine. *Acta Neurochirugica Supplement*, 79, 49-51.

Mbakile-Mahlanza, L., Manderson, L., & Ponsford, J. (2017). Cultural beliefs about TBI in Botswana. *Neuropsychological Rehabilitation*, 27 (1), 38-59.

Menon, D.K., Schwab, K., Wright, D.W. & Maas, A.I. (2010). Demographics and clinical assessment working group of the international and interagency initiative toward common data elements for research on traumatic brain injury and psychological health. Position statement: definition of traumatic brain injury. *Archives of Physical Medicine and Rehabilitation*, 91(11),1637-1640. https://doi: 10.1016/j.apmr

McColl, M. A. (2007). Postacute programming for community integration: A scoping review. Experiences of returning to work after acquired brain injury. *Brain Impairment*, 8 (3), 238–250.

McDonald, S. & Genova, H. (2021). The effect of severe traumatic brain injury on social cognition, emotion regulation, and mood. In Heilman, K.M & Nadeau, S.E. *Handbook of Clinical Neurology*, 183, 235-260.

https://doi.org/10.1016/B978-0-12-822290-4.00011-6.

McDonnell, E. & Ryan, A.A. (2014). The experience of sons caring for a parent with dementia. *Dementia*, 13 (6), 788 – 80. https://doi:10.1177/1471301213485374

Mokhosi, M. T., & Grieve K. W. (2004). African families' perceptions of traumatic brain injury. *South African Journal of Psychology*, 34 (2), 301–317.

Moustakas, C. (1994). *Phenomenological research methods*. Sage.

Naidoo, D. (2013), Traumatic brain injury: The South African landscape. *South African Medical Journal*, 103(9), 613-614. https://doi:10.7196/SAMJ.7325

National Department of Health. (2017). South African National Home-Care Based Guidelines and National Policy Framework and Strategy on Palliative Care. Pretoria

Neuman, W. L. (2013). *Social research methods: Qualitative and quantitative approaches.* Pearson Education.

Newcomb, A., Moore, L.G. & Matto, H.C. (2018). Family-centered caregiving from hospital to home: Coping with trauma and building capacity with the HOPE for Families model. *Patient Experience Journal*, 5 (1), 66-75.

Niemeier, J.P., Hammond, F.M., O'Neil-Pirozzi, T.M., Venkatesan, U.M., Bushnik, T., Zhang, Y. & Kennedy, R.E. (2021). Refining understanding of life satisfaction in elderly persons with traumatic brain injury using age-defined cohorts: a TBI model systems study. *Brain Injury*, 24, 35(10), 1284-1291. https://doi: 10.1080/02699052.2021.1972153.

Nkoana, S., Sodi, T., Makgahlela, M. & Mokwena J. (2022). Cancer survivorship: Religion in meaning making and coping among a group of black prostate cancer patients in South Africa. *Journal of Religion and Health,* 61(2), 1390-1400. https://doi: 10.1007/s10943-021-01406-3.

Noggle, C. A. & Pierson, E.E. (2010). Psychosocial and behavioural functioning following paediatric TBI: Presentation, assessment, and intervention. *Applied Neuropsychology*, 17, 110–115.

Otero, P., Torres, A.J., Vazquez, F.L, Blanco, V., Ferraces, M.J & Diaz, O. (2019). Does the disease of the person receiving care affect the emotional state of non-professional caregivers? *Frontiers in Psychology*, 10:1144. https://doi:10.3389/fpsyg.2019.01144

Palacio, C., Krikorian, A., Gomez-Romero, M.A. & Limonero, J.T. (2020). Resilience in caregivers: A systematic review. *American Journal of Hospice and Palliative Medicine*, 37 (8), 648-658. https://doi: 10.1177/1049909119893977

Parkinson, F., Kent, S.J.W., Aldous, C. Oosthuizen, G. & Clarke, D. (2014). The hospital cost of road accidents at a South African regional trauma centre: A micro-costing study. Injury 45 (1), 342-345.

Parks, S.S. (2021). Caregivers' mental health and somatic symptoms during COVID-19. The *Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 76 (4), e235–e240. https://doi:10.1093/geronb/gbaa121

Peeters, W., van den Brande, R., Polinder, S., Brazinova, A., Steyerberg, E.W., Lingsma, H.F et al. (2015). Epidemiology of traumatic brain injury in Europe. *The European Journal of Neurosurgery*, 2512-2517

Pendergrass, A., Hautzinger, M., Elliott, T.R., Becker, C., Pfeiffer, K. & Schilling, O. (2017). Family caregiver adjustment and stroke survivor impairment: A path analytic model. *Rehabilitation Psychology*, 62 (2), 81 - 88.

Phalane, K.E. (2017). *African families' perceptions of traumatic brain injury in the Capricorn District, Limpopo Province: An Afrocentric perspective.* Unpublished Masters Dissertation. University of Limpopo.

Pham, T.T.M. (2018). Qualitative approach to research: A review of advantages and disadvantages of three paradigms: positivism, interpretivism and critical inquiry. doi: 10.13140/RG.2.2.13995.54569 https://www.researchgate.net/publication/324486854

Pharr, J.R., Francis, C.D., Terry, C. & Clark, M.C. (2014). Culture, caregiving, and health: Exploring the influence of culture on family caregiver experiences. *Hindawi Publishing Corporation*, 1-8.

Piccenna, L., Lannin, N.A., Scott, K., Bragge, P. & Gruen, R. (2017). Guidance for community-based caregivers in assisting people with moderate to severe traumatic brain injury with transfers and manual handling: evidence and key stakeholder perspectives. *Health and Social Care in the Community*, 25(2), 458-465. https://doi: 10.1111/hsc.12327

Pietkiewicz, I. and Smith, J. A. (2014). A practical guide to using interpretative phenomenological analysis in qualitative research psychology. *Psychological Journal*, 20 (1), 7 – 14.

Ponsford, J. (2013). TBI mechanisms and sequalae. In J. Ponsford, J., S. Sloan., & P. Snow. (Eds.) *Traumatic brain injury: Rehabilitation for everyday adaptive living*, 2nd Edition (pp 1-33). Psychology Press.

Pretorius, C. & Steadman, J. (2018). Barriers and facilitators to caring for a child with cerebral palsy in rural communities of the Western Cape, South Africa. *Child Care in Practice*, 24 (4), 413 – 430. https://doi.org/10.1080/13575279.2017.1347146

Psarra, E. & Kleftaras, G. (2013). Adaptation to Physical Disabilities: The role of meaning in life and depression. *The European Journal of Counselling Psychology*, 2(1), 79–99. https://doi.org/10.5964/ejcop.v2i1.7

Pugh, M.J., Swan, A.A., Carlson, K.F., Jaramillo, C.A., Eapen, B.C., Dillahunt-Aspillaga. C., Amuan, M.E., Delgado, R.E., McConnell, K., Finley, E.P. & Grafman, J.H. (2018). Traumatic brain injury severity, comorbidity, social support, family functioning, and community reintegration among veterans of the Afghanistan and Iraq wars. *Archives of Physical Medicine & Rehabilitation*, 99 (2S), 40–49. https:// doi: 10.1016/j.apmr.2017.05.021

Puvanachandra, P. and Hyder, A.A. (2009). The burden of traumatic brain injury in Asia: A call for Research. *Pakistan Journal of Neurological Sciences*, 4(1), 27-32.

Quang, H., McDonald, S., Huynh-Le, P., Nguyen, T.-V., Le, N.-A., Lam-Nguyen, N.-T., & Kumfor, F. (2022). Apathy in a high prevalence population of moderate to severe traumatic brain injury: An investigation in Vietnam. *Neuropsychology*, 36(1), 94–102. https://doi.org/10.1037/neu0000781

Quinn, C., Nelis, S.M., Martyr, A., Morris, R.G., Victor, C. & Clareon, L. (2020) Caregiver influences on ‘living well’ for people with dementia: Findings from the IDEAL study. *Aging & Mental Health*, 24 (9), 1505-1513. https://doi: 10.1080/13607863.2019.1602590.

Raggi, A., Leonardi, M., Covelli, V., Sattin, D., Scaratti, C., Schiavolin, S., Willems, M & Meucci, P. (2015). The ICF as a framework to collect and interpret data on the extent and variety of disability in neurological conditions. *NeuroRehabilitation,* 36 (1), 17 – 22. https:// doi: 10.3233/NRE-141186.

Ram, D. (2017). Distress tolerance, psychosocial burden and its relationship with self-management of health in women with mental illness. *Journal of Psychopathology*, 23, 4-11.

Rao, P., Grover, S. & Chakrabarti, S. (2020). Coping with caregiving stress among caregivers of patients with schizophrenia. *Asian Journal of Psychiatry*, 54. https://doi: 10.1016/j.ajp.2020.102219.

Rashid, M., Goeza, H.R, Mabooda, N., Damanhouryc, S., Yagera, J.Y., Joyce, A.S., & Newtona, A.S. (2014). The impact of paediatric traumatic brain injury (TBI) on family functioning: A systematic review. J*ournal of Paediatric Rehabilitation Medicine: An Interdisciplinary Approach*, 7 (3), 241–254.

https://doi: 10.3233/PRM-140293

Rawlins-Alderman, L., A. (2014). A Qualitative exploration of the experiences of primary caregivers to individuals with traumatic brain injuries. *Physical Medicine and Rehabilitation - International*, 1 (4), 1 – 6

Robinson, O.C. (2014). Sampling in interview-based qualitative research: A theoretical and practical guide. *Qualitative Research,* 11(1), 25- 41.

https://doi.org/10.1080/14780887.2013.801543

Rochat, L., Manollov, R., Aboulafia-Brakha, T., Berner-Burkard, C., & Van Der Linden, M. (2019). Reducing anger outbursts after a severe TBI: A single-case study. *Neuropsychological Rehabilitation*, 29 (1), 107-130.

https://doi: 10.1080/09602011.2016.1270837

Rosino, M. (2016). *ABC-XModel of family stress and coping. The Wiley Blackwell Encyclopedia of Family Studies*. Retrieved from https://scholar.google.co.za/scholar?q=ABCX+Model+of+Family+Stress+and+Coping&hl=en&as_sdt=0&as_vis=1&oi=scholart.
https://doi:10.1002/9781119085621

Roy, C. (2009). *The Roy Adaptation Model*, 3rd edition. Prentice Hall Health.

Roy, C. & Zhan, L. (2005). Sister Callista Roy's adaptation model and its applications. In M.E. Parker, Ed, *Nursing theories and nursing practice* (2nd ed.) (pp. 268-280). F.A. Davis Company.

Rubenson, C., Svensson, E., Linddahl, I., & Bjorklund. (2007). Experiences of returning to work after acquired brain injury. *Scandinavian Journal of Occupational Therapy*, 14 (4), 205–214.

https://doi: 10.1080/11038120601110934

Ruet, A., Bayen, E., Jourdan, C., Pradat, D.P., & Azouvi, P. (2018). 8-year outcome after severe traumatic brain injury: Results from the Paris-TBI Study. *Annals of Physical & Rehabilitation Medicine*, 61, 38-38.

https://doi.org/10.1016/j.rehab.2018.05.084

Russell, B.S., Hutchison, M., Tambling, R. (2020). Initial Challenges of Caregiving During COVID-19: Caregiver Burden, Mental Health, and the Parent–Child Relationship. Child Psychiatry Hum Dev 51, 671–682. https://doi.org/10.1007/s10578-020-01037-x

Ryan, G. (2018). Introduction to positivism, interpretivism and critical theory. *Nurse Researcher,* 25(4), 41–49. https://doi.org/10.7748/nr.2018.e1466

Ryan, P., Van Bijnen, L., Catroppa, C., Beauchamp, M.H., Crossely, L, Hearps, S., & Anderson, V. (2015). Longitudinal outcome and recovery of social problems after pediatric traumatic brain injury (TBI): Contribution of brain insult and family environment. *International Journal of Developmental Neuroscience*, 49, 23-30. https://doi10.1016/j.ijdevneu.2015.12.004

Sabella, S.A., & Suchan, C.S. (2019). The contribution of social support, professional support, and financial hardship to family caregiver life satisfaction after traumatic brain injury. *The Journal of Head Trauma Rehabilitation*, 34(4), 233-240. https://doi: 10.1097/HTR.0000000000000471

Saloojeei, G. & Bezuidenhouti, M. (2020). Community-based peer supporters for persons with disabilities: Experiences from two training programmes. In South African Health Review 2020. *Health System Trust*, 89 – 97.

Santos, R.L., Sousa, M.F., Ganem, A.C., Silva, T.V. & Dourado, M.C. (2013). Cultural aspects in dementia: differences in the awareness of Brazilian caregivers. *Trends in Psychiatry and Psychotherapy*, 35(3),191-197.

https://doi:10.1590/s2237-60892013000300006.

Schonberger, M., Ponsford, J., Olver, J., & Ponsford, M. (2010). A longitudinal study of family functioning after TBI and relatives' emotional status. *Neuropsychological Rehabilitation*, 20 (6), 813–829.

https://doi: 10.1080/09602011003620077

Shaffer, K. M., Kim, Y., Carver, C. S., & Cannady, R. S. (2017). Effects of caregiving status and changes in depressive symptoms on development of physical morbidity among long-term cancer caregivers. *Health Psychology*, 36(8), 770–778. https://doi.org/10.1037/hea0000528

Shaikh, B.T. & Hatcher, J. (2005). Health seeking behaviour and health service utilization in Pakistan: Challenging the policy makers. J*ournal of Public Health,* 27(1), 49-54. https://doi: 10.1093/pubmed/fdh207

Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*, 22 (2), 63 – 75.

https://doi:10.3233/EFI-2004-22201

Sherer, M., Sander, A.M., Nick, T.G., Melguizo, M.S., Tusky, D.S., Kisala, P, Hanks, R. & Novack, T.A. (2015). Key dimensions of impairment, self-report, and environmental supports in persons with traumatic brain injury. *Rehabilitation Psychology*, 60 (2), 138-146. https://doi:10.1037/rep0000030

Sloan, A. & Bowe, B. (2014). Phenomenology and hermeneutic phenomenology: the philosophy, the methodologies and using hermeneutic phenomenology to investigate lecturers' experiences of curriculum design. *Quality & Quantity*, (48), 3, 1291-1303. https://doi:10.1007/s11135-013-9835-3

Smith, J. A., Flowers, P. & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research*. Sage

Smith, J. A., & Osborn, M. (2007). Pain as an assault on the self: An interpretative phenomenological analysis of the psychological impact of chronic benign low back pain. *Psychology and Health*, 22(5), 517-534.

https://doi.org/10.1080/14768320600941756

Smith, J.A, Harre, R, & Van Langenhoven, L. (1995). *Rethinking Psychology*. Sage Publishers

Snellman, I., Gustafsson, C., & Gustafsson, L. K. (2012). Patients' and caregivers' attributes in a meaningful care encounter: Similarities and notable differences. *ISRN Nursing*. https://doi.org/10.5402/2012/320145

Sodi, T. & Kgopa, B. (2016). Coping strategies of mother carers of children living with chronic illness and disease in a rural South African community. *Journal of Psychology in Africa,* 26(5), 432-435. https://doi:10.1080/14330237

Spinelli, E. (2005). *The interpreted world: An introduction to phenomenological psychology*, 2nd Ed. Sage.

Stalnacke, B.M. (2007). Community integration, social support and life satisfaction in relation to symptoms 3 years after mild traumatic brain injury. *Brain Injury*, 21(9), 933-942. https://doi: 10.1080/02699050701553189

Stevensa, L.F., Perrin, P.B., Hubbard, R., D´ıaz Sosac, D. M., Jove, I.G. & Arango-Lasprillae, J. C. (2013). Using multiple views of family dynamics to predict the mental health of individuals with TBI and their caregivers in Mexico. *NeuroRehabilitation*, 33, 273–283. https://doi: 10.3233/NRE-130955

Sullivan, K. (2015). An application of family stress theory to clinical work with military families and other vulnerable populations. *Clinical Social Work Journal*, 43 (1), 89–97. https://doi:10.1007/s10615-014-0500-7

Sun, F., Ong, R. & Burnette, D. (2012). The influence of ethnicity and culture on dementia caregiving: A review of empirical studies on Chinese Americans. *American Journal of Alzheimer’s Disease & Other Dementias*, 27(1) 13-22.

https://doi: 10.1177/1533317512438224

Teahan, A., Lafferty, A., McAuliffe, E., Phelan. A., O’Sullivan, L., O’Shea, D. & Fealy., G. (2018). Resilience in family caregiving for people with dementia: A systematic review. *Geriatric Psychiatry*, 33 (12), 1582-1595. https://doi.org/10.1002/gps.4972

Tsai, P. (2003). A Middle-Range Theory of caregiver stress. *Nursing science quarterly*, 16 (2), 137-145. https://doi.org/10.1177/0894318403251789

Tsai, Y.C., Liu, C.J., Huang, H.C., Lin, J.H., Chen, P.Y., Su, Y.K., Chen, C.T. & Chiu, H.Y. (2021). A meta-analysis of dynamic prevalence of cognitive deficits in the acute, subacute, and chronic phases after traumatic brain injury. *Journal of Neuroscience Nursing*, 53 (2), 63-68.

https://doi: 10.1097/JNN.0000000000000570

Turner, D. W. (2010). Qualitative interview design: A practical guide for novice investigators. *The Qualitative Report*, *15*(3), 754- 760. https://doi.org/10.46743/2160-3715/2010.1178

Tzitzika, M., Lampridis, E., & Kalamaras, D. (2020). Relational satisfaction of spousal/partner informal caregivers of people with multiple sclerosis: relational commitment, caregiving burden, and prorelational behavioral tendencies. *International Journal of MS Care*, 22(2), 60–66. https://doi.org/10.7224/1537-2073.2019-003

Van Manen, M. (2017). Phenomenology in its original sense. *Qualitative Health Research,* 27(6), 810–825. https://doi:10.1177/1049732317699381

Van Nistelrooy, I. (2014). Self-sacrifice and self-affirmation within care-giving. *Med Health Care Philos*, 17(4), 519-528. https://doi: 10.1007/s11019-013-9523-z.

Van Nistelrooij, I., Schaafsma, P. & Tronto, J.C. (2014). Ricoeur and the ethics of care. *Med Health Care Philos,* 17(4):485-91.

https://doi: 10.1007/s11019-014-9595-4

Vigna, P.M., de Castro, I. & Fumis, R.R.L. (2020). Spirituality alleviates the burden on family members caring for patients receiving palliative care exclusively. *BMC Palliative Care*, 19 (1), 77. https://doi: 10.1186/s12904-020-00585-2

Vilchinsky, N., Dekel, R., Revenson, T.A., Liberman, G. and Mosseri, M. (2015). Caregivers' burden and depressive symptoms: The moderational role of attachment orientations. *Health Psychology*, 34 (3), 262–269. https://doi: 10.1037/hea0000121

Viner, R. (1999). Putting stress in life: Hans Selye and the making of Stress Theory. *Social Studies of Science,* 29(3), 391-410. https://doi:10.1177/030631299029003003

Wacker, J. G. (1998). A definition of theory: research guidelines for different theory-building research methods in operations management. *Journal of Operations Management*, 16 (4), 361–385.

https://doi.org/10.1016/S0272-6963(98)00019-9

War, F.A., Jamuna, R., & Arivazhagan, A. (2014). Cognitive and sexual functions in patients with traumatic brain injury. *Asian Journal of Neurosurgery*, 9(1), 29–32. https://doi: 10.4103/1793-5482.131061

Webster, J., Taylor, A. & Balchin, R. (2015). Traumatic brain injury, the hidden pandemic: A focused response to family and patient experiences and needs. *South African Medical Journal*, 105(3), 195- 198.

https://doi: 10.7196/samj.9014

Wekesa, V., Ogengo, J. A., Siongei, C. V., Elbusaidy, H., & Iwaret, M. (2013). Demographics of patients admitted with traumatic intracranial bleeds in Kenyatta National Hospital in Nairobi, Kenya. *East and Central African Journal of Surgery*, 18(3), 67-70.

Wells, R., Minnes, P., & Phillips, M. (2009). Predicting social and functional outcomes for individuals sustaining paediatric traumatic brain injury. *Developmental NeuroRehabilitation*, 12(1) 12–23. https://doi: 10.1080/17518420902773109

White, C.L., Korner-Bitensky, N., Rodrigue, N., Rosmus, C., Sourial, R., Lambert, S. & Wood-Dauphinee, S. (2007). Barriers and facilitators to caring for individuals with stroke in the community: The family's experience. *Canadian Journal of Neuroscience Nursing*, 29 (2), 5–12.

Whitlatch, C. J, Schur, D., Noelker, L.S., Ejaz, F.K., & Looman, W.J. (2001). The stress process of family caregiving in institutional settings. *The Gerontologist,* 41 (4), 462-473. https://doi: 10.1093/geront/41.4.462.

Widayanti, A. W., Green, J. A., Heydon, S., & Norris, P. (2020). Health-seeking behavior of people in Indonesia: A narrative review. *Journal of epidemiology and global health*, 10(1), 6–15. https://doi.org/10.2991/jegh.k.200102.001

Wong, J.C., Linn, K.A., Shinohara, R.T. & Mateen, F.J. (2016). Traumatic brain injury in Africa in 2050: A modeling study. *European Journal of Neuroscience*, 23(2), 382-386. https://doi: 10.1111/ene.12877

APPENDICES

Appendix 1a: Information sheet and telephone consent – English version

My name is Edzisani Sodi

I am a doctoral student at the University of South Africa (UNISA). I am conducting research that is focusing on the care of adults who suffered severe traumatic brain injury to fulfil the requirements of my degree.

The title of my study is: Caregiving for adults who suffered severe traumatic brain injury (sTBI): Towards a psychological explanatory model.

The aim of the study is to explore caregiving in a family context for adults who suffered sTBI with a view to develop a psychological explanatory model.

As a potential participant, you are expected to share your experience of being a caregiver.

This is a research project and there may be no direct benefits to you as an individual. Your details will not be linked to the interview schedule and the interview will strictly remain confidential.

You have a right to withdraw from the study at any point should you wish to do so and that this decision will not have negative implications for you.

Should there be a need for emotional support resulting from our engagement, such will be offered and referrals for further management will be done to local health care facilities.

Please reflect on my request to decide if you would like to participate in this study. Should you be willing to participate, I will call you to arrange for the date of the interview.

Thank you.

Appendix 1b: Hlalošo ya dinyakišišo le tumelelo ya go tšea karolo – Northern Sotho version

Ke nna Edzisani Sodi. Ke moitthuti wa dithuto ya bongaka ka Unibesithing ya Afrika Borwa, UNISA. Ke dira dinyakišišo ka dikgobalo tša bjoko tše di tseneletšego go batho ba godilego. Hogo ya tho ye ya ka ere "Hlokomelo ya batho ba godilego bao ba hweditšego kgobalo ya bjoko: Tšweletšo hlalošo ya mokgwa wa go hlokomela. Maikemišetšo a thuto ye ke go dira tseneletšego go batho ba godilego go re ke gone go tšweletša hlalošo ya mokgwa wa go hlokomela.

Bjalo ka motšiakarolo, ke ile go kgopela gore o gore o nhlalošetše ka botlalo gore naa wena o ikwa bjang ka karolo ye o e kgathago bjalo ka mohlokomedi wa yo mongwe wa ka mo lapeng la geno yo a hweditšego dikgobalo tša bjoko?

Ka ge tše e no ba dinyakišišo tša go tšweletša thuto pele, ga gona le moputso wo o fiwago motšiakarolo. Maina a gago a ka se ke a fiwa batho ba bangwe. Go feta fao, tšohle tše re ilego go di bolela e ile go ba sephiri.

Bjalo ka motšiakarolo, o na le tokelo ya go ka gogela morago ge o ka kwa e le gore ga o sa rata go tšwela pele ka go kgatha tema mo dinyakišišong tše. Go gogela morago gag ago go ka se be le ditlamorago tše mpe mo go wena.

Ge go kgatha tema mo dinyakišišong tše go ka dira gore o ikwe o nyaka thušo go fodiša matswalo, ke tla beakanya gore o kgone go humana thušo yeo lefelong la kgauswe la tša kalafo.

Ke kgopela gore o gopodišiše gore naa e ka ba o ikemišeditše go tšea karolo mo dinyakišišong tše. Ge e le gore o dumela go tšea karolo, ke tla go swara ka mogala go beakanya letšatši leo re ka kopanago.

Ke a leboga.

Appendix 1c: Ṱalutshedzo ya ṱhoḓisiso na thendelo ya u dzhenelela

Nne ndi pfi Edzisani Sodi.

Ndi musthudeni wa pfuzo dza vhu dokotela Yunivesithi ya Afurika Tshipembe, UNISA. Ndi khou ita ṱhoḓisiso nga ha ṱhogomelo ya vhathu vho wanaho khuvhalo ya vhuluvhi. Ṱhoho ya idzi dzinyagisiso dzo ima nga ndila hei: “Vhulondoti ha vhathu vho tshenzhelaho dambudzo ḽa khuvhalo ya vhuluvhi: Ndivhanyoni na mveledzo ya nḓila ya ṱhaluso ya u ṱhogomela.”

Ndivho ya ino ṱhoḓisiso ndi ya u tandula vhulondoti miṱani ine ya vha na vhathu vho tshenzhelaho khuvhalo ya vhuluvhi hu u ṱoḓa u bveledza nḓila ine ya nga ṱalutshedza zwa u thogomela.

Sa muthu ane a nga vha munwe wa vhadzheneleli, vha khou humbelwa uri vha ambe nga ha tshezhelo yavho ya u vha muthogomeli wa munwe wa muta wavho o tshenzhelaho khuvhalo ya vhuluvhi.

Heyi I tou vha ṱhoḓisiso lune a huna mbuelo dzine vha do dzi wana sa mudzheneleli. Madzina avho anga si ḓivhadziwe. Na hone hu nga si kone u vhonala uri zwe vhone vha amba ndi zwifhio.

Vho tendelwa uri vha litshe u bvelaphanda na u vha mudzheneleli tshifhinga tshinwe na tshinwe hu si na uri vha nga vhonwa mulandu.

Arali u dzhenelela kha ino ṱhoḓisiso zwi tshi nga dzikusa vhuṱungu muyani, ndzudzanyo dzi do itiwa uri hu vhe na thuso yo teyaho ubva kha tshumelo ya zwa mutakalo ire tsini navho.

Ndi khou humbela uri vha humbule nga hei Khumbelo u kona u dzhia theo arali vha tshi ḓo kona u dzhenelela. Ndi ḓo vha lidzela luṱingo futhi uri ri kone u pfana nga uri mbudzisavhathu dzi ḓo vha lini?

Ndi a livhuwa.

Appendix 1d: Papila ra Vuxokoxoko na mpfumelelo wa riqingho

Vito ra mina i Edzisani Sodi.

Ndzi muchudeni wa digiri ya vudokodela eYunivhesithi ya Afrika-Dzonga, UNISA, naswona ndzi endla ndzavisiso lowu nhlokomhaka ya wona ku nga “Vunyiki bya vuhlayiseki eka vanhu lava khomiweke hi vuvabyi byo vaviseka ka byongo na miehleketo hi matimba (severe traumatic brain injury – sTBI): Nsusumeto wo tirhisa thiyori ya nhlamuselo timhaka ta miehleketo”.

Xikongomelo xa ndzavisiso lowu i ku xopaxopa vunyiki bya vuhlayiseki emindyangwini eka vanhu lava khomiweke hi sTBI hi xikongomelo xo tumbuluxa thiyori ya nhlamuselo timhaka ta miehleketo.

Tanihi hi mutekaxiave, u ta komberiwa ku bula na hina hi ntokoto wa wena tanihi munyiki wa vuhlayiseki eka murhandziwa wa wena loyi a nga khomiwa hi sTBI.

Leyi i phurojeke ya ndzavisiso, kutani swi nga endleka ku nga ri na mbuyelo lowu ku kongomeke hikokwalaho ka ku tinghenisa ka wena eka ndzavisiso lowu. Vuxokoxoko bya wena a byi nga nghenisiwi eka nongoloko wa nhlokisiso naswona nhlokisiso wu ta tshama wu ri wa xihundla.

Tiva leswaku u na mfanelo yo tihumesa eka ndzavisiso lowu nkarhi wun’wana na wun’wana hi ku rhandza ka wena naswona ku tihumesa ka wena eka ndzavisiso a swi nge vi na switandzhaku eka wena.

Loko u vaviseka emoyeni hikokwalaho ka ku tinghenisa ka wena eka ndzavisiso lowu, kutani u lava ku seketeriwa, hi tshembhisa ku nyika nseketelo lowu naswona hi nga tlhela hi ku hundzusela eka switirhisiwa swa rihanyo leswaku u ya kuma pfuno wo engetela.

Hi ndlela leyi, hi kombela leswaku u hi veka erivaleni leswaku u ta swi kota ku teka xiave eka ndzavisiso lowu. Loko kuri leswaku u ta swi kota ku endla tano, ndzi ta ku fonela ndzi ku tivisa hi ta siku leri nhlokisiso wu nga ta khomiwa hi rona.

Inkomu

Appendix 2a: Interview guide – English version

1. As I have shared with you that I am conducting research regarding the care of adults who suffered severe traumatic brain injury, I would like you to share with me your experience of being the primary caregiver in your family. How has it been?
2. What is your understanding of the injury? What does it mean for you?
3. May you please share with me what you perceive as barriers and facilitators in the process of providing the care?
4. What are the strategies or ways that help you to cope as you continue caring?
5. What do you think can assist you to provide better care?

Appendix 2b: Lenaneo la dinyakišišo – Northern Sotho version

1. Ka ge ke šetše ke boletše, ke moithuti yo a dirago dinyakišišo ka dikgobalo tša bjoko tše di tseneletšego go batho ba godilego. Ke ile go kgopela gore o nhlalošetše ka botlalo gore naa wena o ikwa bjang ka karolo ye o e kgathago bjalo ka mohlokomedi wa yo mongwe wa ka mo lapeng la geno. Go bile bjang mo go wena go fihla bokgole bjo blalo ka mohlokomedi?
2. Naa o kwišiša kgobalo ye ya bjoko bjang? Ka mantšu a mangwe, naa kgobalo ye e ra go reng mo go wena?
3. Ke kgopela gore o nlhalošetše ka botlalo gore naa o bona e le eng tšeo di ka bago di go šitiša le tšeo di go kgontšhago go hlokomela moleloko wa gago yo a nago le dikgobalo tša bjoko?
4. Naa o bona e le mekgwa ye efe ye e go thušago go kgotlelela le go tšwela pele mo hlokomelong ya gago ya moleloko wa gago yo a nago le dikgobalo tša bjoko?
5. Ke eng seo o bonago e le gore se ka go thušago gore o kgone go fa hlokomelo moleloko wa gago yo a nago le dikgobalo tša bjoko?

Appendix 2c: Mbudzisavhathu - Tshivenda version

1. Sa izwi ndo no ṱalutshedza uri ndi mutshudeni ane a khou ita dzinyagisiso nga ha ṱhogomelo ya vhathu vho tshenzhelaho khuvhalo ya vhuluvhi, ndi nga takalela uri vhone vha n ṱalutshedze nga ha vhuḓipfiwa havho kha u vha muṱhogomeli. Vhuḓipfiwa havho ndi vhu fhio musi ro sedza ṱhogomelo?
2. Vha pfesesa-hani khuvhalo iyi? Khuvhalo iyi i amba mini khavhone?
3. Ndi khou humbela uri vha mmbudze nga ha zwithu zwine vha vhona uri zwi a thithisa ṱhogomelo, na zwine zwa i thusa.
4. Ndi mini zwine zwa vha thusa u kona u bvela phanda na u thusa?
5. Ndi mini zwine zwa nga vha thusa uri vha kone u fha thuso ya khwine?

Appendix 2d: Nongoloko wa nhlokosiso – Xitsonga version

1. Tanihilaha ndzi ku hlamuseleke hakona leswaku ndzi endla ndzavisiso mayelana na vuhlayiseki bya vanhu lava khomiweke hi vuvabyi byo vaviseka ka byongo na miehleketo hi matimba (severe traumatic brain injury – sTBI), ndzi navela leswaku hi burisana hi ntokoto wa wena tanihi munyiki wa vuhlayiseki emutini wa wena. Xana mhaka leyi yi fambe njhani?
2. Xana ku twisisa ka wena mayelana na ku vaviseka loku hi kwihi? Mhaka leyi yi vula yini eka wena?
3. Xana u nga ndzi byela leswaku swirhalanganyo na swisusumeti loko u karhi u nyika vuhlayiseki eka vanhu lava hlaseriweke hi ku vaviseka ebyongweni na le miehleketweni hi swihi?
4. Xana hi tihi tindlela leti u ti tirhisaka ku lwa na ku tikeriwa loku u hlanganaka na kona hikokwalaho ka ntirho wa wena wo nyika vuhlayiseki?
5. Xana u vona ongeti incini lexi nga ku pfunaka leswaku u nyika vuhlayiseki byo tlula lebyi u byi nyikaka sweswi?